



A Development Framework for Hospice Palliative Care (HPC) Enhancements within an Existing Health Call Centre Program

Report of the Pallium HPC Telenursing Protocols Subproject (December 2005)



Developed by

HPC Telenursing Protocols Subproject Steering Committee

In collaboration with

PHCTF Multi-jurisdictional Health Lines Project Steering Committee

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FOREWORD

The Pallium Project is a strategic initiative focused on facilitating improved access, enhanced quality and additional system capacity for hospice palliative and end-of-life care, as part of primary health care renewal in Canada. The Project is based on the idea that *many hands make light work*. The Project functions as a Community of Practice (CoP). Communities of Practice are self-organized, deliberate collaborations of people who share common practices, interests and aims, to the end of advancing the quality and application of their specific domain of knowledge.

With a one-time investment from Health Canada's, Primary Health Care Transition Fund (PHCTF), the Project's Phase II activities comprise some 55 major activities, initiatives and subprojects. In 2004, a group of Canada's senior hospice palliative care (HPC) program leaders came together and presented a detailed outline to the Project development team, for consideration as part of the Project's telehealth initiative. United in their resolve that new health technology innovations, particularly telenursing-based health lines, could be an important driver for enhancing hospice palliative care quality and access in the community, they made a major commitment of time, energy and learning focused on telenursing and systems integration.

Over the last year, the HPC Telenursing Protocols subproject has evolved into one of the most important and strategic initiatives of the Pallium Project, Phase II. It was a journey that, at the outset, presented as a relatively straightforward clinical content and technology integration exercise. It has, however, highlighted and juxtaposed some of the greatest strengths and corresponding weaknesses of Canada's health delivery systems, particularly in how they are currently organized and resourced to support those in the community who are living with a life-threatening or life-limiting illness.

Dr. Donald Berwick, CEO of the Harvard University-based Institute for Health Care Improvement (IHI), has noted that how we care for the dying exposes the "under belly" of our current delivery systems. He notes that care of the dying is both a "keystone" and a "keystone species" in health care delivery systems. Failure to care well for seriously ill and dying patients reflects the limitations that permeate health care systems, while excellent care of the dying often reflects a system's core strengths.

At the 2005 Ontario Provincial Palliative Care Conference, well-known system commentator Dr. Michael Rachlis discussed the potential for hospice palliative care to drive broader system change and renewal. He discussed quality based on tangible constructs of misuse, underuse and overuse of health delivery system resources. This subproject has highlighted, in part, the growing risk of Call Centre Programs to contribute to potential misuse and overuse of health delivery system resources when engaging patients who are otherwise "known to the system" to be palliative, in the absence of better integration of HPC enhancements and overall improved coordination.

We are also at a time in the evolution of Canada's health delivery systems where there has been great concern expressed about the sustainability, quality and appropriateness of public-funded health delivery systems. This has manifested in some key public confidence and trust issues. Well-publicized reports, such as those issued by Senator Michael Kirby and Commissioner Roy Romanow, illustrate that Canadians need to "see and feel that the system is there" when their family and friends need it. Call Centre Programs offer great promise in this regard.

Moreover, we are in the early days of leading delivery system renewal and transformation efforts which are responsive to the needs of an aging society. Canada will experience a predictable increase of expected deaths and these will involve a range of progressive chronic illness. The current reality for many Canadians is that systems have evolved, but not been designed for long periods of progressive chronic illness leading to death; they are currently not able to respond well to a range of needs that patients and families have which are associated with expected deaths; gaps exist across settings of care; and too many live and die in pain, experience distress/difficult symptoms and lead to families who are frustrated, "worn down" and whose trust in their respective system is shaken. But it simply does not have to be this way.

Initiatives such as jurisdiction-based, partnership projects that serve to enhance the capacity of existing health Call Centre Programs to provide quality hospice palliative care are a tangible expression of the kinds of smart investments that respective provincial/federal governments and their agents can make in sustained public confidence. As the Fraser Health case study which accompanies this development framework highlights, workable solutions to a changing population's health needs are possible. They demand, however, ways of thinking, acting, relating, applying resources and moving forward which reflect "new ground to be broken," as well as a different set of front-line, program-development leadership and process management skills.

Residents of Canada, as well as the Canadian hospice palliative care and telenursing communities, owe a great debt of gratitude to our colleagues from British Columbia. As will become readily apparent in reviewing this development framework document, they have shown tremendous early leadership illustrating one pathway to better HPC access and quality. The partnership between the Fraser Health region and the British Columbia NurseLine (BCNL), supported by the Ministry of Health Services, is an important early "beacon" initiative. It highlights potential model elements, key considerations, critical success factors, predictable resource requirements, formative evaluation concepts and possible pitfalls to avoid.

It has been said that this document and the corresponding information products are a "great gift." Having journeyed as an ex officio member of the HPC Telenursing Protocols Subproject Steering Committee for the last year, I can assure readers that this information and the corresponding resources have been presented with great consideration and respect for the jurisdictional, technical, operational, staffing, regulatory, legal/risk management, quality assurance and service design context in which they might be applied as a development framework. Everything has been carefully vetted, is grounded in the reality of current Canadian practice and is in the process of being evaluated within the integrated end-of-life care program/telenursing operations of a major Canadian health region.

Finally, in addition to expressing my personal appreciation to all subproject Steering Committee members and our project manager, Ms. Jacquie Béasse, I would be remiss to not acknowledge the unique contributions of Velda Clark and Carolyn Tayler. I have come to appreciate there is a great sense of serendipity in hospice palliative care. Nowhere has this been more apparent in the Project than with Velda Clark's leadership in this subproject.

Velda Clark is one of Canada's longest serving hospice palliative care program leaders. While continuing her role as Director, Palliative Care Services in Regina, Mrs. Clark was seconded to lead the commissioning and implementation of Saskatchewan's 24/7 *HealthLine* service. This unique perspective of having had "one foot in both worlds" has been critical to brokering understanding and relationships for this subproject. Mrs. Clark has also consistently remained a voice true to those residents in rural/remote parts of Canada, whose only potential immediate access to their respective health care system for guidance/support, health information and wayfinding, is via a telephone.

Carolyn Tayler provided thoughtful, consistent leadership of the subproject Steering Committee over the last year, navigating the waters of complexity and intersectoral and multijurisdictional relationships with great sensibility and sensitivity. She has been a passionate advocate for HPC innovation using telenursing and has been a sounding board and source of support for our HPC colleagues as they have started the process of early consultation with their respective Call Centre Program counterparts.

The use of multi-jurisdictional, telenursing content development initiatives as part of primary health care renewal is relatively new and represents untested waters. The colleagues who have led with passion and resolve are pioneers of these new health care delivery models. They believe in building on the vision of *Quality End-of-Life Care* for every person in Canada – one which assures comfort, dignity, peace of mind, reduces the burden of undue pain and suffering, and supports the health status of all caregivers and the bereaved.

It has been an honor to serve with this group of health care leaders over the last year and a privilege, at the outset of this Report, to situate the work which they have produced within the broader context of HPC developments and primary health care renewal in Canada.

Michael Aherne, B.Com., M.Ed., CMC
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Pallium Project, Phase II
December 2005

Note to reader: This report is ideally considered in conjunction with the DVD/streaming video briefing by Carolyn Tayler, Subproject Steering Committee Chair, and the Fraser Health/BC NurseLine case presentation by Della Roberts and Diane MacCormack (originally recorded September 29, 2005).

ACKNOWLEDGMENTS

The Pallium Project functions as a tangible expression of commitment by practitioners, scholars, citizens, and health system/government/voluntary sector leaders to work together towards a vision of *Quality End-of-Life Care* in Canada.

This vision will be realized when all people in Canada can live well until death, with dignity, as free of pain, distress and undue suffering as possible, and surrounded by loved ones in a setting of their choice. We gratefully acknowledge and thank the people involved in the work resulting in this Report and the corresponding information products/companion resources. They have shared their time, talents, perspectives and passion to bring us one step closer to this vision.

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EXECUTIVE SUMMARY

Due to Canada's aging population and the increase in difficult, expected deaths associated with demographic changes, health care decision makers will need to plan for a correspondingly large number of deaths in the coming years. Advances in health care technology and chronic illness management have extended our lifespan, but will predictably increase complex health needs during the last years and months of life. Innovative, cost-effective strategies will be required to meet the future primary health care needs and expectations of this population.

Over the past decade, the knowledge base to support hospice palliative care (HPC) in Canada has improved significantly. In releasing the national *Model to Guide Hospice Palliative Care* after a 10-year consensus process, the Canadian Hospice Palliative Care Association (CHPCA) has sent clear signals in terms of a national framework of principles, values and norms to guide the development of consistent, high-quality hospice palliative care throughout Canada.

In 2001, the Pallium Project was formed by Canadian leaders and experts in hospice palliative care, and in 2003 received one-time funding through the National Envelope of the Primary Health Care Transition Fund (PHCTF) to make a demonstrable and enduring contribution to the foundation of Canada's primary health care system with a focus on HPC. Based on the philosophy that *many hands make light work*, the Pallium Project began pooling HPC expertise and collaborating on tool development, learning resources and other strategic initiatives to increase longer-term, health system capacity throughout Canada's provinces and territories. In 2004, the Pallium Project began exploring the potential for Canadian health Call Centre Programs and community HPC programs to collaborate as a viable option for after-hours access to HPC care providers and information.

Between 1994 and 2003, publicly-funded Call Centre Programs were commissioned in Alberta, British Columbia, Manitoba and Saskatchewan. Available to residents 24 hours per day, seven days a week (i.e., 24/7), they are staffed primarily by registered nurses (RNs). These centres are capable of delivering a variety of nursing teleservices to support primary health care and foster collaborative work among health disciplines and sectors. Nursing telepractice is recognized as being within the scope of nursing practice by all Canadian nursing jurisdictions.

Telenursing is consistent with the philosophy and approach of primary health care, and has the potential to enhance the application of the five principles of the Canada Health Act – comprehensiveness, universality, portability, accessibility and public administration. Nursing telepractice is governed by a growing number of provincial, national and international practice standards/guidelines and research studies that support a role for telenursing in primary health care delivery.

Health authorities in Canada and around the world struggle with the cost and logistics of providing patients and families with 24/7 access to health care providers. Advantages of partnering with a Call Centre Program include access to an adaptive, specially trained, pre-existing 24/7 RN workforce which is technology-enabled and experienced in being virtual members of a health care team.

In 2004, Fraser Health (FH) in partnership with the BC NurseLine (BCNL) launched the first Canadian HPC/Telenursing After-hours Service with the goals of:

- reducing unnecessary admissions to hospitals
- increasing support to patients and their caregivers in the home
- providing current, accurate information to family caregivers

- assisting with decision-making
- enhancing communication and support between health professionals and family caregivers

This document is a record and repository of the Pallium HPC Telenursing Protocols Subproject. It is intended to facilitate the integration of HPC services into Call Centre Programs, towards the goal of providing palliative patients and caregivers 24/7 telephone access to relevant HPC assessment, information and referral to appropriate existing resources. It is based on a set of core assumptions. The integration of HPC and Call Centre Programs:

- is grounded in the practice-based reality of partners
- is dependent on the readiness of all stakeholders
- augments current resources for enhancing community care, does not replace them
- is competency-based and evidence-informed
- is dependent on implementing standardized protocols as provided for in this document, which are aligned with both the CHPCA norms and principles and telenursing protocols for triage of symptoms and empowerment of callers through informational support
- is grounded in the Pallium ideal of pooling expertise – *many hands make light work*
- is subject to early and ongoing stakeholder involvement, testing and peer-review
- is dependent on the collaboration of leaders and experts in both HPC and telenursing and contribution of other in-kind resources
- will leverage primary health care investments in infrastructure of Call Centre Programs
- is dependent on a partnered approach to program evaluation and ongoing quality improvement

Call Centre Programs use a variety of commercial decision support software to guide telenursing practice, and strict adherence to the medically-approved protocols (including assessment, triage process and recommended caller disposition) is required to ensure safe practice and consistent service delivery. One of the key contributions of this subproject has been the development of guidelines for modifying telenursing protocols to reflect the reality of the hospice palliative patient.

Modification of standard telenursing protocols is only recommended for identified HPC callers who are known to or linked to a partnering community HPC service provider.

Recommendations for enhancing and localizing HPC content to complement the standard end-of-life care content built into the Call Centre Program's decision support software are also included.

Numerous supporting tools and sample documents have been developed to facilitate communication, decision making, business planning, partnership building, curriculum development, training, risk management and quality improvement. These are shared in this document. Additionally, a selected bibliography provides a comprehensive overview of the HPC/telenursing literature and recognized standards, protocols and guidelines.

A web-enabled PDF version of this document, featuring hyperlinks to selected additional resources referred to in this document, is available on the Pallium Project website at <http://www.pallium.ca>.

GLOSSARY OF TERMS

Definitions for the following terms have been included to clarify meaning and ensure consistency of language within this document. These terms may not reflect the way they are used in all organizations.

Business Plan (also referred to as a business case)

Document that identifies a specific need or gap, outlines the risks and benefits of developing a new line of business (service, program or product) to address the need, and proposes a feasible, high-level implementation strategy that includes an assessment of required resources (cost) and timeline.

Call Centre Programs

Publicly-funded Canadian health Call Centres that are staffed primarily by registered nurses (RNs) and provide 24/7 service. Many terms are used to describe health care consultation models provided by registered nurses (e.g., Nurselines, Nursing triage, telehealth centres). For this document the generic term Call Centre Program will be used.

Call Flow Process

A schematic diagram of a call, from incoming status through to disposition of the caller, that shows the system requirements and business processes that enable the handling of that call from start to finish.

Decision Support Software

Refers to any one of a number of commercially-available, external vendor-based software programs that facilitate the standardized triage of callers' health concerns and information needs. Examples of programs used by Canadian Call Centre Programs include: HealthWise Inc., McKesson, Ambulatory Innovations Inc., and HealthLine Systems.

End-of-Life Care

Refers to the reliable, skillful and supportive care of people with advanced, *potentially* fatal illnesses and those close to them. (Institute of Medicine, 1997)

The development of an advanced care plan is often encouraged as an integral part of end-of-life care. In some knowledge databases used by Call Centres, the term 'end-of-life care' may be associated with terminal care, or care given to patients in the last days or hours of life. The term end-of-life care is an evolving term in Canada. It is often used interchangeably with hospice palliative care. However, end-of-life care is usually used in reference to a period of time that may precede the use of hospice palliative care services which are most often employed within the last six months of life, while end-of-life care planning may be initiated for patients with chronic disease, many years prior to death.

Enhanced Telenursing Practice

"Enhanced telenursing practice is an enriched or strengthened application of the nursing process (assessment, intervention, plan and evaluation) which is focused on specific call types or target populations and augments the fundamental or essential competencies of a telenurse." (BC NurseLine, 2005)

Hospice Palliative Care (HPC)

Aims to relieve suffering and improve the quality of living and dying. Is appropriate for any patient/family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age and at any time they have unmet expectations or needs and are prepared to accept care. (Canadian Hospice Palliative Care Association, 2002)

HPC Caller

Hospice Palliative Care patient or his/her caregiver who is eligible to participate in a HPC/Telenursing service. Eligibility will differ from one jurisdiction to another.

HPC Community Partner/Provider

Health care team or professional who is responsible for receiving and responding to HPC referrals from Call Centre Programs. This will differ from one jurisdiction to another. Examples may include: HPC after-hours program nurses, home care nurses, HPC clinical nurse specialist (e.g., palliative response nurse or PRN), physician or outpost nurse in rural areas, etc.

Telenursing

The scope and nature of providing nursing care in a Call Centre Program as described in the November 2001 Canadian Nurses Association's *Position statement: The role of the nurse in telepractice*. Telenursing may sometimes be referred to as Nursing Telepractice.

Telenursing Protocol

Standardized, triage-based, medically-approved nursing responses to the caller's health concerns that are generally embedded within, or facilitated through, the use of decision support software.

Stakeholders

People with whom we share ideas/consult/engage and who are invested in, or impacted by, the outcome of a process or development. (Pallium Project definition)


HOW TO USE THIS DOCUMENT

The purpose of this document is to guide and/or inform the standardized development, implementation and evaluation of nursing Call Centre initiatives that support the delivery of 24/7 hospice palliative care (HPC) according to Canadian national standards.^{1,2}

By beginning with mutually held core assumptions about partnerships between community HPC programs and telenursing, and building on the lessons learned by inaugural Canadian HPC/telenursing initiatives, the document offers potential partners an efficient and cost-effective development framework to approach hospice palliative care and end-of-life care program development, particularly for patient inreach and after-hours care.

A full-colour, colour-coded version of this document offers (available as PDF):

Critical or core content

 Corresponding program development tools in the form of templates, checklists, guidelines, videos, curriculum outlines, teaching materials, etc. Please see the web-enabled PDF version of this document (available at <http://www.pallium.ca>), where users can access selected tools and resources by holding down the control key and clicking on the underlined text (hyperlink)

 Samples of actual materials and processes developed for an existing Canadian HPC/telenursing initiative

Who will find it useful?

- administrators and managers within health authorities/regions and other service delivery organizations who are responsible for end-of-life care strategic planning and program development
- administrators, managers and program development staff of nursing Call Centre Programs interested in exploring a partnership with home health care and existing community services to meet the 24/7 needs of callers and their families at end-of-life
- HPC providers including family physicians and other primary health care professionals who want to understand the benefits and limitations of telenursing programs.
- educators/trainers of nursing Call Centre Programs and community health care programs
- quality improvement personnel within nursing Call Centres and Community Health Care Programs
- health services researchers
- advocates for 24/7 quality end-of-life care

SECTION I: BACKGROUND

1. Hospice Palliative Care and Telenursing: The Potential for Partnership

As Canadians consider their health care needs into the 21st century, they will find at least one unavoidable truth. As a result of our large, aging population we must prepare for a correspondingly large number of deaths in the coming years. Advances in health care technology and chronic illness management continue to extend lives. Longer lives are also associated with complex health needs during the last years, months and days. It is predictable that the baby boomers, moving along their natural life course, will have as much interest in dying well as they have had in living well, for their parents and themselves. It is also predictable this will cause health care resources to be stretched, to manage both expectations and volume. The current demographic composition of the health care delivery workforce in Canada is also reflective of Canadian society, effectively creating a dual challenge of providing more timely hospice palliative care in strained delivery environments coping with limited health human resources.

In Canada, quality hospice palliative care (HPC) has developed significantly over the past decade.

1.1 About Hospice Palliative Care (HPC) in Canada

Over the past decade, the foundations for quality HPC in Canada have developed significantly. Two specific initiatives have helped shape thinking about telehealth and hospice palliative care services delivery. One is the creation of the Canadian Hospice Palliative Care Association's (CHPCA) Model based on national principles and norms.³ Developed through a 10-year consensus process, these norms represent an opportunity to standardize approaches to hospice palliative care. The Model was designed to ensure that all Canadians have access to consistent, high-quality hospice palliative care which aims to relieve suffering, improve quality of living and dying, and signal grief and bereavement as a part of the HPC care continuum.

The second is a cluster of initiatives supported by the Pallium Project, which are intended to improve supports to primary caregivers in the community. The Pallium Project draws expertise from more than 40 organizations and 300 leaders and collaborators from major universities, health authorities, voluntary sector organizations and federal, provincial and territorial governments. Based on the idea that 'many hands make light work', the Pallium Project began pooling expertise and collaborating around tool development, learning resources and other strategic initiatives to support hospice palliative care and focused efforts on improving access to HPC, enhancing quality of living and dying and making contributions to system capacity to respond in the longer-term.

In December 2003, Pallium received \$4.3 million over three years under the National Initiatives Envelope of the Primary Health Care Transition Fund (PHCTF). The goal of this initiative, entitled Pallium Project (Phase II), is to make a demonstrable and enduring contribution to the foundation of

Canada's primary health care system early in the 21st century, with focused emphasis on HPC, by increasing access, enhancing quality and building longer-term delivery systems capacity. Focused efforts were organized according to three program streams: outreach education and continuing professional development; knowledge management and workplace learning; and service development and system readiness (activities that enable service delivery).

1.2 About telenursing in Canada

Between 1994 and 2003, Call Centre Programs were launched in Alberta (AB), British Columbia (BC), Manitoba (MB), and Saskatchewan (SK). Available to residents 24 hours a day, seven days a week, they are staffed primarily by registered nurses (RNs) and are capable of delivering a variety of nursing teleservices to support primary health care and foster collaborative work among health disciplines and sectors.

In every nursing jurisdiction in Canada, nursing telepractice is recognized as being within the scope of nursing practice.

RN telenurses provide consultation in the management of specific symptoms or health problems, referral to other services (i.e., wayfinding/navigation), and health information.⁴ Working at the interface of health care and technology, advice is delivered according to medically-approved protocols, guided by professional nursing expertise and enabled by the integration of the Call Centre's computer and telephone systems.

In *A clinical and economic review of telephone triage services and survey of Canadian Call Centre Programs*⁵ completed in August 2004, the authors note that evaluations of Canadian telephone triage programs, which are very limited in number, show minimal evidence of the services' clinical impact. The document also summarizes the similarities and differences among existing Call Centre Programs and suggests that it may be premature to talk about a best model for delivering telenursing services when comparative studies are still virtually non-existent. Developing, implementing and evaluating new lines of business (services based on shared assumptions and targeting common outcomes) within different Call Centre Programs is one way of continuing to build evidence for 'best models'.

Nursing telepractice is recognized as being within the scope of nursing practice by all Canadian nursing jurisdictions. It is consistent with the philosophy and approach of primary health care and has the potential to enhance the application of the five principles of the *Canada Health Act* – comprehensiveness, universality, portability, accessibility and public administration. Like all nursing practice, nursing telepractice is guided by the values articulated in the *Code of Ethics for Registered Nurses* and is subject to relevant legislation.⁶ While telenursing in Canada has not yet evolved into a recognized nursing sub-specialty with nationally defined competencies and standards of care, it has been shaped by international standards for telenursing⁷, United States' health Call Centre standards⁸, Canadian initiatives such as the National Initiative for Telehealth Guidelines (NIFTE)⁹ and a growing body of research literature.

Health service delivery organizations in Canada and around the world struggle with the cost and logistics of providing patients and families with 24/7 access to health care providers. Financial constraints mean that only response systems demonstrating cost effectiveness can be considered and staffing challenges for 24/7 programs are among the realities of nursing and other resource shortages. In this context, it is clear why innovative partnerships with Call Centre Programs are becoming more common.

Advantages of partnering with a Call Centre Program include access to an adaptive, specially-trained, pre-existing, 24/7 RN workforce that is technology-enabled and who are experienced in being 'virtual members' of a health care team. Telenurses are generalists by training due to the broad population they are expected to serve, although most RNs come to telenursing with a clinical specialty. While a lack of face-to-face contact and absence of an existing patient-provider relationship are often cited as limitations of telenursing in the context of traditional health care delivery, it is also true that telenurses rapidly become exceptional at assessing patients without visual cues and establishing functional patient-provider relationships in minutes.

In existing Call Centre Programs, telenurses have rapidly developed the ability to assess patients over the phone without visual cues and to establish functional patient-provider relationships.

1.3 Why partner?

The following case study exemplifies some of the common health care needs and concerns hospice palliative patients and their caregivers seek help for, particularly after hours.

Mr. B is a 66-year-old man with metastatic lung cancer. A 'No CPR' order has recently been established with his doctor's support, and he has expressed a strong desire to die at home. His wife Helen is his primary caregiver at home. He is spending all his time in bed these days. On Friday night about 11 PM, Mr. B. began experiencing sharp, localized pain under his left breast, but no other new symptoms. His wife was concerned he was having a heart attack, but when she called the home care office, the message said they were closed until morning and if it was an 'emergency situation', patients should go to the closest hospital or call 911. Mr. and Mrs. B have a 30 minute drive to the nearest hospital. They tried the family doctor, and his answering machine said to call the provincial health line or call 911 if it was an emergency. Mrs. B was afraid to give him anything 'extra' for pain in case it made the 'heart attack' worse. Mr. B refused to go to the hospital, and Mrs. B was tearful and anxious. She didn't want him to die yet. She called the provincial health line and explained the situation. While the telenurse understood the intent of a 'No CPR' order, the decision support software she was using to triage Mr. B's symptoms indicated he should seek immediate medical assessment. She had been trained never to downgrade a software-recommended disposition. Mr. B reluctantly allowed Mrs. B. to call an ambulance....

Below, the same case is used to demonstrate the response that, for example, Fraser Health is able to offer HPC clients in partnership with the BC NurseLine:

Telenursing can be a useful resource in rural settings for supporting family caregivers and community nurses.

Mrs. B's first call was to the After-hours Hospice Palliative Care/Telenursing Service, using the phone number the home care nurse had given them along with a pamphlet that described the service. In less than two minutes, Mrs. B was speaking to a telenurse about Mr. B's symptoms. The nurse could tell Mr. and Mrs. B were registered with the FHA HPC Program by the number on her telephone call display and after confirming this with Mrs. B., proceeded to assess Mr. B's condition, asking questions that were especially relevant to palliative care patients. Was this a new or expected symptom? Had his activity level changed significantly in the last few days? Did Mrs. B think he was nearing the last days or hours? Had he discussed his wishes for end-of-life care with his family physician and family? Using a modified triage system that reflects the realities of palliative patients, the telenurse made an immediate telephone referral to the After-hours Palliative Response Nurse (PRN), who in turn called Mr. and Mrs. B at their home 10 minutes later. After further assessment, the After-hours Palliative Response Nurse determined that the home care nurse and hospice palliative care physician had prepared her for her husband's death in the next days to few weeks. She was able to allay most of Mrs. B's anxiety by explaining how Mr. B's pain was likely a progression of his lung cancer and advising on how Mr. B might best manage his pain through the night. She then sent off an electronic referral to the palliative care physician and home care nurse for a medical assessment and further follow-up in the morning. Mr. B spent a relatively comfortable, less stressful night in his own bed, and Mrs. B. was less anxious knowing she could call the FHA HPC/Telenursing Service again if the situation deteriorated.

HPC enhancements at the Call Centre Program changed the outcome of the case as follows, it:

- reduced unnecessary admissions to hospitals
- increased support to patients and caregivers in the home
- provided current, accurate information to family caregivers
- assisted with decision making
- enhanced communication and support between patients, care providers and family caregivers

In addition, the literature suggests that telenursing services are an extremely useful resource for family caregivers and community nurses working in rural settings.¹⁰ Environment, infrastructure and resource differences often result in a lack of well-organized services in rural communities, where HPC is most often provided by family physicians and community nurses. Education and training, bereavement counseling, symptom control, hospice care and information for caregivers are generally more difficult to access.

With the exception of a pilot project (launched January 2005) between the Fraser Health Hospice Palliative Care Program and BC NurseLine, partnerships between HPC programs and Call Centre Programs have remained largely unexplored in Canada. The activity and information products of this subproject can assist, in part, as a development framework to guide planning work in other jurisdictions. It also enables other jurisdictions and health delivery organizations to lever the public investments and learnings made to-date.

2. About this Pallium HPC Telenursing Protocols Subproject

2.1 Creating the vision

As part of the Pallium Project's commitment to improve supports for hospice palliative care at the community-level, especially for enhanced systems access and quality, several regional palliative and end-of-life care program leaders initiated discussions in 2004. They viewed working through the Project as a pathway for initiating development and integration of hospice palliative care telephone protocols within western Canada Call Centre Programs. Subsequent to the launch, other nursing colleagues joined the group and met at the November 2004 Pallium Service Development Institute. They reiterated their common vision for ensuring 24/7 telephone access to HPC to all people living in Western Canada. They committed to dedicate time, knowledge and expertise by forming a Steering Committee and pursuing an alliance with the Pallium Project.

The vision of this project is to improve the availability and quality of primary health care information, to further develop Canada's hospice palliative care system and to promote collaborative development.

This vision is aligned with key goals and objectives of the Pallium Project as defined in the Health Canada proposal *Pallium Integrated Care Capacity Building Initiative*. They are to:

- improve the availability and quality of information on primary health care
- lead further development of Canada's hospice palliative care system, ensuring human resources and organizational development supports are available for a range of settings and learning needs
- promote collaborative development as a model to ensure appropriate attention is given to both caregiver development (i.e., knowledge, skills and attitudes) and to organizational development (i.e., enabling, appropriately designed and resourced care environments, consistent, standards-based care, etc.)

This subproject also meets the needs expressed by Canadians in the 2004 National Hospice Palliative Care survey. Some 50 per cent of respondents in a national survey conducted by Ipsos-Reid indicated that they would use a provincial telephone or telehealth service for HPC information.¹¹

2.2 Core Assumptions underlying this project

This document has been created as an outcome of the Pallium HPC Telenursing Protocols Subproject. It is intended to facilitate the development and integration of HPC services into western Canada's Call Centre Programs, towards the goal of providing hospice palliative care patients and caregivers 24/7 telephone access to relevant HPC assessment, information and referral to appropriate and existing resources.

It is based on the following set of core assumptions, which project stakeholders and contributors have identified as being critical to successful integration of HPC and Call Centre Programs.

☑ Core Assumptions

The integration of HPC enhancements within existing Call Centre Programs:

- is grounded in the practice-based reality of both partners
- is dependent on the readiness of all stakeholders
- augments current resources for enhancing community care, does not replace them
- is competency-based and evidence-informed
- is dependent on implementation of standardized protocols, such as those provided in this document, which are aligned with both the CHPCA norms and principles and telenursing protocols for triage of symptoms and empowerment of callers through informational support
- is grounded in the Pallium Project ideal of pooling expertise – *many hands make light work*
- is subject to early and ongoing stakeholder involvement, testing and peer-review
- is dependent on the collaboration of leaders and experts in both HPC and telenursing and contribution of other in-kind resources
- will leverage primary health care investment in infrastructure of Call Centre Programs
- is dependent on a partnered approach to program evaluation, research and ongoing quality improvement

A core assumption of this project is that the integration of HPC and Call Centre Programs is competency-based and evidence-informed. It is also based on the Pallium ideal that 'many hands make light work'.

📖 This section will be useful to introduce stakeholders to the current state of both hospice palliative care and telenursing in Canada, and outlines the rationale for the development and implementation of integrated HPC telenursing services in western Canada. The above content has been captured in a PowerPoint presentation with speaker's notes entitled *Hospice Palliative Care and Telenursing: A Proposal for Partnership*.

A web-enabled PDF version of this document, featuring hyperlinks to selected additional resources referred to in this document, is available on the Pallium Project website at <http://www.pallium.ca>.

SECTION II: MODIFYING TELENURSING PROTOCOLS AND HOME HEALTH PRACTICES

1. Clarifying Assumptions

☑ Each Call Centre Program may use different commercial decision support software to guide its telenursing practice. The protocol modifications recommended in this document are built based on the following assumptions:

- modified triage of hospice palliative care patients can occur only when they are registered with a partnering HPC program or service in the community, which identifies their life-limiting status and care plan as palliative in nature
- all commercial decision support software uses standard/widely-accepted, medically-approved protocols
- all commercial decision support software applies the concept of symptom triage to recommended caller disposition
- all recommended dispositions that are embedded into commercial decision support software (disposition = type of medical attention, if any, that callers are advised to seek) are based on widely accepted timeframes for accessing 911, emergent and urgent care, or waiting to access non-urgent care or try home remedies

Telenurses are discouraged from freelancing, or arbitrarily overriding the decision support software to offer a different disposition without medical approval.

These assumptions should allow users of this document to feel confident that a caller with no previous cardiac history, complaining of severe chest and left arm pain, accompanied by shortness of breath and sweating, would be triaged similarly across all Call Centre Programs and directed to 911 services immediately, *regardless of the software being used*. Hemorrhage, fever, vomiting and diarrhea, trauma, seizures – almost all symptoms/conditions have widely accepted medical protocols for assessment and management that can inform the triage process.

But what if the caller with the above symptoms is a bed-ridden patient with late-stage Multiple Sclerosis who has made it clear to his family and doctors that he does not want to leave his home to die?

☑ Telenurses are strongly discouraged from *freelancing* – a term used to describe the arbitrary process of overriding decision support software to determine a different disposition without medical approval. Therefore, to meet the special needs of a hospice palliative care patient and his/her caregiver(s), and support telenurses to engage in the patient advocacy required by their professional standards of practice, it is critical that Call Centre Programs conduct an enhanced assessment of *eligible* HPC callers, and modify disposition guidelines to reflect the reality of the palliative patient, rather than alter the medical protocols or triage process that provides a foundation for safe, standardized telenursing care. Call Centre Programs must work together with health care service

providers to establish a process for identifying eligible callers (those who are known to HPC Community Partners), as this will be the main trigger for telenurses to legally deviate from the Call Centre's usual call flow process.

2. Process for Making HPC Modifications

2.1 Call Flow Process

All Call Centre Programs rely on established call flow processes to deliver each type of service or line of business they provide. Among other things, the call flow process takes the reason for the call into consideration. Is the caller seeking advice about a symptom? Is the caller seeking health education information? Is it a 'way finding' call to help them locate a particular health resource in the community (i.e., system navigation)? Development and analysis of a call flow process that reflects the hospice palliative care reality is a critical function of the Call Centre Program/HPC Community partnership. While beginning with a generic call flow is helpful, it is recognized that customization is necessary to accommodate the needs and capacity of all partners.

 [See Generic HPC Call Flow Diagram Showing Call Flow Components A-H \(Page 22\)](#)

 [See Example of HPC Enhanced Assessment incorporated in BC NurseLine Call Flow Process \(Page 23\)](#)

Description of Generic HPC Call Flow Components A-H (refer to Page 22)

A Identifying Eligible Callers

The HPC Community Partner must work with the Call Centre Program to develop a means for identifying eligible callers. Call Centre technology offers a variety of mechanisms to achieve this, including having the calls come in on a unique phone line and/or using a call display prompt to alert telenurses. Only these patients are considered *eligible callers*. Telenurses can only deviate from standard medically-approved protocols and use enhanced HPC protocols when they are caring for hospice palliative care patients/families that are registered with/known to a partnering HPC program/primary care provider. In addition, palliative patients do better when they are linked back to a HPC specialist or health care provider who knows them than if they receive episodic care in an emergency department. Therefore, to be most effective, the telenurse must be able to refer callers back to their HPC service to ensure both quality and continuity of care.

New or Expected Symptom?

The telehealth nurse determines the reason for the call. If it is a symptom-related call the telenurse determines whether the patient is experiencing a *new or expected* symptom, as the call flow will proceed differently for each. The rationale for this is to respond appropriately for symptoms that may be unrelated to their hospice palliative diagnosis, as well as prevent unnecessary hospital visits for the hospice palliative patient who is experiencing an expected progression of his/her illness and wishes to die at home/stay at home as long as possible, but still meet the caller's clinical, emotional and informational needs.

B Basic Nursing Assessment

In addition to doing a brief basic nursing assessment (presenting complaint, significant medical history, medications, etc.) and documenting it according to usual Call Centre Program practice, the telenurse will ask the question, 'What has your doctor told you about your illness?' to elicit key information about how advanced the patient's illness is, what expectations the patient has, and/or information about end-of-life care planning.

C, D Enhanced HPC Assessment

For a patient with expected symptoms, the nurse will deviate from the normal triage process and ask a set of questions that seeks to elicit how the patient/family is coping, how near the patient is to death and whether the patient has expressed the wish to die at home. The purpose of this assessment is to determine what support the patient/family needs to continuing providing care in the home if this is their wish.

E Triage Using Decision Support Tool

All patients, except those who are close to death and have expressed a wish to die at home, will have their symptoms triaged as per current Call Centre practice. In British Columbia, for example, Palliative Care Alerts and additional information specific to palliative patients enable the telehealth nurse to provide appropriate information, prevent unnecessary intervention and support/respect patient/family end-of-life care planning.

F Support for Patients Close to Death

The key to this component of the call is for the telenurse to avoid putting family members of a patient who is close to death through triage questions when the symptom relates to the dying process itself. As in these situations the symptoms would otherwise be triaged to 911 or emergency response. If death at home was not planned, referral to the HPC Community Partner will help the patient/family navigate decision-making more effectively, and providing emotional/informational support may prevent unnecessary intervention.

G, H HPC Modified Dispositions

All patients, with the exception of those near death, will have their symptoms triaged according to the Call Centre Program current practices resulting in the telenurse recommending a disposition. These dispositions deviate from the standard Call Centre Program practices to ensure that:

- telenurses reinforce existing medication and treatment plans that have been established between the patient and a HPC Community Partner
- patients with symptoms requiring a medical assessment – from emergent to non-urgent – will be referred to the HPC Community Partner for follow-up rather than a hospital or clinic. Follow-up will range from an overnight visit by the HPC provider to next-day contact by the HPC provider, to same-week contact by the HPC provider, depending upon the assessed condition
- patients with new symptoms unrelated to the palliative care diagnosis will be triaged directly to emergency services if appropriate

The rationale for modifying dispositions for HPC callers is to create a balance between efficiency/responsiveness and expertise/continuity of care in addressing the needs of this specialty population. While expert quality advice and continuity of care can be achieved by linking callers back to HPC experts and health care professionals who know them and/or have access to their health records, pilot projects have demonstrated that a significant number of calls from HPC clients can be immediately addressed through Call Centre Programs and followed up in an appropriate length of time by HPC Community partners, such as home care nurses and HPC physicians.

Educational initiatives will help introduce telenursing staff to dispositions that have been modified to include information on Hospice Palliative Care.

2.2 How to develop/conduct an Enhanced HPC Assessment

Call Centre Programs can incorporate the Enhanced HPC Assessment Tool provided in this document (see Page 24) into their existing call flow process. Telenurses would use the Enhanced HPC Assessment Tool to augment their standard caller assessment when eligible palliative patients and families contact the Call Centre Program. Depending upon the decision support software used, Call Centre Programs may train nurses to use the Enhanced HPC Assessment Tool or build it electronically into their decision support software.

 [See **Enhanced HPC Assessment Tool \(Page 24\)**](#)

 [See **Example of HPC Enhanced Assessment incorporated in the BC NurseLine Call Flow Process \(Page 23\)**](#)

2.3 How to modify disposition guidelines for HPC callers

Dispositions that have been modified to reflect the HPC reality should be introduced to telenursing staff through an educational initiative that reinforces underlying philosophy, principles and standards of HPC in Canada. They need to understand clearly under what circumstances they will apply the modified disposition guidelines (i.e., for eligible patients who are registered with a partnering HPC program). This can be communicated and reinforced by mechanisms already in place for the Call Centre Program.


2.4 How to enhance/localize health information on end-of-life and related topics

Commercial decision support software does differ significantly related to the volume and quality of health information it provides on specific topics – including end-of-life care. Usually, Canadian Call Centre Programs engage in an ongoing process to localize the content so that it reflects national, provincial or regional standards of practice and lists currently available resources and services. It is strongly recommended that Call Centre Programs use the health information included in this document for end-of-life and related topics (reflective of Canadian national standards for HPC) to localize content related to end-of-life care as required. Provincial and regional information can be added by the Call Centre's existing mechanism for localizing and/or updating information.

Reviewing a Call Centre Program's decision support software for all content related to end-of-life care, and then vetting it against approved Canadian norms and practices can be an exhausting exercise if one starts from scratch! This process can be expedited by referring to the list of *End-of-Life Care Topic Areas* included in this document and locating information provided about those topics in a Call Centre Program's software. Review this content against *Recommended Wording for Enhancing HPC Content* found in this report to see where enhancements or localization may be needed and make them using existing local mechanisms and processes. Permission is granted to adapt the exact wording provided in the *Recommended Wording* document, as it was current at the release of this document and has been developed from widely accepted references.

*Additional content and resources are provided with the web-enabled PDF version of this document available on the Pallium Project website:
www.pallium.ca.*

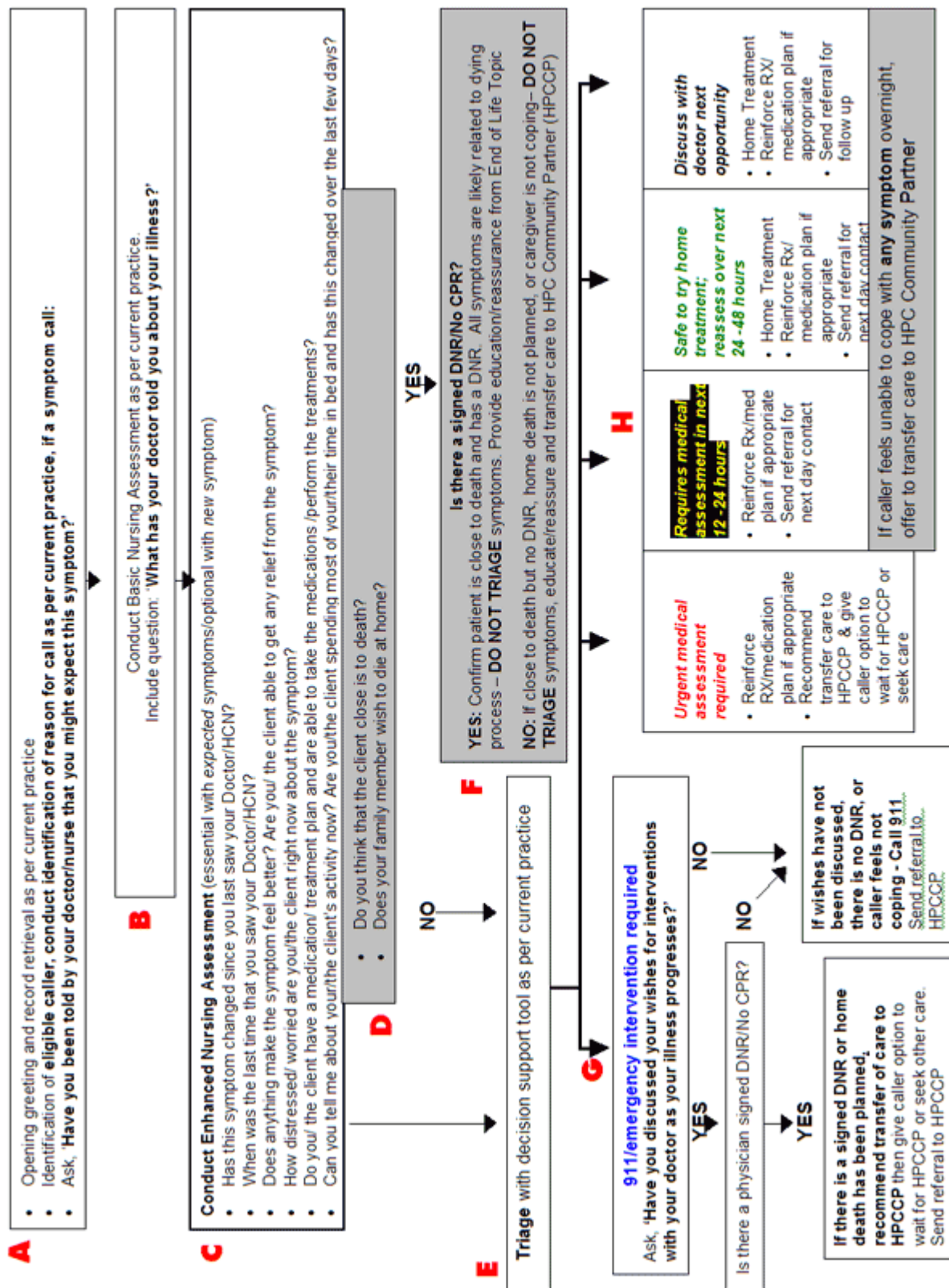
 [See Topics in Decision Support Software & Related Palliative Care Issues \(Page 26\)](#)

 [See Recommended Wording for Enhancing HPC Content in Decision Support Software \(Page 28\)](#)

 [See Example of BC NurseLine Use of 'Alerts' on HPC Topics in Decision Support Tool \(Page 37\)](#)

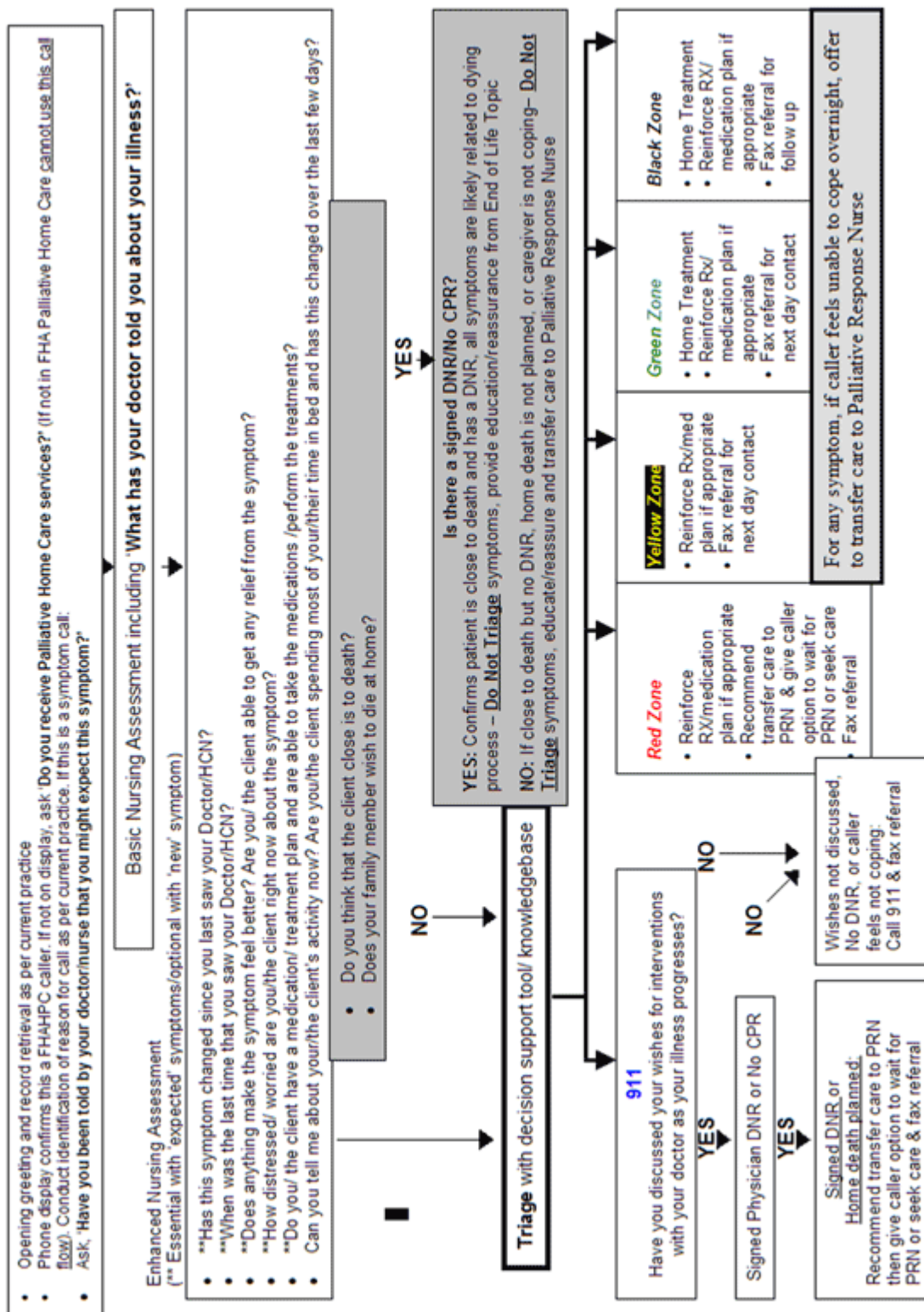
Generic HPC Call Flow Diagram Showing Call Flow Components A-H

Generic HPC Call Flow Diagram Showing Call Flow Components A-H



☎ Example of HPC Enhanced Assessment incorporated in BC NurseLine call flow process

☑ Example of HPC Enhanced Assessment incorporated in BC NurseLine call flow process



 **Enhanced HPC Assessment Tool**

Note: Questions have been phrased to address the client's caregiver and should be modified (you/your) if speaking directly to the client.

Has this symptom changed since the client last saw the Doctor/Home Care Nurse (HCN)?		
Yes		No
More of a concern: symptom could be worsening and may require assessment/ change in treatment plan		Less of a concern

When was the last time the client saw the Doctor/HCN?		
Longer than 24 Hrs		Within 24 Hrs
More of a concern: treatment plan may not be current		Less of a concern

Does <u>anything</u> make the client's symptom feel better?		
Are they able to get <u>any relief</u> from the symptom?		
Yes		No
Less of a concern – determine level of symptom relief		More of a concern: may be less able to cope at home; if not able to get <i>any</i> relief probably causing distress and need to be assessed soon

How <u>distressed/worried</u> are you right now?		
Very		Not very
More of a concern: Not coping and needs HCN visit		Less of a concern: symptoms less intense or better able to cope

Does the client have a <u>medication/treatment plan</u> and are they able to take the medications/perform the treatments?		
Yes		No
Promote the medication/treatment plan and re-evaluate symptom		More of a concern: may need assessment/treatment plan

Can you tell me about the client's <u>activity</u> now?		
Are they <u>spending most of their time in bed</u> and <u>has this changed</u> over the last few days?		
Yes		No
More of a concern; indicates where they are in the trajectory of their illness, i.e., in bed=advanced disease; if it has changed, concern is that illness is changing rapidly		Less of a concern

Do you think that your family member is <u>close to death</u>?		
Yes		No
Could this symptom be an expected end-of-life change?	Example = confusion	Do not consider the symptom to be an expected end-of-life change – more concerned

Does your family member wish to die at home?		
Yes		No
Greater urgency in getting home support		More likely need for assessment/transfer to ER

 **Topics in Decision Support Software & Related Palliative Care Issues
 (courtesy of Fraser Health)**

Note: This tool will be useful in locating and enhancing/modifying HPC related content.

Topic in Decision Support Software	Related Palliative Care Issue
Abdominal Pain, Age 12 and Older	Ascites Bowel Obstruction Diarrhea Fraser Health in Home Drug Box
Abnormal Vaginal Bleeding	Bleed / Exsanguination
Arm Problems, Non-Injury	Drug Box
Back Problems and Injuries	Chest Pain
Basic Dental Care	Sore Mouth
Bowel Obstruction	Bleed / Exsanguination Bowel Obstruction Diarrhea Ostomy
Caregiver Tips	Advanced Directives/ End-of-life Care Planning Caregiver Needs Equipment or Supplies Concern Feeding Tube IV Problems Ostomy
Chest Pain	Chest Pain
Chronic Pain	Chest Pain Drug Box
Colorectal Cancer	Ostomy
Confusion, Memory Loss and Altered Awareness	Agitation Confusion/Hallucinations
Constipation, Age 12 and Older	Constipation
Coughs	Coughing/Secretions
Dehydration	Dehydration
Diarrhea, Age 12 and Older	Diarrhea
Ear Problems and Injuries, Age 12 and Older	Bleed / Exsanguination

Topic in Decision Support Software	Related Palliative Care Issue
End-of-Life Care	Advanced Directives/ End-of-life Care Planning Bowel Obstruction Caregiver Needs Confusion/Hallucinations Coughing/Secretions Death Has Occurred At Home Dehydration Feeding Tube IV problems Sore Mouth
Leg Problems, Non-Injury	Drug Box
Mouth Problems, Non-Injury	Bleed / Exsanguination Sore Mouth
Nausea and Vomiting, Age 4 and Older	Bleed / Exsanguination Bowel Obstruction
Nervous System Problems	Agitation
Nosebleeds	Bleed / Exsanguination
Pressure Sores	Wound care
Respiratory Problems, Age 12 and Older	Ascites Coughing/Secretions Dyspnea
Skin Changes	Jaundice
Suicide Thoughts or Threats	Suicide Ideation
Swelling	Ascites
Urinary Problems and Injuries, Age 12 and Older	Bleed / Exsanguination Urinary catheter problems Voiding Difficulty and Urinary Retention
Weakness and Fatigue	Fatigue and weakness Suicide Ideation

Recommended Wording for Enhancing HPC Content in Decision Support Software

Note: The following content has been adapted from the Enhanced HPC Content developed for Fraser Health/BC NurseLine HPC/Telenursing Initiative. Content areas that need to be localized to reflect jurisdiction or HPC community partner policy, protocols, resources or legislation have been identified.

Palliative Care Issue	Key message	Nursing Action	Decision Support Tool*
Advanced Directives/ End-of-Life Care Planning	<p>In [name of jurisdiction], the only legally recognized option to record your wishes for end of life is the [title of legislation] which formally appoints someone to be your legal representative for health care decision making if you cannot speak for yourself.</p> <p>You can discuss your wishes, fears and concerns with your family and your physician so they can speak for you when you are no longer able to do that for yourself.</p> <p>[name of jurisdiction] currently has a [name of resource for end-of-life planning] For more information contact the HPC community partner for more information.</p>	<p>Refer caller back to the HPC community partner for reassessment of end-of-life planning.</p> <p>If you wish to record your wishes, [name of jurisdiction] has developed a [resource] called [name of resource] which can be helpful. This will provide direction to your decision makers.</p>	Caregiver Tips End-of-Life Care

*Decision support tools are localized for each respective jurisdiction and can either be embedded or developed as a hypertext-based, quick reference tool.

Palliative Care Issue	Key Message	Nursing Action	Decision Support Tool*
Agitation	Restlessness can be a common symptom as patients are approaching the final days of life. Medications can be ordered by a physician to help the patient settle.	If triaged as close to death, reinforce the normality of the agitation, reassure the family. It may be helpful to have someone who can stay with the patient, play soft music, and limit noise. Reinforce the medication plan. Triage symptom with decision support tool.	Confusion, memory loss and altered alertness Nervous system problems
Ascites	Swelling of the abdomen, associated with certain cancers may cause symptoms such as shortness of breath, heartburn/reflux and abdominal pain. Diuretics, drainage of the fluid through a catheter in the abdomen or intermittent drainage (paracentesis) may be used to manage this symptom.	If the patient is describing pain or shortness of breath that cannot be managed, refer to HPC community partner.	Abdominal pain (age 12+) Respiratory problems (age 12+) Swelling
Bleed / Exsanguination	A malignancy may increase the potential for bleeding at the end-of-life. Most causes of bleeding will produce slow blood loss, not massive hemorrhage. However massive hemorrhage may occur in certain cancers. Home care nurses and physicians try and prepare families if a bleed is a possibility.	If there is a rapid bleed instruct the person to call 911. If there is a slow bleed with a DNR in place/ expected death – Refer to HPC community partner.	Mouth problems Non-injury Nosebleeds Ear problems and injuries (age 12+) Urinary problems and injuries (age 12+) Abnormal vaginal bleeding Bowel obstruction Nausea and vomiting (age 4+)

*Decision support tools are localized for each respective jurisdiction and can either be embedded or developed as a hypertext-based, quick reference tool.

Palliative Care Issue	Key Message	Nursing Action	Decision Support Tool*
Bowel Obstruction	Bowel obstruction occurs when the normal process of food is abnormally delayed or prevented altogether. It may be associated with tumors in the abdomen. Symptoms may include intermittent cramping or continuous pain, nausea and vomiting, and no bowel movements. Many patients are managed at home with symptom management	If the patient's symptoms are not managed with current regime: Refer to HPC community partner.	Abdominal pain (age 12+) Nausea and vomiting (age 4+) Bowel obstruction End-of-life care
Chest Pain	In cancer patients, chest pain is most often due to causes other than heart problems, such as bone, muscle, or nerve pain.	If it is consistent with the previous history of pain – reinforce existing pain management plan. If a new or changed pain, triage according to the decision support tool.	Chest pain Chronic pain Back problems and injuries
Caregiver Needs	Care giving can be a very rewarding experience; however, it can be difficult. Three key ideas to remember. Take care of yourself first, set limits and do not do it alone.	Provide emotional support/reassurance. Give additional information if available. [name of Caregiver Association within jurisdiction] If needs reassessment of services/support: Refer caller back to the HPC community partner. If caller indicates that HPC community partner services are not working refer to the Clinical Nurse Specialist if available in the patient's area.	End-of-life care Caregiver tips
Constipation		Refer to HPC community partner bowel protocol if there is one.	Constipation (age 12+)

*Decision support tools are localized for each respective jurisdiction and can either be embedded or developed as a hypertext-based, quick reference tool.

Palliative Care Issue	Key message	Nursing Action	Decision Support Tool*
Confusion/ Hallucinations	Confusion occurs commonly in patients with advanced disease. The incidence of delirium approaches 90-95% as the patient nears death. It is not unusual to have hallucinations at the end-of-life.	Triage symptom with decision support tool. If triaged as the end of life, reinforce the normality of the confusion. Reinforce medication plan.	End-of-life care Confusion, memory loss and altered alertness
Coughing/ Secretions	At the end-of-life it is normal to have gurgling sounding breathing as the person is not able to swallow. When the person is dying there can be dramatic changes in sounds. This is not harmful to the person. It is more distracting to the family to listen and see the changes. There is medication that can be given such as Atropine by injection or by 1% eye drops used sublingually, often prescribed to reduce secretions/bubbling at the back of the throat.	Positioning on their side is also very important in order to drain the secretions. Suctioning is not used commonly. Contact HPC community partner or physician for prescription (Rx).	End-of-life care Respiratory problems (age 12+) Coughs
Dehydration	Dehydration is a normal process in the last days of life. If this occurs before the last phase of life, related to nausea or vomiting, subcutaneous fluids may be given to patients at home.	If requested this could wait until morning to discuss with the HPC community partner or physician.	End-of-life care Dehydration

*Decision support tools are localized for each respective jurisdiction and can either be embedded or developed as a hypertext-based, quick reference tool.

Palliative Care Issue	Key Message	Nursing Action	Decision Support Tool*
<p>Death has occurred at home</p>	<p>Although the timing of a death can be expected or unexpected, when you have a signed a 'No CPR' or 'No DNR' form in the home, the same instructions are followed.</p> <p>Both Registered Nurses and Physicians can pronounce death. In some areas the funeral home requires that the body has been pronounced before they will transport the body from the home. The family may have instructions with regard to contacting the physician. So check with your chosen funeral home – contact physician or home care nurse during home care hours. [This section must be localized for each jurisdiction to ensure accuracy]</p>	<p>Families need extra emotional support at the time of death.</p> <p>What to do at the time of Death? The same instructions apply whether the patient has a signed a 'No CPR' or DNR.</p> <p>No immediate action needs to be taken. The time of death is an intimate time for those present.</p> <p>If the person is alone with the dead body, they may want to call a friend/other family/ spiritual support person to be with them.</p> <p>Typically, a plan for time of death has been developed and discussed and should be supported where possible.</p> <p>Families will need to follow the instructions planned for the time of death, and call the identified provider for the body to be pronounced.</p> <p>Pronouncing Death If pronouncement is required, the family should call their physician or they can call the HPC community partner to come to the home during home care hours.</p> <p>If the death occurs during the night and a physician is not available to pronounce, the family should be provided emotional support and told that they can wait until the morning to contact the home care nurse or their family physician to come to the home to pronounce the body. [This section must be localized for each jurisdiction to ensure accuracy]</p> <p>If the caller is very distressed, then transfer the call to the HPC community partner.</p>	<p>End-of-life care</p>

*Decision support tools are localized for each respective jurisdiction and can either be embedded or developed as a hypertext-based, quick reference tool.

Palliative Care Issue	Key Message	Nursing Action	Decision Support Tool*
Diarrhea	Be aware that severely constipated patients can be bypassing liquid stool and call this diarrhea. Palliative patients are typically prescribed a bowel medication regime.	Triage the symptom as per the [HPC community partner] Bowel Protocol if available.	Diarrhea (age 12+) Bowel obstruction Abdominal pain (age 12+)
Drug Box	Some patients may have a drug box in the home. In most cases, only a physician or HPC community partner can access it. [This section must be localized for each jurisdiction to ensure accuracy]	The medication in the drug box is only accessed by a physician or HPC community partner. Triage the symptom as per protocol. [This section must be localized for each jurisdiction to ensure accuracy]	Chronic pain Abdominal pain (age 12+) Leg problems Non-injury arm problems Non-injury
Dyspnea	Shortness of breath is a symptom that can be managed. Supplemental oxygen is seldom used unless the patient has been evaluated for hypoxemia. Narcotics may be prescribed for dyspnea.	Airflow by fans, open windows, and positioning, are helpful. Reinforce the medication plan if one in place.	Respiratory problems (age 12+)
Equipment or supplies concern	Some select equipment and supplies may be provided no charge through a palliative care benefits program. [Information about available programs and the application process/assessment should be localized to reflect the jurisdiction]	For reassessment/arranging equipment & supplies refer caller back to the HPC community partner. If caller indicates that HPC community partner services are not working for equipment concerns refer to the Clinical Nurse Specialist in the patient's area if one is available. If the caller indicates that patient will need to go to hospital because they do not have the needed supplies/equipment at home refer to HPC community partner.	Caregiver tips

*Decision support tools are localized for each respective jurisdiction and can either be embedded or developed as a hypertext-based, quick reference tool.

Palliative Care Issue	Key Message	Nursing Action	Decision Support Tool*
Fatigue and weakness	Fatigue and weakness are one of the most common symptoms of advanced disease.	If any of the following signs are present, refer to the HPC community partner for urgent assessment new onset of leg weakness associated with back pain, difficulty voiding, gait difficulties, sensory changes and loss of sphincter control may be indicators of Spinal Cord Compression.	Weakness and fatigue
Feeding Tube	Tube feeding is a method to provide supplemental or total nutrition by feeding directly into the GI tract. The feeding tube can be inserted through the nose or through the skin into the GI tract.	If the feeding tube is clogged, displaced or pulled out, request the patient to call the HPC community partner or physician in the morning. If medication is required by this route during the night, refer to HPC community partner.	Caregiver tips End-of-life care
IV problems	Hypodermoclysis Definition: The treatment of dehydration by injecting fluids into the subcutaneous tissues. This practice is sometimes used as a palliative measure to treat people when other methods of re-hydration are not available. Many medications are given by the subcutaneous route. An injection port is placed into the subcutaneous tissue so that families can inject medications into a port. Most patients will have pre-drawn syringes for injection.	Refer to HPC community partner. Subcutaneous Injection procedure. Further questions or concerns about Infusion pumps or IV's or medication injection sites: Refer to HPC community partner.	Caregiver tips End-of-life care

*Decision support tools are localized for each respective jurisdiction and can either be embedded or developed as a hypertext-based, quick reference tool.

Palliative Care Issue	Key Message	Nursing Action	Decision Support Tool*
Jaundice	May be common when the liver is not functioning properly or there is blockage of bile. Other symptoms associated with jaundice may include itchy skin, abdominal pain and anorexia. The urine may also be quite dark and the stool clay-coloured.	If this is a new symptom, this should be reported by the patient to their physician and HPC community partner, not urgent.	Skin changes
Sore Mouth	In the last months of life, changes to the mouth and throat may be caused by natural changes at the end-of-life as well as by treatments and medications causing dryness and/or infections or inflammation. A moist mouth is an important comfort measure when someone is eating and drinking little.	<p>Continue to brush the teeth and clean the tongue with a soft toothbrush for as long as possible. If not possible, on a regular basis use sponge toothettes (available from drug stores and home care) dipped in water.</p> <p>If the patient is complaining of a sore mouth, have them contact either HPC community partner or physician for a visit/appointment for an assessment of their mouth or throat.</p> <p>Reassure that there are treatments to manage problems and ease discomfort.</p> <p>In the meantime, keeping their mouth moist will be comforting.</p>	Mouth problems non-injury Basic dental care End-of-life care
Ostomy		<p>Do not recommend irrigation.</p> <p>If the ostomy is leaking, it can be changed by the patient/family.</p> <p>If it cannot be changed, clean and dry around edges, tape securely and pad until morning.</p> <p>If the patient is very distressed refer to HPC community partner.</p>	Bowel obstruction Colorectal cancer

*Decision support tools are localized for each respective jurisdiction and can either be embedded or developed as a hypertext-based, quick reference tool.

Palliative Care Issue	Key Message	Nursing Action	Decision Support Tool*
Suicide Ideation	A patient at times can feel very depressed and hopeless as their life is coming to an end. Some people have a plan to end their lives or ask of others to help them. Assisted suicide is... [state whether legal or not legal in the jurisdiction]	If patient has a DNR and has a plan of using medication for suicide refer to HPC community partner. If patient has a weapon, follow Call Centre Program protocols.	Weakness and fatigue Suicidal thoughts or threats
Voiding difficulty and Urinary retention	May be related to medications such as opioids, fecal impaction, local tumor involvement, or prostatic disease. Sometimes this may just be decreased urinary output associated with decreased intake.	Assess for new onset of difficulty voiding associated with back pain, leg weakness and gait difficulties, sensory changes and loss of sphincter control as these may be indicators of Spinal Cord Compression and require urgent assessment by the HPC community partner. There may not always be known spinal disease. Triage symptom with decision support. If the patient has not voided in more than 12 hours and is uncomfortable with bladder distention, refer to HPC community partner.	Urinary problems and injuries (age 12+)
Urinary catheter problems	It is called bypassing when the urine is going around the catheter. If a catheter falls out, it can be replaced at the next visit tomorrow.	Use diaper or clean towel to absorb the urine. If patient is very distressed refer to HPC community partner.	Urinary problems and injuries (age 12+)
Wound care		Reinforce and use the existing care plan. Refer to the HPC community partner for any changes to the plan. Should not require a visit during the night.	Pressure sores

*Decision support tools are localized for each respective jurisdiction and can either be embedded or developed as a hypertext-based, quick reference tool.

Example of BC NurseLine Use of 'Alerts' on HPC Topics in Decision Support Tool

The screenshot displays a Microsoft Internet Explorer browser window titled "Healthwise Connect - Microsoft Internet Explorer". The address bar shows "http://tcmsrvr/hwconnect/Default.aspx". The page content includes a navigation menu with "End Call", "Notes", "History", "Fulfillment", "Alerts", and "Help". Below this is a search bar and a list of categories: "Symptoms", "Pediatrics", "Drugs", "Tests", "Self Help", and "List A-Z". The main content area is titled "End-of-Life Care" and includes a "Topic Contents" sidebar with links like "Overview", "Health Tools", "FAQs", "Important Decisions", "The Dying Process", "After Death", "Other Places To Get Help", "Related Information", "References", and "Credits". The main text under "Overview" discusses end-of-life care, stating it is treatment given to enhance quality of life and that ideally, it is compassionate and relieves pain. It also mentions that care is often given in a hospital and focuses on the patient's wishes. A section titled "What type of end-of-life care choices will I need to make?" is partially visible.

An "Alerts" pop-up window is overlaid on the right side of the page. It is titled "Alerts" and contains the following information:

- 2004-12-29 - End of Life Care**
- Call Type:** FHA Palliative
- [Advanced Directives/End of Life Planning](#)
- [Bowel Obstruction](#)
- [Caregiver Needs](#)
- [Confusion/Hallucinations](#)
- [Coughing/Secretions](#)
- [Dehydration](#)
- [Death has occurred at home](#)
- [Feeding Tube](#)
- [IV problems](#)
- [Sore Mouth](#)
- [Agitation](#)
- [Bleed/Exsanguination](#)

The Windows taskbar at the bottom shows several open applications: "Inbox - Microsof...", "powerpoint FHA...", "Microsoft Power...", "Healthwise Con...", "Alerts - Micros...", and "Document1 - Mic...". The system clock indicates the time is 8:55 AM.


SECTION III: IDENTIFYING POTENTIAL PARTNERS AND ASSESSING READINESS

1. Partnering for Success

Partnerships in health care have become an economic and practical necessity. Health care leaders are increasingly conscious that duplicating effort is not a prudent or acceptable use of resources. And how many have leapt into a partnership, excited by a common vision or lured by opportunity without considering whether the capacity or *readiness* to successfully engage is there?

This section presents a functional definition of partnership. Characteristics of successful partnerships and the characteristics of those which are at risk of failure are also examined. It is always a useful exercise to have a shared discussion about the expectations of partnering early in a collaborative relationship.

A partnership is an agreement between two or more parties/ collaborators to work together to achieve common goals

 Included in this section are two checklists that identify [critical readiness indicators](#) (see Pages 40-41) for Call Centre Programs and community HPC programs that should be considered before undertaking program development.

1.1 Definition of 'Partnership'

A partnership is an agreement between two or more partners to work together to achieve common goals. It involves mutual recognition, mutual acknowledgement of needs and equality between players. Too often, the concept of partnership is applied to situations where one powerful organization or individual has a fixed agenda and does no more than consult with others, masking fundamental differences of approach and objectives that will later lead to conflict.

1.2 What are some purposes for partnering?

- positioning your organization through affiliation
- to add value by building on each other's experience
- to impact cost, time and energy of program development
- the whole is greater than the sum of its parts
- as an investment in capacity building
- patients, families and communities benefit from the integration of services
- addressing gaps related to knowledge, money, space, technology, experience, etc.

1.3 What are some predictors of successful partnerships?

- commitment
- motivation
- accountability
- feasible strategic/work plan
- clear roles and responsibilities
- the leadership of respected individuals
- transparency in decision-making and management of finances
- shared mandates or agendas
- time to build the partnership
- experience with partnering
- the development of compatible ways of working and flexibility
- good fit between identified needs
- good communication; healthy interpersonal relationships
- feeling heard by partners; individuals involved are recognized and acknowledged for their perspectives and contributions
- clear and open process where partners declare their intent

Successful, collaborative partnerships result from discussions about expectations. Partnerships should involve mutual recognition, acknowledgment and equality.

1.4 What are some of the 'red flags' of partnership?

- lack of clear purpose; unrealistic goals
- differing philosophy and values
- a history of conflict among stakeholders
- needs and skills are not a fit
- poor track record of one partner; risk to reputation, finances etc.
- underestimation of time or development costs of a project
- unwillingness of partners to acknowledge what's missing; lack of capacity or *readiness*
- unequal or unacceptable balance of power and control
- hidden agendas
- lack of communication; quality of communication inadequate

Critical Indicators of Readiness for Call Centre Programs

- The funder of the Call Centre Program is supportive of concept and agrees with Core Assumptions (provincial/territorial Ministry level).
- Senior leadership assigns priority to project after thorough assessment of required resources – staff, space, time, and technology.
- Staff is identified to provide in-kind support for development and implementation of service and agree with Core Assumptions.
- Staff nurses are aware of proposed service and agree with Core Assumptions.
- Mechanisms and processes exist for making changes to decision support software and medical/nursing protocols.
- Information Technology (IT) support and technical infrastructure can facilitate timely, confidential, electronic exchange of patient information between HPC program staff and Call Centre staff (secure file delivery service).
- Dedicated IT staff time is assigned to plan and problem solve.
- Telephone staff time is dedicated to planning and problem solving.
- Basic infrastructure/system is in place for managing risk/assuring quality of program and participating in ongoing joint Quality Improvement (QI) process.
- Basic infrastructure/system is in place for providing training around enhanced HPC protocols.

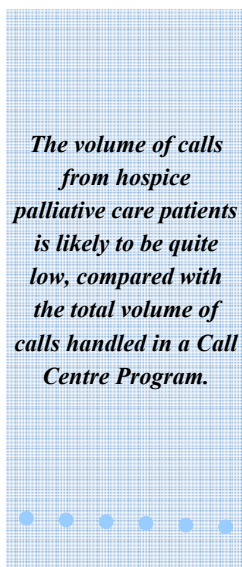
Critical indicators of readiness are important considerations for Call Centre Programs.

Critical Indicators of Readiness for HPC Community Partners

- Senior leadership has been informed, is supportive of the concept and agrees with Core Assumptions (provincial, regional and/or health authority level as required).
- Other key stakeholders support the implementation of service and agree with Core Assumptions.
- A leader with authority for system development decisions and responsibility for program implementation is assigned to the project (health authority level) and agrees with the Core Assumptions.
- A clinical liaison from a HPC program (preferably CNS or HPC clinician) is identified to provide in-kind support for program development and implementation and agrees with Core Assumptions.
- There is support from Home Health staff to implement service and agree with Core Assumptions.
- There is an existing HPC program/service/capacity, or a willingness to create the necessary capacity that:
 - has a mechanism for identifying population palliative patients/families who will be using the service and a system for providing the phone number to only these identified clients

- has an established 24/7-referral mechanism to primary care provider (MD) where possible
- can work within the time frame of responsiveness (triage protocols) used by the Call Centre Program (i.e., return calls to the patient in 15 minutes or less when indicated)
- has the staffing capacity to respond to calls transferred from Call Centre Programs (may require creative systems to establish this aspect of the service – such as an RN on call)
- has established links to HPC resources and decision support tools for nursing staff
- has established links to the Home Health offices where they exist

The volume of calls from hospice palliative care patients is likely to be quite low, compared with the total volume of calls handled in a Call Centre Program.



In rural settings:

The absence of an existing Community HPC Program/service/capacity, or after-hours support, especially in rural areas, should NOT be a barrier to exploring a partnership with a Call Centre Program. As long as a feedback loop can be created between community and Call Centre, and there is a primary care provider who is able and willing to take referrals from the Call Centre Program, innovative situations are possible!

- Computer/telephone/fax hardware and software exist to support communication and information transfer as required.
- IT support and technical infrastructure can facilitate timely, confidential, electronic exchange of patient information between HPC program staff and Call Centre staff (for example, a secure file delivery service).
- Dedicated IT staff time is made available to plan and problem solve.
- Basic infrastructure/system is in place for managing risk/ assuring quality of program and participating in ongoing joint QI process.
- Basic infrastructure/system is in place for providing staff training.


When a hospice palliative care after-hours service already exists:

Innovative partnerships between Call Centre Programs and existing HPC after-hours programs can serve to complement or enhance the existing programs, not replace them. The pooling of expertise, human resources and technology, towards the common goal of 24/7 access, has incredible potential.

SECTION IV: DEVELOPING AND IMPLEMENTING THE BUSINESS PLAN

Operational Considerations

(shows elements that should be standardized, areas for consideration and critical decision points)

Component of Call (Standardized Elements)	Areas for Consideration (Critical Decision Points)
<p style="text-align: center;">Incoming HPC call</p> 	<p>Recommend separate phone number for HPC service so telenurses can pre-identify caller by caller ID function on telephone; can also help determine eligibility of caller</p> <ul style="list-style-type: none"> • What phone number will be given out to HPC clients? • How will integrity of special number be maintained? • What information will HPC clients be given about the service? • What priority will HPC calls be answered in? • Who will answer HPC calls? All nurses? Only nurses that have been trained? How will this be operationalized? (e.g. use of Symposium software) <p>Consider the novice telenurses' ability to manage HPC calls if not yet confident with regular calls – may want to delay having new nurses take HPC for first six months in Call Centre.</p>
<p style="text-align: center;">Collection of demographics and confirmation of eligibility for HPC service</p> <p style="text-align: center;">Browse database for previous client records</p>	<ul style="list-style-type: none"> • What are eligibility requirements for using HPC service? • How will calls from non-eligible palliative clients be handled? • How will previous HPC call records be recognizable to the nurse?

Component of Call (Standardized Elements)	Areas for Consideration (Critical Decision Points)
<p style="text-align: center;">Collection and documentation of presenting concern, history & meds Enhanced HPC Assessment as appropriate</p> <p style="text-align: center;">↓</p>	<ul style="list-style-type: none"> • How will telenurses be prompted to conduct enhanced HPC assessment? • How will this be documented? • Under what circumstances will enhanced assessment not be used for eligible HPC callers?
<p style="text-align: center;">↓</p> <p style="text-align: center;">Triage according to primary symptom/greatest concern using decision support software Refer to enhanced content on HPC topics</p>	<ul style="list-style-type: none"> • How will telenurses get access to enhanced HPC content during call? Where will they find it? <p>Having a knowledge management strategy for locating/accessing content will be important. Consider tools such as Frequently Asked Questions to guide nurses to content.</p>
<p style="text-align: center;">↓</p> <p style="text-align: center;">Provide advice/referral according to HPC modified disposition guidelines</p> <p style="text-align: center;">Transfer care/refer call to HPC community partner</p>	<ul style="list-style-type: none"> • What will referral to HPC community partner look like? How, when, who etc. How will information be exchanged between the Call Centre Program and the HPC community partner? • How will security/confidentiality issues be managed? • How will consent be obtained from the caller? <p>What will the time parameters be around referral process so as not to delay care? What disclaimers need to be developed? How will death at home be managed?</p>

SECTION V: TRAINING – PHILOSOPHY, GOALS AND TOOLS

☑ Cross-training telenurses and HPC community partners to provide an integrated service and work as members of a ‘virtual health care team’ is essential for the success of HPC Telenursing enhancements. While each provides a unique aspect of the care, sharing common beliefs and attitudes about caring for patients at end of life is critical. Having an accurate, respectful awareness of each other’s roles, responsibilities and work environment further supports effective teamwork, and ultimately results in a better experience for patient and family.

Essential to the success of HPC Telenursing enhancements is the cross-training of telenurses and HPC community partners to provide integrated service as members of a “virtual health care team.”

It is important to make a distinction between the type of HPC-specific knowledge and skills required by an RN telenurse versus those required by the community home health nurse who is supporting an after-hours HPC program/service. It may be useful to think of telenurses as generalists who need training to enhance their telenursing practice in this specific area. Knowledge of Canadian HPC norms and principles, an understanding of what it takes to care for a palliative patient at home, and tools to assess and refer HPC patients appropriately give telenurses a solid foundation from which to work.

It is also important to recognize that the volume of HPC calls, compared with the total volume of calls a Call Centre Program handles, is likely to be quite low. It can therefore be somewhat of a challenge to develop and maintain competency and confidence around HPC calls within a generalist RN workforce. Brief, accessible opportunities to refresh learning should be available to staff at all times. One strategy is to create on-line presentation and reminder resources that summarize learning from the original training session. Another is to conduct nursing rounds to review actual calls/cases for lessons learned. These rounds can be brief (15-30 minutes) and combined with staff meetings or other regular gatherings to offset scheduling difficulties and training costs. Some Call Centres have telephone technology (e.g. Symposium) that allows calls, by type, to be directed to specific workstations. This is another way to ensure nurses are equally exposed to these calls or to prevent calls from going to nurses who have not been trained yet to manage them.


☎ The BCNL uses a PowerPoint presentation that RNs can access on-line at their workstations anytime as a refresher learning tool for its HPC/Telenursing service. The presentation, *Fraser Health HPC – How to Take a Call, Self-Learning Module*, takes 15-30 minutes to review.

A web-enabled PDF version of this document, featuring hyperlinks to selected additional resources referred to in this document, is available on the Pallium Project website at <http://www.pallium.ca>.

Community home health nurses and physicians retain their roles as the team experts in HPC and remain available to provide higher level or specialized care to patients and families when they most need it. Learning for these team members involves an in-depth introduction to the benefits and limitations of Call Centre Programs and telenursing, and an understanding of their roles and responsibilities within the referral/follow-up process.

Definition for ‘Enhanced Telenursing Practice’

The following definition was developed by the BC NurseLine to describe enhanced telenursing practice (in the context of new program development) and may be useful for adoption by other Call Centre Programs.



*The BC NurseLine’s
definition of
‘Enhanced
Telenursing Practice’
may be useful for
adoption by other Call
Centre Programs.*

‘Enhanced telenursing practice is an enriched or strengthened application of the nursing process (assessment, intervention, plan, and evaluation) which is focused on specific call types or target populations and augments the fundamental or essential competencies of a telenurse.

Once the fundamental competencies have been mastered, enhanced practice is developed through continuing education activities and nursing experience. It can be supported by a variety of advanced/secondary decision support tools. Education is provided to assist the nurse to move along the continuum of practice from novice to expert.

Examples of enhanced practice include the focused assessment for eligible HPC Calls, Breastfeeding Calls and providing decision support to callers needing to make pressure-sensitive decisions.’

BC NurseLine/FH Curriculum Outline for Call Centre Programs

Training Goals

Prepare Call Centre Program RNs to respond to the needs of hospice palliative callers or their caregivers in the context of integrative service provision.

Core Competencies Required to Support Enhanced HPC Telenursing Practice

- understand the philosophy and principles of HPC
- understand the HPC community partner's service delivery model and the Call Centre Program's role within the service delivery model
- understand the competency expectations of enhanced HPC telenursing practice
- use the palliative specific resources (referral information; assessment protocols/ other tools) to promote access to and facilitate delivery of HPC within the HPC community partner's jurisdiction
- perform an enhanced HPC assessment (history and symptom assessment)
- refer to HPC community partner protocols where they exist (e.g. management of pain; management of bowels)
- identify potential palliative care emergencies
- understand how the Call Centre Program decision support software/tool has been augmented to include enhanced HPC information
- provide medication direction for palliative patients by restricted advice for new over-the-counter (OTC) medications
- utilize modified disposition guidelines for eligible HPC clients
- refer callers to specific HPC community partner grief and bereavement services
- use knowledge of end-of-life care planning and refer to local or regional strategies and resources available
- knowledge of the Palliative Performance Scale [PPS] (Victoria Hospice Society)/ other assessment tools and how they are used to describe the functional status of palliative patients
- recognize options for referring eligible HPC callers if they are dissatisfied with HPC community partner service (HPC Clinical Nurse Specialist)
- understand the normal dying process
- understand the importance of directing patients back to the primary care physician or HPC community partner at end-of-life decision points rather than provide decision support over the telephone
- locate HPC reference material (electronic or paper) within Call Centre knowledge management system
- participate in continuing HPC education through Call Centre Program

Suggested Pre-Reading

- HPC Community Partner materials about their mission and services
- McGoey, Ann. (2003). End-of-life care. *Canadian Nurse*, 99(3), 27-31. This article is third party content published in *Canadian Nurse*. It is not included on the CD-ROM that accompanies this report.
- *When Someone is Dying* pamphlet from Fraser Health (outlines what to expect and what to do when someone is dying and how to manage death at home)
- The Palliative Care Quiz for Nursing (Pre-test) to stimulate personal reflection about end-of-life and HPC care

A web-enabled PDF version of this document, featuring hyperlinks to selected additional resources referred to in this document, is available on the Pallium Project website at <http://www.pallium.ca>.

Append the suggested following examples of training tools developed/used for the Fraser Health/BC NurseLine initiative:

- *When Someone is Dying* pamphlet from Fraser Health (outlines what to expect and what to do when someone is dying and how to manage death at home)
- The Palliative Care Quiz for Nursing (Pre-test) to stimulate personal reflection about end-of-life and HPC care
- McGoey, Ann. (2003). End-of-life care. *Canadian Nurse*, 99(3), 27-31. This article is third party content published in *Canadian Nurse*. It is not included on the CD-ROM that accompanies this report.
- HPC Community Partner materials about their mission and services
- PowerPoint developed by D. Roberts for BCNL training session entitled *Hospice Palliative Care*, January 2005
- HPC workshop case scenarios
- *The BC NurseLine: A Platform for Innovative Partnerships in Health Care Delivery*, a PowerPoint presentation prepared for the Home and Community Care Leaders Conference in BC, provides an overview of how the FHA/BCNL initiative unfolded including lessons learned on implementation, March 2005
- *Telenursing: Two Innovative projects to increase access for Hospice Palliative Care Patients & Families*, a PowerPoint presentation prepared for the 2005 British Columbia Hospice Palliative Care Association (BCHPCA) Conference, May 2005
- HPC Workshop Outline (sample workshop training agenda)
- Steps to transfer care and fax referral – a checklist for telenurses
- Shift Leader/Designate Checklist for HPC Calls – a checklist for the Call Centre supervisor

A web-enabled PDF version of this document, featuring hyperlinks to selected additional resources referred to in this document, is available on the Pallium Project website at <http://www.pallium.ca>.

Example BC NurseLine/FH Curriculum Outline for HPC Community Partners

Training Goals

Prepare HPC Community Partner to work with a Call Centre Program, in the context of integrative service provision, and provide support to HPC clients and families after hours.

Core Competencies Required by HPC Community Partners

- knowledge of telenursing practice in Canada – advantages and limitations
- basic understanding of Call Centre Program operations
- familiarity with end-of-life information available to the public on-line
- familiarity with enhanced HPC content being used by Call Centre Program
- referral process from Call Centre Program including understanding of modified triage protocols
- response/communication with the Call Centre Program
- knowledge of standards of providing telephone advice
- knowledge of the call flow for the after-hours patient call
- clinical management to meet the needs of HPC clients and families
- accessing community resources for clients at home
- documentation of the call
- communication with Home Health for ongoing support for HPC clients and families

Append the following examples of training tools developed/used for the Fraser Health / BC NurseLine initiative:

- Education Plan for After-hours Palliative Response Service
- *The BC NurseLine: A Platform for Innovative Partnerships in Health Care Delivery*, a PowerPoint presentation prepared for the Home and Community Care Leaders Conference in BC, provides an overview of how the FHA/BCNL initiative unfolded including lessons learned on implementation, March 2005
- *Telenursing: Two Innovative projects to increase access for Hospice Palliative Care Patients & Families*, a PowerPoint presentation prepared for the British Columbia Hospice Palliative Care Association (BCHPCA) Conference, May 2005
- HPC Workshop Outline (sample training agenda)

A web-enabled PDF version of this document, featuring hyperlinks to selected additional resources referred to in this document, is available on the Pallium Project website at <http://www.pallium.ca>.

Sample Education Plan for Fraser Health Palliative Response Nurses (PRN)

0830-1630

AM

Orientation to Role

- FHA BC Nurse Line Model
- Orientation to BCNL call flow process
- Triage and Intervention (PRN) role
- Difference between HCN and PRN role
- Overview of telehealth standards and accountabilities.
- Roles of Family physician, CNS, Palliative Physician on call

Palliative care patients and potential reasons for calling

- Building patient capacity to manage their symptoms and crisis management framework

PM

- Tools/systems
- Call Flow
- Database
- Decision making support
- Selecting intervention strategies
- Documentation
- Communication with Home Care Office
- Evaluation data

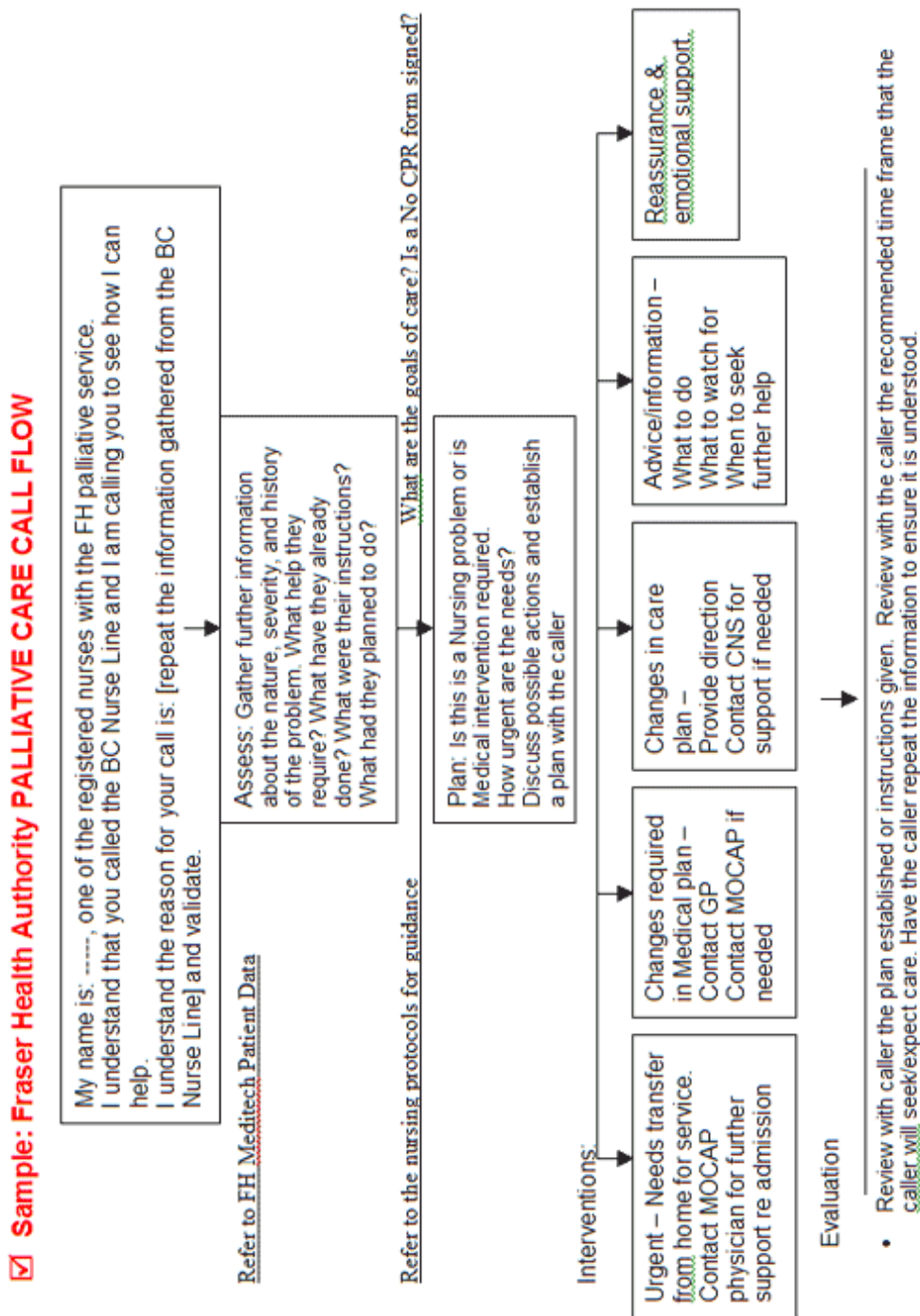
Home Visits

- Decision making
- Security and safety

Technology supports

- On call schedule
- Cell phone
- Accessing patient data from home

☎ Sample: Fraser Health PALLIATIVE CARE CALL FLOW



☎ Sample Fraser Health Support Tool

PALLIATIVE RESPONSE BINDER

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SECTION VI: JOINT QUALITY IMPROVEMENT AND EVALUATION

A joint commitment to risk management and quality improvement by all partners involved in an enhanced HPC Telenursing service is necessary to keep it safe and responsive. While each partner may be responsible for collecting certain data, or monitoring certain aspects of the service delivery, positive health service delivery and patient/family outcomes will only be achieved by working together.

Joint Quality Improvement groups from HPC and telenursing initiatives will help ensure that the protocols are kept safe and responsive in the future.

☑ A good place to start is to plan a regular forum for reviewing and analyzing the data collected, and addressing any risk issues in a timely fashion. A joint Quality Improvement working group should be comprised of members representing both partners and having excellent working knowledge of the enhanced HPC Telenursing service.

The joint QI working group should then identify potential points of risk for clients using the service (e.g., information exchange between Call Centre and after-hours HPC nurse) and decide how they will measure that risk. Conversely, the working group should decide jointly what success will look like, remembering to consider all stakeholders perspectives, and decide from there how they will measure that success. Indicators of both risk and success will form the backbone of data collection. Be cautious about collection of superfluous data just because it is technologically possible. Focused data collection is both ethical and cost-effective.

A thorough review of all calls for the first few months of service for both the Call Centre and after-hours calls is also a good idea. It can provide early indication for tweaking work flow and communication processes and highlight unexpected areas of risk.

Additional assumptions that may help inform this process include:

- Calls related to this project will also be analyzed as a sub-set of all calls handled by the Call Centre Program in terms of core-performance measures.
- Correlation of data from community and Call Centre partners will be required to complete the profile of callers who use this service.
- Both partners will manage this program within their existing quality improvement frameworks (i.e., occurrence reporting, review and quality improvement initiatives, including communication) and as a joint process.

 **Suggested Indicators for Quality Improvement Monitoring**

Indicator	Data source Call Centre Program	Data source HPC Community Partner	Data source Other
Number of calls from eligible HPC clients to Call Centre Program with day/time trends	Telephony stats Caller contact records		
Number of referrals to HPC community partner – reconcile numbers with both partners	Telephony stats Caller contact records	Telephone stats. Documentation by after-hours nurse.	
Actual call volume against potential call volume	Telephony stats	Projected use estimates to come from HPC community Partner.	
Demographics and clinical snapshot of callers most likely to use the service	Caller contact records	Clinical data about nature of each caller’s illness and Palliative Performance Scale rating (PPS) can be collected in the follow-up phone call for the first X calls and on an ongoing basis as part of the joint QI process.	
Reason for call (Reconciling this with HPC community partner data is a separate evaluation project that might be jointly undertaken as funded Research)	Caller contact records: Problem/ problem category Pre-call intent Nurses notes	After-hours HPC community partner documentation – reason for call.	
Disposition of calls	Call contact records: disposition	Documentation of response to referral – action taken and disposition. As well, follow up with the home care nurse of patient within 4 days of the call to identify outcomes.	Follow up with the patient’s home health provider within 4 days of the call to identify the place of care 24 hours after the call (for the initial 4 months of service at least).

Indicator	Data source Call Centre Program	Data source HPC Community Partner	Data source Other
Clinical issues (re: HPC that arise as a result of implementation of this program); most frequently accessed topics in decision support tool; most frequently accessed enhanced HPC content/ protocols	Decision support software data. Call Centre might explore feasibility of correlating 'disposition data' with 'topic accessed data' during analysis to provide more robust clinical snapshot of clients.		
Call and documentation quality	Random call audits. Joint review of calls (all calls initially and then randomly selected calls). All occurrence reports about this program.	Documentation audits. Joint review of calls (all calls initially and then randomly selected calls). All occurrence reports about this program.	
360-degree feedback from staff providing the service through focus group, e-mail and survey and callers. Does staff feel prepared to take the calls? Are resources adequate? What should we stop doing? Start doing? Keep doing? This is part of broader program evaluation (possibly a separate project) and not part of the joint QI process.	Coordinate focus groups x 2 at three month post-implementation. Collect and collate e-mails related to implementation. Survey staff by electronic bulletin board with targeted questions to be jointly determined by joint QI working group.	Coordinate focus groups x 2 at 3 month post-implementation. Collect and collate e-mails related to implementation. Survey staff by electronic bulletin board with targeted questions to be jointly determined by joint QI working group.	This measure will be linked to the provincial strategy and the concept of 24/7 care.

Indicator	Data source Call Centre Program	Data source HPC Community Partner	Data source Other
Caller satisfaction		Mailed survey questionnaire to family member of patient one month following the call.	
Occurrence reports – review of and response to	Joint review with HPC community partner.	Joint review with Call Centre Program.	Levels 3-5 occurrences review.
Clinical issues re: HPC that arise as a result of implementation of this program	Identify through the Call Centre Program's clinical issues resolution process.	Program Coordinator in close contact with HPC community partner after-hours staff for the first 4 months to identify clinical issues requiring resolution.	

SECTION VII: ENDNOTES

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- ¹¹ Ipsos-Reid Survey. (2004). *Hospice Palliative Care study: Final report*. Ottawa: The Canadian Hospice Palliative Care Association and the GlaxoSmithKline Foundation.

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SECTION IX: STANDARDS AND GUIDELINES

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SECTION X: APPENDIX — ADDITIONAL DOCUMENTS/ RESOURCES

Supplemental resources referred to in this document are listed below. The web-enabled version of this document, featuring hyperlinks to these selected additional resources, is available on the Pallium Project website at <http://www.pallium.ca>.

Supporting Document	Short Description	Format	Page #
Transcript from the Hospice Palliative Care Telenursing Subproject, Stakeholder Briefing, Question and Answer Session	Transcript that captures the Question and Answer Session from the DVD/streaming video recorded as part of the HPC Telenursing Subproject, Stakeholder Briefing meeting held on September 29, 2005, in Edmonton, AB. This document also includes the agenda for this meeting and the participant list.	PDF	Foreword
Hospice Palliative Care (HPC) Protocols for Telenursing: Stakeholder Briefing and Orientation	PowerPoint presentation delivered by Carolyn Tayler, Chair of the Subproject Steering Committee, as part of the HPC Telenursing Subproject, Stakeholder Briefing meeting held on September 29, 2005.	PowerPoint	Foreword
Hospice Palliative Care (HPC) Protocols for Telenursing: Proof of Concept—Case Study, BC NurseLine & Fraser Health	PowerPoint presentation delivered by Della Roberts (Fraser Health) and Diane MacCormack (BC NurseLine) as part of the HPC Telenursing Subproject, Stakeholder Briefing meeting held on September 29, 2005.	PowerPoint	Foreword
<i>Hospice Palliative Care and Telenursing: A Proposal for Partnership</i>	PowerPoint presentation that captures the core assumptions of integrating HPC and Call Centre Programs. It is useful for introducing stakeholders to the current state of both hospice palliative care and telenursing in Canada and for arguing for the development and implementation of integrated HPC/telenursing services in western Canada.	PowerPoint	Page 16
<i>Fraser Health HPC—How to Take a Call Self-Learning Module</i>	PowerPoint presentation that RNs can access on-line at their workstations anytime as a refresher learning tool for its HPC/Telenursing service. The presentation takes 15-30 minutes to review.	PowerPoint	Page 44
HPC Community Partner materials about their mission and services	Document that outlines the mission of Fraser Health, criteria for individuals who are referred for Fraser Health HPC services, and the HPC services offered by Fraser Health.	MS Word	Page 47
McGoey, Ann. (2003). End-of-life care. <i>Canadian Nurse</i> , 99(3), 27-31.	This article is third party content published in <i>Canadian Nurse</i> (website: http://www.canadian-nurse.com/). It is not included on the CD-ROM that accompanies this report.	N/A	Page 47
<i>When Someone is Dying</i> pamphlet	Fraser Health pamphlet that outlines how to expect and what to do when someone is dying and how to manage death at home.	MS Word	Page 47

A Development Framework for Hospice Palliative Care (HPC) Enhancements
within an Existing Health Call Centre Program (December 2005)

Supporting Document	Short Description	Format	Page #
The Palliative Care Quiz for Nursing (pre-test)	Pre-test to stimulate personal reflection about end-of-life and HPC care.	MS Word	Page 47
<i>Hospice Palliative Care</i>	PowerPoint developed by Della Roberts for BCNL training session <i>Hospice Palliative Care</i> , January 2005.	PowerPoint	Page 47
HPC Workshop Case Scenarios	Two HPC scenarios that can be used in a training workshop.	MS Word	Page 47
<i>The BC NurseLine: A Platform for Innovative Partnerships in Health Care Delivery</i>	PowerPoint presentation prepared for Home and Community Care Leaders Conference in BC in March 2005. It provides an overview of how the FHA/BCNL initiative unfolded including lessons learned on implementation.	PowerPoint	Page 47, 48
<i>Telenursing: Two innovative projects to increase access for Hospice Palliative Care Patients & Families</i>	PowerPoint presentation prepared for the 2005 British Columbia Hospice Palliative Care Association (BCHPCA) Conference, May 2005.	PowerPoint	Page 47, 48
HPC Workshop Outline	Sample workshop training outline.	MS Word	Page 47, 48
Steps to Transfer Care and Fax Referral – Checklist for Telenurses	Checklist with the steps to transfer care and fax referral.	MS Word	Page 47
Checklist for the Shift Leader/Designate Supervisor for HPC calls	Checklist that outlines the Shift Leader/Designate Supervisor responsibilities for HPC calls.	MS Word	Page 47
Education Plan for After-hours Palliative Response Service	These two documents assist in developing an education plan for an after-hours palliative response service.	MS Word	Page 48
A Development Framework for Hospice Palliative Care (HPC) Enhancements within an Existing Health Call Centre Program	Report of the Pallium HPC Telenursing Protocols Subproject (December 2005). A web-enabled version of this colour-coded report is available on the Pallium Project website at http://www.pallium.ca .	PDF	This Report document