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## Special Report 20-1

### Establishing Comprehensive Cancer Patient Education Services A Framework to Guide Ontario Cancer Education Services

A Special Report of Cancer Care Ontario's Patient Education Program Committee  
and the Program in Evidence-Based Care (PEBC)

Report Date: August 3, 2006

**Special Report 20-1 will permanently stand as CURRENT from its original publication date.**

The report consists of the following 2 sections and is available on the CCO website  
(<http://www.cancercare.on.ca>)

PEBC Patient Education page at:

<https://www.cancercare.on.ca/toolbox/qualityguidelines/clin-program/patient-ed-ebs/>.

1. Evidence Summary
2. Evidence Review

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## Special Report 20-1: Section 1

# Establishing Comprehensive Cancer Patient Education Services A Framework to Guide Ontario Cancer Education Services: Executive Summary

A Special Report of Cancer Care Ontario's Patient Education Program Committee  
and the Program in Evidence-Based Care

**Report Date: August 3, 2006**

The Cancer Care Ontario Patient Education Program Committee in collaboration with the Program in Evidence-Based Care (PEBC) has reviewed the National Cancer Institute's (NCI) guidelines, *Guidelines on Establishing Comprehensive Cancer Patient Education Services*, from the Cancer Patient Education Network (CPEN) and endorses the adoption of the Guidelines, with some revision, for use in Ontario. The resulting report is intended for use by administrators of Regional Cancer Programs, Regional Vice Presidents, and patient education experts to facilitate the rollout of a provincial work plan for patient education services.

The statements below reflect the integration of the NCI CPEN Guidelines with the Cancer Care Ontario Patient Education Program Committee's perspective.

### FRAMEWORK COMPONENTS

The Cancer Care Ontario Patient Education Program Committee recommends that a Patient Education Program (PEP) within a Regional Cancer Program include the following components:

- **Organization and Structure**
  - There is an identifiable PEP positioned within the structure of the cancer program. The leadership of the PEP is empowered to and accountable for providing access to high-quality patient education programs and activities.
  - There is a written description of the organization and structure of the PEP, the roles and functions of those leading the PEP, and the collaborative relationships between the PEP and the various interdisciplinary components of the cancer program.
  - The leadership of the PEP has access to expert staff that is available to implement education programs, services, and activities.
  - There is an explicit link among the PEP of the cancer program, the Cancer Care Ontario Patient Education Program Committee, and CPEN Canada.
- **Philosophy and Mission**
  - The PEP develops a statement of mission and a statement of philosophy that concisely identifies the purpose and reflects the value of the PEP. These statements should align with the mission, vision and values of the cancer program, the Cancer Care Ontario Patient Education Program Committee, and the Ontario Cancer Plan.

- The cancer program has a long-range plan that defines the goals and strategies of the PEP.
- **Functions**
  - The PEP staff provides leadership by supporting, facilitating, and promoting patient education competencies in a variety of settings and approaches, for a variety of audiences, in collaboration with clinical staff across the cancer program.
- **Facilities and Equipment**
  - Facilities, equipment, and resources are provided to achieve the PEP's mission and to enhance the learning experience.
- **Finances**
  - Cancer Care Ontario and the cancer program allocate adequate financial resources for patient and family education.
- **Process**
  - The provision of patient education services is guided by written policies and procedures.
- **Leadership for Quality and Performance Improvement**
  - The PEP staff participates in a process within the cancer program and at the regional and provincial level to ensure continuous improvement of patient education services.
- **Evaluation and Research**
  - Program evaluation is an integral, ongoing, and systematic process of the PEP.
  - The PEP keeps current on cancer patient education research and/or conducts research and uses the results of research activities to improve the current level of practice.
- **Human Resources**
  - The PEP staff possesses appropriate expertise and competencies through academic background, occupational experience, and continuing education.

## DEVELOPMENT OF SPECIAL REPORT

The Ontario framework for comprehensive cancer patient education services was developed by the Cancer Care Ontario Patient Education Program Committee and the PEBC through a comprehensive review and modification of existing guidelines established by NCI CPEN. CPEN is a partnership between NCI in the United States and CPEN Canada and is recognized as a leader in the delivery of cancer patient education. NCI CPEN has developed a set of guidelines, *Guidelines on Establishing Comprehensive Cancer Patient Education Services*, which serve as a model to promote excellence in patient and family education. To avoid duplication and to capitalize on the high-quality existing work, the Cancer Care Ontario Patient Education Program Committee decided to use the NCI CPEN guidelines as the basis for establishing a comprehensive patient education framework for Ontario. The guidelines identify nine key elements that are necessary in establishing comprehensive cancer patient education services. The Cancer Care Ontario Patient Education Program Committee, which is comprised of fourteen patient education experts from ten regions across Ontario, developed the framework by reviewing each of the nine key elements for potential adoption in Ontario and modifying their interpretation, based on the Ontario context, experience, and consensus.

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## Special Report 20-1: Section 2

### **Establishing Comprehensive Cancer Patient Education Services A Framework to Guide Ontario Cancer Education Services: Evidentiary Review**

A Special Report of Cancer Care Ontario's Patient Education Program Committee  
and the Program in Evidence-Based Care

**Report Date: August 3, 2006**

#### **BACKGROUND**

In 2005, an estimated 149,000 new cases of cancer were diagnosed in Canada (1). A diagnosis of cancer is associated with a myriad of adverse emotions, including fear, anxiety, and helplessness. In addition, patients and their families also face many complex decisions regarding the management of the disease. Patient education is a distinct and definable activity that supports the learning and behaviour of patients; and includes all learning experiences that patients engage in with the conscious intent of improving their understanding of and becoming active participants in managing their care. These learning experiences can be formal or informal, and initiated by the patient or the healthcare provider (2). In providing a holistic, patient-centered approach to patient education, health providers, patients, and their families form a key partnership that ensures patients receive education, support and care that is tailored to their individual needs and preferences (3-5).

Research has shown that effective patient education enhances patients' knowledge and understanding of their disease and its treatment (6,7), while also improving treatment compliance (8) and symptom management (9), the ability to cope, and overall satisfaction with care (10). There is also evidence that a well-coordinated programmatic approach to the delivery of patient education positively impacts other areas, including obtaining informed patient consent and health resource utilization (11-13).

The intense scrutiny of program costs and outcomes, combined with increased competition for limited resources, has created a need for a better understanding of how costs and outcomes are related to hospital activities. Programs are increasingly called upon to show that clinical and supportive activities are a good investment of operating dollars. A review of published research by Bartlet (13) concluded that "on the average, for every dollar invested in patient education, three or four dollars were saved." As an example, the review reports on a study demonstrating a 36% reduction in clinical visits for individuals with chronic pain at a cost-benefit ratio of 1:3 (14). Bartlett's analysis also offers support for the notion that providing patient education not only saves costs but also improves quality outcomes (13).

Despite the demonstrated benefits of patient education, a 2002 survey conducted to determine the status of patient education services in Canadian cancer centres indicated significant variability in the scope of educational resources available to patients (15). Of 22 employees responsible for, or knowledgeable about, patient education at 22 cancer centres across Canada, only 32% indicated that their centres had a strategic plan for delivering patient education and, of those centres, only 36% had an identifiable patient education program. While

43% reported having a program leader responsible for patient education, in only two centres was there a full-time dedicated position. The lack of institutional commitment, program leadership, and financial resources were cited by staff as the major barriers to establishing an infrastructure for patient education within cancer centres. The survey revealed patient education activities are primarily being coordinated and carried out by motivated healthcare providers as an add-on to already demanding workloads, because they advocate for and recognize the importance of patient education (15).

Variability in the quality of patient education services largely reflects the fact that there are no national or provincial guidelines or standards that articulate best practices for cancer patient education. While the Canadian Council on Health Services Accreditation (CCHSA) and other health-governing agencies (e.g., College of Nurses of Ontario, College of Physicians Canada) all consider patient education a necessary component of patient care, the criteria upon which patient education services are measured are vague and lack explicit requirements for a comprehensive patient education program. For example, the CCHSA standards base accreditation on whether a centre provides appropriate education to patients and their families but fail to address important elements such as organizational structure for delivering patient education, program leadership, resource allocation, education research, and outcome and performance measures (16).

The Ontario cancer system has undergone substantial change in the past four years, with a shift in mandate for Cancer Care Ontario (CCO) from the management of cancer services to overseeing a cancer quality agenda. That agenda is defined, in part, by the establishing of evidence-based standards and guidelines that promote best patient care and measuring of system performance against recommendations emerging from these reports. The emergence of Regional Cancer Programs (RCP) and Local Health Integration Networks (LHINs), which serve as the new authority responsible for planning, integrating, and funding local health services, provide a new structure for provincial engagement around the cancer quality agenda.

With integration, it is important to ensure that patient education is an entity within cancer programs and that oncology-specific priorities are recognized. The CCO Patient Education Committee (Provincial Committee) was established to advance the quality mission of CCO by contributing to a provincial work plan focussing on patient education. The Provincial Committee is comprised of patient education experts from across Ontario. The Provincial Committee responsibilities align with the core competencies defined by the CCO Clinical Accountability Framework.

To move their quality agenda forward, the Provincial Committee entered into a formal collaboration with the Program in Evidence-Based Care (PEBC). The PEBC is a provincial initiative of CCO with a mandate revolving around guideline and standard development, dissemination, implementation, and evaluation. The Provincial Committee in collaboration with the PEBC identified two key projects to contribute to the Committee mandate. The first project, which is summarized in this report, was to establish a framework for patient education services and examine the current status of patient education efforts in Ontario. The framework will serve as the foundation on which the Provincial Committee's mandate can build. It will ensure a common voice and strategy for the Provincial Committee in their role of influencing the development of a quality agenda around patient education and will also provide explicit guidance for RCP concerning expectations for their regional patient education programs (PEP). The framework is intended for use by administrators of Regional Cancer Programs, Regional Vice Presidents, and patient education experts to facilitate the rollout of the provincial work plan for patient education services.

## PART 1: PRINCIPLES OF A COMPREHENSIVE PATIENT EDUCATION SERVICE

### 1. Strategy

The National Cancer Institute's (NCI) Cancer Patient Education Network (NCI CPEN) was established in 1988 by the Patient Education Branch of the NCI to provide a forum for patient educators to exchange information, with the aim of improving the delivery, management, and overall quality of patient education services in NCI-sponsored cancer centres (17). NCI CPEN is recognized by cancer patient education experts in the United States as a leader in the delivery of patient education. In an effort to broaden its reach to a larger audience of patient educators beyond NCI-designated centres, a newly independent CPEN was launched, which maintains a strong collaborative partnership with the NCI. In 2003, CPEN Canada was established as a collaborative partner of CPEN to provide similar expertise and leadership in the provision of patient education services in Canadian cancer centres.

NCI CPEN has developed a guidance document for establishing comprehensive cancer patient education services that serves as a model to promote excellence in patient and family education. To avoid duplication and to capitalize on high-quality existing work, the Provincial Committee decided, a priori, to use the NCI CPEN guidelines as the foundation document for its deliberations to establish a comprehensive patient education framework for Ontario.

### NCI CPEN Guidelines

In 1993, a task force of NCI CPEN patient educators developed a set of guidelines, *Guidelines for Establishing Comprehensive Patient Education Services*, to provide educators and other healthcare professionals with guidance related to program planning, development, and evaluation activities (18). The guidelines were adapted from other education standards including those produced by the American Society for Healthcare Education and Training, the American Hospital Association, the Oncology Nursing Society, the Joint Commission on the Accreditation of Healthcare Organizations, and the Association of Community Cancer Centers. The guidelines were last updated in 2002 and identify the following nine key elements that are necessary in establishing comprehensive cancer patient education services:

- 1) philosophy and mission;
- 2) organization and structure;
- 3) function;
- 4) facilities, equipment and resources;
- 5) financial management;
- 6) policy and procedure;
- 7) quality/performance improvement, evaluation and research;
- 8) record keeping; and
- 9) professional development.

Each element is accompanied with an interpretation and criteria that operationalize the guidelines so they can be used in practice.

### CCO Patient Education Committee's Perspectives on the NCI CPEN Guidelines for Establishing Comprehensive Cancer Patient Education Services

In September of 2005, the Provincial Committee convened to review each NCI CPEN guideline for its potential adoption in Ontario. Fourteen committee members representing ten regions across Ontario participated in the review (please see Appendix 1 for a list of the Provincial Committee Members). The principle of using the NCI CPEN guidelines as a foundation document received the unanimous support of the Provincial Committee members. Based on this support, each of the nine elements reflected in the guidelines were reviewed in turn. The Provincial Committee identified the areas where modifications or alternatives to its interpretation were required to reflect the Ontario context or changes were made, based on professional experience and consensus. The original NCI CPEN guidelines are at

## SPECIAL REPORT 20-1

[www.cpencanada.org](http://www.cpencanada.org) but are accessible only to CPEN members. The following framework reflects the integration of the NCI CPEN guidelines with the Provincial Committee's perspective for Ontario. In the proceeding sections, the term "PEP staff" refers to staff with expertise in patient education.

## 2. Ontario Framework for Cancer Patient Education Services

### I. Organization and Structure

#### **Guidance**

*There is an identifiable patient education program (PEP) positioned within the structure of the cancer program. The leadership of the PEP is empowered and accountable to provide access to high-quality patient education programs and activities.*

*There is a written description of the organization and structure of the PEP, the roles and functions of those leading the PEP, and the collaborative relationships between the PEP and the various interdisciplinary components of the cancer program.*

*The leadership of the PEP has access to expert staff that may be used to implement education programs, services, and activities.*

*There is an explicit link among the PEP of the cancer program, the Provincial Committee, and CPEN Canada.*

#### ***Provincial Committee Interpretation***

Effective patient education cannot take place without the commitment of the leaders of the cancer program. This commitment includes establishing patient education as an organizational priority and ensuring that adequate resources are dedicated to education, processes are established to facilitate effective education, and that performance improvement includes education as an appropriate component.

There is no single best way to structure a PEP, although the goal is a comprehensive and systematic approach to patient education. The key is for the cancer program to develop a structure that both supports patient education and establishes accountability to best meet patient education goals. The Provincial Committee recognizes the important role of the cancer program in facilitating dialogue around patient education needs and ensuring that this perspective is incorporated into regional cancer planning.

Given the unique circumstances in Ontario among CCO, the cancer programs, and their regional partners, the Provincial Committee recognizes the importance of communication and engagement with patient education leaders within hospitals and institutions. The objective is that the unique needs of the cancer patient and his/her family can be appropriately integrated while ensuring service duplication is avoided and roles, responsibilities, and accountabilities are clear.

#### ***Strategies for Implementation:***

- a. The cancer program ensures there is clarity around roles, authority, responsibility, and accountability for the development, implementation, administration, coordination, and evaluation of PEP activities.
- b. The PEP applies teaching-learning theories to the development, implementation, and evaluation of patient/family educational experiences.
- c. Educational materials of the PEP are appropriate to the unique learner (i.e., age, gender, culture, language, and functional and health literacy and disability).
- d. The PEP ensures that information about community resources is available and current.

## **II. Philosophy and Mission**

### ***Guidance***

*The PEP develops a statement of mission and a statement of philosophy that concisely identifies the purpose and reflects the value of the PEP. These statements should align with the mission, vision and values of the cancer program, the Provincial Committee and the Ontario Cancer Plan.*

*The cancer program has a long-range plan that defines the goals and strategies of the PEP.*

### ***Provincial Committee Interpretation***

The mission statement defines a direction for PEP and the essential functions to be accomplished. The philosophy statement establishes the basic premises regarding the patient education function. A long-range plan provides the PEP with a focus and outlines its goals and strategies. The mission and philosophy statements and the long-range plan all should align with the overall strategy of the cancer program, the Provincial Committee and the Ontario Cancer Plan.

### ***Strategies for Implementation***

- a. The philosophy statement should reflect the beliefs about and the value assigned to the patient education function. This statement clarifies the values and beliefs about:
  - i. The role that patient education plays as an intervention for achieving the cancer program's goals.
  - ii. The use of patient education principles and practices such as:
    - Cancer patients and their families and caregivers have a right to appropriate cancer research and treatment information.
    - Healthcare providers play an important role in patient/family health care and decision making.
    - The religious, social, cultural, and ethnic practices of patients and their families are respected, and the needs of special populations are addressed.
    - Every healthcare provider is a patient educator.
    - Interdisciplinary collaboration is a vital component of the patient education process.
- b. The mission statement should define and limit the scope of the services provided. Specifically, it should indicate what the PEP does for the cancer program and describe the relationship between the PEP and its constituencies.
- c. The statements provide guidance in decision making and in all areas of practice related to the patient education function.
- d. The statements should align with the strategic goals of the Provincial Committee and the Ontario Cancer Plan.
- e. The statements should be evaluated by the larger community and reviewed routinely.
- f. The long-range plan should include the following:
  - i. Mission.
  - ii. Assessment of internal and external environment.
  - iii. Assessment of program strengths and weaknesses.
  - iv. Identification of program goals, objectives, and strategies.
  - v. Identification of the gap between what exists now and the Program goals.
  - vi. Action steps to move toward the Program goals, including the periodic evaluation of effectiveness and outcome.
- g. The long-range plan should receive input from the appropriate interdisciplinary team member.

### **III. Functions**

#### ***Guidance***

*PEP staff provides leadership by supporting, facilitating, and promoting patient education competencies in a variety of settings and approaches, for a variety of audiences, in collaboration with clinical staff across the cancer program.*

#### ***Provincial Committee Interpretation***

PEP staff plan and collaborate with a variety of stakeholders, including patients/families and healthcare providers, to implement and evaluate education programs and activities for patients and their families. Interdisciplinary collaboration is an important part of the PEP development process, because collaboration reinforces patient education as an integral component of clinical patient care.

#### ***Strategies for Implementation***

- a. The PEP clearly defines its scope of services, identifying its customers, functions, and activities.
- b. The PEP staff is involved in program-wide activities through participation on committees, task forces, and projects to ensure that patient education needs are reflected in the broader mission of the cancer program.
- c. The PEP will capitalize on existing patient education activities within hospitals, institutions, and the cancer programs of the province.

#### **IV. Facilities and Equipment**

##### ***Guidance***

*Facilities, equipment, and resources are provided to achieve the PEP mission and to enhance the learning experience.*

##### ***Provincial Committee Interpretation***

The value of patient education is enhanced by adequate facilities or environments conducive to learning and by equipment that supports the patient education function. Adequate facilities must be provided for the achievement of the intended learning outcomes; appropriate educational facilities include space suitable for patient/family teaching and self-directed learning.

##### ***Strategies for Implementation***

- a. Audiovisual (AV) support is available, which includes printing and graphic support and AV equipment.
- b. A library and/or current reference materials are available for the development of educational activities and research by the PEP staff.
- c. The PEP staff will have regular access to a computer for data management, electronic communication, distribution of information within the cancer program, and to keep pace with emerging technologies.
- d. Adequate, private, comfortable space should be provided to accommodate patient and family education.
- e. A patient education library/resource centre is available for patients, family members, and significant others. The library/resource center will provide access to the National Cancer Institute's Physician Data Query (PDQ)/ Patient Information File (PIF). PDQ is a computerized database that provides health professionals, patients, and the public with quick access to the latest treatment information for most types of cancer, descriptions of clinical trials that are open for enrolment, and names of organizations involved in cancer care.

**V. Finances**

**Guidance**

*CCO and the cancer program allocate ongoing adequate financial resources for patient and family education.*

***Provincial Committee Interpretation***

Allocated financial support is necessary to provide the staff and resources (e.g., computers, print resources) for an effective PEP.

***Strategies for Implementation***

- a. The PEP is a line item in the budget of the cancer program.

## **VI. Process**

### ***Guidance***

*The provision of patient education services is guided by written policies and procedures.*

### ***Provincial Committee Interpretation***

Policies are the foundation for systems and serve as a guide for decision making by outlining a general course of action. Procedures define the specific steps for carrying out policies and responsibilities and relate to the tasks involved in daily operations. Policies and procedures provide evidence of performance for accrediting bodies.

### ***Strategies for Implementation***

- a. Policies and procedures are written and easily accessible in print or electronic format. They encompass interdisciplinary responsibilities, development, and provision of patient and family education.
- b. Policies and procedures are communicated to staff, departments, and units in the cancer program.
- c. Processes are in place to ensure:
  - i. Development and periodic evaluation of patient education resources are performed prior to endorsement and dissemination to assess the accuracy and applicability of cancer information.
  - ii. Mechanism for approval of materials.
  - iii. Development of patient education documentation forms.
  - iv. Review and approval of outside patient education materials.
  - v. Responsibility for purchasing equipment/material.
  - vi. Education and competency verification of staff who provide patient and family education.
  - vii. Training for volunteers involved in direct patient education activities.
  - viii. Administration/operations of patient education resource centre/library or archive of resources.
  - ix. Approach to quality improvement and performance improvement.
- d. Policies and procedure are reviewed annually and revised as necessary.
- e. Records of programs and services are maintained as part of ongoing documentation.

**VII. Leadership for Quality and Performance Improvement**  
**Guidance**

*The PEP staff participates in a process within the cancer program and at the provincial level to ensure continuous improvement of patient education services.*

***Provincial Committee Interpretation***

Quality/performance improvement is an integral, ongoing, and systematic process to ensure the excellence of patient education. Based on data from monitoring and improvement activities, actions are implemented to maintain and/or improve the patient education function.

***Strategies for Implementation***

- a. The PEP's quality/performance improvement is consistent and integrated with the organization's quality/performance improvement process.
  - i. PEP staff participates in the organization's quality/performance improvement structure.
  - ii. Results of the organization's quality/performance improvement actions and monitoring activities are used to improve patient education services.
- b. The PEP approach to quality and performance improvement addresses patient satisfaction, effectiveness of services and expected outcomes, and quality indicators.
- c. The PEP has a system for obtaining feedback from its patients.
- d. The PEP uses results of its monitoring and improvement activities to revise patient education systems, processes, and services.
- e. PEP staff serve as expert patient education leaders/mentors to other healthcare providers responsible for patient education and members of CPEN Canada with regard to program/resource development, planning, implementation, and evaluation.

## **VIII. Evaluation and Research**

### ***Guidance***

*Evaluation is an integral, ongoing, and systematic process of the PEP.*

*The PEP keeps current on cancer patient education research and/or conducts research and uses the results of research activities to improve the current level of practice.*

### ***Provincial Committee Interpretation***

Program evaluation produces data which can be used in future planning, improves the current program, helps justify the activity, and/or compares the outcomes with the intended objectives. Within Ontario, the panel recommends the future development of specific quality indicators around patient education for public reporting.

PEP staff should strive for innovative means to improve patient teaching strategies and program planning, development, and evaluation. Patient educators should keep up-to-date on cancer patient education research in the associated literature. When possible, they should conduct research, publish results of research efforts, and share the results with other patient educators.

### ***Strategies for Implementation***

- a. An evaluation of the education activities is performed regularly.
- b. A variety of evaluation methods is used, such as pre-testing, post-testing, feedback questionnaires, focus groups, and other methods.
- c. Evaluation techniques measure stated learning outcomes.
- d. Participants evaluate the education activity.
- e. Educators use evaluation summary data to modify the content, delivery processes, and/or materials of an education activity.
- f. Where appropriate, a follow-up evaluation of participants is made in order to determine change in skills, knowledge, and/or attitudes.
- g. The cancer program has an internal channel for distributing research literature to staff members.
- h. Staff members change practices based on data from literature reviews of field research.
- i. Staff is encouraged to develop knowledge and skills in systematic problem solving and research.
- j. Patient education staff participates in the cancer program's research activities.
- k. The PEP has a list of research questions that would improve the function of the PEP, the cancer program, or the practice of patient education.
- l. Staff members use research data to prepare a proposal or to justify an intervention.
- m. Staff members use operating situations to design a research study.
- n. Staff members conduct investigations, using standard research protocols to determine the effectiveness of an intervention.

## **IX. Human Resources**

### ***Guidance***

*PEP staff possesses appropriate expertise and competencies through academic background, occupational experience, and continuing education.*

### ***Provincial Committee Interpretation***

The purpose of professional development for PEP staff is to expand upon the educational and experiential knowledge bases to enhance the level and performance of practice. By enhancing practice, professional development contributes to quality improvement. PEP staff participation in professional development opportunities demonstrates competencies and an understanding of current trends in patient education.

### ***Strategies for Implementation***

- a. The PEP staff has a minimum of a bachelor's degree in education nursing, healthcare administration, health education, or a related field.
- b. New personnel in the PEP receive an orientation of sufficient duration and content to prepare them for their respective role.
- c. PEP staff regularly participates in continuing education and in-service programs based on findings from the monitoring and evaluation of education services and processes, emerging technology, organizational need, and changes occurring in the healthcare industry in general and in patient education specifically.
- d. PEP staff participates in regular performance assessment and establishes goals for professional development in collaboration with their supervisor.
- e. Relevant texts and journals are available to staff, and a system exists so that staff can request or offer input into the purchase of reference material.
- f. PEP staff is encouraged to demonstrate professional role responsibility by membership and active participation in professional organizations and by voluntary service in professional groups or community agencies.

## PART II: CURRENT STATUS OF CANCER PATIENT EDUCATION IN ONTARIO

The status of cancer patient education services in Ontario was last examined in 2002 (15). Since then, the cancer system has changed substantially, with the integration of regional cancer centres with their host hospitals and the emergence of RCP as the primary entities responsible for cancer planning, delivery, and quality of care. To examine the status of patient education services post-integration, staff members most responsible for patient education within RCP were surveyed using the same questionnaire that was administered in 2002. The survey is adapted from the CPEN Institutional Self-Assessment Tool (18), which is designed to identify strengths and weaknesses of a cancer patient education program. The survey focuses on the key elements described in NCI CPEN's *Guidelines for Establishing Comprehensive Patient Education Services*, specifically, whether or not a cancer centre has a philosophy or mission statement for patient education, the nature of the organizational structure of the patient education program, what resources and funding are available to support patient education activities, and whether evaluation of the patient education program and other related research are conducted.

Nine out of 12 surveys were returned, which represented eight different RCP in Ontario. Of the nine RCP, only six (67%) indicated they had an identifiable cancer patient education program. Table 1 summarizes the main results of the survey. The survey results show variability in what constitutes a cancer patient education program in Ontario RCP. This infers that the quality of patient education services received is largely dependent on where patients are receiving their cancer care.

Just over half of RCP (56%) have a mission statement and strategic plan for patient education activities, and only 44% of cancer patient education programs have a program leader or manager and a dedicated space to carry out patient education activities. The majority of programs do not have their own operating budgets to fund patient education services; most rely on funding from external sources such as foundation grants, other program budgets, and private or pharmaceutical company donations. Most RCP are well resourced in terms of learning materials such as a patient library, a patient and family resource centre, books, pamphlets, videos, and a Web site. A few RCP also have an information phone line.

In terms of staffing, only a minority (33% to 44%) of RCP have access to sufficient staff who can be used to implement and organize patient education services (i.e., librarians, educators, or administration support), and almost all make use of volunteers for delivering patient education. The majority of RCP (67%) report that they engage in the evaluation of patient education activities; however, few report that they actually measure patient outcomes related to patient education.

**Table 1: Results from the Ontario Cancer Patient Education Survey (2005).**

Survey Questions	Responses n (%)
<i>Philosophy &amp; Mission</i>	
Does your cancer centre have a patient education mission and statement of philosophy that identifies the purpose and reflects the values of the program?	Yes: 5/9 (56) No: 4/9 (44)
Does your cancer centre have a strategic plan for patient education that identifies the program's goals and objectives?	Yes: 5/9 (56) No: 4/9 (44)
<i>Organization &amp; Structure</i>	
Does your cancer centre have a patient education program leader, i.e., Director or Manager?	Yes: 4/9 (44) No: 5/9 (56)
Does the patient education leader have access to sufficient staff who may be used to implement and organize education programs, services, and activities?	Librarian: 3/9 (33) Administrative support: 4/9 (44) Research: 3/9 (33) Educator: 4/9 (44) Other: 3/9 (33)
Is there a patient education advisory committee?	Yes: 5/9 (56) No: 4/9 (44)
Do you have a written document that describes the organization and structure, role and functions of the patient education program?	Yes: 4/9 (44) No: 5/9 (56)
Does patient education have an operating budget?	Yes: 4/9 (44) No: 5/9 (56)
<i>Patient Education Resources</i>	
Does your centre have any of the following resources?	Patient library: 8/9 (89) Patient & family resource centre: 7/9 (78) Computers: 8/9 (89) Pamphlets: 9/9 (100) Books: 9/9 (100) CDs: 8/9 (89) Videos: 8/9 (89) Website: 9/9 (100) Phone info line: 3/9 (33)
What topics does your centre provide a specific curriculum for?	Orientation: 8/9 (89) General cancer information: 6/9 (67) Treatment: 7/9 (78) Rehabilitation: 4/9 (44) Psychosocial support programs: 7/9 (78) Clinical trials: 6/9 (67)
What different learning formats does your centre use to provide education?	1:1 teaching: 8/9 (89) Small group teaching: 8/9 (89) Lectures: 6/9 (67) Informal self-study: 6/9 (67) Formal self-study: 0 Other: 2/9 (22)
Who is the target audience for your educational activities?	Patients: 9/9 (100) Family members/friends: 9/9 (100) Community: 6/9 (67) Staff: 6/9 (67)

SPECIAL REPORT 20-1

Survey Questions	Responses n (%)
Is there a dedicated space for patient education programs?	Yes: 4/9 (44) No: 5/9 (56)
Are volunteers involved in education activities?	Yes: 8/9 (89) No: 1/9 (11)
Is there a formal training program for volunteers?	Yes: 6/9 (67) No: 3/9 (33)
<i>Evaluation &amp; Research</i>	
Is there a regular evaluation of patient education activities in the centre?	Yes: 6/9 (67) No: 3/9 (33)
Are patient outcomes measured?	Yes: 4/9 (44) No: 5/9 (56)

### **PART III: PRACTICE IMPLICATIONS**

The Ontario framework for cancer patient education services describes nine core elements required for a comprehensive patient education service. The Provincial Committee recommends that these serve as the core defining features expected of RCP as they relate to patient education. While the Provincial Committee fully supports that the specific design and implementation of a PEP must meet the unique needs, circumstances and opportunities of the region, adoption of the nine elements within the planning and execution of these activities are considered essential. It is also recommended that critical resources be available to RCP to meet these objectives and that ongoing funding be linked to performance outcomes. Each element includes specific guiding principles and strategies for implementation that may facilitate their adoption.

The recent survey results suggest that most RCP have already adopted some of the recommended elements, which is very encouraging. However, none of the RCP PEPs encompasses all of the recommended elements. Each of the RCP has a representative on the Provincial Committee, individuals who could serve as key experts and core facilitators who could work collaboratively with the Regional Vice Presidents to promote the quality cancer patient education agenda in their region.

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**Appendix 1: Cancer Care Ontario's Patient Education Program Committee.**

Audrey Jusko Friedman, Chair Director, Patient Education, Princess Margaret Hospital University Health Network Toronto, ON	Tamara Harth Patient Education Manager Toronto Sunnybrook Regional Cancer Centre Toronto, ON
Marcie Flynn-Post Nurse Manager, Oncology Clinic Peel Regional Cancer Centre Mississauga, ON	Siobhan McArdle Chair, CPEN Canada & Education Co-ordinator Cancer Centre of Southeastern Ontario at Kingston General Hospital Kingston, ON
Sarah Etheridge Manager, Radiation Therapy Peel Regional Cancer Centre Mississauga, ON	Jane Hatton-Bauer (Interim Representative) Clinical Director Supportive Care Grand River Regional Cancer Centre Kitchener, ON
Anne Snider Director Academic Programs and Quality Improvement Juravinski Cancer Centre Hamilton, ON	Michelle Arbuckle Patient Education Manager Princess Margaret Hospital University Health Network Toronto, ON
Gail Macartney Advanced Practice Nurse, Malignant Hematology The Ottawa Hospital General Campus Ottawa, ON	Patti Marchand Clinical Educator, Oncology R.S. McLaughlin Durham Regional Cancer Centre Oshawa, ON
Gale Turnbull Manager, Patient & Professional Education & Manager, Supportive Care Unit London Regional Cancer Centre London, ON	Kim Sinasac Windsor Regional Cancer Centre Windsor, ON
Lori Della Vedova Cancer Education Coordinator Regional Cancer Care of TBRHSC Thunder Bay, ON	Melissa Brouwers Director, Cancer Care Ontario Program in Evidence-based Care McMaster University Hamilton, ON
Susan Boyko Coordinator, Quality Improvement, Patient Safety and Education Regional Cancer Program of the HRSRH Sudbury, ON	Tricia Waldron Research Co-ordinator Cancer Care Ontario Program in Evidence- Based Care McMaster University Hamilton, ON



## Special Report 20-1: Section 3

# **Establishing Comprehensive Cancer Patient Education Services**

## **A Framework to Guide Ontario Cancer Education Services: Development and External Review**

A Special Report of Cancer Care Ontario's Patient Education Program Committee  
and the Program in Evidence-Based Care

**Report Date: August 3, 2006**

### **CANCER CARE ONTARIO PATIENT EDUCATION COMMITTEE AND THE PROGRAM IN EVIDENCE-BASED CARE**

The Patient Education Committee (Provincial Committee) of Cancer Care Ontario (CCO) was established to advance the quality mission of CCO by contributing to a provincial work plan pertaining to patient education. Comprised of patient education experts from across Ontario, the Provincial Committee is responsible for improving the quality and access to care through the development of provincial guidelines and standards, quality indicators, knowledge brokering, linking quality to funding, and championing innovation. The Provincial Committee engages in environmental scanning in order to bring regional, national, and international best practices to Ontario, in addition to mutual information sharing, so that CCO is informed on relevant issues from the regions, and regional stakeholders are aware of provincial initiatives.

The Program in Evidence-Based Care (PEBC) is an initiative of the Ontario provincial cancer system, Cancer Care Ontario (CCO) (1). The PEBC mandate is to improve the lives of Ontarians affected by cancer, through the development, dissemination, implementation, and evaluation of evidence-based products designed to facilitate clinical, planning, and policy decisions about cancer care. The PEBC is best known for producing evidence-based practice guideline reports, using the methods of the Practice Guidelines Development Cycle (1,2). The PEBC reports consist of a comprehensive systematic review of the clinical evidence on a specific cancer care topic, an interpretation of and consensus agreement on that evidence by our Disease Site Groups and Guideline Development Groups, the resulting clinical recommendations, and an external review by Ontario clinicians in the province for whom the topic is relevant. The PEBC has a formal standardized process to ensure the currency of each report, through the periodic review and evaluation of the scientific literature and, where appropriate, the integration of that literature with the original report information. In this instance, however, the Provincial Committee in collaboration with the PEBC decided to avoid duplication of effort and capitalize on high-quality existing work by using a set of existing guidelines as the foundation for its deliberations to establish a comprehensive patient education framework for Ontario.

## The Special Report

The *Special Report on Establishing Comprehensive Cancer Patient Education Services – A Framework to Guide Ontario Cancer Education Services*, is comprised of the following three sections:

### **Section 1: Executive Summary**

This section contains a synopsis of the framework components derived by the Provincial Committee after reviewing and modifying the National Cancer Institute's Cancer Patient Education Network's (NCI CPEN) Guidelines for use in Ontario.

### **Section 2: Evidentiary Review**

This section contains the framework components in their entirety, the results of a survey examining the current status of cancer patient education services in Ontario, and a discussion of practice implications relating to the adoption of the framework in Ontario.

### **Section 3: Development and External Review—Methods and Results**

This section summarizes the framework development process and the results of the external review.

## DEVELOPMENT OF THE SPECIAL REPORT

### **Developing the Framework**

This Special Report was developed by the Provincial Committee in collaboration with the PEBC. The framework was derived from a review and modification of the NCI CPEN *Guidelines for Establishing Comprehensive Cancer Patient Education Services*; the guidelines identify nine key elements that are necessary in establishing comprehensive cancer patient education services. The Provincial Committee, which is comprised of fourteen patient education experts from ten regions across Ontario, developed the framework by reviewing each of the nine key elements for potential adoption in Ontario and modifying their interpretation, based on the Ontario context, experience, and consensus. Following the review of the draft report by the PEBC Report Approval Panel, it was circulated to practitioners in Ontario for their review and feedback.

### **External Review by Ontario Practitioners**

The Special Report was circulated to Ontario practitioners. Box 1 summarizes the draft framework developed by the Provincial Committee.

#### **BOX 1. DRAFT FRAMEWORK (Sent for external review May 10, 2006)**

The Cancer Care Ontario Patient Education Program Committee recommends that a Patient Education Program (PEP) within a Regional Cancer Program include the following components:

- **Organization and Structure**
  - There is an identifiable PEP positioned within the structure of the cancer program. The leadership of the PEP is empowered to and accountable for providing access to high-quality patient education programs and activities.
  - There is a written description of the organization and structure of the PEP, the roles and functions of those leading the PEP, and the collaborative relationships between the PEP and the various interdisciplinary components of the cancer program.
  - The leadership of the PEP has access to expert staff that is available to implement education programs, services, and activities.
  - There is an explicit link among the PEP of the cancer program, the Cancer Care Ontario Patient Education Program Committee, and CPEN Canada.

- **Philosophy and Mission**
  - The PEP has a statement of mission and a statement of philosophy that concisely identifies the purpose and reflects the value of the PEP. These statements should align with the mission, vision and values of the cancer program, the Cancer Care Ontario Patient Education Program Committee, and the Ontario Cancer Plan.
  - The cancer program has a long-range plan that defines the goals and strategies of the PEP.
- **Functions**
  - The PEP staff provides leadership by supporting, facilitating, and promoting patient education in a variety of settings and approaches, for a variety of audiences, in collaboration with clinical staff across the cancer program.
- **Facilities and Equipment**
  - Facilities, equipment, and resources are provided to achieve the PEP's mission and to enhance the learning experience.
- **Finances**
  - Cancer Care Ontario and the cancer program allocate adequate financial resources for patient and family education.
- **Process**
  - The provision of patient education services is guided by written policies and procedures.
- **Leadership for Quality and Performance Improvement**
  - The PEP staff participates in a process within the cancer program and at the regional and provincial level to ensure continuous improvement of patient education services.
- **Evaluation and Research**
  - Program evaluation is an integral, ongoing, and systematic process of the PEP.
  - The PEP keeps current on cancer patient education research and/or conducts research and uses the results of research activities to improve the current level of practice.
- **Human Resources**
  - The PEP staff possesses appropriate expertise and competencies through academic background, occupational experience, and continuing education.

## Methods

External review feedback was obtained through a mailed survey of 35 individuals in Ontario, including patient educators, clinical educators, members of CPEN Canada, and Regional Vice Presidents. The survey consisted of items evaluating the methods used to develop the draft framework, the individual framework components, and overall support for the draft framework. Written comments were invited. The survey was mailed out on May 10, 2006. Follow-up reminders were sent at two weeks (post-card) and four weeks (complete package again). The Provincial Committee reviewed the results of the survey.

## Results

Sixteen responses were received out of 35 surveys sent (46% response rate). Responses include returned completed surveys as well as phone, fax, and email responses. Results of the external review survey are summarized in Table 1. Overall, 93.3% of those who responded supported the framework and felt that its implementation would improve patient care in Ontario.

**Table 1. Responses to items on the external review survey.**

Survey Items	Strongly agree/agree n (%)	Neither agree or disagree n (%)	Strongly disagree/disagree n (%)
With respect to this draft framework report, do you think:			
(a) The process was described in sufficient detail?	14 (100)	0	0
(b) The methods were rigorous and sound?	10 (77)	3 (23)	0
(c) The composition of the panel was appropriate	10 (71.5)	4 (28.5)	0
1. Please indicate your level of agreement that the elements listed below are necessary components of a Comprehensive Cancer Patient Education Service:			
(a) Organization and structure	13 (86.6)	2 (13.4)	0
(b) Philosophy and mission	14 (93.3)	1 (6.7)	0
(c) Functions	13 (86.6)	1 (6.7)	1 (6.7)
(d) Facilities	15 (100)	0	0
(e) Finances	15 (100)	0	0
(f) Process	13 (86.6)	1 (6.7)	1 (6.7)
(g) Leadership for quality and performance improvement	14 (93.3)	1 (6.7)	0
(h) Evaluation and research	13 (86.6)	2 (13.4)	0
(i) Human resources	13 (86.6)	2 (13.4)	0
2. Overall, I support the Ontario Framework for Cancer Patient Education Services to promote best patient care in Regional Cancer Programs in Ontario	14 (93.3)	0	1 (6.7)
	positively n (%)	no impact n (%)	negatively n (%)
If the Framework was implemented, how would it impact on:			
(i) Patient care in Ontario?	14 (100)	0	0
(ii) The healthcare system in Ontario?	11 (78.6)	3 (21.4)	0

## Summary of Written Comments

Twelve respondents (34%) provided written comments as part of their completed questionnaires. Overall, the comments emphasized support for the implementation of a provincial framework for cancer patient education services; additional substantive comments focused on three key issues. The issues and the Provincial Committee's response to these issues are summarized below:

1. *Implementation issues.* While there was general agreement with the framework components, some respondents put forward additional ideas around required infrastructure to facilitate implementation, while other respondents believed the draft framework components were, at times, too prescriptive and argued that they might inhibit successful implementation. The implementation issues were re-examined by the Provincial Committee, and modifications were made to the report to strike a balance between these two perspectives.
2. *Evaluation issues.* Some respondents put forward ideas around how the framework components could be evaluated and monitored, including patient outcome and process outcome suggestions. The Provincial Committee will consider these in the context of

another project, the development of patient education quality indicators.

3. *Context and clarification.* There were several excellent suggestions by the respondents regarding word changes, modifications to context, and elaborations of ideas that could further strengthen and clarify the framework components. The Provincial Committee reviewed these suggestions and made modifications in areas where they agreed that clarification or elaboration were required.

### **Report Approval Panel**

The PEBC Report Approval Panel (RAP) reviewed the Special Report in an advisory capacity in May 2006. The RAP consists of two members, including an oncologist, with expertise in clinical and methodological issues. Two key issues emerged from the RAP review:

1. As with the external reviewers, excellent questions emerged with respect to defining the implementation strategy and evaluation protocol. While not specifically the mandate of this report, these issues will be brought forward as priorities for the Provincial Committee as the roll-out of this framework unfolds.
2. Greater clarity was provided regarding the intended audience for the document, as requested.

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