

Report *on the* Palliative Care Roundtable

June 5, 2001



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Introduction

The purpose of this **Cancer Care Nova Scotia (CCNS)** Roundtable was 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.

One hundred and sixty five (165) people participated in the Roundtable including patients and survivors, family members and informal caregivers, nurses, physicians, administrators, volunteers, allied health professionals and cancer agency staff.

The approach was strategic in orientation, building capacity and enhancing and utilizing existing expertise for provincial benefit and outcomes.

Expected outcomes for the Roundtable are included in this report: a draft plan with action steps, accountabilities for key issues areas for the province, all in the context of caring for patients with cancer.

A glossary of acronyms used in this report is included in Appendix #1.

Prior to the Roundtable, a Palliative Care Advisory Committee was struck. This was a group of professionals from across the Province and included the following:

Dr. David Abriel, Family Physician, Western Region

Ms. Shauna Blundon, Project Officer, **CCNS**

Ms. Sandra Cook, Director, Home Care, Home Care Nova Scotia, Department of Health

Ms. Barb Farmer, Victorian Order of Nurses

Dr. Gerry Farrell, Family Physician, Northern Region

Dr. Gerri Frager, Medical Director Pediatric Palliative Care Service, IWK Health Centre

Ms. Heidi Little, Secretary, **CCNS**

Ms. Ann McKim, Project Manager, RPHCPP, Northern Region

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

Ms. Tamara Plante, Receptionist/Secretary, **CCNS**

Mr. Brent Powers, Administrative Coordinator, **CCNS**

Ms. Judy Simpson, President, NS Hospice Palliative Care Association

Ms. Glenna Thornhill, QEII Health Sciences Centre

Ms. Theresa Marie Underhill, Chief Operating Officer, **CCNS** and Committee Chair

Roundtable

The Roundtable was opened by Mr. Jamie Muir, Nova Scotia Minister of Health, who welcomed participants and congratulated **Cancer Care Nova Scotia** on making this event possible. Mr. Muir confirmed the provincial

government's commitment to quality and compassionate end-of-life care, and that the government recognizes the benefits of such care and wants to improve it both in the hospital and at home.

Mr. Muir further stated that the provincial government supports the need for a national strategy and is prepared to work with the federal government on recognizing the excellence of the Rural Palliative Home Care Pilot Project and considering it as a model for use across Canada. Mr. Muir closed his remarks by thanking participants for their contribution to palliative care. He commented on the importance of the Roundtable to ensure that ideas from as many perspectives as possible are included in strategic and action planning.

Four keynote presentations contributed to an overview of the current situation in palliative care in Nova Scotia. The four presentations and their subjects were:

End-of-Life	Dr. Louise Cloutier, Past President, Medical Society of Nova Scotia & Chair of MSNS Interdisciplinary Working Group on End-of-Life Care Issues
The Northern Region Palliative Care Model	Ms. Ann McKim, Project Manager, Rural Palliative Home Care Project
Service Delivery Inventory and Overview of the Current Situation	Ms. Theresa Marie Underhill, Chief Operating Officer, Cancer Care Nova Scotia
National Norms (Standards) for Palliative Care	Ms. Janet Carver, Palliative Care Coordinator, Lunenburg and Queens.

This Committee reviewed background information and a preliminary needs assessment and identified the following six issues as the key elements in a provincial strategic plan for implementing palliative care throughout the province:

1. Education of Palliative Care Professionals
2. Patient Referral
3. Inter-District Coordination
4. Access to Services
5. Inter-Disciplinary Collaboration
6. Volunteer Development.

Roundtable Process:

In planning the Roundtable, the Advisory Committee members wanted to ensure that this workshop did not repeat recommendations and discussions held at previous events that focussed on palliative care. As a result, prior to the Roundtable, **CCNS** staff summarized for each issue area a list of previous initiatives, what was going well and what needed improvement.

Participants then worked in small groups to:

- (a) review and update these current situation tables; and
- (b) develop strategies for each issue, including accountability and timelines.

Due to the large number of participants (165), each issue was discussed by three groups. Results have been synthesized in this report to avoid duplication.

Reviewing the results of this Roundtable and finalizing a strategic approach to palliative care in the province is a collaborative challenge. To this end, **CCNS** has shared the report with the Roundtable Advisory Committee to get their input and advice prior to finalizing the plan and moving to implementation. The Report will be circulated broadly for information purposes as well as to support the implementation.

Palliative Care in Nova Scotia: a Strategic Approach

The table below and on the successive pages represents the action plan developed through a consensus based process. In the left column are excerpted statements from participants on the needs in the system and comments from participants' evaluations.

Please note that common abbreviations used in the following table include:

PC	Palliative Care
CPCA	Canadian Palliative Care Association
DHA	District Health Authority
DOH	Department of Health
MSNS	Medical Society of Nova Scotia
RNANS	Registered Nurses Association of Nova Scotia

1. Education of PC Professionals

The challenge is to (a) increase the investment in palliative care education for health professionals and (b) provide universal, consistent, accessible, knowledgeable and up-to-date curricula and education for each health care provider group in Nova Scotia in a timely, cost effective manner.

“There needs to be developed training programs for team members – together with care providers and the general public.”

“Increase palliative care education to all health care professionals, especially at the undergraduate level”

	Strategy	Accountability	Timeline
1.1	Build capacity by identifying health care professionals within each District who can deliver/facilitate PC education.	DHAs	Dec/ 01
1.2	Identify interdisciplinary local champions and develop their expertise as opinion leaders and educators, e.g., through an opinion leaders conference.	QEII/IWK PC	Nov/ 01
1.3	Review/revise/implement the Rural Palliative Care Pilot Project's education curriculum (front-line, resource teams and faculty development) in all Districts in Nova Scotia.	CCNS/ PC Coordinator	June/ 03
1.4	Establish agreements with licensing bodies for health professional academic institutions to ensure PC content is included as <u>core</u> content.	CPCA and NSHPCA	June/ 03
1.5	Lobby the government to champion new curricula for PC education.	CCNS	Nov/ 01
1.6	Explore creative methods of delivering PC education, e.g., accommodating shifts, audiotaping, videotaping. (3)	Provincial PC Coordinator/ Employers and professional bodies	Immediately

2. Patient Referral

a. Identifying Patients

The challenge is to identify patients at the optimal point in the trajectory to ensure that necessary services are offered/delivered to all patients.

“The creation of a widely available document or manual on Palliative care...which includes peer-reviewed, user friendly, guidelines.”

“Cancer patients must have open and honest communication with their health providers so they can access palliative care early instead of at the end of their life.”

	Strategy	Accountability	Timeline
2a.1	Develop a provincial information package on PC for patients and families regarding provincial- and District-specific PC services. The package should: <ul style="list-style-type: none"> • indicate that PC is both a resource and a treatment option • address fears and misunderstandings • identify who may refer • be provided early in an illness. 	CCNS	June/ 02
2a.2	Identify and develop creative consumer education strategies about PC benefits and services.	MSNS/ RNANS	June/ 02
2a.3	Ensure available PC services are advertised extensively and creatively.	Regional Service Providers	Dec/ 02
2a.4	Enhance clinician/patient communication in areas related to health care transitions to promote informed choices, e.g., through <ul style="list-style-type: none"> • skill development • presentation of PC as a treatment option in the cancer care setting • via pamphlets and • discussions with oncologist/oncology nurse/Homecare. 	CCNS Commissioner and PC Coordinator/ MSNS	June/ 02
2a.5	Ensure that PC and related expertise is introduced as a resource at the time of diagnosis and have a District-specific 1-800 telephone number available for referrals on a 24 hour/7 days/week basis.	Oncologist/ Oncology Nurse	Nov/ 01

b. Interdisciplinary Team

The challenge is to establish and finance an interdisciplinary team based on population numbers and make it accessible to all Nova Scotians.

	Strategy	Accountability	Timeline
2b.1	Determine and implement systems and resources necessary to ensure optimal patient referral.	DOH	Oct/ 02
2b.2	Educate community and health care professionals on available services and how they can be accessed.	Interdisciplinary Team	Oct/ 02
2b.3	Establish provincial standards for referrals, including an evaluation of the effectiveness of the current referral process.	Interdisciplinary Team	June/ 02

3. Inter-District Coordination

a. Provincial PC Model

The challenge is to implement a provincial PC model that enables single point access, case management and resource allocation in each District.

	Strategy	Accountability	Timeline
3a.1	Establish and approve a provincial framework for funded essential core PC services similar to the Diabetes Care Program and the Reproductive Care Program.	DOH and partners	March/ 02
3a.2	Develop and implement a Case Management Model.	DOH: Policy DHA: Implementation	March/ 02
3a.3	Make each District accountable for development of a communication/referral process in PC in and between Districts.	CEOs of each District	Nov/ 01
3a.4	Implement a single access system.	DOH: Policy DHA: Implementation	April/ 02

“We need to develop a provincial strategy for palliative care, including provincial standards now.”

b. Provincial PC Standards

The challenge is to adopt and implement palliative care standards through leadership at the DHA level and with the commitment of the Department of Health.

	Strategy	Accountability	Timeline
3b.1	Reach consensus on standards for PC and endorse these through partnering; build on current work on national norms.	DOH and partners (e.g., DHAs, RNANS, MSNS, CPCA)	March-June/ 02
3b.2	Establish collaborative leadership to facilitate integration and coordination of PC standards among various sectors inter/intra District levels.	DOH	March-June/ 02
3b.3	Review, revise and adopt the 1998 Document on Integration of PC in Nova Scotia.	DOH and Partners	March-June/ 02

“The NS Working Group on Palliative Care came out with a detailed plan in 1998. So far nothing has happened to it.”

4. Access to Services

The challenge is to (a) standardize access to integrated, comprehensive, equitable PC services and resources in all Districts and across all care settings, e.g., home, hospital and long term care, and (b) decrease fragmentation by increasing awareness and coordination.

	Strategy	Accountability	Timeline
4.1	Develop a business case for PC, including key definitions, e.g., PC, end-of-life.	CCNS and NSHPCA task force	Dec/ 01
4.2	Based on the business case, secure funding to implement a comprehensive, integrated PC approach in Nova Scotia.	CCNS in partnership with government	April 1/ 02
4.3	Review what has been learned about access to services in the Northern Region Project and initiate a customized approach in each District.	DOH/ CCNS	June/ 02
4.4	Develop/improve education programs to increase public and health care professional awareness of PC resources and how to use them effectively.	DOH/ CCNS /DHAs	June/ 02
4.5	Initiate and develop a PC outreach clinic.	CCNS	June/ 02
4.6	Review and re-define social values in each District regarding end-of-life issues and educate/communicate to consumers.	Interdisciplinary collaborative team initiated by CCNS	Dec/ 03
4.7	Develop a single, 24 hour, provincial access number that will coordinate triage and access to services at the District level, i.e., a PC hotline.	DOH	Dec/ 02

“24/7 assistance is needed with a help line for families and health professionals.”

5. Interdisciplinary Collaboration

The challenge is to create mandatory, funded, community-based, accessible, interdisciplinary palliative care teams for all areas of the province based on clear roles, relationships and standards.

“Interdisciplinary teams and assessment are crucial to build in.”

	Strategy	Accountability	Timeline
5.1	Review the steps in this strategy and develop a business plan to obtain the funding for implementation.	DOH/ CCNS	Sept/ 01
5.2	Establish core PC teams reflective of patient and family needs for each hospital/CHC in the District.	DHA	Dec/ 01
5.3	Ensure appropriate remuneration for all PC team members including physicians and coordinators of volunteers.	DHA/DOH/ MSNS/RNANS/ VON Canada	Dec/ 01
5.4	Ensure that patient chart data is accessible to all PC team members, e.g., using the Rural Palliative Home Care Pilot Project model.	CCNS (model provincial format)	Dec/ 01
5.5	Develop a curriculum to train team members to work effectively together. Create innovative learning strategies to meet the needs of various Districts, e.g., distance learning.	PC Provincial Coordinator/ Commissioner, CCNS	June/ 02
5.6	Have curriculum reviewed and endorsed by a respected academic institution.	PC Provincial Coordinator/ Commissioner, CCNS	June/ 03
5.7	Disseminate curriculum information to all Districts.	CCNS	June/ 03
5.8	Ensure ongoing support for effective teambuilding.	DHA/Individual team	Dec/ 01

6. Volunteer Development

The challenge is to recognize and develop the volunteer role through appropriate recruitment, screening, training, support and ongoing education, including the establishment of a paid coordinator of PC volunteers, programs and services.

	Strategy	Accountability	Timeline
6.1	Develop a generic provincial role description for PC volunteers based on a review of the current situation in each District. Involve volunteers in the process.	CCNS in partnership with NSHPCA	Jan/ 02
6.2	Get approval to apply NSHPCA volunteer standards province-wide.	CCNS	Jan/ 02
6.3	Based on this report, develop a business case in support of volunteer involvement in PC services and take it to DOH for appropriate funding.	CCNS	March/ 02
6.4	Establish a paid position for the coordinator of PC volunteers in each health District.	DHA	Jan/ 02
6.5	Ensure care and ongoing education and support for volunteers, including appropriate programs and financial support.	Local volunteer programs/ Provincial and District Coordinators	Begin Immediately; programs in place by June, 02
6.6	Conduct regular public information sessions to aid in recruitment of PC volunteers.	District PC Coordinators	June/ 02
6.7	Include PC volunteers and managers as part of the PC development process.	Provincial PC service directors	Immediately

District-Specific Considerations

Working in District groups, participants identified considerations unique to their District that will have an impact on how a provincial strategy for palliative care in cancer is implemented. **CCNS** will consider the following factors when implementing a provincial approach.

District 1

Population and size, e.g.,

- geographical isolation/separation
- transportation is an issue for patients with little or no family or financial resources.

Recently became an assigned program within the District structure.

Resources and services, e.g.,

- a District program for palliative care is already in existence (hospital-based with community outreach and a bereavement program)
- accessible interdisciplinary education at university or through distance education is not available
- caseload size and incomplete teams impairs effective teamwork
- linkages are being developed with chemotherapy
- small community resources - advertising being globally funded
- there are regular interdisciplinary team rounds (hospital and community agencies)
- there is a lack of available respite and acute care beds dedicated to Palliative Care
- there is a volunteer program
- there is increased demand on resources; more funding and human resources are required to meet growing needs
- there is no core team in the District or county
- there is not enough back-up staff; home support services are underfunded and understaffed.

There is increased interest in and profile for palliative care in the community.

District 2

Population and size, e.g.,

- distance is a problem
- there are multicultural populations in clusters throughout the District.

Human resource issues, e.g.,

- we need a funded, non-hospital based coordinator for palliative care
- incentives are required to attract physicians and other health professionals to our District
- key people have been lost as a result of cutbacks.

Three hospitals offer different services and there is no defined program for palliative care.

District 3

Human Resources, e.g., we need

- a designated palliative care physician
- a designated District Palliative Care Coordinator
- pharmacists, social workers and spiritual advisors.

Ongoing education for all disciplines and the community at large.

Quality monitoring.

Seamless, integrated interdisciplinary delivery of care needs to be developed.

We need a designated palliative care program that includes children.

District 4

Transfer the culture and knowledge to other areas.

We need to grow service and skills in palliative care so that we work ourselves out of a job.

District 5

A functional palliative care model is in practice now.

Communication can be a challenge, e.g., out of province ownership and territorial problems.

Human Resources, e.g., a crisis in number of caregivers (home care workers).

Population/geography, e.g.,

- large area with small population
- close to Moncton
- transportation for patients.

District 6

We currently benefit from:

- Rural Palliative Care Module
- interdisciplinary team

- common assessment tools
- 1-800 home care number for referrals
- Aberdeen Palliative Care Society
- smaller size
- education services for general public.

District 7

Established partnerships need development.

Long term care is lacking and needs to be developed.

Population and geography, e.g.,

- large rural area/small population
- demographics are significant, e.g., high cancer rates and percentage of elderly population; language and cultural uniqueness of the population, i.e., people who are French Canadian/Native/Black.

Resources and services, e.g.,

- "Aging in Place"
- financial and human resources are limited in rural areas
- Inadequate amount and type of respite service
- palliative care is in place as a core service
- Palliative Care Coordinators exist in all facilities
- there is a nurse consultant at the regional facility
- traditional/existing family support is not always available to support patients at home.

District 8

Environmental concerns

Population/geography, e.g.,

- aging population and decreased family support
- cancer rates are high and increasing
- isolated for service delivery
- population is a mix of urban and rural; the First Nations population is the largest in the province
- referred 480 patients to District 9 (80% cancer, 20% other).

Resources and services, e.g.,

- excellent surgical/medical specialties
- high patient/family physician ratio
- limited options for the elderly and access to bereavement services

- linkages with oncology, volunteers, community
- palliative care patients are identified; number of referrals is increasing
- there is a cancer centre in our District
- there is a commitment to open a palliative care unit in the District
- there is a structured/funded palliative care service
- very active hospice society
- well developed urban palliative care program; the rural program is still being developed.

District 9

Access, e.g.,

- 1/3 of population doesn't have a community hospital
- many family physicians don't have hospital admitting privileges
- palliative care needs to be introduced early in the patient journey
- patients may be confused about where to go, e.g., primary vs. tertiary care.

Population and geography, e.g.,

- large centres may not have the most efficient access to services; smaller centres can provide better access
- "master plans" developed in large urban areas may not be effective in other communities
- program development has to reflect cultural diversity
- the need to commute for services means extra costs for some patients
- there is a high incidence of poverty and a large transient population
- there is a large mixed urban/suburban/rural population with diverse needs.

Resources, e.g.,

- a palliative care interest group is in place
- although the expertise exists, there is a lack of resources throughout the District to implement an inter-regional model
- broad base of physicians and education
- concentrated, highly trained staff
- flow of resources needs to follow patients
- higher concentration of private nursing agencies
- Home Care Care Coordinators and community based care providers
- large number of long-term care facilities
- large number of salaried spiritual caregivers

- less family support
- metro volunteer initiative/joint volunteer training program
- more health care professions to educate
- need to increase awareness of community resources within the District and across the province to facilitate transfer from site to site
- there are many great resources and services for palliative care in the core metro area, but some other areas in the District have no access. The challenge is to ensure equity and continuity in access and services, and avoid stratification in types of available services
- there is a high potential for fragmentation of care because there are too many players; service/program coordination needs to be improved and linkages enhanced
- university city with affiliations to medical school and other health related alliances
- wealth of volunteer expertise.

Major referral centre for the province.

Linkages between tertiary care and the community; tertiary care facilities serve very broad areas (all of Nova Scotia and even other parts of the Maritimes) and their role is very different from primary care.

Greater need for liaison with other Districts for follow-up palliative care.

VISION:

Palliative Care: One Year From Today

Participants discussed what they would like to see in place at this time next year and identified the following points (alphabetical order).

Common Themes

The following themes were common to most Districts.

- A fulltime funded Palliative Care Coordinator has been hired.
- Access for patients is facilitated by a fulltime Volunteer Coordinator.
- All palliative care patients have access to Palliative Care Consultation Teams in outreach throughout the District.
- An accessible, integrated and coordinated Palliative Care Program is in place serving both patients and families and with equitable access for all Nova Scotians.
- Core palliative care services are being funded, maintained and enhanced. There is a fully integrated functioning palliative care core team based at each hospital site with expertise in the local community.
- Education about palliative care is ongoing and being given by trained professionals.
- Financial and human resources are available to ensure that effective, trained palliative care core teams are in place to meet increased demands for services.
- There is 24 hour access to palliative care services in the District.
- There is funding for a Coordinator of Palliative Care Volunteers (1.0 FTE for rural areas).
- There is increased awareness in the community of what palliative care is.

District 1

- A Palliative Care Consultation Team and a District Palliative Care Group/Committee are established.
- An accessible, integrated and coordinated palliative care program is in place serving both patients and families.
- Dedicated palliative care units are operating in hospitals.
- Financial and human resources are available to ensure that effective, trained palliative care core teams are in place to meet increased demand for services.
- Financial support is available for (a) volunteer expenses, (b) family leave and (c) maintaining person at home.
- Practical education is available for family caregivers.

- There has been a change in the mindset of care providers regarding the interdisciplinary approach, especially buy-in, of doctors who are the primary consumers when it comes to "selling the concept".
- There is 24 hour home support at final stages and a 24 hour symptom management/crisis team.
- There is accessible inter-disciplinary education at university, e.g., distance education.
- There is increased awareness in the community of what palliative care is.

District 2

- A fulltime funded Palliative Care Coordinator has been hired.
- District consultation services are available.
- Educational programs sponsored by the DHA are provided locally.
- The District's needs assessment and resources are updated and top priorities identified.
- There is a fully integrated functioning Palliative Care Core Team based at each hospital site with expertise in each community.

District 3

- Education about palliative care is ongoing and being given by trained persons.
- Human resources issues around recruitment and compensation are resolved.
- There is an accessible, integrated palliative care system in place with equitable access for all Nova Scotians.

District 4

- Colchester East Hants Health Authority achieves excellence through an integrated palliative care program. We are known for our best practices and our caring approach. Outcomes are optimal. Patients, families and our health care team are informed partners who take pride in our palliative care program.

Goals to reach this vision include:

- increasing the percentage of cancer patients referred to this program
- integrating palliative care with long term care
- creating a hospice society or foundation to develop a hospice facility
- sustaining continuing education
- developing and maintaining an information system with an electronic medical record for each patient.

District 5

- Access for patients is facilitated by:
 - a fulltime Volunteer Coordinator
 - a funded transportation program
 - an oncology clinic at HVRH
 - **are** able to utilize palliative care services, e.g., designated insured hospice beds in each large nursing home
 - cancer treatment drug coverage
 - long-term care
 - more collaboration and inter-provincial linkages.

District 6

- Day care services are available.
- Education for rural areas is improved.
- Palliative care has been further integrated into long term care, community based services, and First Nations communities.
- Respite care is utilizing long term care.
- There are an increased number of early referrals.

District 7

- All palliative care patients will have access to outreach palliative care consultation teams throughout the District.
- Core palliative care services are being maintained and enhanced.
- Palliative care is identified as a separate service team during accreditation.
- Respite services in communities have been increased.
- The ability and understanding of family physicians of who and how to refer is enhanced.
- The family physician is the key referral point in our District.
- There is heightened sensitivity toward diverse cultural issues.
- There is improved communication between family physicians and palliative care resource teams.

District 8

- A Patient Navigator is in place and working collaboratively with palliative care.
- A small option/hospice/unit has been developed.
- A traveling consultation team is in place.

- Human resources have been increased.
- Information Technology services are available for rural areas.
- Palliative Home Care services have been enhanced, e.g., through an increase of the entitlement.
- The District is actively part of the provincial palliative care education initiative for physicians and other health care professionals.
- The palliative care unit is fully functional by June, 2002.
- The provincial Home Care entitlement developed as part of the RHCPP is available in our District.
- There is 24 hour access to palliative care services in the District.
- There is a palliative care core service with appropriate funding.
- There is equal access to medication and supplies.
- There is funding for a Volunteer Coordinator (1.0 FTE for rural areas).
- Visiting palliative care clinics have been established in rural areas.

District 9

- 24/7 access to palliative care consultation is available.
- A coordinated, integrated, interdisciplinary team meets on a regular basis.
- A District palliative care program based on the framework of the Northern Project is in place by June, 2002. The program includes a single point of access to palliative care services, standardized training for all, case management/coordination and funding for dedicated personnel.
- A Palliative Care Foundation has been initiated.
- A system is in place that provides for a cost effective, integrated palliative care in both urban and rural areas of the District while recognizing the unique leadership role of the District in liaising and providing palliative care to clients from other Districts in Nova Scotia.
- A traveling consultation team is in place.
- All DHAs are working collaboratively to create a comprehensive, accessible inter-disciplinary approach to palliative care in Nova Scotia.
- An effective paper flow system is being used for patient information, e.g., a chart in the home with a uniform assessment tool and summary sheet available to other parts of the program.
- Appropriate care setting is defined by wishes/needs of the patient, not resources.
- Collaboration with primary care physicians is increased.
- Comprehensive bereavement care for both adults and children is part of the Palliative Care Program.
- Core services are mandated with funding to follow the patient and entitlements are given regardless of place of residence.

- Core training and support for volunteers is increased.
- Everyone in the District has equal access to palliative care.
- Expertise for core teams has been identified and developed.
- Families have access to compassionate leave and 24 hour support.
- Funding is available for respite care, drug coverage outside the hospital, caregiver funding/insurance. Increased palliative care resources allow best care in the final month of life without financial impact on family financial resources, e.g., through income support for family caregivers.
- Funding of care is equal in all locations of care.
- Intermediate level beds are available for end-of-life care when care is not feasible at home and an acute care bed is not needed.
- Paid, trained palliative care teams are in place in rural areas.
- Palliative care is accessible to all regardless of geographical location.
- Palliative care is seen as a treatment option.
- Patients have the right to die at home or in their preferred place.
- Practice guidelines and evidence based standards are implemented.
- Respite care is available.
- Standardized intake assessment and outcome measurement data is included in a computerized data base for utilization and financial management.
- There is a Palliative Care Director for the District.
- There is a truly integrated patient/family centred program based on clear standards that includes the entire District.
- There is consistency in access to and quality of both palliative care services and resources.
- There is increased education for patients and staff.

Concluding Remarks

In closing, Dr. Andrew Padmos, Commissioner, **Cancer Care Nova Scotia**, acknowledged the commitment, experience, energy and expertise of participants. He confirmed that **CCNS** will "commit with gusto" to implementing the final action plan and will carry the Roundtable Report forward to The Department of Health, the District Health Authorities, the Medical Society of Nova Scotia and other key organizations.

Dr. Padmos noted two important themes that emerged during the event: the need to:

- (a) add more professional and volunteer caregivers; and
- (b) make better use of existing care providers.

Cancer Care Nova Scotia is committed to working with the community to do both.

Cancer Care Nova Scotia planning is predicated on an understanding of palliative care as an inclusive discipline including symptom management, supportive care, end-of-life care and bereavement. **CCNS** will continue to work collaboratively with others involved in palliative care, particularly in the areas of education, communication and promotion of palliative care services.

Dr. Padmos concluded with his personal vision statement for palliative care in Nova Scotia: "Not the biggest, not the richest, but still the best".

Cancer Care Nova Scotia
Palliative Care Roundtable – June, 2001
Synthesis of Evaluations

1. From your perspective how successful was this Roundtable in meeting its purpose? (Circle one)

1	2	3	4	5
		(3)	(53)	(57)
N = 113	Average = 4.6			

2. What I liked most about this roundtable was:

- How the workshop was organized and facilitated (51), e.g.,
 - brainstorming and sharing of visions, ideas and solutions
 - breaking down into District groups
 - building on what was already done, then integrating teams and existing resources
 - changing tables to work with different groups
 - communication was facilitated through microphones at each table
 - discussion in small groups enabled us to voice our concerns; everyone had a chance to contribute
 - pacing: the meeting moved along quickly.
- Networking (33), e.g.,
 - interacting with individuals from different disciplines
 - it's always so positive to meet other champions
 - meeting with others from our District
 - sharing new ideas and meeting with others in palliative care across the province.
- Variety of people involved (36), e.g.,
 - participants came from a broad base
 - participants represented a good cross section of perspectives
 - there was a diverse mixture of disciplines and volunteers present
 - there was representation from Districts across the province
- Outcomes (18), e.g., we
 - came out with a product; a plan is in place

*“Action!
 Networking,
 changing
 tables to work
 with different
 groups.”*

*“Excellent
 facilitation;
 topic on target;
 very action
 oriented.”*

"It was well focused and well directed."

- had input into the development and integration of palliative care
- identified unique needs of each District
- learned more about the rest of the province
- produced valuable and concrete information.
- Focus of the meeting (14), e.g., the meeting was
 - focused on Palliative Care for all Nova Scotians
 - on track: participants were committed to the same topic
 - future- and action-oriented – “we will implement...”
 - focused on practical, “do-able” strategies and the aims were realistic.

3. What I liked least about this Roundtable was:

"Bit slower by afternoon when more “zip” needed."

- Meeting processes (22), e.g.,
 - some of the discussion was from previous sessions
 - table groups could have used some help with keeping on time and on track
 - the afternoon was somewhat repetitive with the reporting back; the afternoon reports were too intense to absorb
 - the focus was on Northern Region Palliative Home Care Pilot Project and no mention was made of the Eastern Region’s project
 - the preview of what the strategy might be was inadequate
 - there was an emphasis on the role of family physicians to the exclusion of other health professionals
 - there was not enough evidence provided on what does and does not work
 - too much time was spent on giving instructions; they were confusing and too structured, i.e., identifying challenge and vision
 - we moved around constantly
 - we needed more representation from Long Term Care; I would liked to have seen more input from family members, patients and volunteers
 - we spent a little too much time on the triangle.
- Room was too cold. (16)
- Time constraints (10), e.g.,
 - a later start time would have made it easier for those who traveled on day of the meeting
 - more time could have been spent on our own Districts/concerns/vision
 - the pace was daunting – a lot of excellent material covered

"Could have been more time allotted for roundtable discussions."

“Sometimes frustrating to realize the lack of awareness of palliative care even among policy makers.”

- the meeting was long but unavoidable.
- It was difficult to hear people in small groups because of large tables; too many people at some tables. (6)
- Outside factors (4), e.g.,
 - lack of awareness of palliative care among policy makers
 - there was little input, time and interest shown from the Minister of Health
 - who is accountable?
 - who will fund follow-up on today?
- Personal factors (3), e.g.,
 - as a staff nurse (not a physician, unit manager, or director) I felt over my head
 - given that I was not involved with the development of the palliative care program, I felt like an outsider at times
 - having to present to a large group
 - I sat at a table that was not from my District to provide insight into an issue.

4. Further Comments:

Many of the comments here echoed feedback already included above under *What I liked most about this roundtable* and they are not repeated here. The comments below relate to taking action on the results of this meeting; these were not mentioned above.

“This has been very encouraging and renews my commitment to Palliative Care.”

- Looking forward to what happens next (25), e.g., as a result of this meeting I hope that:
 - we receive a copy of the meeting report
 - suggestions and visions will be implemented; let’s get to work
 - there are more gatherings like this one where we come to consensus on what palliative care looks like in Nova Scotia
 - we follow-up on the results one year from today
 - we keep the discussions (sharing) going.
- Other comments and questions, e.g.,
 - can I get reports of previous meetings?
 - extend support services into rural areas
 - have a member from Department of Health answer questions and concerns
 - how committed is the Department of Health to enhancing palliative care services?

“Great job! Incredibly heart warming to see this provincial focus and action plan coming to fruition. Hats off to CCNS for the palliative care recognition and focus!!”

- include non-malignant diagnosis in a specific way, e.g., ALS
- more funding is needed for a core palliative care service
- we need work to define palliative care and when it should start; if it is defined as supportive care, CSTS should look at when and how supportive/palliative care is introduced.

5. Would you/your organization like to be involved with CCNS in implementing a provincial strategy on palliative care in the future?

89 of the 119 evaluations responded “Yes”.

Some of the key areas included:

- with volunteers
- in education
- any level/any way
- district specific requests
- information dissemination
- long term care perspective
- implementation of services/strategy

“...would like to continue to be a part of the continued efforts to strengthen linkages with CCNS and Palliative Care Program.”

Appendix #1: Acronyms and Terms

ACHHR	Advisory Committee on Health Human Resources (F/P/T)
CAM	Complementary and Alternative Medicine
CAMO	Canadian Association of Medical Oncologists
CAMRT	Canadian Association of Medical Radiation Technologists
CANO	Canadian Association for Nurses in Oncology
CAPCA	Canadian Association of Provincial Cancer Agencies
CAPhO	Canadian Association of Pharmacy in Oncology
CAPO	Canadian Association of Psychosocial Oncology
CARO	Canadian Association of Radiation Oncologists
CAT scan	Computed Axial Tomography
CBCC	Cape Breton Cancer Centre
CBHC	Cape Breton Healthcare complex
CBHCC Program	Cape Breton Health Care Complex Palliative Care Program
CCNS	<i>Cancer Care Nova Scotia</i>
CCOCS	Canadian Coalition on Cancer Surveillance
CCS	Canadian Cancer Society
CFPC	College of Family Physicians of Canada
CHN	Canadian Health Network
CHS	Canadian Hematology Society
CIHI	Canadian Institute for Health Information
CIHR	Canadian Institutes for Health Research
CIS	Cancer Information Service
CME	Continuing Medical Education
CNA	Canadian Nurses Association
COMP	Canadian Organization of Medical Physics
COS	Canadian Oncology Society
CPCA	Canadian Palliative Care Association
CPCN	Canadian Prostate Cancer Network
CPCRI	Canadian Prostate Cancer Research Initiative
CPG	Clinical Practice Guideline
CSPCP	Canadian Society of Palliative Care Physicians
CSCC	Canadian Strategy for Cancer Control
CST	Cancer Site Team
DHA	District Health Authority
DM	Deputy Ministers
DOH	Department of Health
F/P/T	Federal/Provincial/Territorial
FTE	Full Time Equivalent
HRPWG	Human Resources Planning Working group

IARC	International Agency for Research on Cancer
ICR	Institute of Cancer Research
IPCNS	Integrating Palliative Care in Nova Scotia (Discussion Document)
LTC	Long Term Care
MRI	Magnetic Resonance Imaging
MSNS	Medical Society of Nova Scotia
NA	Needs Assessment – Cancer Care Nova Scotia Needs Assessment Synthesis
NCIC	National Cancer Institute of Canada
NGOs	Non-government Organizations
NSCC	Nova Scotia Cancer Centre
NSHPCA	Nova Scotia Hospice Palliative Care Association
PC	Palliative Care
PCNH	Palliative Care in Nursing Homes.
PNWG	Patient Navigation Working Group (CCNS)
QEII Program	Queen Elizabeth II Health Sciences Centre Palliative Care Program
RCPSC	Royal College of Physicians and Surgeons of Canada
RCTs	Randomized Clinical Trials
RNANS	Registered Nurses Association of Nova Scotia
RPHCPP	Rural Palliative Home Care Pilot Project
RT	Radiation Therapy
SC	Supportive Care
SC/R	Supportive Care/Cancer Rehabilitation
SDI	Service Delivery Inventory – Cancer Care Nova Scotia Service Delivery Inventory Document
Senate Report	Quality End-of-Life Care: The Right of Every Canadian
SON	Surgical Oncology Network
ST	Systemic Therapy
VON	Victorian Order of Nurses