

**Discussion Paper**  
**Structure, Accountability and Role of the Erie St. Clair End of Life Care Network**  
**Proposed Next Steps - January 2010**  
**For implementation April 1, 2010**

**Executive Summary**

**Purpose of Report**

This report provides recommendations related to the “next steps” in the evolution of the Erie St. Clair (ESC) End of Life Care Network (EOLCN) structure, role and accountability. This report is narrowly focused on the Network structure/ accountability /role. For the sake of conciseness this report will not address the many other aspects of Hospice Palliative Care (HPC) delivery and ESC EOLCN work.

This report is prepared for the ESC EOLCN Executive Council and the ESC Local Health Integration Network (LHIN) and is informed by:

- outcomes and recommendations from discussions at the ESC EOLCN Steering Committee and at local EOLCN committees
- input from LHIN staff
- input from CCAC CEO,
- a review of the Ministry of Health and Long Term Care (MOHLTC) original intent for EOLCNs ,
- a review of current status of EOLCNs across the province,
- a review of current status of ESC EOLCN,
- a review of emerging priorities from the newly created Ontario Hospice Palliative Care Coalition/Consortium.

In Sept. 2009 the request for this report was made by the ESC EOLCN Executive Council for presentation at the January 2010 meeting. This report is prepared by Julie Johnston, Nancy Snobelen, and Beth Lambie.

**Timing of this review**

Just over 4 years ago, the ESC EOLCN was initiated by the outgoing District Health Councils; the ESC EOLCN Director position was filled Sept. 2006. During this time much has been accomplished through the collective work of the partner agencies and individuals of the ESC EOLCN. The ESC EOLCN is regarded across the province as a high functioning EOLCN.

The evolution of the ESC EOLCN structure, role and accountabilities has been robust and organic, responding to opportunities and demands as they presented themselves (e.g. Aging at Home proposals, Physician education [LEAP], LHIN request for review of services, system design work etc). This flexibility has served the region well; however it is generally agreed that now it is time for consolidation of the ESC EOLCN with a more defined and stable structure and clearer accountability.

Timing for this review is ideal because:

- At a provincial level there is a growing initiative related to the system design for Hospice Palliative Care across the province. A key priority of this provincial level initiative is clarification of accountability structures and accountability mechanisms regionally and provincially that would facilitate a system level approach to Hospice Palliative Care delivery,
- The ESC LHIN is currently reviewing/revising the role of a number of advisory networks,
- There is a repeatedly articulated request for clarity related to the “advisory role” of the ESC EOLCN in the Aging a Home initiatives,
- The role of and funding for the Director position will change in April 2010 to that of only Network Director (currently the role is a joint portfolio between the Windsor Regional Cancer Program [WRCP] and the EOLCN),

All of the ESC EOLCN foundational work has been completed. Funding for new programs (previously identified as gaps) is in place through the Aging at Home Initiatives and the respective Transfer Payment Agency (TPA)

organizations are in process of implementing these programs. Several existing sectors/programs are being re-tooled to meet new standards. Baseline education of physicians (LEAP) and other team members has been provided and evaluated. A system mapping review has been completed. Task forces are in place working on a number of projects. An Education Subcommittee is very active. Now is the time for the ESC EOLCN to move from “planning to performance”<sup>1</sup>. A new structure with clear accountabilities will facilitate this next step role.

### **Context - Background related to End of Life Care Networks across Ontario**

End of Life Care (EOLC) Networks were created in 2005 as part of Ontario’s End of Life Care Strategy. Ontario’s EOLC Strategy occurred in response to the priorities of the Federal / Provincial Health Accord which targeted funding for enhanced care in the home and enhanced end-of-life care. The Ontario MOHLTC took a systems perspective in recognition of the fact that changes in the home care sector could best be made if system partners were involved. The role of and the base funding for the End of Life Care Networks (EOLCN) evolved from this system-wide perspective.

Networks were expected to represent all sectors and be representative of all sectors (i.e. EOLCNs are to be objective and impartial). Networks are to focus on integration/system design/service innovations etc. and are not expected to engage in operational roles related to any one sector.

The original mandate for the EOLCNs across Ontario, as outlined in the MOHLTC Strategy (Nov.2004) was articulated as follows:

- broad system design
- coordination and integration of services at a system level
- monitoring and assessment of community needs
- promotion of service innovations

This mandate was to be advanced regionally and provincially.

Additional advisory roles and expectations emerged as part of the EOLC Strategy, Cancer Care Ontario’s support for and endorsement of the EOLCN function and in response to expectations of other associations (e.g. Ontario Palliative Care Association, Seniors Health Research Network etc.) .

Currently there are 14 EOLCNs across the province, aligned with LHIN boundaries. Thirteen of the 14 have Directors in place or are actively recruiting; 10 of the Directors positions are full time 3 are part time. (The remaining region has submitted to the LHIN for additional funding to support this position.)

The level of functionality of the regional EOLCNs appears to be related to the region’s ability to recruit and retain a Director. The two Networks currently without Directors report only “partial” establishment of an effective Network.

In addition to the regional EOLCNs a provincial level EOLCN is in place. The MOHLTC provided funding to facilitate ongoing networking among the leaders of the regional EOLC Networks. This funding covers for face to face meetings of the regional EOLCN leadership. No funding was allocated for provincial level leadership. Provincial level activities are undertaken by individual regional Network personnel as “in-kind” time contributions. This Provincial End of Life Care Network (PEOLCN) has operated since the implementation stage of the EOL Care Strategy. The role of the PEOLCN is to champion an integrated quality strategy of end-of-life care for all individuals across the province through collaboration and best practice.

Outcomes from the EOLCNs work have been significant (details are reported elsewhere and are not included in this report).

### **Recommendations for next steps for Erie St Clair EOLCN**

#### ***i. Network Accountability***

##### ***Formalize the accountability mechanism of the ESC EOLCN to the ESC LHIN.***

Discussion - The LHIN is offering to the ESC EOLCN “more formal alignment and support”<sup>2</sup>.

#### ***ii. Advisory Committee Structure:***

<sup>1</sup> Alec Anderson – presenting at ESC EOLCN Steering Committee January 11th 2010

<sup>2</sup> Ibid

**Align ESC EOLCN Advisory Committee Structure with the structure recommended by the LHIN related to their other advisory networks.**

Discussion: In the process of re-creating the Advisory Committee the following will occur:

- the current Steering Committee and Executive Council will be collapsed,
- one new advisory level committee will be created ,
- membership for this new committee will be suggested by current members of ESC EOLCN with final selection done by LHIN staff.

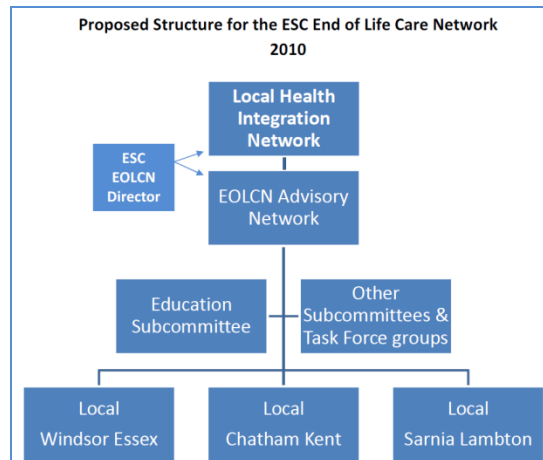
**iii. Local Committees, Education Subcommittee and other Subcommittees and Task Force groups**

**Continue the activities of each of the three local committees and the Education Subcommittee and clearly define the accountability mechanisms. Consider creating a membership agreement so that the expectations for members are clearly delineated.**

**Include the broad membership for task force groups and other subcommittees as required.**

Discussion – The local committees are committed to enhancing integration and care at a local service delivery level. These groups

pull a large membership from Community Service Providers, Volunteers, Hospice, Hospital, Long Term Care, etc.



**iv. Leadership**

**Clearly define leadership roles.**

Discussion - The Director of the ESC EOLCN will provide leadership for the ongoing activities and identified priorities of the ESC EOLCN and will report jointly to the ESC LHIN and the Advisory Committee.

**v. Network Role**

**Clearly define the role of the ESC EOLCN incorporating initial role mandates with the newly emerging expectations from the LHIN, insuring that clarity is provided regarding advisory role as it relates to A@H initiatives.**

Discussion - Refer to “Role of End of Life care Networks” page 2 for details of initial role expectations.

**vi. Director position accountability and funding**

**Clearly define the role and accountability of the ESC EOLCN Director based on the part time funding available. Initiate plans for sustainable funding for a full time position once the incumbent has retired.**

Discussion – The incumbent Director has agreed to stay on in a part time position (with current salary/benefits/other costs prorated based on the available funding from MOHLTC [\$70,000 in 2005].).

The CCAC is agreeable to continue as Transfer Payment Agency . As indicated above the Director will report jointly to the LHIN and to the Advisory Network. The incumbent Director has agreed to continue in this role in a part time position and to work with partners to create a sustainable funding model for a full time position (once the incumbent retires).

The LHIN has offered to support the Director position in terms of clerical/administrative functions and budget oversight.

**Summary**

The Steering Committee and Executive Council of the Erie St. Clair End of Life Care Network each unanimously endorsed these recommendations for the next steps in development of the ESC EOLCN (January 11th, 2010 and January 26<sup>th</sup> respectively). This realignment of structure, accountability and role will help answer many of the ongoing questions of current members of the ESC EOLCN. These questions have evolved around ESC EOLCN accountability and details of the advisory role.

To date all of the consulted members of the ESC EOLCN have embraced the concept of moving our focus from “planning to performance” with closer alignment with the LHIN. A new structure with clear accountabilities and role definitions will facilitate this next step.

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## **1. Introduction**

The Erie St Clair End of Life Care Network (ESC EOLCN) has been in place for over 4 years, with a Director in place since Sept. 2006. Much has been accomplished through the collective work of the partner agencies and individuals of the ESC EOLCN.

Patient Care has been positively impacted. Erie St. Clair leads the province in the use of standardized palliative care assessment tools. ESC was the first region to receive funding for specialized consultation teams through the aging at home initiative, paving the way for 3 other regions to follow suit. Standards for care in several individual organizations have been enhanced and palliative programs improved through the collective energies of the EOLCN.

Integration outcomes have been remarkable, with cross sector algorithms and work plans being implemented. A project related to “Right Patient, Right Place and Right Time” was one of the first joint initiatives undertaken. Enhancing understanding of the relative roles of various sectors and services continues to be a priority. Cross sector education sessions, held in February 2010 expanded on this theme of care across the continuum; case studies helped clarify when a patient is best cared for in which setting.

Through the work of the ESC EOLCN members, duplication of service has been reduced through a clearer understanding of the relative contributions of each provider agency. Much progress has been made towards standardizing and streamlining education.

Outcomes from the collaborative relationships in ESC are the envy of many regions in Ontario, for example the linkages between the Palliative Pain and Symptom Management Program and the EOLCN membership, is considered as a “best practice” model.

Reports and documents from the ESC EOLCN are being referenced by EOLCN leaders throughout the province. Several of these Networks have hired consultants to replicate the work done by the ESC EOLC Director and partner agencies.

Palliative Care public relations have improved as the ESC EOLCN advanced the notion of all sectors serving as partners to enhance the care of the patient. The membership of the EOLCN has embraced an inclusive language concept when it comes to describing who provides palliative care. The “mantra” of the EOLCN membership has become: “it is not an ‘either...or...’ scenario when it comes to which sectors s are required, but instead it is a ‘both...and...’ situation - where both institutional based and community based sectors are necessary to adequately care for the Palliative Care patient population.”

The EOLCN completed a comprehensive review of regional Hospice Palliative Care services and from that report established consensus recommendations for action. All summary recommendations have been undertaken.

The evolution of the ESC EOLCN has been organic and robust. The inception of the ESC EOLCN occurred at the same time as the LHINs were being introduced and many formal and informal connections have been established between LHIN priorities and those of the EOLCN. Now is the time to formalize these connections with the LHIN and to more clearly articulate the accountability and ongoing structure of the ESC EOLCN.

The report which follows sets the stage for this next step in the evolution of ESC EOLCN. The report below:

- Provides provincial context in terms of:
  - the historical evolution of the Regional EOLCNs and the original intent of the MOHLTC as it relates to the EOLCNs
  - the current status of EOLCNs across Ontario
- Briefly examines the current status of the ESC EOLCN
- Presents a summary of “next steps” recommendations.

This report was prepared for the ESC EOLCN Executive Council and the ESC Local Health Integration Network (LHIN) and is based on outcomes and recommendations from discussion at the Steering Committee and at local committees. The Executive Council requested preparation of this report at the Sept. 2009 meeting. This current report incorporates recommendations from the Executive Council. (Note – discussion of outcomes and other aspects of HPC work and HPC service delivery, provincially and regionally is excluded from this report in the interests of concision)

## **2. Provincial Context for End of Life Care Networks (EOLCN)**

### **2.1. Background related to End of Life Care Networks in Ontario**

(Refer to Appendix one for additional details on the Background of HPC/EOLC Networks and other relevant activities related to EOLC and the EOLC Strategy in Ontario. Note: the information in this first section below is adapted from work done by Barbara Pidcock, Julie Darnay and Chris Sherwood)

#### **Initiation of End of Life Care Networks**

Ontario's End of Life Care (EOLC) Networks were created as part of the End of Life Care Strategy (initiated November 2004). Initially the District Health Councils were directed to establish these Networks in each planning district. Alignment of EOLC Networks with the LHIN boundaries began with the inception of the LHINs and by 2007 the 14 EOLC Networks were all aligned with the LHIN boundaries

Ontario's EOLC Strategy was created in response to the priorities of the Federal / Provincial Health Accord which targeted funding for enhanced care in the home and enhanced end-of-life care. The Ontario Government took a systems perspective in recognition of the fact that although the emphasis was on home care, changes can't be made in one part of the system without involving the system as a whole. The role of the EOLC Networks evolved from this system-wide perspective.

#### **Funding of Networks**

The MOHLTC provided base funding of \$70,000 per LHIN region (in 2005) to support these EOLC Networks. This funding was flowed to all regions through Community Care Access Centres (CCAC). MOHLTC Regional Offices worked with regions to determine details of this funding and augmented funding for the role. Discussions at the Advisory Table of the EOLC Strategy indicated that regions were expected to provide in-kind support for the EOLCNs.

#### **Role of End of Life Care Networks**

The expected role of the Regional End of Life Care Networks is fivefold:

a) Original Role Expectation of EOLCNs:

The initial MOHLTC EOLC Strategy articulated a role and mandate for the EOLCNs.

This role was: to provide regional leadership for the improvement of the system of hospice palliative care required by clients, families and service providers.

The original mandate for the EOLCNs across Ontario, as outlined in the MOHLTC Strategy (Nov.2004) was articulated as follows:

- broad system design
- coordination and integration of services at a system level
- monitoring and assessment of community needs
- promotion of service innovations

This mandate was to be advanced regionally and provincially.

All Networks across Ontario were expected to embrace this role.

b) Advisory Role with Palliative Pain and Symptom Management Consultation Program (PPSMCP):

All Networks are to have explicit linkages between the PPSMCP and the EOLC Networks as described in the advisory statements which were updated as part of the MOHLTC EOLC Strategy.

In August 2006 the revised policy of Pain and Symptom Management (now titled Palliative Pain and Symptom Management Consultation [PPSMC]) was released. This policy indicated that the End of Life Care Networks were to advise and support the provision of the PPSMC service across the designated sectors/regions.

In March, 2007 the revised policy of Community and Facility Palliative Care Interdisciplinary Education was released by the MOHLTC. This service provides education to front line health care providers. HPC/EOL Care Networks and PPSM Consultants are to act in an advisory capacity in planning, implementation and evaluation of the local area's palliative/EOL care education needs.

c) Regionally vested roles and responsibilities:

Under the auspices of the original mandate (i.e. System Design etc.) it was expected that EOLC Networks would be regionally vested, by the LHIN, with specific roles and responsibilities related to service integration.

d) Provincial Responsibilities:

Each Regional Network has a mandate to work with the Provincial End of Life Care Network (PEOLCN) to advance best practice and enhance provincial consistency in HPC. Therefore each regional EOLCN must consider the mandate of the PEOLCN and its regional impact (see comments below related to Provincial EOLCN)

e) Collaborative Responsibilities with Cancer Care Ontario's Regional Cancer Programs (RCP) and others: Cancer Care Ontario's (CCO) Palliative Care Strategy (released 2006) articulates a collaborative role between the Regional Cancer Programs and the EOLC Networks. As CCO launched its "Ontario Cancer Symptom Management Collaborative" (previously PPCIP) the EOLC Networks were included in the launch with an expectation that these Networks would facilitate the uptake of this initiative across care sectors. Additionally there is a clause, in the accountability agreements with the RCP Palliative Care Physician Leads, which describes the expectation that these physicians will participate in the regional EOLCNs.

Other organizations have articulated explicit expectations related to collaborative work between the End of Life Care Networks and those partners. These partners include the: Ontario Palliative Care Association and the Hospice Association of Ontario.

### **Structure/Organization of the Regional End of Life Care Networks**

Discussions at the MOHLTC End of Life Care Strategy advisory table included high level expectations about the structure and organization of the Regional EOLC Networks including the following:

- Networks are to represent all sectors and be representative of all sectors (i.e. EOLCNs are to be objective and impartial) ,
- Networks are to focus on integration/system design and are not expected to engage in operational roles related to patient care service delivery or supervision of patient care service delivery in any one sector,
- Networks are to link with their Regional LHINs (details of these 'linkages' were not defined as LHINs were very new at that time)
- It was expected that the Networks would create a Committee/Venue for cross sector activities.

### **Network Accountability**

The issue of regional EOLC Network Accountability was not clearly articulated within the original documentation or discussion relating to the EOLC strategy. The general expectation was that 'the Network is accountable to its members', but the mechanism or structure for this accountability was not described or uniformly understood. These networks were being implemented at the same time as the LHINs were being created and so the accountability to the LHIN was not clearly articulated at that time.

It was understood that the key accountability for the Regional Network Directors was to be to the Steering Committee. If the Director is an employee (vs. a contract position) it was anticipated that the Director would abide by the policies and procedures of the employer agency in terms of payroll, confidentiality, etc. If the Director is a contract position it was expected that the terms of employment would be clearly articulated within this contract. It was expected that whatever the employment status of the Director, every effort would be made to insure the perception of neutrality for the Director's role. The Director is to be viewed as a regional resource.

Provincial level accountability was initially quite clear. While the EOLC Strategy was in place with a MOHLTC representative leading the process, this provincial level accountability was evident. When the strategy was

“completed” and the MOHTLC role discontinued this accountability became “muted”. In 2009 initiatives were undertaken to create a provincial level HPC coalition. There is some thought that this may provide a forum for provincial level accountability for the Regional EOLC Networks and the Provincial End of Life Care Network.

### **Provincial End of Life Care Network**

Funding was provided by the MOHLTC to facilitate ongoing networking among the leaders of the regional EOLC Networks. The Ontario Association of Community Care Access Centres is the transfer payment agency for these provincial funds. This funding covers for face to face meetings of the regional EOLCN leadership. No funding was allocated for provincial level leadership. Provincial level activities are undertaken by individual regional Network personnel as “in-kind” time contributions.

This Provincial End of Life Care Network (PEOLCN) has operated since the implementation stage of the EOL Care Strategy.

The role of the PEOLCN is to champion an integrated quality strategy of end-of-life care for all individuals across the province through collaboration and best practice.

In April 2008 the PEOLCN became the sponsor organization of the Hospice Palliative Care Community of Practice through the Senior Health Research Transfer Network (SHRTN). Through the HPC Community of Practice, education opportunities are made available and the development of provincial documents are shared.

In 2009 the PEOLCN was asked to take a leadership role in a number of initiatives related to the creation of a Palliative Care Coalition within Ontario.

## **2.2. Current State of EOLC Networks across Ontario**

(Refer to Table 1 below, for summary of information in this section summary was “as of” January 2010)

**Establishment of Networks** There are 14 Networks across Ontario. Terminology for these Networks includes: End of Life Care Networks (EOLCN), Palliative Care Networks (PCN) and Hospice Palliative Care Networks (HPCN). The boundaries of these networks correspond to the boundaries of the Local Health Integrated Networks (LHINs). Originally there were more networks, but beginning in 2007 they changed boundaries to conform to the new LHIN boundaries.

The current level of functionality of each Network varies across the province. All 14 LHIN regions report having some degree of EOLC Network established, with 2 of the 14 being “partially established” These two Networks have had difficulty in recruiting/ retaining a Director, which has slowed their development of a functioning Network.

The membership of each network is broadly based – usually the general membership is made up of individuals representing organizations that provide palliative care.

### **Director/Coordinator**

- 13 of the 14 Networks either have Directors in place or are actively recruiting. The remaining region (Central West) has submitted to the LHIN for additional funding to support this position.
- 10 of the Directors are Full time, 3 are part time
- 10 of the Directors serve in a single portfolio role as Director of the EOLC Network for their regions; 2 of the Directors have a joint portfolio role as Director of the EOLC Network and Administrator of the PPSMC program; 1 director has a joint portfolio role as Director EOLCN and Regional Cancer Program Director of Regional Palliative Care Integration (including regional responsibility for the OCSMC).

### **Funding and support**

- 2 networks use only the \$70,000 designated by the MOHLTC to support the Network – Directors here are part time
- 3 have additional funding from hospitals
- 2 have additional funding from Regional Cancer Programs (1 of these Directors assumed a joint portfolio role with RCP)

- 2 have funding from the Palliative Pain and Symptom Management program (in these cases the EOLCN Director has assumed a management role for these programs)
- 2 have additional funding from CCAC ,
- 1 has additional funding from a University,
- 1 has additional funding from a hospice program.
- 1 has membership fees.
- In-kind support is provided by CCAC in 11 regions
- In-kind support is provided by a university and a hospital in one region

### **Structure**

Network Structures vary – only one is incorporated, with one more considering incorporation. All have a Steering Committee and most have subcommittees or task force groups.

### **Mandate/Role**

As described above the EOLC Networks are to be perceived in the community as a regional resource with each of the member agencies being equal partners. The Network, as an objective impartial body has a fivefold role and mandate (see description above).

The degree to which these mandates have been operationalized within each region vary.

- Original Mandate

The original mandate (broad system design, coordination, integration) for the EOLCNs across Ontario, as outlined in the MOHLTC Strategy (Nov.2004), has been embraced by all EOLC Networks across Ontario. This mandate is articulated in Network publications and documents and is considered the cornerstone for Network functioning. To this end many Networks have undertaken a comprehensive review of Hospice Palliative Care Services within their regions and have developed recommendations/priorities for action. Many regions have submitted proposals and facilitated innovative approaches to education and service delivery.

- Advisory Role with PPSMCP

All EOLC Networks are to have explicit linkages between the PPSMCP and the EOLC Networks. Currently all Networks have some degree of formality in their relationship with the PPSMCP. This relationship continues to evolve across the province. All EOLCNs include the PPSMCP staff as Network members. Two regions have operationally joined the PPSMCP with the EOLCN, pooling funds and administrative support.

- Regionally vested roles and responsibilities.

Under the auspices of the original mandate (i.e. System Design etc.) a number of regional networks have been vested with specific roles. For example several networks have been vested, by the LHIN, with an advisory role related to the EOLC projects that have been funded through the Aging at Home initiative. Additionally several regions' LHINs have supported the EOLCN in a system mapping/system review process. Some EOLC Networks have been vested, by the RCP, to serve as the regional advisory body for the Ontario Cancer Symptom Management Collaborative.

The type and degree of regionally vested roles varies across the province.

- Provincial Responsibilities

Each Regional Network has a mandate to work with the Provincial End of Life Care Network (PEOLCN) to advance best practice and enhance provincial consistency in HPC. Leaders from all EOLCNs have attended Provincial EOLCN meetings and workshops. EOLCN leaders from several of the Regions have assumed formal leadership roles within the PEOLCN and several others have provided leadership for task forces and project groups. The importance of the Provincial level work is universally endorsed within the Leadership of the PEOLCN.

- Collaborative Responsibilities with Cancer Care Ontario and others

All EOLCNs include the Regional Cancer Program (RCP) as one of their members. All Palliative Care Physician Leads are members of the Regional EOLCNs. Generally there is strong collaboration between the RCP and the regional

EOLCNs. One Region has a shared portfolio role between the RCP and the EOLCN. Several other EOLCNs receive support from the RCP. All EOLCNs endorse the adoption of common tools as described in the “Ontario Cancer Symptom Management Collaborative” (previously PPCIP) and most EOLCNs have actively advanced the adoption of these tools.

At a regional level many EOLCNs members are also members of the Ontario Palliative Care Association and/or the Hospice Association of Ontario. Many EOLCNs include, at their meetings, regular standing reports from these provincial bodies and are actively involved in collaborative work.

### **Regional Network Accountability**

Lack of clarity on accountability is an issue for all EOLCNs across Ontario. There is universal agreement within the leadership of the PEOLCN that a priority for action is the need to formalize and standardize EOLC Network accountability both regionally and provincially.

The summary below highlights some of the levels of ambiguity related to EOLCN accountability.

*Member Accountability* -Each member of the EOLCN has accountability to his/her own organization/sector and he/she represents that accountability at the EOLCN table. In addition to this sectoral accountability, all members also “signal” that they are making a commitment to the larger mandate of developing a cross sector “system” of HPC when they become a part of this Network.

Only two EOLCNs have formalized this membership accountability through a “membership agreement” signed by each Network Member. This agreement describes the role related to developing a cross sector system. One of these regions has membership fees.

*Network Accountability* - The EOLCN is accountable to:

- the member organizations- this accountability occurs through the membership
- the LHIN in each region – this accountability typically is not yet well defined in any of the 14 regions.

Additionally there is provincial accountability. There is an expectation that each regional EOLC Network will work collaboratively with the other 13 EOLC Networks to advance the work of the PEOLCN.

EOLCNs across Ontario have very differing understanding of Network Accountability. No Networks have clear mandates related to accountability with the LHINs

*Director Accountability and Role*-Accountability is aligned with role. Most EOLCN Directors have a single role as Directors of the End of Life Care Network – therefore the key accountability is to the Steering Committee of the EOLCN. In two regions Directors have assumed some operational responsibility (along with commensurate funding) relating to the PPSMCP (this has occurred in regions where this service was previously dispersed). In these cases key accountability continues to be to the Steering Committee (since the EOLCN is to serve in an advisory role for the PPSMCP).

In one region (ESC) the EOLCN Director’s role and responsibilities have been somewhat unique. This role has been a joint portfolio which includes responsibility for the EOLC Network and for a Regional Palliative Care Cancer Program (which includes oversight of the Ont. Cancer Symptom Management Collaborative at a regional level and interaction with WRCC and CCO on this and other initiatives). This Director has dual accountability to the EOLCN Steering Committee and to the Vice President of the Regional Cancer Program.

In addition to accountability to the Steering Committee, all of the Directors, have some form of contractual or employment accountability to a transfer payment agency.

The relative strength of the various levels of accountability for Directors is not clearly defined or uniformly applied across the province.

No EOLCN Director in any LHIN region in Ontario is currently involved in operations of one specific sector. The EOLCN structure was originally set up in this manner so that the neutrality of the EOLCN and of the Director can be maintained. The Network and the Network Director are to be seen as a regional resource “not connected to or owned by” only one sector/organization.

No Directors, at this time, have defined accountabilities with the LHIN.

Refer to Table which follows for summary of status of EOLCNs across the province.

Table 1 – Summary of Current status of End of Life Care Networks across Ontario – December 2009

LHIN # & Name	LHIN Region Background Information				End of Life Care Network Information						
	Population 2006	% Pop. change 2001-2006	Land Area (square km)	Pop. Density / square km	Network Established	Director/ Coordinator	Chair - Name and Affiliation	Source of funding for EOLCN - in addition to \$70,000 from MOHLTC	Director Role/ Status- Full Time or Part Time/ accountability (acc)	Other sources of support	Structure - brief description Note - * indicates that structure is currently under review
1. Erie St. Clair	630,195	3.4	7,323.70	86.1	yes	Beth Lambie	Steering C. chair - Nancy Snoblen - Hospital; Executive C. chair - Betty Kutchta - CCAC	RCP	Joint Role EOLCN and RCP - FT; 3 way acc.	CCAC	*Executive council; Steering council with Education subcommittee; 3 local committees & tasks force groups
2. South West	901,123	3.6	20,903.51	43.1	yes	Paul Cavanagh	Co- chairs - Donna Ladouceur - CCAC; Angela Hurtado - Community Health Services, Canadian Red Cross	CCAC	EOLCN - FT 2 way acc.	CCAC	*Steering committee, subcommittees, local committees; considering Executive committee.
3. Waterloo Wellington	686,324	8.4	4,746.62	144.6	yes	Andrea Martin	Connie Dwyer, Executive Director from Lisaard House	CCAC	EOLCN - 1FT 2 way acc.	CCAC	Steering Council; 3 subcommittees ( adapted from CHPCA categories)
4. Hamilton Niagara Haldimand Brant	1,315,964	4.3	6,472.99	203.3	yes	Julie Darnay	Beth Ellis - Hospice	PPSMCP & Interdisciplinary Education	.6 FTE Network & .4 FTE - Administrator to these services	CCAC - in kind	*HNHB HPC Network Advisory Committee; regional committees, local planning committees, standing committees and ad hoc project committees
5. Central West	739,957	18.1	2,589.95	285.7	partially	No Director	Maureen Riedler - Hospice; Christine Nuernburger - CCAC	Submitted to LHIN for additional funding	No Director		Steering Committee
6. Mississauga Halton	1,008,004	12.1	1,053.65	956.7	yes	Barbara Pidcock	Co- chairs - Ann Stirling - CCAC; Ron Lirette, Hospice	Hospitals	EOLCN - PT single acc.	CCAC	Steering Committee; project committees
7. Toronto Central	1,090,301	-0.3	191.99	5,679.0	yes	Siu Mee Cheng	Dr. Larry Librach -	membership fess	EOLCN - FT single acc.	?	Executive council; & tasks force groups
8. Central	1,532,649	13.3	2,730.49	561.3	yes	Jane Wangui	Co- chairs - Marta Krywonis - LTC & Terry Winston - Hospice;	none	EOLCN - PT single acc.	CCAC	Steering Committee
9. Central East	1,432,695	6.3	15,274.06	93.8	yes	Kirsten Schmidt-Chamberlain	Theresa Morris - Peterborough Regional Health Centre	RCP	EOLCN - FT single acc.	CCAC - in kind	Steering Committee
10. South East	466,669	3.2	17,887.16	26.1	yes	Maggie George	Dr. Deb. Dugeon - RCP PC lead	Queens University	EOLCN- FT 2 way acc	CCAC	*Steering Committee; Executive council; "at large" membership; Subcommittees (CHPCA categories); task force groups
11. Champlain	1,147,209	4.3	17,631.05	65.1	yes	Gwen Barton		none	EOLCN- PT; single acc.	CCAC	Steering Committee
12. North Simcoe Muskoka	422,902	12.2	8,373.34	50.5	yes	Cate Root	Carol Lambie - president & CEO of the Mental Health Care Centre Penetanguishene; Garth Matheson VP - Regional Cancer	PPSMCP; two Hospices	joint role EOLCN & PPSMCP - FT single acc.	CCAC	Incorporated Board, 4 standing committees and several task forces.
13. North East	551,691	-0.3	395,576.72	1.4	partially	offer pending	Frankie Vitone - CCAC	Hospitals	Advertised as EOLCN - FT	?	
14. North West	234,599	0.6	406,819.56	0.6	yes	hiring underway	Dr. Mary Lou Kelley - Lakehead University & Katherine Campbell, ED Family Health Team Dryden (co-chairs)	2 hospitals (annual renewable)	Full time (contract)	CCAC & CERAH/LU	Steering Committee, 3 standing committee,

### 3. Erie St. Clair End of Life Care Network Current Status

#### Funding

The current funding for ESC EOLCN includes:

- the \$70,000 allocated as part of the initial EOLC MOHLTC strategy in 2005; annualized and added to the base of CCACs. CCAC is the transfer payment agency for this funding in ESC
- 60,000 from Windsor Regional Cancer Program
- Support from CCAC

This funding and support covers salary/benefits/ mileage /activities. Additionally WRCP and CCAC together supported up to 1.0 FTE in clerical support.

The funding from WRCP will cease at the end of March 2010..

#### Director's Current Roles/Responsibilities/Accountabilities

Current responsibilities for the ESC EOLCN Director have been unique in the province, including joint accountability for the EOLC Network and for a Regional Palliative Care Cancer program (which included oversight of the Ont. Cancer Symptom Management Collaborative at a regional level and interaction with WRCP and CCO on this and other initiatives)

This current ESC set of responsibilities and accountabilities will continue "as is" only until the end of March 2010.

#### ESC EOLCN Structure/ Role /Accountability

*Historical overview* - The structure and role of the ESC EOLCN has evolved over its four years of operations. The evolution has been "organic" in nature as the ESC EOLCN responded to new opportunities and demands (e.g. A@H initiatives etc.). This agility and flexibility of structure was effective and allowed "form" to follow "function".

The terms of reference (ToR) and purpose of the various committee levels have gone through 3 iterations. The first were created by Ann Baker and Carole Gill based on recommendations from Marlene Close (consultant) and in consultation with other provincial networks (e.g. Simcoe). These first ToR for the Steering Committee were approved by the standing Steering Committee at that time; the ToR for the 4 recommended sub –committees were held in abeyance, as the need for these additional committees was unclear. Instead it was decided that there would be task force groups formed as the need arose.

At that time it was decided that there continued to be a valuable role for the Local Committees and they should continue to work on local issues (the recommendation from Marlene Close was to disband the locals and have just one committee, but that never met with general approval). This structure was presented to the general membership at the "Moose Lodge" as part of the EOLCN/PPCIP education session sponsored by RCP and CCAC.

The second change in structure/role came with the introduction of the Executive Council. It was felt that this level of leadership was needed to give impetus to some of the pending initiatives. This new structure was presented to the membership at large at the education session held at the Wheels Inn. At that time Carole Gill and Ann Brignell were thanked for chairing and leading the original EOLCN work. Betty Kuchta volunteered to serve as the initial interim chair of the newly created Executive Council. (The chart of this second structure is shown below). At this same time the RCP created a joint portfolio position for the EOLCN Director and contributed funding to the Network operations. This change was also presented at the Wheels Inn session. (This session was attended by several LHIN members and Chris Sherwood was the key note speaker).

The third iteration of structure/role came with the implementation of the Aging at Home initiatives and the creation of an Education Subcommittee to address these and other education initiatives. Through consensus at the Executive Council, it was generally understood that this Education Committee would report to the Executive Council for Approval and Direction and to the Steering Committee to work with them to create the education recommendations.

Subsequent to this re-structuring, discussion has ensued related to the overlapping membership between the Steering Committee and the Education Committee questioning if we needed both Committees and the Executive Committee. Additionally it was noted that there is a Volunteer Hospice Committee (VHC) which meets "semi-regularly" and also meets with counterparts in the Southwest region. Beth has attended these meetings and

linkages exist with the overall EOLCN, but questions were raised about this VHC group potentially being part of the “formal structure” of the EOLCN. Individual members of the VHC are members of each local committee.

*Accountability and Advisory role of the EOLCN* -One of the ongoing “quandaries” related to the EOLCN (and other newly created networks like the Regional Infection Control Network) is ‘to whom is the Network accountable?’.. Recommendation #4 in the Dec. 2008 ESC EOLCN Report highlights the need to have this clarified. Subsequent minutes from various ESC EOLCN meetings reiterate this.

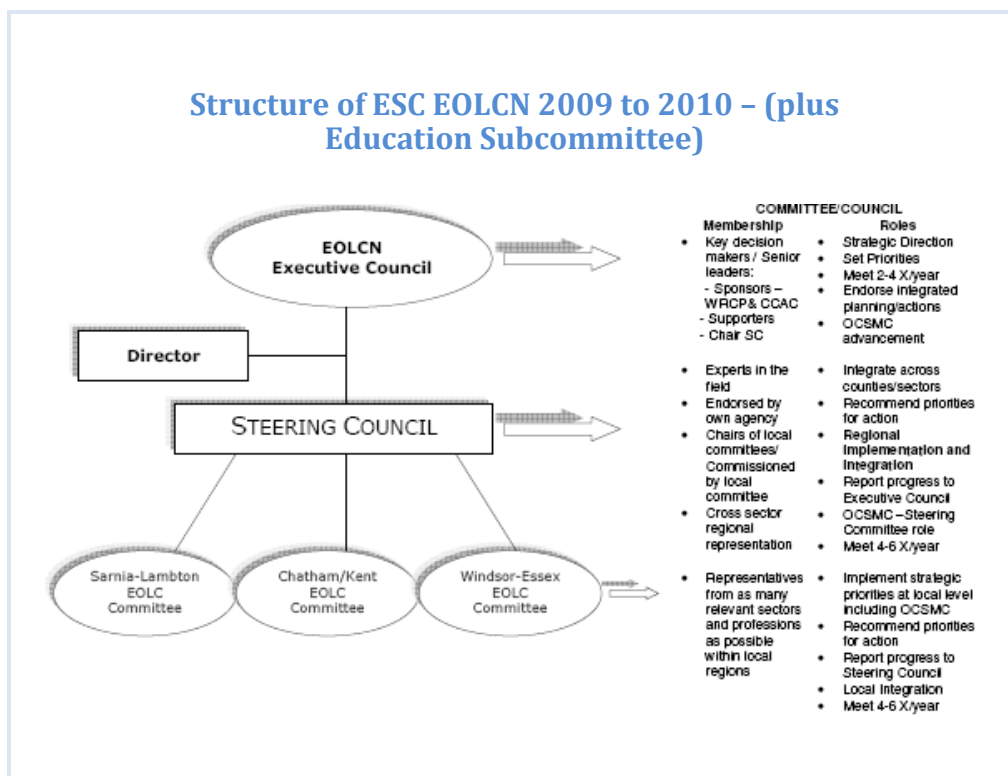
Additionally the level to which the EOLCN is to be advisory to the A@H initiatives needs to be clarified.

*Several other points of ambiguity currently exist related to structure and accountability and role of EOLCN:*

*General membership* – Who is the “general membership” of the EOLCN? If we consider that to be everybody who may have attended that original DHC meeting at the Wheels Inn in 2005/06 – do those people know they are members? How do they signal their membership? What obligation does the current EOLCN have to communicate with that large group? What membership obligations do they have?

Current thinking is that perhaps the general membership should be anyone on any of the committees (Local, Education, Task forces and Advisory Committee). It would then be the responsibility of this membership to communicate more broadly. If this is the subset considered to be general membership, how do they “signal” that they are members? Should there be a membership understanding/agreement developed?

**Table below illustrates the EOLCN Structure; the Education subcommittee is not shown in this schematic.. The Education Subcommittee (created to address A@H initiative) was formed to craft recommendations related to A@H funding. These recommendations have been endorsed by the Executive Council.**



## 4. Recommendations for next steps for ESC EOLCN

### **i. Network Accountability**

**Formalize the accountability mechanism of the ESC EOLCN to the ESC LHIN.**

Discussion - The LHIN is offering to the ESC EOLCN “more formal alignment and support”.

### **ii. Advisory Committee Structure:**

**Align ESC EOLCN Advisory Committee Structure with the structure recommended by the LHIN related to their other advisory networks.**

Discussion: In the process of re-creating the Advisory committee the following will occur:

- the current Steering Committee and Executive Council will be collapsed,
- one new advisory level committee will be created ,
- Membership for this new committee will be suggested by current members of ESC EOLCN with final selection done by LHIN staff.

### **iii. Local Committees, Education Subcommittee and other Subcommittees and Task Force groups**

**Continue the activities of each of the three local committees and the Education Subcommittee and clearly define the accountability mechanisms. Consider creating a membership agreement so that the expectations for members are clearly delineated.**

**Include the broad membership for task force groups and other subcommittees as required.**

Discussion – The local committees are committed to enhancing integration and care at a local service delivery level. These groups pull a large membership from Community Service Providers, Volunteers, Hospice, Hospital, Long Term Care, etc.

### **iv. Leadership**

**Clearly define leadership roles.**

Discussion - The Director of the ESC EOLCN will provide leadership for the ongoing activities and identified priorities of the ESC EOLCN and will report jointly to the ESC LHIN and the Advisory Committee.

### **v. Network Role**

**Clearly define the role of the ESC EOLCN incorporating initial role mandates with the newly emerging expectations from the LHIN, insuring that clarity is provided regarding advisory role as it relates to A@H initiatives.**

Discussion - Refer to “Role of End of Life care Networks” page 2 for details of initial role expectations.

### **vi. Director position accountability and funding**

**Clearly define the role and accountability of the ESC EOLCN Director based on the part time funding available.**

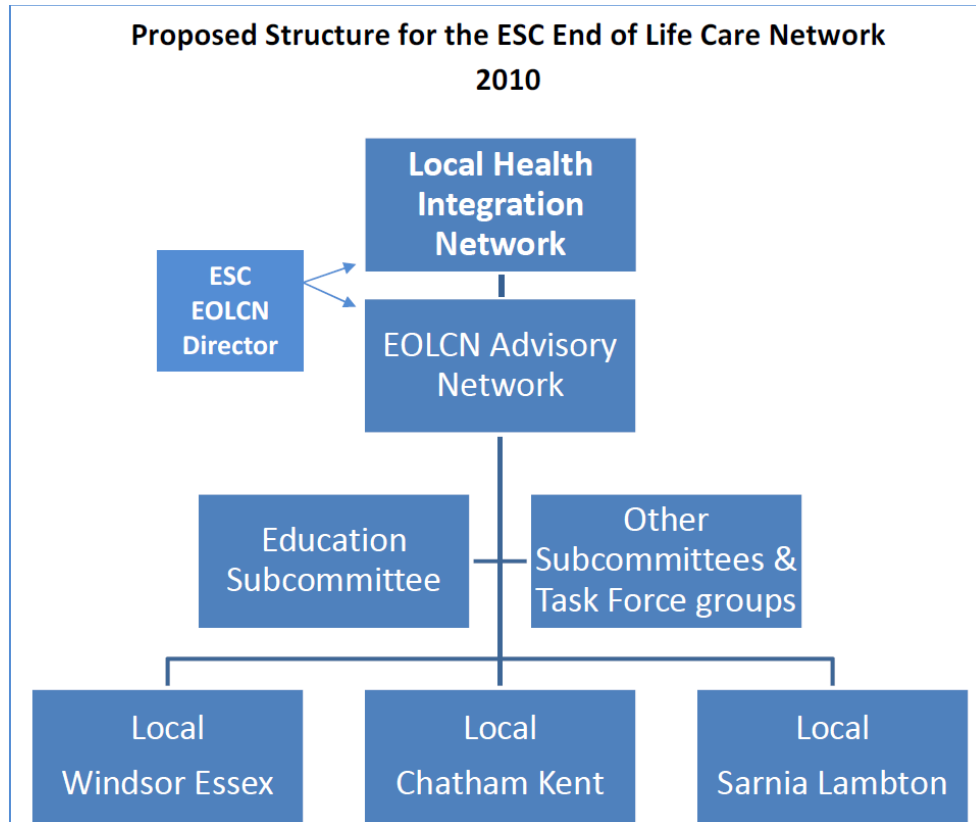
**Initiate plans for sustainable funding for a full time position once the incumbent has retired.**

Discussion – The incumbent Director has agreed to stay on in a part time position (with current salary/benefits/other costs prorated based on the available funding from MOHLTC [\$70,000 in 2005].).

The CCAC is agreeable to continue as Transfer Payment Agency . As indicated above the Director will report jointly to the LHIN and to the Advisory Network. The incumbent Director has agreed to continue in this role in a part time position and to work with partners to create a sustainable funding model for a full time position (once the incumbent retires).

The LHIN has offered to support the Director position in terms of clerical/administrative functions and budget oversight.

**Refer to chart which follows for a schmatic representation of the proposed structure and accountability model.**



### 3. Summary

The Steering Committee and Executive Council of the Erie St. Clair End of Life Care Network each unanimously endorsed these recommendations for the next steps in development of the ESC EOLCN (January 11th, 2010 and January 26<sup>th</sup> respectively). This realignment of structure, accountability and role will help answer many of the ongoing questions of current members of the ESC EOLCN. These questions have evolved around ESC EOLCN accountability and details of the advisory role.

To date all of the consulted members of the ESC EOLCN have embraced the concept of moving our focus from “planning to performance” with closer alignment with the LHIN. A new structure with clear accountabilities and role definitions will facilitate this next step.

## **Appendix 1**

### **Historic overview**

(Note: the information in this first section below is summarized from work done by Barbara Pidcock, Julie Darnay and Chris Sherwood)

#### **Important Dates and Developments for Hospice Palliative Care (HPC) in Ontario**

##### **1992**

The government of the province of Ontario got involved in providing broader system support for hospice palliative care with the advent of the “Palliative Care Initiatives”. These Initiatives were divided into four distinct categories:

- Interdisciplinary Education (*previous 23A*)
- Physician Education (*previous 22A*)
- Volunteer Hospice Services (*previous 08D*)
- Palliative Pain and Symptom Management (*previous 24A*)

Eventually the Palliative Pain and Symptom Management Consultants across the province organized themselves into a Network (Palliative Care Consultants (PCC) Network) at a provincial level – the only one of the four Initiatives to do so. There was no government mandate for this to occur. Instead, it occurred organically as a result of informal relationships that developed initially amongst these individuals and their recognition that they could be more effective at doing their work if there was a formal mechanism to share and learn from each other.

##### **November, 2004**

Presentation from the MOHLTC describes the policy for a new End-of Life Care Strategy. The four-year provincial end-of-life strategy was to begin planning in 2004/05 and to implement over three years ending the strategy in 2007/08.

The overarching goal of the Provincial EOL Care Strategy was *to provide comprehensive, consistent and high quality of end-of-life care across the province by shifting the care of the dying from the acute settings; enhancing and developing a client-centred and interdisciplinary end-of-life service delivery capacity; and improving access, coordination and consistency of services and supports.*

The EOL Care Strategy led to the establishment of Palliative/End-of-Life Care Networks across the province. The role of the Network is to provide regional leadership for the improvement of the system of care required by clients, families and service providers. District Health Councils were directed to establish, in each district planning area end-of-life regional system networks for:

- broad system design
- coordination and integration of services at a system level
- monitoring and assessment of community needs
- promotion of service innovations

Shortly after the implementation of the EOL Care Strategy, the leaders of the EOL Care Networks decided that there would be value in forming a provincial structure that would champion an integrated quality strategy of end-of-life care for all individuals across the province through collaboration and best practice.

##### **October, 2005**

Provincial Government announced \$115.5M for the end-of-life care strategy to:

- Help shift care of persons in the last stages of their life from hospitals to home or another appropriate setting of their choice;
- Enhance an interdisciplinary team approach to care in the community; and
- Work towards better coordination and integration of local services.

##### **April, 2006**

MOHLTC provides new policy describing Volunteer Hospice Services.

### **May, 2006**

Provincial Government announces \$117.8M to improve home care and community support services. The funding includes \$26.7 million for Ontario's end-of-life care strategy.

Details of how residential hospices will receive funding from the MOHLTC (through the CCACs) released by the MOHLTC.

E-mail from MOHLTC describes funding for EOL networks (through the CCAC), "\$70,000 has been provided in base funding per LHIN to support the activities of the EOL Networks, for a total of \$980,000."

### **August 2006**

Revised policy of Pain and Symptom Management announced, now titled Palliative Pain and Symptom Management Consultation. This service supports service providers in home care agencies, LTC, community support services and primary care by providing access to PPSM Consultants. These positions provide consultation, education, mentorship and linkages to PC resources across the continuum of care. The service also helps to build capacity amongst front line service providers in the delivery of palliative care. The service does not provide direct client/patient assessment or care planning.

The role of the HPC Networks is to advise and support the provision of the PPSMC service across the designated sectors/regions. The sponsoring agency (transfer payment organization), which differs across the province, is accountable for the funding provided for the PPSMC service. The agency/organization is responsible for submitting yearly service plans, budgets and statistics to the MOHLTC (transferred to LHINs in 2007). The PPSM Consultant is to be perceived in the community as a regional resource that is independent from the sponsoring agency's operations.

### **September, 2006**

MOHLTC ended the strategy phase of the EOL strategy and the Provincial EOL Care Strategy Advisory Body disbands.

### **March, 2007**

Revised policy of Community and Facility Palliative Care Interdisciplinary Education released by the MOHLTC. This service provides education to front line health care providers. HPC/EOL Care Networks and PPSM Consultants will act in an advisory capacity in planning, implementation and evaluation of the local area's palliative/EOL care education needs.

The role of the EOL Care Networks will be to also provide advice related to the delivery of the Palliative Interdisciplinary Education service in the local area. The sponsoring agency (transfer payment organization), which differs across the province, is accountable for the funding provided for the PPSMC service. The agency/organization is responsible for submitting yearly service plans, budgets and statistics to the MOHLTC (transferred to LHINs in 2007).

The MOHLTC recognizes the synergies that exist between the PPSMC service and the PC Interdisciplinary Education Service. In areas where the administration and funding for these services have been aligned/consolidated significant benefits have been noted. As noted in the August 2006 revised policy for the PPSMC services, the Community and Facility Palliative Care Interdisciplinary Education is to be perceived in the community as a regional resource that can support the learners through coaching and mentoring.

### **April 2008**

The PEOLCN is the sponsor organization of the Hospice Palliative Care Community of Practice through the Senior Health Research Transfer Network (SHRTN). Through the HPC Community of Practice, education opportunities are

made available and the development of provincial documents are shared. SHRTN has made available to the PEOLCN teleconference, webinar meeting services, librarian services and the services of a knowledge broker. The purpose of this community of practice is to give palliative care providers mechanisms to work collaboratively, therefore supporting the objectives of the Provincial End-of-Life Care Network. The objectives of this CoP are to provide a forum and mechanisms to:

- Facilitate the exchange of information
- Identify and recommend areas of common interest for shared project planning and implementation
- Work collaboratively on joint strategic and action planning, including grant applications
- Facilitate system coordination, decrease duplication and increase efficiencies
- Facilitate consensus building and consistency in best practice
- Support the development of common evaluative tools and processes
- Explore avenues to share information with other key provincial organizations
- Network with other CoP to share best practice information and content area expertise