



**Education Standards
for Adults Affected by Cancer**

Quick Reference Version

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Introduction

Cancer is a leading cause of morbidity and mortality in Canada. Nova Scotia has high cancer incidence and mortality rates amongst both males and females compared to the national rates^{5,13}. Given the complex nature of the disease, the cancer care system and treatment modalities, those diagnosed with cancer and their family members will experience a variety of informational/educational needs throughout their cancer journey.^{3,17,18,21}

The Nova Scotia Cancer Patient Education Committee (NSCPEC) is a collaborative effort of CCNS, the Capital Health Cancer Care Program, the Cape Breton Cancer Centre and the District Health Authorities in Nova Scotia. Membership is multidisciplinary; inclusive of experts in oncology practice and patients and family members. The mandate of the committee is to ensure every adult cancer patient receives excellent, evidence-based, consistent and timely education in an appropriate format and setting³⁴. This mandate is achieved by establishing and maintaining processes related to patient education. Patient education is provided to cancer patients and families by Health Care Providers (HCPs) in districts across Nova Scotia.

Several qualitative studies commissioned by *Cancer Care Nova Scotia (CCNS)* as well as the research within the patient education literature highlight the variety of information needs and preferences amongst people affected by cancer as well as, the inconsistent, incomplete and, on occasion, insensitive approaches of HCPs attempting to address these needs^{9,10,11,12,18,20,23,24,31,27,37,48}. The 2007 Ambulatory Oncology Patient Satisfaction Survey identified specific education, information and communication needs as “top priority” because improvements in these areas would have the greatest impact on overall

patient satisfaction⁷. Building on this work, a needs assessment conducted for the NSCPEC affirmed that standards for the education of people affected by cancer were needed by HCPs in District Health Authorities (DHAs) across the province.

CCNS envisions a system where cancer patients throughout Nova Scotia receive excellent, evidence-based, consistent and timely education concerning their cancer journey in an appropriate format and setting. These standards have been written to assist HCPs and DHAs in achieving this vision. Guidelines accompanying the standards provide the HCP and/or organization/facility providing cancer care specific approaches to meet the particular standard.

Assumptions:

These standards were written with the following assumptions:

- Person affected by cancer is inclusive of the person with cancer and their family.
- Person refers to an adult.
- Family is defined by the person with cancer.

These standards will be reviewed in three years from publication date. Current versions of these standards (full and quick reference versions) are available on the *Cancer Care Nova Scotia* website www.cancercare.ns.ca

STANDARD 1. Collaborative Person-Centred Practice¹

Members of the interprofessional team work together and with the person(s) affected by cancer to meet the individual's (family's) educational/informational needs.

Rationale:

The variety of informational needs experienced by people affected by cancer requires an interprofessional approach to education.

Guidelines:

An interprofessional team delivers cancer care and oncology services^{1,2}

- The team works with the individual diagnosed with cancer and his/her family to identify their needs^{1,2}
- Each member of the team is aware of the other team members' roles and responsibilities related to providing education services to people affected by cancer^{1,2}
- The team collaborates with organization/facility and community resources to meet the educational and informational needs of the person affected by cancer^{1,2}
- The team shares the plan of care (inclusive of educational and informational support) with other care providers in a timely and coordinated way^{1,2}
- The person affected by cancer is provided the name and contact information of the team member who coordinates his/her care^{1,2}
- At times of transition, the team communicates to the person affected by cancer and their family/caregivers: the plan of care, a summary of care provided; any outstanding issues; the process of transition and contact information for concerns and/or follow-up^{1,2}.

¹ Collaborative patient-centred practice is an approach to care that involves two or more professionals or disciplines continuously working together and with the patient to address common concerns⁴¹. Much research exists exploring various frameworks, models and determinants of successful collaborative practice^{30,79}. From a recent review of the literature, four elements must exist within a team: a willingness to collaborate; communication; mutual trust and respect⁷⁹.

STANDARD 2. Teaching and Learning

Principles of adult learning, teaching theories and current research are used to guide the assessment, development, implementation and evaluation of individual and/or group educational activities.

Rationale:

Education is provided to people affected by cancer in a way that meets their unique needs.

Guidelines:

- People affected by cancer will have their information needs assessed at various points throughout the cancer continuum, such as:
 - At the time of diagnosis;
 - At the time of disease progression or recurrence;
 - At the time of transition to palliative care;
 - Prior to any treatment or procedure;
 - At the completion of therapy;
 - Prior to discharge from hospital;
 - Regularly throughout the follow-up period;
 - At the time of transition to survivorship ^{1,2,18,20,21,22,24,31,39}.
- People affected by cancer may be offered a summary of the consultation (letter or audio-recording), may as permitted by the policies institution ^{25,38,39,40,41,45}.
- The Health Care Professional:
 - Assists the person affected by cancer to identify their individual learning needs; considering prior knowledge, level of understanding and preferences for information ^{1,2,23,39}.
 - Assesses the person's values and beliefs, language, literacy, intellectual and physical abilities, health status, gender/gender identity, sexual orientation, culture and ethnicity, age/stage of life, emotional, cognitive, social and economic status as they relate to learning abilities and teaching methods ^{1,2,6,15,29,36}.
 - Respects a person's choice not to learn ^{1,2}.
 - Encourages the presence of a support person; recognizing that this is a personal preference ^{37,39}.
 - Establishes an effective learning environment, where the person affected by cancer feels safe and comfortable expressing themselves and is ready to learn ³⁶.
 - Involves the person affected by cancer in the development of an appropriate and flexible education plan to meet their individual learning objectives. The approach may include, where appropriate:
 - Behavioral objects linked to the learning need(s).

- Content and methods appropriate for the objectives and reflective of the person's preferences for information and preferred learning style.
- Techniques to actively involve the person affected by cancer.
- Employs methods to evaluate the learning experience, method/style of instruction and need to adjust the education plan^{29,36}.
- Obtains feedback from the person to assess understanding and to evaluate the learning experience^{29,36,39}.
- Modifies the education plan if needed based on the outcome/evaluation³⁶.

Resources provided by CCNS:

- Patient Education Fundamentals, available via www.cancercare.ns.ca

STANDARD 3. Educational Content

Each person affected by cancer receives relevant and timely information/education throughout the cancer continuum.

Rationale:

People affected by cancer require information that assists them to: make treatment decisions; manage treatment side effects or symptoms of their disease and cope with their cancer experience.

Guidelines:

- Content is individualized to be reflective of the person's preferences for information, preferred role in decision making, age/stage of life, culture and ethnicity, gender/gender identity, sexual orientation, and intellectual and physical abilities ^{1,2,6,15,47}.
- The healthcare professional assists the person affected by cancer to identify their individual learning needs; considering prior knowledge, level of understanding and preferences for information ^{1,29,23,36}.
- Timely, complete and accurate information is provided related to:
 - Cancer prevention and screening ^{16,36}
 - Diagnosis and prognosis ^{1,2,16,36}
 - Treatment plan and alternatives to treatment ^{1,2,7,16,36}
 - Tests: reason for and results from ^{7,43}
 - Preparation for medical procedures ^{1,2,39}
 - Evaluating the credibility of information/cancer therapies ^{36,42}
 - Evidence, research, and best practice ^{1,2}
 - Resolving issues/concerns, decision-making, and self-management ^{1,2, 36}
 - Healthy lifestyle and cancer prevention strategies ^{19,36,47}
 - Management of potential physical symptoms, pain and psychosocial responses (e.g. anger, fear, uncertainty, body image and/or sexuality concerns) ^{1,2,7,16}
 - Nutrition ^{1,2,7,26,47}
 - Complimentary and Alternative Medicine ^{42,47}
 - Financial supports and practical issues (e.g., accommodation, parking, orientation to cancer centre, system navigation) ^{46,47,48}
 - Recovery, rehabilitation, return to work, follow-up and survivorship ^{7,16,36}
 - Support for families and caregivers ^{1,2,4}
 - Palliative care, end of life care and bereavement ^{1,2,4,7,16}
 - Patient rights and responsibilities including their role in patient safety ^{1,2,16}
 - Resources and services available both within the healthcare setting(e.g., counseling/support, occupational therapy and/or physiotherapy) and the community, including recommended websites ^{1,2,16,27,28, 32,36,47}
- Information is provided according to institutional policies and procedures (e.g., chemotherapy administration, consent, blood/blood product administration) ^{17,33}.

STANDARD 4. Resources

Facilities, equipment and resources are available to support the individual's/group's learning experience and achievement of learning outcomes. Resources are approved by the NSCPEC².

Rationale:

Facilities, equipment and resources are necessary to support the teaching/learning process and reinforce the importance of patient education.

Guidelines:

- An effective learning environment is maintained where the person affected by cancer feels safe and comfortable expressing themselves and is ready to learn.^{33,36}
- Make every effort to provide sufficient, private, and comfortable space to accommodate individual or group education services¹⁷
- Facilities and resources are available to support self-directed learning (e.g., access to computers and training)¹⁷
- Make every effort to provide access to audiovisual support (e.g., printing and graphic support and audiovisual equipment)^{17,33}.
- Make every effort to provide a patient education library/resource centre for people affected by cancer which houses resources approved by the NSCPEC.
- Standardized educational materials (e.g., pamphlets, computer software, decision aids) are developed and/or approved prior to implementation according to *Cancer Care Nova Scotia's* guidelines, Guidelines for the Development of Patient Education Materials.
- Educational materials/resources are available to meet the needs of a diverse population, reflecting language, literacy, culture and ethnicity, gender, sexual orientation, age/stage of life, and physical or intellectual abilities^{1,2,9,10,11,14,15,30,35,36,47}
- Additional personnel resources are available to support learning (e.g., interpreters, librarians)^{14,15,35,36,44}.

Resources provided by CCNS via cancercare.ns.ca:

- CCNS website provides a wide range of information including: publications for patients and families; questions patients should ask during their first visit to the cancer centre; and information about treatment, clinical trials, palliative care and support services.

² Refer to the Patient Education Resource Approval Process, defined within the Guidelines for the Development of Patient Education Materials, available via cancercare.ns.ca

- Cancer Answers- a lecture series designed by *Cancer Care Nova Scotia*. Four lectures, each dedicated to a specific cancer-related topic, are held each year.
- Cancer Medication Patient Information Sheets –these resources address how to take medications, pre-cautions and side effects. Patients and HCP can search for medications by name or by cancer diagnosis on our website. Print copies are available via the CDHA print shop.
- Catalog of Patient Education Materials
- Guidelines for the Development of Patient Education Materials
- Living Well with Cancer patient information sheets covering a wide range of topics
- Patient Education Resource Approval Process, defined within the Guidelines for the Development of Patient Education Materials
- Navigating the System: A Guide for Patients, Families and Caregivers. This booklet answers some practical questions about the first appointment, staying in the hospital, what to expect during treatment, and additional services in the area. Two versions of the booklet are available - one for patients who will be receiving treatment at the Cape Breton Cancer Centre and another for those receiving treatment at the QEII.
- Nova Scotia Cancer Centre Radiation Therapy video

Resources provided by other organizations:

- Canadian Cancer Society website cancer.ca provides information for cancer patients, survivors, caregivers and health professionals, as well as linkages to support services for cancer patients and families.
- Canadian Cancer Society Cancer Information Service info@cis.cancer.ca or **1 888 939-3333** is a national, multi-lingual service available to cancer patients, their families, the general public and healthcare professionals. The service provides access to a Cancer Information Specialist who can answer questions and provide print resources, website cancer.ca
- Canadian Virtual Hospice provides information and support on palliative and end-of-life care, loss and grief, website virtualhospice.ca
- CancerCare, a national (USA) non-profit organization that provides information and support services to anyone affected by cancer; people with cancer; caregiver, children, loved ones and the bereaved, website: cancercares.org
- CancerQuest is a cancer education and outreach program at Emory University, providing reliable information about cancer biology and treatment, website: cancerquest.org. The videos and animations on this website are particularly helpful.
- Cultural Competence resources, Nova Scotia Department of Health and Wellness, website: gov.ns.ca
- National Cancer Institute's Physician Data Query (PDQ)/Patient Information File (PIF), website: cancer.gov. This site provides information related to: cancer treatment, clinical trials that are open for enrollment and the names of facilities connected with cancer care.

- Nova Scotia Cancer Centre Radiation Therapy video, available via cancercare.ns.ca
- Pink Rose Program is a system of information and guided support developed to aid the patient diagnosed with breast cancer. Available from the Nova Scotia Breast Screening Program, website: breastscreening.ns.ca
- “Provider-Patient Communication: A Report of Evidence-Based Recommendations To Guide Practice in Cancer”, available via the CCO website, cancercare.on.ca
- Reef Knot Kit an information kit, is available for all Nova Scotian men newly diagnosed with prostate cancer through their Urologist. The kit contains a welcome letter, “Prostate Cancer: A Booklet for Patients” and contact information for support groups in Nova Scotia.
- Smoking Cessation: Addictions Services, Nova Scotia Department of Health and Wellness, gov.ns.ca; Canadian Cancer Society Smokers Helpline 1-877-513-5333, cancer.ca

STANDARD 5. Documentation

The education process is documented in the person's health record and reflects its ongoing nature.

Rationale:

Documentation of the education process helps to ensure that identified information needs have been addressed and acts as a tool to monitor progress related to the teaching plan and ongoing learning needs.

Guidelines:

- Documentation follows institutional policies and procedures.
- Documentation should include the following:
 - The person's learning needs;
 - Prior knowledge, level of understanding and preferences for information;
 - Learning objectives;
 - Teaching plan and outcomes ^{1,2}
 - Person's choice not to learn/participate in learning process (if applicable);
 - Contact information for question or concerns.
- When transferring a patient to another DHA or to another discipline within your DHA, ensure information concerning the nature and status of patient's education process is communicated.

STANDARD 6. Quality/ Performance Improvement, Evaluation and Research

Each organization/facility providing cancer care has an integrated, ongoing and systematic process to ensure continuous improvement of patient education services.

Rationale:

Education provided to people affected by cancer is evidence-based, continuously improved and responsive to changing information needs.

Guidelines:

- Patient education services reflect the organizations quality/performance improvement initiatives. Results from relevant monitoring and improvement activities are used to revise patient education systems, processes and services^{17,33}
- The approach to quality/performance improvement considers “patient satisfaction, effectiveness of services and expected outcomes, and quality indicators”¹⁷.
- A system is in place to obtain feedback from people affected by cancer^{1,2,17,33}.
- A process is in place to evaluate and approve new education services/resources prior to implementation⁸.
- Education services/resources/materials are evaluated regularly using a variety of methods (e.g., focus groups, pre and post tests)^{17, 29,33}.
- Expected learning outcomes are measured as part of the evaluation process for education programs^{17,33}.
- Educational activities are evaluated by the people who participated^{17,33}.
- Education services/resources (e.g., pamphlets, OIES, group learning programs and individual structured learning programs) are modified based on results from the evaluation process^{17,33}.
- To determine a change in attitudes, understanding or behaviour a follow-up evaluation of participants may be appropriate^{17,33}.
- HCPs involved in providing education to people affected by cancer have access to and knowledge of current literature. Current literature/research is used to guide practice/interventions^{1,2,33}.
- Policies and procedures are in place to guide the provision of education to people affected by cancer^{17,33}.

Resources provided by CCNS via cancercare.ns.ca:

- Guidelines for the Development of Patient Education Materials
- Patient Education Resource Approval Process, defined within the Guidelines for the Development of Patient Education Materials

STANDARD 7. Health Care Provider Competency

Each HCP providing education to people affected by cancer has the necessary competencies for this role.

Rationale:

HCPs need to develop the knowledge, skills and judgment to provide beneficial education to people affected by cancer.

Guidelines:

- HCPs demonstrate competency related to the education of people affected by cancer consistent with professional standards³³
- HCPs demonstrate competency related to Standards 1 through 6 of this document, “Education Standards for People Affected by Cancer”
- HCPs involved in providing education to people affected by cancer have access to and knowledge of current literature and educational resources. Current literature/research is used to guide practice/interventions^{1,2,33}.
- Education sessions/opportunities are available that may benefit HCPs. These include but are not limited to:
 - Information needs of people affected by cancer(generally);
 - Collaborative patient-centred practice^{1,2,75}
 - Therapeutic Communication²⁹
 - Coping styles (blunter versus monitor)²⁹;
 - Principles of adult learning²⁹
 - Teaching strategies and available educational resources²⁹
 - Literacy level & health literacy²⁹
 - Cultural competence^{6,8,9,10,11,29,34}
 - Gender-based learning considerations²⁹
 - Institutional policies and procedures related to education (e.g., chemotherapy administration, consent, documentation)
 - Observation, modeling and coaching by competent, proficient or expert teachers⁷⁵.

Resources provided by CCNS via cancercare.ns.ca:

- Guidelines for the Development of Patient Education Materials
- Patient Education Fundamentals

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