

# **Provincial Hospice Palliative Care Project**

Final Report and Recommendations  
October 4, 2005

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## Executive Summary

### **Context:**

Palliative care (also known as “hospice palliative care”) relieves suffering and/or improves the quality of living and/or dying for those individuals who are living with a progressive life-threatening illness/injury at the end of life and/or who are bereaved.

The Department of Health initiated a project in November 2002 to develop a provincial approach to hospice palliative care. The work of this project is based on the Canadian Hospice Palliative Care Association document, *A Model to Guide Hospice Palliative Care* and is designed to be consistent with those recommendations. The overall objective was to ensure that all Nova Scotians who need end-of-life care have access to appropriate and quality hospice palliative care services. Specific objectives of the project were to:

- make recommendations for service delivery guidelines
- assist with understanding existing services relative to these guidelines
- provide information for further planning purposes

To fulfill the established objectives, the project structure included an Executive Steering Committee, four working groups, and a Project Management Team comprised of the working group chairs and Department of Health support staff.

The Executive Steering Committee has endorsed service delivery guidelines found in the recommendations of the working groups which incorporates feedback from the information sharing and consultation sessions. These guidelines are based on evidence of best practice and existing research at the national and provincial levels.

The provincial approach incorporates the vision, mission, values, and guiding principles previously endorsed by the Executive Steering Committee. The working group recommendations also describe Functional Elements/Components of the Service Delivery Guidelines which are:

- Referral or Access
- Referral Source
- Coordination and Continuity of Care
- Care Planning and Delivery
- Palliative Care Consult Team
- Interdisciplinary Primary Care Team
- Timely and Consistent Review
- Community Support
- Bereavement Support

It is important to note that the service delivery guidelines do not represent a model which prescribes the resources and care/treatment processes and services to be funded in each DHA and the IWK Health Centre. Rather, they encompass guidelines for a provincial approach that is consistent with the provincial vision, is client-centred,

integrated, effective, evidence-based and uses reasoned resources.

### **Information Sharing Sessions:**

The project is now moving from planning to the operational phase. As an initial step in this transition, information sharing sessions were held with key stakeholders in each District Health Authority and IWK Health Centre in the Fall of 2004. The Service Delivery Guidelines developed by the working groups were presented at these sessions.

Survey templates for both DHAs and Continuing Care and Long Term Care Facilities were completed by participants to determine where the districts are relative to the provincial approach to inform initial planning and change management.

### **Recommendations:**

The analysis of the district survey findings has led to the following recommendations. It is recommended that:

1. The Department of Health approve the Service Delivery Guidelines, based on the National Guidelines, as a framework for program development to be used by the DHAs and IWK Health Centre;
2. a shared chart system be adopted, for example, that used in the former Rural Hospice Palliative Care Project (CEHHA, CHA, PCHA);
3. a single entry access point be adopted for palliative care programs, for example, Continuing Care 1-800#;
4. a common assessment tool that is evidence-based be adopted;
5. the Provincial Hospice Palliative Care Volunteer Resource Manual be adopted for palliative care volunteers;
6. consistent program indicators of performance be adopted to support service delivery and evaluation supported by consistent information technology;
7. service delivery be community based and based on an integrated interdisciplinary approach; and
8. Common consistent entitlements be made available across the province.

Over the longer term, it is recommended that the Functional Elements/ Components as identified in the Provincial Approach be the foundation for collaborative action to:

1. Identify priorities from a provincial perspective, particularly in view of potential federal cost-sharing opportunities;
2. Develop a framework and evidence-based process for program planning which acknowledges DHA opportunities; and
3. Develop an implementation plan for a province-wide integrated, community-based palliative care approach.

As the provincial palliative care program evolves it must remain consistent with the national norms of practice.

# Provincial Approach to Hospice Palliative Care Project Final Report and Recommendations

## BACKGROUND

### Introduction:

The work of Senator Sharon Carstairs<sup>1</sup>, Senator Michael Kirby, and Commissioner Roy Romanow<sup>2</sup>, have brought into focus the variable and fragmented nature of hospice palliative care services across Canada. As a result, attention to and recognition of hospice palliative care as an essential service for all Canadians has become a major part of the current health care debate.

In Nova Scotia, hospice palliative care services have developed unevenly across districts and care settings. In 1998 the Nova Scotia Working Group on Palliative Care produced a discussion document detailing a framework for comprehensive and integrated palliative care. In 2000, the Department of Health initiated the Rural Palliative Home Care Pilot Project in the Northern Region. In June 2001, Cancer Care Nova Scotia held a Palliative Care Roundtable “to develop strategies for facilitating the implementation of a comprehensive, accessible, integrated approach to the delivery of palliative care services for cancer care in Nova Scotia.”<sup>3</sup>

Recognizing the important work that has been done, both provincially and nationally, the Department of Health initiated a project to provide guidance to a provincial approach to hospice palliative care to ensure that all Nova Scotians who need end of life care have access to appropriate and quality hospice palliative care services. This became the vision for the project.

### Definition:

Palliative care (also known as “hospice palliative care”) relieves suffering and/or improves the quality of living and/or dying for those individuals who are living with a progressive life-threatening illness/injury at the end of life and/or who are bereaved. Hospice Palliative Care is a combination of active and compassionate therapies that address the physical, psychological, social, spiritual and practical needs of individuals who are living with a life threatening illness and their families. Hospice palliative care cuts across care settings and involves a network of health professionals as well as family care givers and volunteers.

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<sup>1</sup>The Senate Subcommittee to Update “Of Life and Death”, chaired by Senator Carstairs, Minister with Special Responsibility for Palliative Care, released its final report in June 2000 . For more information see [http://sen.parl.gc.ca/scarstairs/PalliativeCare/PalliativeCare\\_e.asp](http://sen.parl.gc.ca/scarstairs/PalliativeCare/PalliativeCare_e.asp).

<sup>2</sup>The Commission on the Future of Health Care in Canada chaired by Roy Romanow released its final report in November 2002, For more information see <http://www.healthcarecommission.ca/default.asp?DN=cn=2,ou=Stories,ou=Suite247,o=HCC>.

<sup>3</sup>Cancer Care Nova Scotia. (June 2001). Report on the Palliative Care Roundtable. CCNS: Halifax. p. 1.

Hospice palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.

Hospice palliative care may complement and enhance disease-modifying therapy or it may become the total focus of care.

Hospice palliative care is most effectively delivered by an interdisciplinary team of health care providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice. These providers are typically trained by schools or organizations that are governed by educational standards. Once certified, providers are accountable to standards of professional conduct that are set by licensing bodies and/or professional associations<sup>4</sup>.

Hospice palliative care is most applicable in those situations where disease modifying interventions are not expected to save or significantly prolong life. For the purposes of this project, hospice palliative care essentially refers to end of life care and bereavement support.

Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement.

Hospice palliative care aims to:

- treat all active palliative care issues; i.e., management of symptoms, loss, grief, and transitions
- prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

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<sup>4</sup>Canadian Hospice Palliative Care Association. (2002). A Model to Guide Hospice Palliative Care: Ottawa, pp. 17-18.

## **PROVINCIAL APPROACH TO HOSPICE PALLIATIVE CARE PROJECT**

### **Project Purpose and Objectives:**

The purpose of the project was to develop a provincial approach to hospice palliative care. Specific objectives were to:

- make recommendations for service delivery guidelines
- assist with understanding existing services relative to these guidelines
- provide information for further planning purposes

### **Project Structure:**

To fulfill the established objectives, the project structure included an Executive Steering Committee, four working groups, and a Project Management Team comprised of the working group chairs and Department of Health support staff.

Approximately 60 people from across the province were directly involved in the project as members of the project steering committee or working groups, over 70% of whom came from the District Health Authorities, IWK Health Centre, universities, community colleges, Nova Scotia Hospice Palliative Care Association, home care agencies, long term care facilities, and other organizations in the health system.

The role of the Executive Steering Committee was to provide overall direction for the development of a provincial approach to hospice palliative care including approval of the project structure and scope, and monitoring progress against predetermined targets.

The four working groups were Individual and Family Care, Human Resources/ Management Infrastructure, Research and Evaluation, and Education and Orientation.

The names and affiliations of the Executive Steering Committee and working group members is attached in Appendix "D".

The working groups developed Service Delivery Guidelines which were endorsed by the Executive Steering Committee to guide the discussion at the information sharing and consultation sessions with the District Health Authorities and IWK Health Centre and the Continuing Care sector. The provincial approach incorporates the vision, values, guiding principles, service delivery guidelines, functional elements, and roles and responsibilities of the palliative care team as presented below and was validated at the Information Sharing and Consultation Sessions with the DHAs and Continuing Care and the Long Term Care facilities.

### **Vision:**

All Nova Scotians who need end-of-life care have access to appropriate and quality hospice palliative care services.

### **Values:**

Hospice palliative care is based on and ***continuously supported*** by the following values:

- The central and unique value of each and every person. This includes those who are independent and able to make decisions for themselves as well as infants, children, and cognitively impaired adults who may require someone else to act on their behalf.
- The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualization.
- The need to address individuals' and families suffering, expectations, needs, hopes and fears.
- Care is only provided when the individual and/or family is prepared to accept it.
- Care is guided by quality of life as defined by the individual.
- Caregivers enter into a therapeutic relationship with individuals and families based on dignity and integrity.
- A unified response to suffering strengthens communities

### **Guiding Principles:**

The following principles are essential to and ***continuously guide*** the development and delivery of hospice palliative care services:

#### **1. Individual and Family Focussed**

As individuals are typically part of a family, when care is provided the individual and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the individual and family's personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

#### **2. High Quality**

All hospice palliative care activities are guided by:

- the ethical principles of autonomy, beneficence, non-maleficence, justice, truth-telling and confidentiality.
- policies, procedures, and care processes that are based on the best available evidence or opinion-based preferred practice guidelines

- data collection / documentation guidelines that are based on validated measurement tools.

### **3. Safe and Effective**

All hospice palliative care activities are conducted in a manner that:

- is interdisciplinary and team-based
- is collaborative
- ensures confidentiality and privacy
- is without coercion, discrimination, harassment or prejudice
- ensures safety and security for all participants
- ensures continuity and accountability
- aims to minimize unnecessary duplication and repetition
- complies with laws, regulations and policies in effect within the jurisdiction, host and hospice palliative care organization.

### **4. Accessible**

All individuals and families have equal access to hospice palliative care services:

- as they choose and at an easily accessed point of entry
- wherever they live and /or choose to receive services, recognizing that creative efforts are required to overcome geographic isolation.
- in a timely manner as identified by the service delivery organization

### **5. Adequately Resourced**

Resources are allocated based on the DHA's capabilities and priorities. The financial, human, information, physical and community resources are sufficient to sustain the program activities, as determined in strategic and business plans.

### **6. Collaborative**

Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership with the District Health Authority.

### **7. Knowledge-Based**

Ongoing education of all individuals, families, caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.

## **8. Advocacy-Based**

Regular interaction with legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and associations, and the public is essential to increase awareness about, and develop, hospice palliative care activities and the resources that support them. All advocacy recognizes the Canadian Hospice Palliative Care Association's *A Model to Guide Hospice Palliative Care*. (Ottawa, 2002). The work of this project is based on that document.

## **9. Research-Based**

The development, dissemination, and integration of new knowledge is critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations governing research and the involvement of human subjects in effect within the jurisdiction.

## **SERVICE DELIVERY GUIDELINES**

The Individual and Family Care Working Group developed service delivery guidelines which were endorsed by the Executive Steering Committee as well as the other working groups. These guidelines are based on evidence of best practice and existing research at the national and provincial levels and incorporates feedback from the information sharing and consultation sessions.

It is important to note that the service delivery guidelines do not represent a model which prescribes the resources and care/treatment processes, services, and standards to be funded in each DHA and IWK Health Centre. Rather, they encompass guidelines for a provincial approach that is consistent with the provincial vision, is client-centred, integrated, effective, evidence-based, and uses reasoned resources.

This range of services is delivered by an interdisciplinary network of providers knowledgeable and skilled in hospice palliative care, to those who are living with or dying from a progressive life-threatening or life-ending illness/injury and to those who are bereaved. The range of services are supported by or offer support to family caregivers and volunteers.

## **HUMAN RESOURCES/MANAGEMENT INFRASTRUCTURE RECOMMENDATIONS**

Hospice palliative care services are comprehensive in nature, addressing the physical, psychological, social and spiritual needs of individuals and families in the care setting of choice and by the most appropriate team members at any point in the care experience. The roles and responsibilities of the various members of the palliative care team, as developed by the Human Resources/Management Infrastructure Working Group, are included in Appendix "C".

### **Functional Elements/Components of Service Delivery Guidelines:**

To actualize consistent application of the purpose, values and guiding principles, the service delivery guidelines include the following elements or service components.

#### **1. Referral or Access**

To ensure easy and consistent access, Continuing Care will be identified as the single entry point for access to the service via the existing 1-800 # for the district. This can be in addition to established traditional access points. Registration with the service, intake, screening for quick response, baseline data collection, education/

public information, and case deployment will occur at the point of entry. A flow chart depicting a sample single point of entry is included in Appendix “A”.

## **2. Referral Source**

To ensure an individual/family-centred approach, increased access, and a timely response to services, referrals to the service can be made directly by the individual/family or by health professionals.

## **3. Coordination and Continuity of Care**

To ensure that care is integrated across the continuum of care (i.e. across all care settings), a case management approach will be applied. A case coordinator or manager will be identified. This may be a continuing care coordinator or a palliative care consult RN, whichever resource is the most appropriate or available to the case. The case coordinator or manager will facilitate care plan development and weekly case review, as needed, to ensure that needs and expectations are managed in a timely manner.

## **4. Care Planning and Delivery**

The individual and family will be included in care planning and all decision making around care delivery. A palliative care assessment tool will guide assessment and a palliative care plan will be developed to meet the needs and expectations of the individual and family in all settings of care. A palliative care chart could be constructed and utilized by all team members and should stay with and follow the individual throughout the care experience.

## **5. Palliative Care Consult Team**

The service and primary provider team will be supported by an interdisciplinary clinical team with expertise and skill in the management of complex symptom management, advanced care planning, and bereavement counselling. This team will consist of a palliative care physician, palliative care consult RN, pharmacist, and social worker. Spiritual support will also be available. This consult team will provide leadership, advice, guidance and support to individuals, families, and care providers.

## **6. Interdisciplinary Primary Care Team**

An individual/family-centred care plan will be developed and implemented by a team of knowledgeable and skilled providers who will collaborate to meet the individual and family’s physical, psychosocial, and spiritual needs. The team includes, but is not limited to, the family physician or attending physician, designated continuing

care coordinator/case manager, registered nurse/licensed practical nurse, and other providers as available and deemed appropriate to the situation.

## **7. Timely and Consistent Clinical Review**

Weekly palliative care rounds will be held to facilitate effective provider and consult team communication, timely referral to needed interventions or resources, progress evaluation of care outcomes and individual/family expectations, and to ensure that the complex needs of the individual and family are accurately met.

## **8. Community Support**

Volunteers, family caregivers, and other supports available in the community will be included in the plan of care as deemed appropriate by the individual and family. These supports will be assisted by the interdisciplinary consult and provider teams in appropriately meeting the needs of the individual and family as well as their own needs for learning and support.

## **9. Bereavement Support**

Grief counselling may be provided by those prepared in offering support with spiritual support available as requested or deemed appropriate. Bereavement care will be part of the care plan for the surviving family and caregiver system. As such, it will be coordinated and managed by the case manager in consultation with the primary care team and, as required, with the palliative care consult team.

A flow chart depicting a sample approach for navigating individuals through hospice palliative care is included in Appendix "B".

### **Assumptions:**

The Service Delivery Guidelines were developed in the context of underlying considerations that were identified by the Executive Steering Committee at the outset of the project. The underlying considerations that influenced and impacted this project were:

- Financial resources are a constant challenge
- Health Human Resource issues such as recruitment and retention present challenges
- The respective roles and responsibilities of the Department of Health and District Health Authorities as outlined in the Health Authorities Act are understood.

## **INFORMATION SHARING AND CONSULTATION SESSIONS**

The Service Delivery Guidelines were presented to key stakeholders in each district and the IWK Health Centre in the Fall of 2004. The discussion was further supported by the companion survey document which was used to gain an understanding of what processes and services are in place within these core areas. It is important to note that the survey template was not a tool for assessing and evaluating current service provision nor was it a gap analysis. Rather, it was intended as a means of gathering information to inform initial planning and change management.

Survey templates for DHAs, IWK Health Centre, and Continuing Care and Long Term Care facilities were completed by participants to determine where the districts and IWK Health Centre are relative to the provincial approach. An overview of the collated information for each of the functional elements as well as the raw data with details by individual districts has been maintained as a separate document.

## **RECOMMENDATIONS**

The analysis of the district survey findings has led to the following recommendations. It is recommended that:

1. The Department of Health approve the Service Delivery Guidelines, based on the National Guidelines, as a framework for program development to be used by the DHAs, IWK Health Centre, and Continuing Care;
2. a shared chart system be adopted, for example, the one used in the Rural Hospice Palliative Care Project (CEHHA, CHA, PCHA);
3. a single entry access point be adopted for palliative care programs, for example, Continuing Care 1-800#;
4. a common assessment tool that is evidence-based be adopted;
5. the Provincial Hospice Palliative Care Volunteer Resource Manual be adopted for palliative care volunteers;
6. consistent performance indicators of programs be adopted to support service delivery and evaluation supported by consistent information technology;
7. service delivery be community based and based on an integrated interdisciplinary approach; and
8. Common consistent entitlements be made available across the province.

Over the longer term, it is recommended that the Functional Elements/ Components as identified in the Provincial Approach be the foundation for collaborative action to:

1. Identify priorities from a provincial perspective, particularly in view of potential federal cost-sharing opportunities;
2. Develop a framework and evidence-based process for program planning which acknowledges DHA opportunities; and
3. Develop an implementation plan for a province-wide integrated, community-based palliative care approach.

Although outside of the project scope, it is evident that some human resource issues exist as identified from the district information sharing sessions. Specifically, it is noted that dedicated medical expertise and palliative care coordinators were considered essential for a functioning palliative care program to be developed.

## **EDUCATION AND ORIENTATION RECOMMENDATIONS**

Education and Orientation recommendations are:

1. that Hospice Palliative Care be included in core educational programming for all disciplines;
2. the acknowledgment and inclusion of the following Stakeholder groups in all related initiatives:
  - Agencies - Direct Support Services
  - Volunteer Associations
  - Professional Associations
  - Providers
  - Public
  - Policy Decision Makers (i.e. Department of Health/District Health Authorities/Department of Community Services/Community Health Boards)
  - Industry Associations
  - Individuals/Families
  - Educational Institutions
3. the development of a Change Management strategy which would be embedded in all education and orientation including the following elements of change management:
  - identification of champions;
  - create a sense of urgency;

- a communication plan;
  - emphasis on outcomes; and
  - consistent message using a number of different venues.
4. the development of an orientation program to palliative care (administrators, providers, public) which has both generic and specific components to be offered to various groups within the system:
    - philosophy (care and comfort)
    - holistic model for service delivery
  5. the development of an orientation to the Service Delivery Guidelines:
    - purpose
    - origin
    - pathways to services
  6. the development of a specialized training program to meet the needs of specific providers;
  7. that Education and Orientation be included in the Evaluation Framework (reference Research and Evaluation Recommendations) for Hospice Palliative Care.
  8. that Education and Orientation is ongoing:
    - focus on existing and future workforce; and
    - include both professionals and non-paid workers.
  9. the endorsement and implementation of the Provincial Hospice Palliative Care Volunteer Resource Manual across Nova Scotia.

## **RESEARCH AND EVALUATION RECOMMENDATIONS**

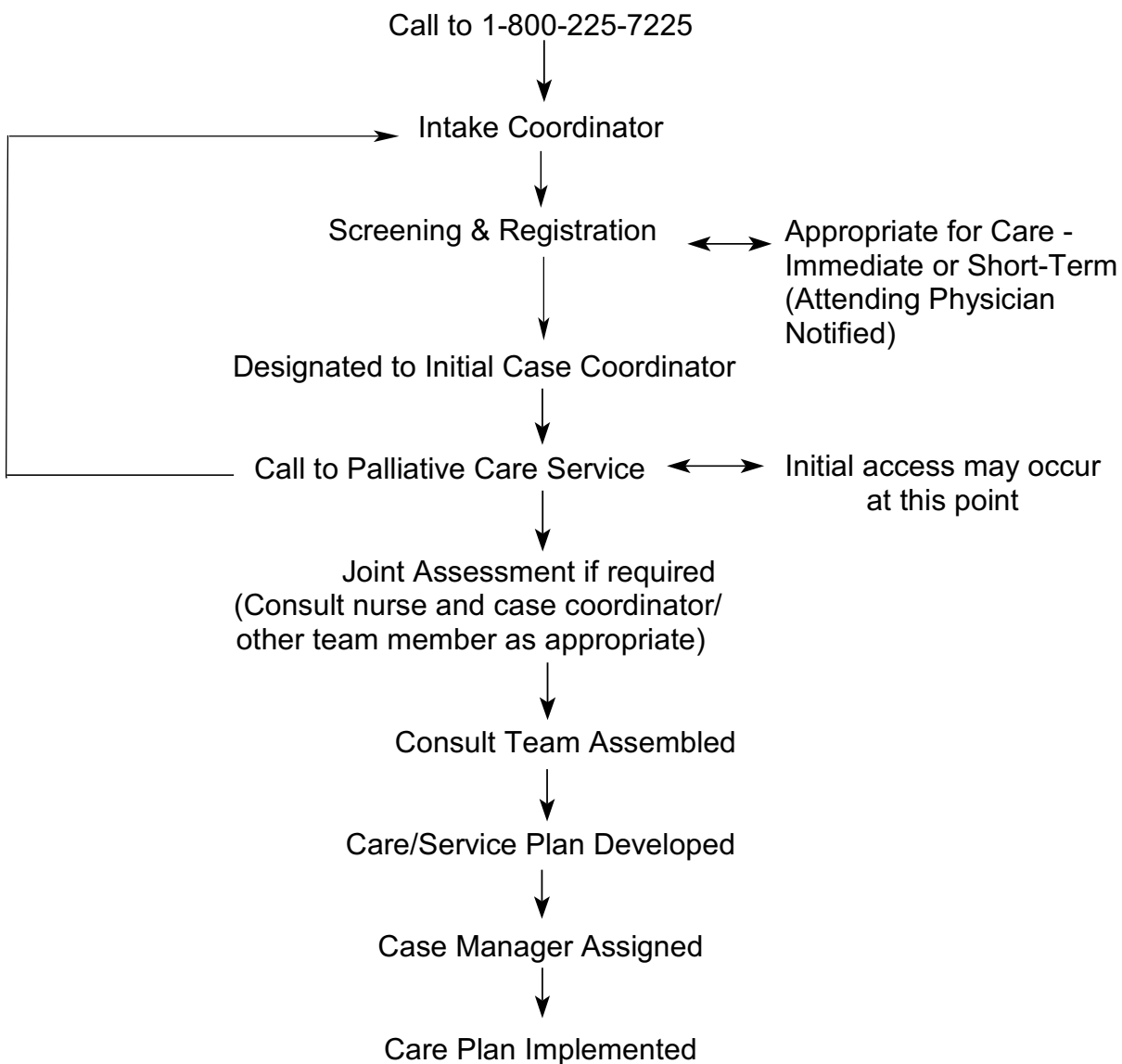
Research and Evaluation recommendations are:

1. the implementation of the Evaluation Framework attached in Appendix “D”;
2. the implementation of the Indicators attached in Appendix “E”;
3. the development of a clearing house/database of current and past research activities and resources including websites, other clearing houses which log HPC research (i.e. CHPCA, Canadian Virtual Hospice etc.) and/or journals and associations;

4. the Identification and development of best practices regarding the acquisition of research related resources, funding etc. (e.g. provincial memberships to electronic journals etc. - economically appropriate/responsible approaches);
5. the identification of training and educational requirements to support a better understanding of the research and the promotion of best practice literature (i.e. knowledge transfer activities); and
6. The development of a provincial HPC network (with national and international ties) to facilitate the exchange of ideas on needed research, ways to partner for access to funding, and announcements (i.e. research related forums) etc.

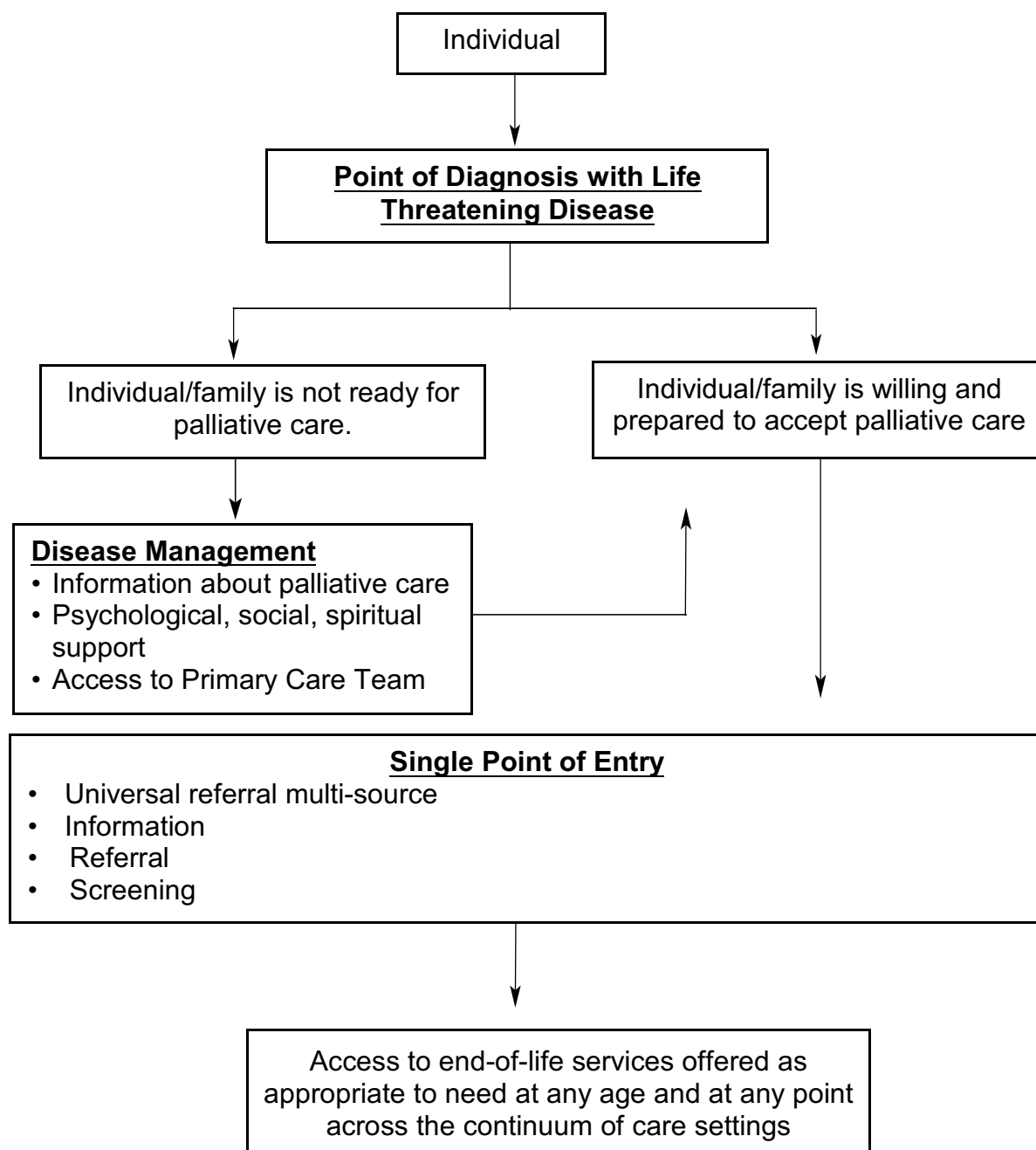
## APPENDIX "A"

### Sample Single Point of Entry Requiring/Requesting Care



## APPENDIX "B"

### Sample Approach for Navigating Nova Scotians Through Hospice Palliative Care



## APPENDIX “C”

### Roles and Responsibilities of the Palliative Care Team

To protect or insure the integrity of palliative care services, as a minimum, the following resources need to provide direction to the service.

**The Palliative Care Consult Team** - provides consultation and leadership to interdisciplinary frontline staff

#### 1. Palliative Care Resource Physician

- Provides a palliative care medical assessment for individuals referred by their family physician.
- Supports family physicians in the care of palliative care individuals and families
- Provides education to family physicians in the care of palliative care individuals and families
- Participates in weekly palliative care rounds
- Provides consultation to palliative care team members
- Participates in the development, implementation, and evaluation of clinical protocols and practice guidelines
- Contributes to the palliative care knowledge of the team

#### 2. Palliative Care Consult Nurse

- Provides palliative leadership to the team
- Collaborates in the assessment of all palliative care individuals and families
- Collaborates in the development of the palliative care plan
- Coordinates educational programs in collaboration with the team
- Coordinates palliative care rounds
- Provides clinical advice and recommendations to providers and individuals and families with complex pain and symptom management issues
- Develops nursing care plan with primary nurses for individuals and families with complex pain and symptom management issues
- Advises on advanced care planning
- Collaborates with the continuing care coordinator to facilitate meeting the individual and family needs and expectations
- Provides clinical support to primary nurses in all care settings
- Provides leadership in the evaluation of individual and family outcomes
- Collaborates with the team in the delivery of bereavement follow-up services for families
- Provides educational resources for individuals and families
- Contributes to the knowledge of the team by keeping current with the palliative literature

Roles and Responsibilities  
of the Palliative Care Team  
Continued

**3. Palliative Care Resource Pharmacist**

- Participates in weekly palliative care rounds
- Provides pharmaceutical care to ensure the drug-related needs of the individual are met and drug related problems are prevented, and if not, identified and resolved
- Communicates the detection of any existing or potential problems in drug therapy to the physician and makes recommendations for alternate therapy
- Provides drug information to the team
- Contributes to the drug knowledge of the team
- Provides support and education to pharmacy colleagues in all care settings in the safe and efficient dispensing of palliative related medications
- Provides recommendations to the team and to Home Care Nova Scotia regarding medication entitlements

**4. Palliative Care Consult Social Worker**

- Participates in weekly rounds
- Provides linkages to their social worker colleagues throughout the district to follow up on specified individual and family counseling
- Provides counseling to individuals and families who are experiencing conflict
- Provides adjustment, grief support and resource counseling to individuals and families who are faced with complicated grief issues
- Provides consultation to individual, family and team members regarding children's grief issues
- Receives referrals to follow families with complicated grief issues
- Links with Mental Health Services and other community resources as appropriate
- Provides assistance with securing financial benefits
- Facilitates transfer from acute care to continuing care
- Participates in bereavement care

**5. Palliative Care Case Manager**

- May be the Palliative Care Consult Nurse or the Continuing Care Coordinator as assigned in consultation with the palliative Care service
- Facilitates and coordinates the continuous palliative care plan for the individual and family
- Provides continuity to the plan of care
- Acts as a liaison between and among the palliative care service, direct providers, and the individual and family.

**The Interdisciplinary Care Team in Palliative Care**

The direct service delivery encompasses a network of providers which may include the following:

Roles and Responsibilities  
of the Palliative Care Team  
Continued

**Family Physician**

- Responsible for the day to day medical management of the palliative care individual in all care settings
- Provides medical assessment and intervention to palliative care individuals
- Provides pain and symptom management in all care settings
- Collaborates with the interdisciplinary and consultative team members
- Participates at rounds for new referrals and complex situations when available
- Participates in individual/family conferences
- Provides individual and family with information and support to assist them in decision making and advanced care planning
- May provide follow-up bereavement care

**Continuing Care Coordinator**

- Collaborates with the palliative care nurse in palliative care assessment process
- Collaborates with the individual, family, and team in the identification of individual/family needs and expectations
- Facilitates the development, implementation, and evaluation of the palliative care plan with the individual, family and team
- Collaborates with the team in the development and monitoring of a resource allocation plan that reflects individual's actual and potential needs
- Coordinates services in the home or care setting
- Communicates changes to team
- Attends weekly rounds
- Coordinates referrals for specialized services
- Coordinates medications and equipment
- Facilitates individual/family conferences
- Coordinates transfers between care settings
- Provides statistical/ budgetary data

**Intake Coordinator**

- Provides information to the public about the regional palliative care program
- Receives referrals to the district palliative care program
- Provides an initial screening
- Completes pre-home visit risk assessment
- Initiates quick response as needed
- Refers to the appropriate team member for the completion of the palliative care assessment
- Refers to other organizations as appropriate
- Collects baseline data and information
- Provides statistical data

**Nurse**

Roles and Responsibilities  
of the Palliative Care Team  
Continued

- Provides timely pain and symptom management to palliative care individuals
- Provides continuity of care as detailed in the palliative care plan
- Participates in the initial and ongoing assessment of the palliative care individual and family needs and expectations
- Provides comfort care measures
- Provides individual/family teaching
- Provides timely communication to appropriate team members to ensure individual/family needs and expectations are met
- Provides continuous assessment for individuals who require monitoring for unstable pain and symptom management
- Supports individuals and families in care decision making
- Participates in palliative care in-servicing
- Responsible for ongoing development, planning, and evaluation of nursing care plan
- Attends weekly rounds
- Collaborates with the interdisciplinary and consultation team in meeting the needs and expectations of the individual and family

**Continuing Care Assistant (Home Support Worker/Personal Care Worker)**

- Provides family relief
- Supports family in preparation for a home death
- Provides personal care to individuals
- Provides meal preparation and feeding
- Provides emotional support to individual and family including support following a death at home
- Provides light housekeeping and laundry
- Collaborates with the team through ongoing communication verbally and in the chart

**Coordinator of Palliative Care Volunteers**

- Coordinates recruitment, screening, and training of palliative care volunteers
- Provides liaison between the team and the volunteer
- Matches individuals/families with volunteers in consultation with the palliative care nurse and/or continuing care coordinator
- Provides leadership and support to volunteers
- Assists with the coordination of bereavement follow-up
- Attends palliative care rounds
- Coordinates remembrance services
- Provides monthly and annual reports on volunteers activities
- Collaborates with the team in identifying individual/family needs that can be met by a volunteer

**Palliative Care Volunteers**

- Provides emotional support
- Provides social and leisure support

## Roles and Responsibilities of the Palliative Care Team

Continued

- Communicates with the team through the palliative care chart
- Collaborates with the team in identifying unmet needs and expectations of individual and family
- Provides bereavement follow-up as requested
- Provides support to family when death appears imminent, and immediately after their loved one dies

### **Social Worker**

- Provides counseling for individuals individually and as a family
- Provides assistance with securing financial benefits
- Facilitates transfer from acute care to continuing care
- Participates in bereavement care

### **Spiritual Care**

- Supports the individual and family with spiritual needs
- Participates in bereavement care
- Participates in the remembrance services
- Supports and advises the team on spiritual issues as it relates to palliative care where there is a spiritual care person designated to participate on rounds

### **Pharmacist**

- Provides prescribed medications in a manner that optimizes comfort and safety
- Provides pharmaceutical care to ensure the drug-related needs of the individual is met and drug related problems are identified, prevented and resolved
- Communicates the detection of any existing drug related problems
- Educates individual and family
- Ensures palliative care medications and supplies are available 24 hours/day

### **Physiotherapist**

- Provides assessment for and recommendations about treatment services to promote comfort

Roles and Responsibilities  
of the Palliative Care Team  
Continued

- Collaborates with the team in the development and implementation of comfort measures
- Provides education to the individual and family

**Occupational Therapist**

- Assesses individual for specialized equipment to promote comfort
- Investigates and implements energy conservation techniques with the individual and family
- Promotes maintenance of independence through the provision of aids and adaptations
- Provides education to individual and family

**Respiratory Therapist**

- Carries out treatment services to promote individual comfort
- Assesses individual need for specialized equipment such as home oxygen
- Provides education to the individual and family on comfort measures related to their respiratory status.

**Dietician**

- Acts as a resource to team on all aspects of food and nutrition
- Provides education to the individual and family on nutritional management, supplements and coverage

**APPENDIX “D”**

**FRAMEWORK FOR EVALUATION OF THE PROVINCIAL APPROACH TO HOSPICE/PALLIATIVE CARE**

This table can be used by the Provincial Hospice Palliative Care Working Groups in the document as an introduction to the evaluation framework

<b>Framework Category</b>	<b>Indicator Area</b>	<b>Indicator</b>	<b>Measurement Methodology</b>
<b>System</b>	<b>Congruence with Service Delivery Guidelines:</b> <ol style="list-style-type: none"> <li>1. Functional Elements</li> <li>2. Human Resource Elements</li> <li>3. Education and Orientation</li> </ol>		
<b>Outcomes and Quality of Client-centered Delivery</b>  <b>Goals:</b>  Relieve suffering  Improve quality of life  Promote psycho-social well-being	<b>Acceptability</b> <ul style="list-style-type: none"> <li>• Satisfaction</li> </ul>		
	<b>Safety</b> <ol style="list-style-type: none"> <li>1. Safety considerations</li> <li>2. Adverse events</li> </ol>		
	<b>Accessibility</b> <ol style="list-style-type: none"> <li>1. Assessment</li> <li>2. Pain and symptom control</li> <li>3. Interdisciplinary team</li> <li>4. Consult team</li> <li>5. Bereavement</li> </ol>		
	<b>Appropriateness</b> <ol style="list-style-type: none"> <li>1. Assessment</li> <li>2. Case Management</li> </ol>		
	<b>Effectiveness</b> <ol style="list-style-type: none"> <li>1. Pain and symptom management</li> <li>2. Able to die in setting of choice</li> <li>3. Service accessed when needed (timely access)</li> </ol>		

# **Recommended Indicators**

## **Integrated Hospice Palliative Care Service Guidelines**

**Recommended Indicators**  
**Integrated Hospice Palliative Care Service Guidelines**

**Framework Category:** System and Outcomes and Quality of Client-centered Care Delivery

**Indicator Topic:** Assessment, Referral or Access.

**Rationale:** A comprehensive palliative care assessment will determine appropriateness for admission to program and related treatment plan. The assessment should include physical, psycho-social, emotional, cultural and supportive needs either immediate or anticipated.

**Audit:** Is a comprehensive palliative care assessment tool being used at present?

**Indicator:**

The number of admissions to program after assessment

The number of intake referral for the integrated hospice palliative care program

The number of client records in which a comprehensive palliative care assessment is documented

The number of client records for the integrated hospice palliative care program

**Definition of Terms:**

*Comprehensive Palliative Care Assessment:*

*Intake referral:* barrier-free access, referral can be made by individual or family, family physician, social worker etc.

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**Framework Category:** System

**Indicator Topic:** Referral or Access

**Rationale:** A single entry point of access supported by a system of multi-provider point of care access is recommended to ensure easy and consistent access.

**Audit:** Is there a single point of entry for persons requiring hospice palliative care service in your district?

Is there multi-provider point of care access to intake for hospice palliative care in your district?

Individual and provider satisfaction questionnaire can include satisfaction indicator question about ease and consistency of access/referral.

**Indicator:** The number of intakes through single entry access number  
Total referral intakes

The number of intakes providers rather than single entry access  
Total referral intakes

**Definition of Terms:**

*Single Entry Access:* To ensure easy and consistent access, Continuing Care will be identified as the single entry point for access to the service via the existing 1-800# for the district. This can be in addition to established traditional access points. Registration with the service, intake, screening for quick response, baseline data collection, education/public information, and case deployment will occur at the point of entry.

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**Framework Category:** System

**Indicator Topic:** Referral Source

**Rationale:** Referrals to the service can be made by individuals, significant others or providers to ensure an individual/family centered approach, ease of access and facilitate timely access to service. The purpose is to identify the scope of those making referrals to the program for planning purposes.

**Audit:** Is the hospice palliative care referral process in place? Who is able to make referrals to the program?

**Indicator:** The number of referral sources by defined category\*  
Total number of new referrals to program

\* client, significant other, physician, other providers

**Definition of Terms:**

*Referral source:* To ensure an individual/family-centered approach, increased access, and a

timely response to services, referrals to the service can be made directly by the individual/family or by health professions.

*Person centered approach:* As individuals are typically a part of a family, when care is provided the individual and family are treated as part of a unit. All aspects of care are provided in a manner that is sensitive to the individual (and family's) personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

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**Framework Category:** System and Outcomes and Quality of Client-centered Care Delivery

**Indicator Topic:** Coordination and Continuity of Care/ Timely Consistent Clinical Review

**Rationale:** A case management approach will be used to facilitate access to an integrated continuum of care for individuals and their families in need of hospice palliative care services through the interdisciplinary primary care and the palliative care consult team. The case manager will ensure ongoing, timely care planning that is individual/ family centered. Palliative care rounds will be held to forward effective provider and consult team communication as needed to support care planning.

**Audit:** Describe the interagency case management process utilized in your district or community.

Random chart audit for documentation of case management function and evidence of interdisciplinary team planning and service.

**Indicator:** # charts with documented evidence of case management function/ team  
# charts audited \*

**Definition of Terms:**

*Interdisciplinary primary care team:* An interdisciplinary team of experts that provides a mix of consultative and primary care services in one or more settings where patients and families receive care.

*Palliative care consult team:* At minimum, includes a palliative care physician and a palliative care consult registered nurse and other professionals as required. This team meets weekly to review all patients in the palliative care program while available to the PC service providers throughout the care

process.

*Case Management:* Coordination of the care plan by a member of the palliative care consult team.

\* Consider recommended number for periodic chart audits.

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**Framework Category:** System

**Indicator Topic:** Interdisciplinary Care Team for Hospice Palliative Care;  
Primary Care and Palliative Care Consult Teams.

**Rationale:** An interdisciplinary primary care team with support of a palliative care consult team is recommended to ensure individual/ family access to a comprehensive palliative assessment that includes physical, social, spiritual, emotional, cultural needs of the client with pain, symptom management and bereavement support. The purpose of this indicator is to determine the existence and scope of primary care and palliative care consult teams in each district.

**Audit:** Who are the active members of the interdisciplinary primary care team in your district? Of the palliative care consult team?

**Indicator:** Number of Nurse/ Care Coordinator/ Physician with palliative care focus  
District

**Definition of Terms:**

*Interdisciplinary primary care team:* An interdisciplinary team of experts that provides a mix of consultative and primary care services in one or more settings where patients and families receive care.

*Palliative care consult team:* At minimum, includes a palliative care physician and a palliative care consult registered nurse and other professionals as required. This team meets weekly to review all patients in the palliative care program while available to the PC service providers throughout the care process.

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**Framework Category:** System and Outcomes and Quality of Client-centered Care Delivery

**Indicator Topic:** Individual/ Family Centered Care

**Rationale:** Hospice Palliative Care providers must demonstrate the active participation of the individual/ family in assessment and care planning. An interdisciplinary primary care team with support of a palliative care consult team works with the individual/ family to address physical, social, spiritual, emotional and cultural needs.

**Audit:** Periodic audit of client records for documentation of individual/ family participation in assessment, care planning and delivery. Satisfaction Survey Question about care plan participants.

**Indicator:** # of records with documentation of individual/family involvement  
Total number of records audited

# of individuals/family self reporting satisfaction with their participation in care planning  
Total number of survey respondents

**Definition of Terms:** N/A

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**Framework Category:** System and Outcomes and Quality of Client-centered Care Delivery

**Indicator Topic:** Community Supports - Education/orientation

**Rationale:** Volunteers, family and other supports available in the community, including informal care providers, will be involved in the plan of care as appropriate. Education and support should be provided to facilitate this objective.

**Audit:** Is there a volunteer component to the Hospice Palliative Care Service in your District?

**Indicator:** \_\_\_\_\_ The number of education sessions for formal and informal care providers and the community in keeping with provincial awareness and education programs as recommended.

# client records with volunteer involved in care documented  
Total number of client records



Self reporting audit

**Indicator :** Number of patients who achieve 50% reduction in pain value (self-reported)  
Total Number of patients audited

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Number of patients with pain having a documented pain assessment  
Total Number of patients audited

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Number of patients with pain having a second pain assessment documented  
Total Number of patients audited

**Definition of Terms:**

*Patient with pain:* Any new or registered patient presenting for pain management.

*Pain measurement:* A value rated by the patient or staff from a specified scale that represents the experience of pain.

*Pain:* An individual, subjective, unpleasant sensory and emotional experience that is primarily associated with tissue damage or described in terms of tissue damage, or both.

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**Framework Category:** Quality Client Centered Care Delivery

**Indicator Topic:** Death in Setting of Choice

**Rational:** Patients will be made aware of resources etc. that will empower each individual to make choices surrounding preferred place of death.

**Audit:** Did the patient die in their setting of choice?

Chart audit

**Indicator:** Number of patients who determined the setting of death  
Total Number of patients audited\_\_

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**Definition of Terms** N/A

## APPENDIX “F”

### EDUCATION AND ORIENTATION STAKEHOLDER LIST

#### **AGENCIES**

Long Term Care Facilities  
Home Care  
Hospital  
Community Health Centres  
Home Support Agencies  
Nursing Agencies  
Red Cross  
Residential Care Facilities

#### **VOLUNTEER ORGANIZATIONS**

Legion  
NS Hospice Palliative Care Association  
Palliative Care Societies  
Canadian Cancer Society  
H & S F

#### **PROFESSIONAL ASSOCIATIONS**

Doctors Nova Scotia  
College of Registered Nurses of NS  
College of Licensed Practical Nurses  
Nova Scotia Association Social Workers  
College of Pharmacy  
College of Family Physicians  
NSPA (4)  
College/Association Dieticians  
College/Association of Occupational  
Therapists

#### **PROVIDERS**

Physicians  
Nurses  
Pharmacists  
Spiritual Care/Hospital Chaplains  
Nutritionist/Dietician  
Volunteer - Client Care  
Home Support Workers  
Social Workers  
Physiotherapists  
Occupational Therapists  
Psychologists  
Alternative Care Therapists  
Patient Navigators  
Family Care Givers  
Intake Workers

Care Coordinators  
Continuing Care Assistants

#### **PUBLIC**

#### **POLICY/DECISION MAKERS**

Veteran's Affairs  
Department of Health  
District Health Authorities  
Community Health Boards  
Department of Community Services  
Cancer Care Nova Scotia  
Elected Officials (Municipal and Provincial)

#### **INDUSTRY ASSOCIATIONS**

Nova Scotia Association of Health  
Organizations  
Continuing Care Association of Nova Scotia  
Home Support Nova Scotia  
Continuing Care Forum  
NSRAA  
ARC/RRC  
Directions Council  
Aids Coalition  
Heart and Stroke  
Health Charities

#### **INDIVIDUALS AND FAMILIES**

In Receipt of Care

#### **EDUCATIONAL INSTITUTIONS**

Nova Scotia Community College  
Mount Saint Vincent University  
Dalhousie University  
ST. Francis Xavier University  
University of Cape Breton  
UCST  
Acadia University  
Saint Mary's University  
Private Schools  
Curriculum Committees

**Appendix “G”**  
**Provincial Hospice Palliative Care Project**  
**Executive Steering Committee Members (established December 17, 2002)**

Keith Menzies (*Chair*)  
Executive Director, Continuing Care  
Department of Health

Cheryl Doiron (*Ex-officio*)  
Associate Deputy Minister  
Department of Health

Dr. Graeme Bethune  
Family Physician & Medical Director of Oceanview Manor

Dr. Nuala Kenny  
Professor & Head, Department of Bioethics, Faculty of Medicine  
Dalhousie University

Ruby Knowles  
A/Director, Continuing Care  
District 4,5,6 (Northern)  
Department of Health

David MacIver  
Vice-President, Community and Continuing Care Services  
Cape Breton District Health Authority

Anne McGuire  
Chief Executive Officer  
Annapolis Valley District Health Authority

Judy Simpson  
Palliative and Supportive Care Coordinator  
Cancer Care Nova Scotia

Linda Mills  
Senior Hospice Nurse  
Northwoodcare Inc.

Dr. Murray Nixon  
Provincial Medical Advisor, Continuing Care  
Department of Health

Dr. David Rippey  
Executive Director, Quality, Emergency Health Services & Health Promotion  
Department of Health

Brenda Payne  
Director, Acute and Tertiary Care  
Department of Health

## Provincial Hospice Palliative Care Project Working Group Members

### Individual and Family Care

Sheila Scaravelli (Co-chair)  
Vice-President, Patient Care Services  
Pictou County Health Authority

Fran Duggan (Co-chair)  
Director of Continuing Care  
Annapolis Valley District Health Authority

Lillian Cochrane  
Supportive & Palliative Care Program Coordinator,  
Victorian Order of Nurses - Annapolis Valley

Dennis MacDonald  
Palliative Care Consult Nurse  
Aberdeen Hospital

Dr. David Abriel  
Family Physician, Mahone Bay

Dr. Gerri Frager  
Medical Director of Palliative Care Services  
IWK Health Centre

Pauline Fowlie  
Interim Manager Palliative Care Program  
QEII Health Science Centre

Beth MacDonald  
Supervisor, Assessment Services  
Continuing Care (Eastern) 7, 8, Dept. of Health

Ms. Terri-Lynn Smith  
Director of Social Work  
Cumberland County District Health Authority

Dawn Frail  
Manager, Drug Technology Assessment  
Pharmaceutical Services, Department of Health

Jennifer MacInnes  
Policy Analyst, Continuing Care Branch  
Department of Health  
(Resigned August 2003)

Lynn Yetman  
Coordinator of Volunteer Services  
Colchester Regional Hospital

Patricia O'Halloran  
Staff Chaplain, Spiritual Care Department  
Queen Elizabeth II Health Sciences Centre

Donna Smith  
Patient Navigation Community Liaison  
Cancer Care Nova Scotia

### Human Resources/Management Infrastructure

Eleanor MacDougall (Chair)  
Vice President Community Health  
Colchester East Hants District Health Authority  
(Resigned June 2003)

Donna Dill (Chair, effective June 2003)  
Director, Monitoring & Evaluation  
Continuing Care  
Department of Health

David Macdonald  
Policy Analyst, Continuing Care  
Department of Health

Janet Carver  
Manager, Palliative Care  
South Shore Regional Hospital

Gail Gordon  
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Valley Regional Hospital

Nan Holden  
Chair District Palliative Care Committee/Site Manager  
South West Nova District Health Authority

Ann McKim  
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Colchester Regional Hospital

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Peggy Kaiser-Kirk  
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Wanda Heading  
Oncology Social Worker  
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## Working Group Members, cont.

### Research and Evaluation

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Gael Page  
Director of Research and Clinical Development  
Northwood Incorporated

Buffy Cooper  
IWK Health Centre

JoAnn Martell  
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(Resigned May, 2003)

Kathy Greenwood  
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Quality, Emergency Health Services &  
Quality & Patient Safety  
Department of Health

Mary-Anne Finlayson  
Evaluation Coordinator  
Public Health  
Office of Health Promotion  
Department of Health  
(Resigned Spring 2003)

Kerry Deagle  
Acting Senior Policy Analyst  
Continuing Care Branch  
Department of Health  
(seconded from Dept. of Community Services)  
(Resigned October 2003 at end of secondment)

### Education and Orientation

Woodie Hewitt (Chair)  
(Retired) Professor of Sociology

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Palliative Care Consult Nurse  
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VON Canada Eastern Region

Sandi Jantzi  
Director of Volunteer Services  
Aberdeen Hospital

Allene MacIsaac  
Assistant Professor, School of Nursing  
Saint Francis Xavier University  
(Resigned Spring 2004)

Dr. David Dupere  
Palliative Medicine Specialist  
Department of Medicine, QEII HSC  
(Joined May 2003)

Sherry Keen  
Administrator, Windsor Elms  
(Joined May 2003)

Curtis MacDonald  
Chaplain, Spiritual Care  
IWK Health Centre/QE11 HSC  
(Joined November 2003)

Cathy Blades  
Vice President Community Health  
South Western District Health Authority

Roseanne d'Eon  
Supportive Care Services  
Southwest Health (replaced Cathy Blades Dec./03)