

Cancer Journey Action Group

The Framework for Achieving Excellence in the Provision of Cancer Patient Education in Canada

Education Committee, Cancer Journey Action Group,
Canadian Partnership Against Cancer

March 2009

Acknowledgements

The Education Committee, Cancer Journey Action Group (CJAG) of the Canadian Partnership Against Cancer wishes to acknowledge previous work accomplished in the area of cancer patient education. More specifically, the Cancer Patient Education Network (CPEN), Cancer Care Ontario (CCO) and Cancer Care Nova Scotia (CCNS) have pioneered work around standards and guidelines in cancer patient education. The quality documents produced as a result of this work form the basis of *The Framework for Achieving Excellence in the Provision of Cancer Patient Education in Canada (The Cancer Patient Education Framework)*. In addition, previous work of the Education Committee (CJAG) has provided the informing Framework for the development of the Cancer Patient Education Framework.

The following Source Documents have served as the foundation for *The Framework for Achieving Excellence in the Provision of Cancer Patient Education in Canada*:

- Cancer Care Ontario Patient Education Program Committee and Cancer Care Ontario Program in Evidence-Based Care (August 2006). Establishing Comprehensive Cancer Patient Education Services: A Framework to Guide Ontario Cancer Education Services.
- Cancer Care Ontario Program in Evidence-Based Care (PEBC) (March 2008). Effective teaching strategies and methods for patient education: a systematic review. (*in progress*)
- Cancer Care Nova Scotia, Nova Scotia Cancer Patient Education Committee (2008). Education Standards for People Affected by Cancer. (*draft document*).
- Education Committee, Rebalance Focus Action Group, Canadian Strategy for Cancer Control (March 2007). National Psychosocial Oncology Education Framework.
- National Cancer Institute Cancer Patient Education Network (1999). Guidelines for Establishing Comprehensive Cancer Patient Education Services.
- University Health Network (March 2003). Evidence Based Best Practice Guidelines for Delivering Patient Education Curriculum.

Without the authorization of these groups to adapt and/or adopt portions of their documents, this present document would not have been possible.

The Education Committee (CJAG) wishes to thank the members of the Patient Education Subcommittee and its Patient Education Draft Strategy Document Working Group (Appendix1), who have contributed their knowledge and expertise in the development of this document. Their passion for cancer

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patient education has been evidenced by the generous sharing of their time as they persevere in further developing a quality cancer patient education agenda in Canada.

Production of this document has been made possible through a financial contribution from Health Canada.

Note to the reader:

Readers are encouraged to review Appendix 2 - "Background to the Project" of this document for the vision of the Canadian Partnership Against Cancer, an overview of its Action Groups, in particular the Cancer Journey Action Group and its subgroup, the Education Committee.

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Executive Summary

Cancer is one of the leading threats to health faced by Canadians and is one of the two leading causes of death. In spite of the challenges, there are over one million people living with a personal history of cancer in the country. It has been demonstrated that most people affected by cancer will experience a variety of informational and educational needs throughout their cancer experience. The literature and evidence around patient education supports the positive outcomes of quality cancer education, including improved:

- Knowledge and understanding of disease
- Treatment compliance
- Symptom management
- Ability to cope
- Self-management and self-care
- Quality of life

Improvements in these areas also amount to a positive return on investment for the healthcare system (on average, for every dollar invested in patient education, three to four dollars are saved).

Despite this compelling evidence, cancer patient education is often overlooked and the needs of those living with cancer and their families are not well defined or expressed. There also tends to be a lack of institutional commitment, leadership, and financial resources to support cancer patient education.

It has also been noted that cancer patient education activities and services can vary significantly, both geographically and institutionally, and there tends to be some variability in what is considered to be quality patient education. In the absence of national standards and guidelines that define best practice for cancer patient education, criteria by which patient education services are measured remain vague.

To begin to address this critical issue, *The Framework for Achieving Excellence in the Provision of Cancer Patient Education in Canada* (The Cancer Patient Education Framework) was developed. It provides insight on the present state of evidence and best practice regarding person-centered cancer education. Building upon the existing body of knowledge, a conceptual model for the provision of cancer patient education was developed. Principles and recommendations were put forward in a bold attempt to achieve excellence in the delivery of cancer patient education. These recommendations, targeting all health care providers and volunteers who provide information and support to people affected by cancer, focus on the following four key elements:

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- Assessing the educational needs of persons affected by cancer
- Developing the learning plan
- Delivering person-centered cancer education, and
- Evaluating and monitoring the teaching-learning process

The conceptual model for the delivery of cancer patient education was further developed to acknowledge the organizational infrastructure required to ensure the effectiveness and sustainability of an education program. Principles and recommendations around key enablers have been defined to provide explicit guidance to decision makers around the establishment of a formal, comprehensive cancer patient education program, including:

- Philosophy and mission
- Organization and structure
- Functions
- Facilities, equipment, and resources
- Finances
- Policies and procedures
- Leadership for quality and performance improvement
- Evaluation and research
- Professional development

Even with an organization's recognition and support for cancer patient education, there will be variability in how The Cancer Patient Education Framework can be applied based upon the organization's resources, limitations, and competing priorities. It is further acknowledged that provincial or regional cancer centres may have differing capacities and opportunities to establish a more formal comprehensive patient education program.

The Cancer Patient Education Framework has limitations. Person-centered cancer education is an integral part of the human experience in all phases of the cancer control continuum. While the principles underlying cancer education across the cancer control continuum may be similar, there are unique aspects to **cancer patient education**. Cancer patient education focuses on persons affected by cancer, families, and significant others from the time of diagnosis through treatment, and then on to survivorship, or possibly palliative and end-of-life care.

While there is connection and collaboration among experts in cancer education when developing and designing cancer education programs, there is an additional body of knowledge which specifically addresses the starting points of the continuum—in particular, prevention and screening. For example, there are

multiple challenges in learning how to motivate the well public to change their behavior. This involves understanding how elements of social marketing can equip health educators with valuable intervention tools for prevention and screening education. In the long term, it is crucial that The Cancer Patient Education Framework evolve to address these phases of the continuum. However, it is important to note that cancer education related to prevention and screening is not within the scope of this document.

In summary, The Cancer Patient Education Framework will create awareness in the cancer care community about the critical importance of cancer patient education in helping to ensure the best possible outcomes for persons affected by cancer. The Cancer Patient Education Framework provides the foundation to ensure that a consistent approach is used in structuring and delivering patient education across all health care disciplines and organizations providing cancer patient education. Further, this framework will enhance the cancer care system's ability to respond to the educational needs of a diverse population. For example, there are unique challenges involved in meeting the specific needs of First Nations, Aboriginals, Métis, Inuit and immigrant populations, children, seniors, and newcomers to Canada who speak languages other than French or English.

The development of The Cancer Patient Education Framework is but a first step towards achieving excellence in the provision of cancer patient education. Key stakeholders across the country will need to actively disseminate The Cancer Patient Education Framework document and begin to consider its implementation and its impact. Much commitment, time, energy, and resources will be required in the coming years to mobilize decision makers, health care professionals, and volunteers who provide cancer education to persons affected by cancer. In the end, those persons affected by cancer will benefit greatly from these efforts.

I. Introduction

The *Framework for Achieving Excellence in the Provision of Cancer Patient Education in Canada* (The Cancer Patient Education Framework) document provides the foundation for improving the cancer journey of persons affected by cancer. Section I of the document outlines the need for person-centered education, the purpose, the goals, the objectives, and the methodology pursued in the development of The Cancer Patient Education Framework. Limitations are also acknowledged.

The Cancer Patient Education Framework consists of two distinct and complementary components which are described in Sections II and III of the document. Section II defines *cancer patient education* and delineates this activity within the cancer control continuum. Further, principles underlying the generic competency/skill requirements of health care providers (HCP) are defined and recommended to promote excellence in the **provision of evidence-based cancer patient education**. These principles, embedded and depicted within a conceptual model of cancer education, are described in detail. This section targets two major audiences:

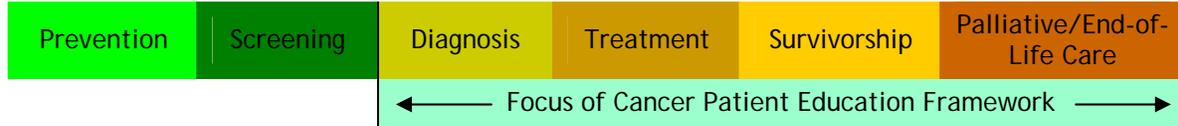
- Those involved in cancer patient education: all HCP (including, but not limited to, patient educators, oncologists, nurses, patient navigators, social workers, allied health care professionals)
- Volunteer and community-based organizations providing information and support to people with cancer

The principles described in Section III of The Cancer Patient Education Framework document are clearly defined for those organizations wishing to establish a **formal comprehensive cancer patient education service**, for example, within provincial or regional centers. This section provides explicit guidance to decision makers, including health care managers, administrators, and those in senior positions in major cancer centers, about the necessary resources, requirements, and expectations for the development of such a program.

The concluding comments set the stage for a call to action in achieving excellence in the provision of cancer patient education¹ in Canada.

¹ Cancer patient education in this context is inclusive of person-centered cancer education provided to persons affected by cancer and includes patient, family and/or significant others.

Figure 1: Cancer Control Continuum



1.0 Why Create a Framework

Cancer is one of the leading threats to health faced by Canadians and is one of the two leading causes of death. In spite of the challenges, there are over one million people living with a personal history of cancer in the country. It has been demonstrated that most individuals affected by cancer will experience a variety of informational and educational needs throughout their cancer experience [3]. The literature and evidence around patient education supports the notion that good patient education:

- Leads to more satisfied patients [1, 2, 3, 9]
- Can have positive outcomes such as change in behaviours, increased patient understanding, improved health status, and reduced patient anxiety [1, 2, 3, 9]
- Can encourage patients to develop helpful coping strategies and better manage their disease [1, 3, 6, 10]
- Assists patients to self-manage the treatment of their condition and prevent avoidable complications, while maintaining or improving quality of life [7, 8]

There is also evidence that a well coordinated programmatic approach to the delivery of patient education positively impacts other areas, including obtaining informed consent and health resource utilization [21, 22, 23]. A 1995 review of published research on the costs and benefits of providing patient education concluded that, on the average, for every dollar invested in patient education, three to four dollars can be saved. It was further concluded that if patient education remained stable over time, the return on investment increased, but if patient education stopped, the benefits ceased [23].

A 2002 survey that was conducted to determine the status of patient education services indicated significant variability in the scope of educational services and resources available in Canadian cancer centres [8]. Although patient education is considered a vital component of health care, the evidence demonstrates that it is often overlooked, the needs are not well articulated, and there is a lack of institutional commitment, leadership, and financial resources [1].

In spite of this reality, patient education is primarily being coordinated and delivered by well-intentioned HCP who recognize the importance of patient education [1]. These health care providers, however, may lack the knowledge and skills to provide the needed information and have too little time to

educate their patients and significant others. These issues can lead to inconsistent, incomplete and, on occasion, insensitive approaches by health care providers attempting to address the needs of patients/families/significant others [1, 3].

There is a need for better quality cancer patient education services and programs in Canada [1, 3]. It has been noted that cancer patient education activities and services can vary significantly, both geographically and institutionally, [1, 3] and there tends to be some variability in what qualifies as effective patient education [1]. In the absence of national standards and guidelines that define best practice for cancer patient education, criteria upon which patient education services are measured remain vague [1].

A national Cancer Patient Education Framework will provide the structure to ensure that a consistent approach is used in structuring and delivering cancer patient education across all organizations and institutions providing cancer patient education. Further, The Cancer Patient Education Framework will enhance the cancer care system's ability to respond to the educational needs of a diverse population of individuals, including First Nations, Aboriginals, Métis and Inuit, children, seniors, and newcomers to Canada who do not speak English or French.

1.1 Goals And Objectives Of The Cancer Patient Education Framework

The primary goals of The Cancer Patient Education Framework are to:

- Develop an evidence-based process for the delivery of person-centered cancer patient education
- Foster a culture of person-centered cancer patient education

More explicitly, the objectives of The Cancer Patient Education Framework are to:

- Ensure that evidence-based processes are used for the delivery of cancer patient education
- Provide a frame of reference for HCP and decision-makers for planning, implementation, and evaluation of cancer patient education

1.2 Methodology

There is a growing demand in Canada for the development of guidelines and standards for cancer patient education. Cancer Care Ontario (CCO), the University Health Network (UHN) - Toronto General Hospital, Toronto Western Hospital and Princess Margaret Hospital, Cancer Care Nova Scotia (CCNS), and the National Cancer Institute Cancer Patient Education Network (NCI CPEN) have all conducted significant work in this area.

To avoid duplication and to capitalize on high quality existing work, relevant documents produced by these organizations and cancer patient education experts were used to develop an integrated, comprehensive, and credible evidence-based framework document. The existing knowledge has been summarized, synthesized and presented in a conceptual model to represent a formal, comprehensive cancer patient education program.

In summary, a systematic and transparent process was used in the development of The Cancer Patient Education Framework, including:

- An extensive review of the noted Source Documents
- Adaptation and/or adoption of the evidence-based content and recommendations from the Source Documents
- Expert review and feedback on the draft framework document at various levels, including:
 - internal review of document by the Patient Education Draft Strategy Working Group and the Patient Education Subcommittee
 - an external review of the document by key stakeholders—specifically the CCO Patient Education Committee, the Program in Evidence-Based Care, CCO, the University Health Network, the Nova Scotia Cancer Patient Education Committee, CCNS, and the Education Committee, CJAG
- Revision of the document on the basis of feedback received from the internal and external reviews, including comments received at the National Cancer Patient Education Workshop, held in Montreal in early March 2009.

1.3 Scope of The Cancer Patient Education Framework

Person-centered cancer education is an integral part of the human experience in all phases of the cancer control continuum (Figure 1). While the principles underlying cancer education across the cancer control continuum may be similar, there are unique aspects to **cancer patient education**. Cancer patient education focuses on persons affected by cancer, from the time of diagnosis through treatment, and on to survivorship, or possibly palliative and end-of-life care.

While there is collaboration and an interrelationship among experts in cancer education when developing and designing cancer education programs, participants at the National forum held in March 2009, recognized that there is an additional body of knowledge which specifically addresses the starting point of the cancer control continuum, more specifically prevention and screening. In the long term, it is crucial that The Cancer Patient Education Framework evolve to address these phases of the continuum. However, at this time, cancer education related to prevention and screening is not within the scope of this document.

Note: The Cancer Patient Education Framework acknowledges that, in some agencies, the scope of cancer patient education does include prevention, screening, and patient education for those at risk for cancer due to heredity or other factors.

II. Principles of Cancer Patient Education

2.0 Cancer Patient Education

Cancer patient education is an integral part of treatment and care for persons affected by cancer, from the time of diagnosis through treatment, and on to survivorship and possibly palliative and end-of-life care. The Source Documents have defined cancer patient education as:

- A distinct and definable activity that supports the learning and behaviour of persons affected by cancer [1, 6]
- A learning relationship between the HCP and the person affected by cancer [1, 6]
- Any set of planned, structured, organized educational activities designed and delivered using a combination of teaching methods to improve understanding and knowledge, health behaviours, health outcomes and health status [6,11, 12, 13]
- All learning experiences that persons affected by cancer engage in with the conscious intent of improving their understanding of and becoming active participants in managing their care [1]

The provision of cancer patient education is, first and foremost, a collaborative patient-centered practice [3], which takes into account that:

- Individuals may have various needs and concerns based on their particular situation, including coping style, culture and ethnicity, gender, age, etc. [3, 6, 14, 15]
- People affected by cancer may want information that assists them to make treatment decisions, manage treatment, side effects or symptoms of their disease, and to cope with their cancer experience [2, 3, 6, 9, 10]
- Effective cancer patient education programs can improve patient knowledge, reduce anxiety, increase patient involvement and satisfaction in treatment decisions, help patients to develop coping strategies to manage disease and treatment, decrease hospital stays, and greatly improve health outcomes [3, 9, 16, 17, 18,19]

2.1 Conceptual Model for Cancer Patient Education

The Conceptual Model for Cancer Patient Education illustrated in Figure 2 is intended to be a dynamic and interactive process; it includes a range of elements that may vary in their application depending on resources—human, material, and financial. The model is flexible, applicable at appropriate points along the cancer control continuum, from diagnosis to end-of-life, is based on needs and preferences of persons affected by cancer, and should be adaptable to system change. It is anticipated that the proposed model and its underlying principles will lead to improved patient care outcomes.

The Model for Cancer Patient Education acknowledges:

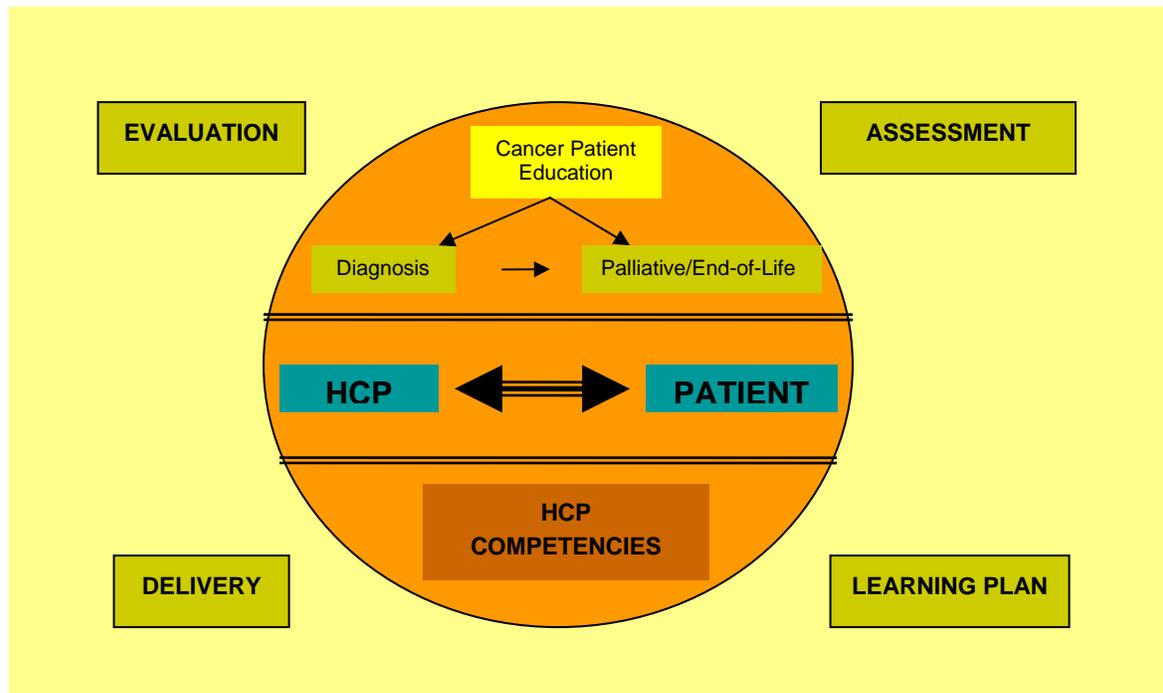
- the relationship between the HCP and the person affected by cancer
- that cancer patient education must be specific to each phase of the cancer continuum—diagnosis, treatment, survivorship, and palliative and end-of-life care

The Model for Cancer Patient Education further recognizes that:

- since every HCP is an educator, the skills and the competencies of the HCP are essential to the delivery of quality cancer patient education
- the principles related to the teaching-learning process will promote excellence in cancer patient education

These elements of the model will be further described in the following pages. The primary sources of information for the principles defined in the model for cancer patient education were adapted from the Education Standards for People Affected by Cancer (Draft document) from Cancer Care Nova Scotia, and the Nova Scotia Cancer Patient Education Committee, and are further supported by other key Source.

Figure 2: Conceptual Model for Cancer Patient Education



2.1.1 Assessing the Learning Needs

It is well established in the literature that some people affected by cancer want as much information as possible about their illness, but the specific type of information may vary on the basis of individual needs. It is also recognized that some individuals cope best with less information [3]. When assessing the learning needs of the person affected by cancer, the HCP takes into account the unique attributes of individuals within specific groups (including First Nations, Aboriginals, Métis, Inuit, immigrant, non-English or French-speaking, seniors, and children).

Principles for assessing the learning needs of persons affected by cancer:

- Persons affected by cancer can expect to be full participants along with the HCP in assessing their educational needs.

The HCP will:

1. Assist the person affected by cancer to identify their individual learning needs, considering prior knowledge, level of understanding, preferences for information, and readiness to learn
2. Assess the person's functional abilities and health literacy, taking into account the following:
 - age
 - developmental level and language skills

- culture and ethnicity
- gender
- the person’s health status
- physical or mental challenges
- emotional, cognitive, social, and economic status

3. Respect a person’s choice not to learn

2.1.2 The Patient Learning Plan

Cancer patient education programs that are well developed, organized, and structured improve the person’s ability to understand and utilize the information provided. A person-centered approach to the development of the learning plan promotes a collaborative relationship between the HCP and the person affected by cancer. This further ensures that persons affected by cancer will receive the education, support, and care that is tailored to their individual educational needs and preferences.

Principles for developing a patient learning plan:

- Persons affected by cancer have a right to expect that they will be an integral part of developing their learning plan in collaboration with their health care team.

The HCP will:

1. Involve the person affected by cancer in the development of an appropriate and flexible education plan to meet their individual learning objectives. The plan includes:
 - a. behavioural objectives linked to the learning needs
 - b. content and methods appropriate for the objectives and reflective of the learner’s preferences for information and preferred learning style
 - c. techniques to actively involve the learner
 - d. methods to evaluate the learning experience, effectiveness and efficiency of instruction, and any necessary revisions to the teaching plan.
2. Obtain feedback from the learner to evaluate the teaching-learning process by providing opportunities to share remarks, concerns, and comments.
3. Modify the teaching plan, if needed, based on evaluation data.
4. Use the policies and procedures of the organization to guide the development and provision of education to people affected by cancer.
5. Document the teaching-learning process on the person’s health record, including the following information:
 - a. the person’s learning needs

- b. prior knowledge, level of understanding, and preferences for information
- c. learning objectives
- d. teaching plan and outcomes
- e. contact information for questions or concerns.

2.1.3 Delivery of Cancer Patient Education

Teaching strategies are the methods used to deliver patient education curricula. They should enhance the capacity of the patient to obtain, retain, and apply knowledge and skills. The literature demonstrates that a combination of teaching methods has been shown to be the most effective in delivering education to persons affected by cancer.

Principles for tailoring cancer patient education to the unique learner:

- Persons affected by cancer are entitled to receive cancer education tailored to their needs and provided by knowledgeable and skilled health care providers.

The HCP will use:

1. Teaching methods that best fit with the learning style of the person based on consideration of age, gender, socio-economic status, sexual orientation, cultural background, language, and the person's current health status and prognosis
2. Education interventions early in the person's cancer journey to promote their involvement in decision making processes
3. Educational content that is accurate, current, and credible (based on evidence, research, and best practice)
4. Resources and materials written in plain language (simple, clear, direct and uses common words) with an appropriate reading level (grade 8 for the general public²)
5. Standardized education materials (for example, pamphlets, computer software, decision aids) which have been developed and approved by the respective organization prior to implementation
6. Ensure availability and timely access to educational materials and resources to meet the needs of a diverse population, reflecting culture and ethnicity, gender, and physical or mental challenges
7. Additional personnel resources to support the learning (for example, interpreters, librarians)

² Even though research indicates that a grade 4 to 5 reading level is most understandable, many cancer educators consider a grade 8 reading level to be a more realistic target with the use of standard cancer terminology

In addition, the HCP will ensure the person's environment is conducive to learning by:

1. To the extent possible, providing adequate, private and comfortable space within the organization to accommodate individual or group education services
2. Making audiovisual and technical support available (for example, printing and graphic support and audiovisual equipment)
3. Ensuring that resources are available in the organization or in the person's home environment (if that is the preference), in order to support self-directed learning. Examples are: patient education library, resource centre, access to websites such as the Canadian Cancer Society, www.cancer.ca.

2.1.4 Evaluation of Cancer Patient Education

Cancer patient education is an interactive learning relationship between the HCP and the person affected by cancer (the learner), and as such, the teaching-learning processes must be evaluated. The ongoing monitoring of the teaching-learning process through the use of performance and outcome indicators will provide data about its effectiveness and efficiency. Optimal education programs are evidence-based and include mechanisms to improve services and ensure responsiveness to the patient's changing information needs.

Key indicators of the immediate effect or impact of the cancer education intervention include:

- Satisfaction of persons affected by cancer
- Effectiveness of person-centered education as evidenced in
 - Behavioural and/or attitudinal change
 - Level of knowledge and skills
- Perception of persons affected by cancer regarding quality of life/health outcomes

Principles for the evaluation of cancer patient education:

- Persons affected by cancer can expect that teaching-learning interventions will be closely monitored to ascertain quality cancer education that meets their individual needs. Recognizing the limitations of time and resources in all organizations, the following processes can be put in place progressively over a period of time.
 1. The cancer patient education quality/performance improvement process will be integrated with the organization's quality/performance improvement program.
 2. The evaluation process will provide a mechanism for continuous feedback from the people affected by cancer.

3. The results from monitoring and improvement activities will be used to revise patient education systems, processes, and services.
4. A process will be in place to evaluate and approve new education services/ resources prior to implementation.
5. The education services/resources/materials will be evaluated by HCP providers regularly using a variety of methods (for example, focus groups and pre-post tests) and modified based on results from the evaluation process.
6. The evaluation instruments will be developed to measure learning outcomes.
7. The HCP will have the necessary competencies and have access to/use of current literature/research to guide their practice.
8. The teaching-learning process will be guided by written policies and procedures.

2.1.5 Development of Health Care Provider Competencies

To effectively carry out cancer patient education, the HCP should possess the competencies necessary to achieve the expected performance criteria relevant to the professional standards of the specific provider. Levels of expertise, knowledge, and skills will vary amongst the various HCP. Educational programs and/or continuing education opportunities should therefore be tailored to the needs of the different types of HCP who are engaged in cancer patient education. Organizations should provide learning opportunities that are likely to positively influence HCP attitudes and behaviours [4, 6, 20].

Principles for developing competencies of HCP:

- Persons affected by cancer are entitled to education by health care providers who are competent in the provision of person-centered cancer education.

Educational programs for HCP who provide cancer education should:

1. review the roles and responsibilities of team members who provide cancer patient education services
2. promote interprofessional collaboration (i.e. with agencies and communities and among different care providers) across the cancer continuum
3. review communication strategies among team members
4. create professional associations to support HCP in their learning (e.g., the Cancer Patient Education Network)

Programs must educate HCP as to:

5. the patient education resources available to them, and methods of finding further resources as needed

6. social issues and inequalities, such as poverty, socio-economic disparities, racism, cultural differences, literacy, gender discrimination, homophobia, and ablism
7. the theoretical principles of adult learning and how to apply them, i.e. problem-centred learning, relating materials to patient's experience, selecting teaching methods to fit different learning styles
8. different methods of teaching, i.e. lecture, small group discussion, personal reflection
9. the basic principles of counselling, i.e. empathic communication, active listening

III. Establishing Comprehensive Cancer Patient Education Services

The previous section presented the Conceptual Model for Cancer Patient Education and described its underlying principles.

This section focuses on how to **establish an organizational infrastructure to promote and sustain quality cancer patient education in Canada. It provides guidance to health care managers, administrators, and those in senior positions in the development of a formal cancer patient education program.** It is recognized that special consideration may be needed when promoting and sustaining quality cancer patient education for First Nations, Aboriginals, Métis and Inuit communities because of the complexities in jurisdictional health care delivery.

3.0 Background

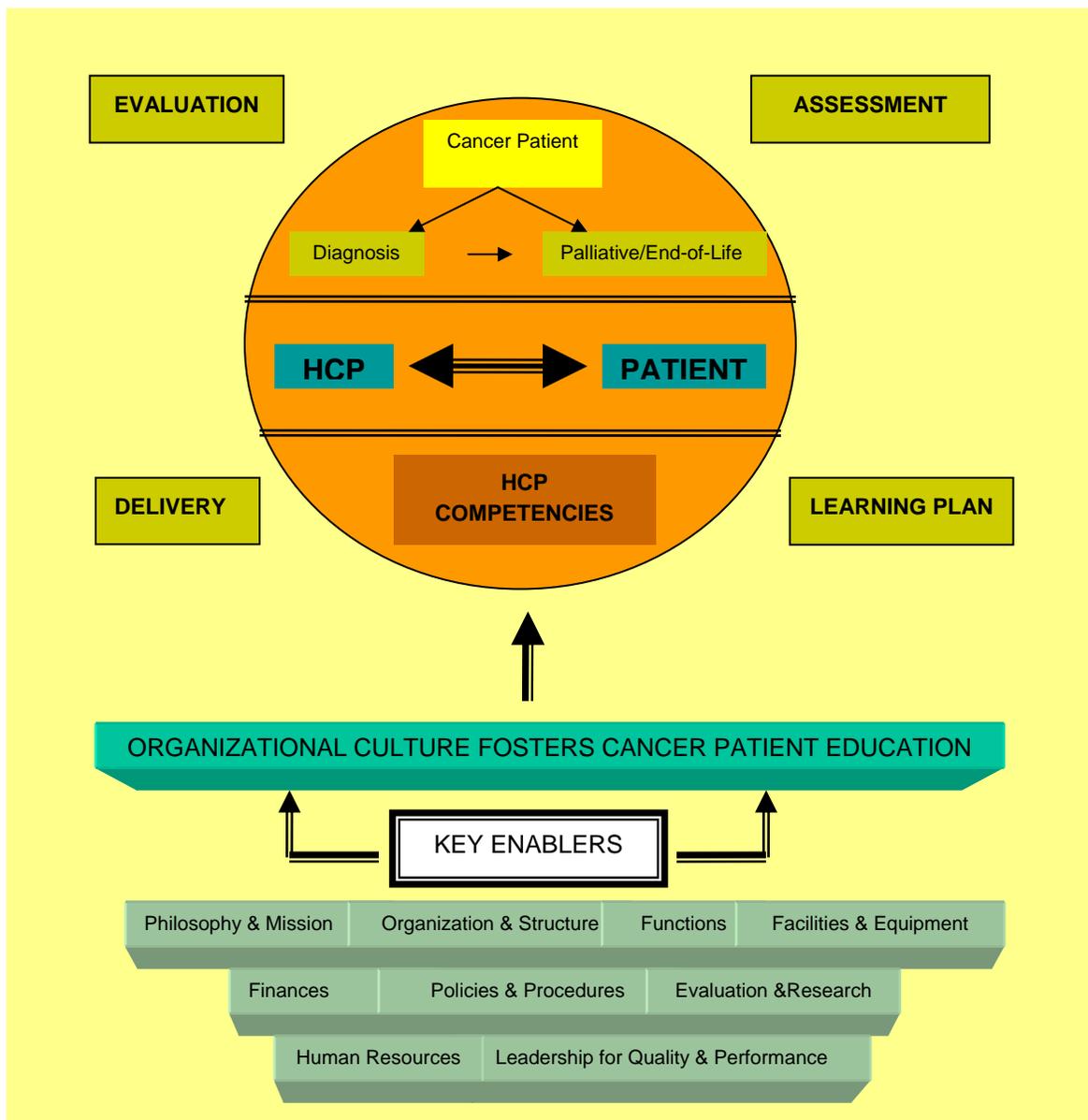
The National Cancer Institute's (NCI) Cancer Patient Education Network (CPEN) was established in 1988 by the Institute's Patient Education Branch with the aim of improving the delivery, management, and overall quality of patient education services in NCI-sponsored cancer centres in the United States. CPEN Canada was formed in 2002 to similarly support cancer patient educators across Canada. These Networks have become leaders in the delivery of cancer patient education. In 2005, CPEN took steps to establish itself as an independent professional organization; it is now separate from, but maintains a collaborative partnership with, NCI. Following this separation, CPEN Canada became the first international chapter of CPEN; it is open to all cancer patient educators across the United States and Canada.

In 1993, NCI CPEN developed a set of guidelines to promote excellence in patient and family education. To avoid duplication and to capitalize on existing work, the Cancer Care Ontario Patient Education Program used these guidelines as the basis for a comprehensive patient education framework for Ontario. This document has been adapted for this section of The Cancer Patient Education Framework.

3.1 Key Enablers

Key enablers are the **foundational elements** essential to a **comprehensive cancer patient education program (CPEP)**. These key elements help to ensure the effectiveness and sustainability of quality cancer patient education; as such, they have been added to the Conceptual Model for Cancer Patient Education in the diagram below. The key enablers are subsequently described.

Figure 3: Conceptual Model for a Comprehensive Cancer Patient Education Program (CPEP)



3.1.1 Philosophy and Mission

The mission statement defines a direction for CPEP and the essential objectives to be accomplished. The philosophy statement establishes the basic premises of patient education. This long-range plan provides the CPEP 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 goals of the cancer program.

Principles on which to base the philosophy and mission of a CPEP:

1. The philosophy statement reflects the beliefs about and the value assigned to person-centered education. This statement clarifies the values and beliefs about:
 - a. The role that person-centered education plays as an intervention for achieving the cancer program's goals.
 - b. The use of person-centered education principles and practices such as:
 - i. Persons affected by cancer and their caregivers have a right to appropriate cancer research and treatment information.
 - ii. Healthcare providers play an important role in person-centered health care and decision making.
 - iii. The religious, social, and cultural practices of persons affected by cancer are respected and the needs of special populations are addressed (Aboriginal, immigrant, seniors, children, etc).
 - iv. Every health care provider is an educator.
 - v. Interdisciplinary collaboration is a vital component of the person-centered education process.
2. The mission statement defines and limits the scope of the services provided. Specifically, it indicates what the CPEP does for the cancer program and describes the relationship between the CPEP and its constituencies.
3. The statements provide guidance in decision making and in all areas of practice related to person-centered education.
4. The statements align with the strategic goals of the cancer program.
5. The statements are evaluated by the larger community and reviewed routinely.
6. The long-range plan includes the following:
 - a. Mission;
 - b. Assessment of internal and external environment;
 - c. Assessment of program strengths and weaknesses;
 - d. Identification of program goals, objectives and strategies;

- e. Identification of the gap between what exists now and the program goals;
 - f. Action steps to move toward the program goals, including the periodic evaluation of effectiveness and outcomes.
7. The long-range plan receives input from the appropriate interdisciplinary team members.

3.1.2 Organization and Structure

It is important that administrators and/or managers be centrally involved in creating an organizational culture and infrastructure that prioritizes and supports excellence in person-centered cancer education. Even though these individuals are not directly involved in teaching persons affected by cancer, they are instrumental in promoting the person-centered approach and ensuring that the values, beliefs, and goals of the cancer education program reflect those of the organization. Their commitment is essential to obtaining adequate resources and ensuring that cancer patient education is integrated, where appropriate, in performance improvement throughout the organization.

Principles for the organization and structure of a CPEP:

1. The cancer program ensures there is clarity regarding roles, authority, responsibility, and accountability for the development, implementation, administration, coordination, and evaluation of the CPEP activities.
2. There is a written description of the organization and structure of the CPEP, the roles and functions of those leading the CPEP, and the collaborative relationships between the CPEP and the various interprofessional components of the cancer program.
3. The leadership of the CPEP has access to expert clinical staff who may be called upon to implement education programs, services, and activities.
4. The CPEP staff applies appropriate teaching-learning theories to support the development, implementation and evaluation of cancer patient education.

3.1.3 Functions

Interprofessional collaboration is an important component of a CPEP. While providing leadership, the CPEP staff promote person-centered education competencies in collaboration with clinical staff across the cancer program, persons affected by cancer and other stakeholders as may be appropriate.

Principles for providing leadership of a CPEP:

1. The CPEP clearly defines its scope of services, identifies its customers (patients, families, significant other and other stakeholders), functions, and activities.

2. The CPEP staff is involved on committees, task forces, and projects to ensure that education needs of persons affected by cancer are reflected in the broader mission of the cancer program.
3. The CPEP staff make use of existing person-centered cancer education activities and resources in hospitals, institutions, and provincial cancer programs, as well as those in community-based organizations (for example, Canadian Cancer Society, Willow Breast Cancer Support Canada, Wellspring).

3.1.4 Facilities, Equipment, and Resources

A CPEP requires adequate facilities that are conducive to learning and resources that support person-centered cancer patient education.

Principles for supporting a CPEP in achieving its mission:

- A library and/or current reference materials are available for the development of educational activities and research by the CPEP staff.

The CPEP staff has regular access to appropriate technologies for data management, electronic communication, and distribution of information within the cancer program, and can access emerging technologies as required.

3.1.5 Finances

Allocated financial support is necessary to support an effective CPEP. Expenses might include:

- human resources - clinical, educator, librarian administration salaries, etc. and allocated time for education
- staff training and professional development
- libraries
- patient education resources (books, pamphlets, etc.)
- computers, hardware and software
- access to internet and databases
- subscriptions to health journals

Principles to ensure appropriate financing of a CPEP:

- The CPEP is a line item in the budget of the cancer program/organization.

3.1.6 Policies and Procedures

Policies serve as a guide for decision making by outlining positions, goals, and 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.

Specific policies and procedures provide evidence of professional performance for accrediting bodies.

Principles for the development of policies and procedures for a CPEP:

1. Policies and procedures are written and easily accessible in print and electronic format. They encompass interdisciplinary responsibilities for the development and provision of person-centered cancer patient education.
2. Policies and procedures are communicated to staff, departments, and units in the cancer program/organization.
3. Processes are in place to ensure that:
 - a. Evaluation of cancer education resources is performed prior to approval and distribution to assess the accuracy and applicability of cancer information.
 - b. Mechanisms exist for the development and approval of cancer education materials, including education materials external to the organization.
 - c. The processes for purchasing equipment/materials are clearly delineated.
 - d. Staff and volunteers competencies and education are verified.
 - e. Resources are in place to operate cancer education resource centres, archives or libraries.
 - f. An effective approach to quality and performance improvement is applied in the organization.
4. Policies and procedures are reviewed annually and revised as necessary.
5. Records of programs and services are maintained.

3.1.7 Leadership for Quality and Performance Improvement

Quality/performance improvement is an integral, ongoing, and systematic process to ensure excellence in person-centered cancer education. Although quality improvement is an integral part of everyone's work, the CPEP staff assume a leadership role in designing and improving the cancer education function.

Principles to ensure quality/performance improvement of cancer patient education services within a CPEP:

1. CPEP staff participates in developing the organization's quality/performance improvement structure related to cancer patient education.
2. CPEP staff serve as expert cancer education leaders/mentors to health care providers responsible for the education of persons affected by cancer and to other stakeholder groups such as CPEN Canada with regard to

program/resources development, planning, implementation, and evaluation.

3. CPEP staff is encouraged to join a professional organization such as CPEN Canada with the aim of offering and receiving ongoing collegial mentoring and professional development in areas such as program/resources development, planning, implementation, and evaluation.

3.1.8 Evaluation and Research

CPEP staff should look for innovative ways to improve teaching strategies, program planning, and development. Through research and evaluation, CPEP staff will facilitate the implementation of best practices in person-centered cancer education.

Further, program evaluation will produce data which may be used in future planning and/or to improve the current programs. As a first step in the evaluation process, a process or formative evaluation will be beneficial for decision makers. Data collection and analysis of key findings will enable CPEP staff to determine how well the cancer education program is working. Key indicators to consider may be:

- number and type of promotional strategies for increasing the awareness of CPEP
- number and type of policies and procedures developed
- number of CPEP staff involved in research activities
- number and type of educational activities available to CPEP staff
- type/nature of support provided by stakeholders (persons affected by cancer, physicians, nurses, social workers, etc.)
- number and type of educational resources/programs accessed by persons affected by cancer

Principles to ensure evaluation and research activities within a CPEP:

1. CPEP has an internal channel for distributing research literature to staff members.
2. CPEP staff members facilitate the change of practices based on data from evaluations and literature reviews of field research.
3. CPEP staff is encouraged to develop knowledge and skills in the evaluation process, systematic problem solving, and research activities.
4. CPEP staff participates in the cancer program's evaluation processes and research activities.
5. The CPEP has a list of research questions that would improve the function of the CPEP, the cancer program, or the practice of patient education.

6. CPEP staff members use evaluation and research data to prepare a proposal or to justify an intervention.
7. CPEP staff members use practice-based situations to design a research study.
8. CPEP staff members conduct investigations using standard research protocols and evaluations to determine the effectiveness of an intervention.

3.1.9 Professional Development

The purpose of professional development for CPEP staff is to expand the knowledge base, to enhance education competencies and to keep abreast of the current trends in cancer patient education.

Principles to ensure professional development for CPEP:

1. The CPEP staff has a minimum of a bachelor's degree in education, social work, nursing, healthcare administration, health education, or a related field, such as library sciences.
2. New personnel in the CPEP receive an orientation of sufficient duration and content to prepare them for their respective roles in an oncology environment.
3. CPEP staff regularly participate 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 person-centered cancer patient education specifically.
4. CPEP staff participate in regular performance assessment and establishes goals for professional development in collaboration with their supervisors.
5. 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.
6. CPEP staff are encouraged to demonstrate professional responsibility by membership and active participation in professional organizations and by voluntary service in professional groups or community agencies.

IV. Conclusion

Cancer patient education is an integral component of care that is provided throughout the cancer experience. The evidence illustrates, however, that it is often overlooked, that patient needs are not well articulated, and that there is a lack of institutional commitment, leadership, and financial resources [1, 2, 3,]. Further, it has been demonstrated that a patient's knowledge deficit can result in increased health expenditures, decreased quality outcomes, and patient dissatisfaction with care? [1].

At the present time, there are no national standards or guidelines that drive the cancer patient education agenda in Canada. *The Framework for Achieving Excellence in the Provision of Cancer Patient Education in Canada* was created to begin to address the need for a consistent and standardized approach to the delivery of cancer patient education. A conceptual model has been proposed and recommendations put forward to improve the delivery and quality of person-centered cancer education. For provincial or regional cancer centres who can embrace the development of a formal comprehensive patient education program within their existing cancer program, nine core elements are presented as the key enablers in ensuring a sustainable, comprehensive patient-centered education program.

The development of The Cancer Patient Education Framework is a first step towards achieving excellence in the provision of cancer patient education. Engagement from key stakeholders from across the country is required to disseminate The Cancer Patient Education Framework document and to begin to consider its implementation and its impact. Much time and energy, and many resources will be required in the coming years to mobilize decision makers, health care professionals, and volunteers who provide cancer education to persons affected by cancer. In the end, the persons affected by cancer will benefit most from these extraordinary efforts.

V. References

1. Cancer Care Ontario Patient Education Program Committee and Cancer Care Ontario Program in Evidence-Based Care (August 2006). Establishing Comprehensive Cancer Patient Education Services: A Framework to Guide Ontario Cancer Education Services.
www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=14326
1. Butow P, Devine R, Boyer M, Pendlebury S, Jackson M, Tattersall MH. (Nov 1 2004). Cancer consultation preparation package: changing patients but not physicians is not enough. *Journal of Clinical Oncology*. 22 (21):4401-9.
2. Cancer Care Nova Scotia, Nova Scotia Cancer Patient Education Committee CCNS (2008). Education Standards for People Affected by Cancer. (*Draft document*—Contact: Anne Murray, Coordinator, Education & Patient Navigation Cancer Care Nova Scotia: Anne.Murray@ccns.nshealth.ca)
3. Education Committee, Rebalance Focus Action Group, Canadian Strategy for Cancer Control (March 2007). National Psychosocial Oncology Education Framework.
www.partnershipagainstcancer.ca/sites/default/files/journey/CSCC_CJ_education_framework_0307_E.pdf
4. National Cancer Institute Cancer Patient Education Network (1999). Guidelines for Establishing Comprehensive Cancer Patient Education Services.
<http://cancerpatienteducation.org/admin/resources/CpenGdInsForCaPtEdMay98.pdf>
5. University Health Network (March 2003). Evidence Based Best Practice Guidelines for Delivering Patient Education Curriculum. Contact: Audrey Friedman, Provincial Head Patient Education, Cancer Care Ontario, Princess Margaret Hospital, University Health Network, Audrey.Friedman@uhn.on.ca
6. WHO Working Group (1998). Therapeutic Patient Education: Continuing Education Programmes for Health Care Providers in the Field of Prevention of Chronic Diseases.
7. Jusko Friedman A, Jones J, Nyhof-Young J, Wiljer D, Catton P, (2005). Surveying the Landscape: The Status of Cancer Patient Education in Canada. Longwoods Review: February.
8. Whelan T, Sawka C, Levine M, Gafni A, Reyno L, Willan A, et al. (2003). Helping patients make informed choices: A randomized trial of a decision aid for adjuvant chemotherapy in lymph node-negative breast cancer. *Journal of the National Cancer Institute* Vol 95 (8) (pp 581-587), 2003 Date of publication: 16 APR 2003. 2003;(8):581-7.

9. Riemsma RP, Taal E, Kirwan JR, Rasker JJ. (2004). Systematic review of rheumatoid arthritis patient education. *Arthritis Care & Research* Vol 51 (6) (pp 1045-1059, 2004 Date of Publication: 15 DEC 2004. 2004; (6): 1045-59.
10. Stömberg A DUFB (2006). Computer-based education for patients with chronic heart failure. A randomized, controlled, multicentre trial of the effects on knowledge, compliance and quality of life. *Patient Educ Couns.* 64:128-35.
11. Stokamer C, Tenner CT, Chaudhuri J, Vazquez E, Bini E (2005). Randomized controlled trial of the impact of intensive patient education on compliance with fecal occult blood testing. *Journal of General Internal Medicine.* 20(3):278-82
12. Zernike W, Henderson A. (1998). Evaluation the effectiveness of two teaching strategies for patients diagnosed with hypertension. *Journal of Clinical Nursing.* Jan: 7(1)L37-44.
13. McPherson CJ, Higginson IJ, Hearn J. (2001). Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials. [Review] [40refs]. *Journal of Public Health Medicine.* Sep; 23(3):227-34.
14. Houts PS, Doak CC, Loscalzo MJ. (2006). The role of pictures in improving health communication: a review of research on attention, comprehension, recall, and adherence. [Review] [46 refs]. *Patient Education Counselling.* May; 61(2):173-90.
15. Hutchison C, Cowan, C, MaMahon T, Paul J. (2007). A randomized controlled study of an audiovisual patient information intervention on informed consent and recruitment to cancer clinical trials. *Br J Cancer.* 97(6):705-11.
16. Lee A, Chui PT, Gin T. (2003). Educating patients about anaesthesia: A systematic review of randomized controlled trials of media-based interventions. *Anaesthesia & Analgesia* Vol 96(5) (pp 1424-1431), 2003 Date of Publication: 01 May 2003. 2003;(5):1424-31.
17. Yeh ML, Chen HH, Liu PH. (2005). Effects of multimedia with printed nursing guide in education on self-efficacy and functional activity and hospitalization in patients with hip replacement. *Patient Education & Counselling.* May:57(2):217-24.
18. Wilson SR. (1997). Individual versus group education: Is one better? *Patient Education & Counselling* Vol 32(SUPPL. 1) (pp S67-S75); (SUPPL. 1):S67-S75.
19. Patient Education. American Academy of Family Physicians. *American Family Physician.* 2000 Oct :62(7):1712-4.

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20. Kennard L. (1993). Promoting effective use of print materials in patient education. In: Glioth BE, editor. Managing hospital-based patient education. Chicago: American Hospital Publishing.
21. Wyness MA. (1989). Devising standards of patient education. QRB Qual Rev Bull. 15:279-85.
22. Bartlett EE. (1995). Cost-benefit analysis of patient education. Patient Educ Couns. 26:87-91.
23. Canadian Cancer Society/National Cancer Institute of Canada: (2008). Canadian Cancer Statistics 2008, Toronto, Canada.

Appendix 1. Committee Members

Patient Education Draft Strategy Document Working Group of the Patient Education Subcommittee, Education Committee:

Audrey Friedman, BA, MRT(T), MSW - Chair

Anne Murray, PDt BSc, MAEd

Anne-Marie Stacey, M. Mus, M.Ed

Jan MacVinnie, R.N.

Gale Turnbull

Patient Education Subcommittee of the Education Committee:

Audrey Friedman BA, MRT(T), MSW - Chair

Director Patient Education and Survivorship PMH

Provincial Head of Patient Education Cancer Care Ontario

Princess Margaret Hospital

Brenda Ross

Research Nurse Coordinator

British Columbia Cancer Agency

Loring Gimbel

Patient Education Specialist

Tom Baker Cancer Centre

Anne-Marie Stacey M.Mus, M.Ed.

Patient Education Specialist, Cross Cancer Institute

Alberta Health Services - Cross Cancer Institute

Debbie Arsenault

Provincial Leader Supportive Care

Saskatoon Cancer Agency

Jill Taylor-Brown, MSW, RSW

Director, Patient and Family Support Services,

Chair of Education Committee

CancerCare Manitoba

Susan Kapilik

Volunteer & Community Based Information & Support Programs Coordinator

CancerCare Manitoba

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Tamara Harth, M.Information Science
Program Manager Patient Education
Odette Cancer Centre at Sunnybrook Health Sciences Centre

Gail Turnbull
Manager, Supportive Care & Education
London Regional Cancer Centre

Jan MacVinnie, RN
Manager Cancer Information Service
Canadian Cancer Society

Hinda Goodman M.S.W. B.Sc.
Oncology Program Coordinator
Hope & Cope
c/o Jewish General Hospital

Dawn MacIsaac, RTR, BScR
Acting Manager PEI CTC
Queen Elizabeth Hospital

Anne Murray, Pdt BSc, Med
Provincial Manager, Education and Patient Navigation
Cancer Care Nova Scotia

Lynne Robinson, PhD, RPsych,
Professor, Dalhousie University, School
of Health and Human Performance

Martha Paynter
Coordinator of Education
New Brunswick Cancer Network

Appendix 2. Background to Project

The vision of the Canadian Partnership Against Cancer (the Partnership) for cancer care in Canada is to establish a comprehensive, coordinated person-focused cancer system that responds to the full range of needs of all Canadians and their families through all stages of the cancer experience. In striving to achieve its vision, The Partnership has identified four (4) strategic goals:

- Reduce the gaps in knowledge to enhance cancer control
- Facilitate and accelerate implementation of best available knowledge
- Optimize quality services, and
- Improve the cancer experience for Canadians

As a means of achieving these strategic goals, the Partnership has set forward a mandate for each of its eight (8) Action Groups. One action group in particular, the Cancer Journey Action Group (CJAG), provides leadership to achieving integrated person-centered care throughout the cancer journey. Its goals are:

- Implementation of integrated, person-centred care including uptake and utilization of distress screening and navigation programs and best practice standards and performance indicators in the areas of psychosocial, supportive and palliative care
- Investigation and knowledge building about survivorship issues with special attention to underserved populations
- Development of pan-Canadian educational tools, standards and guidelines in person-centered care that includes psychosocial, survivorship and palliative care

The Education Committee, a subgroup of the CJAG was established in 2004 to focus on pan-Canadian strategies to ensure that health care providers and volunteers have the necessary knowledge and skills to provide compassionate person centred care to people with cancer and their significant others. The Education Committee is composed of an interprofessional working group with representation from across Canada.

The vision of the Education Committee has been articulated as follows:

Destination

- All health care providers and volunteers encountered by people with cancer and their significant others at any point on the cancer trajectory will provide compassionate person centred care within a model of interprofessional care.
- Adequate numbers of expertly trained/educated individuals in the areas of psychosocial, rehabilitative, spiritual, and end of life oncology care will

exist, and be utilized to ensure Canadians affected by cancer will be served by interprofessional, integrated health care teams to meet their individual needs within the health care system in Canada.

Landmarks to Destination

- Health care professionals, (including students, trainees, and current practitioners) have the necessary knowledge and skills in the areas of psychosocial, supportive, rehabilitation and end-of-life care for people with cancer and their families to ensure high quality care in these dimensions
- Health care professionals are educated in and practice within a model of interprofessional practice.
- Volunteers who provide information and support to people with cancer and their families have sufficient education and training in the psychosocial, supportive, rehabilitation and end of life care to provide person centred, compassionate care.
- Health care professionals have the necessary patient education skills and resources to effectively educate and support people with cancer and their families by enhancing their knowledge and understanding of their disease and its treatment and their ability to be active partners in treatment and symptom management decisions throughout their cancer experience.

To support the goals of the CJAG, one of the priority strategic initiatives of the Education Committee for 2008-2009, is to develop a strategy for cancer patient education in Canada. It is anticipated that The Strategy will serve as the foundation to improve quality cancer patient education across the country and ultimately improve health outcomes of patients, families and significant others living the cancer experience.