



**Education Standards
for Adults Affected by Cancer**

Full Version

Acknowledgements

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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 rates¹¹. 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^{5,23,24}.

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 province's District Health Authorities (DHAs). 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 setting⁶⁵. 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) throughout Nova Scotia.

Several qualitative studies commissioned by CCNS 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^{15,16,17,18}. 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 satisfaction¹³. Building on this work, a needs assessment conducted for the NSCPEC affirmed that standards for the education of people affected by cancer were needed in DHAs across the province.

Scope and Purpose

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.

The scope and purpose of this document is to:

- Establish standards for HCPs to guide professional practice as it relates to the provision of information/education to adults affected by cancer.
- Establish standards of excellence that are applicable to all HCPs involved in the care of adults affected by cancer and/or organizations/facilities providing cancer care.
- Ensure that education is provided in a safe, competent and ethical manner to all adults affected by cancer.
- Establish standards which describe to the HCP and/or organization/facility providing cancer care approaches to help improve and maintain high quality education for adults affected by cancer.

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 CCNS website www.cancercare.ns.ca

A Review of the Literature

A literature search was undertaken to identify best practices in cancer patient education. The main research questions were, “What do people affected by cancer want/need to know?” and “How is this information best delivered?”

The literature search included several searches of PubMed with the most comprehensive search using the terms “Neoplasms”[majr] AND “Patient Education as Topic” [majr] AND limited to adults or aged, English only and published in the last two years (as a literature search had already been completed and summarized for articles preceding that date). This search strategy was also used to search the Cumulative Index to Nursing and Allied Health Literature (CINAHL®) and PsycInfo with the exception that the searches included articles published in the past 10 years. Guidelines and standards related to patient education both within oncology and non-oncology populations were also searched specifically under PubMed. In addition to searching these databases the Cochrane Collection of Systematic Reviews, Google and Google Scholar were used. The following additional sources of information were included: Oncology Nursing Society (ONS), Canadian Association of Nurses in Oncology (CANO), Canadian Council on Health Services Accreditation (CCHSA), National Institute for Clinical Excellence (NICE) through the government of the United Kingdom (UK) and the Australian government’s National

Health and Medical Research Council (NHMRC). A variety of relevant qualitative and quantitative research, practice standards and clinical practice guidelines were identified. Articles that focused on prevention, screening and early detection were excluded, as well as case studies, commentaries, opinion articles and studies with very small sample sizes (e.g.) less than 20. It was beyond the scope of this literature search to summarize, recommend or advise on the evidence related to specific educational tools or decision aids developed for specific patient populations. The PubMed, CINAHL®, PsycInfo searches were updated again in the fall of 2010 along with confirmation that the most recent version of other key references were used (e.g., Accreditation Canada Standards, ONS Standards).

The following summary is an update to the literature review completed by G. Spurrell in the fall of 2006 and will refer to conclusions and summaries from this document; A Framework for the Adoption of Cancer Patient Education Guidelines for Nova Scotia (noted as the previous literature search).

Information Needs

It seems well established that *most* people affected by cancer want as much information as possible about their illness^{3,26,27,29,46,47,68,93}. The specific types of information needed include: diagnosis, treatment, and goals of treatment, side effects and quality of life^{3,58,72}. In a study comparing people with gynaecological, breast and colorectal cancers, the top three priority items for all groups were: likelihood of cure, spread of disease and treatment options⁷. This is not to say that all people want or benefit from receiving the greatest amount of information that various

healthcare providers (HCPs) could supply^{46,47}. This has been described in relation to a person's coping style and the use of either a blunting style (minimizing threatening information) or an information seeking style (monitoring)^{26,33,58}. Information seeking behaviours may change over time; generally, a more active style is more common in the pre-treatment phase³³. An active seeking style was associated with a higher level of education and younger age, however passive information seeking was observed across all age groups.

Chelf, et al.'s literature review discusses the correlation of information satisfaction with a person's preferred decision making role. Patients most satisfied with the information they have received, generally want less information and prefer a passive role in decision making²⁷. Reflecting the Nova Scotia experience, a study by Snow et al., highlighted the inconsistent and incomplete information 270 men with early-stage prostate cancer recalled about treatment choices⁸². This was a retrospective study which asked men to indicate which types of information would be important to anyone with early stage prostate cancer making treatment decisions and which types of information they knew well. Statistically significant differences (*P* value less than or equal to 0.0001) were found in all 6 information categories: Treatment choices; surgery treatment details; radiation treatment details; surgery risks and benefits; radiation risks and benefits and personal considerations. Another Canadian study compared information preferences between similar groups of individuals with early-stage prostate cancer and found that the specific types of information needed for decision-making was not common within groups³⁵. No specific type of information was required

by over 50% of the members of either group and demographics were not able to predict which person would want certain types of information, supporting the need for HCPs to work with the individual affected by cancer to determine his/her specific needs.

Information needs are present throughout the cancer continuum, therefore individuals require ongoing assessment of their information needs^{27,33}. The previous literature search identified information needs in the post-treatment phase related to: post-treatment options, long-term side effects, rehabilitation, self-care/home care, follow-up care, the impact of illness on the family and sexuality^{34,36,56}.

In a recent study by Mayer, et al., information from the 2003 Health Information National Trends Survey in the United States showed that almost 68% of cancer survivors had personally sought cancer information⁵⁸. The mean time since diagnosis for this group was 10.5 years. Four variables were found to be predictive of information seeking behaviours: less than 65 years of age; female; income greater than US \$25,000 /year and having a regular HCP. A study of UK patients and caregivers found a smaller proportion of patients (4.8%) versus caregivers (48%) sought information from the internet^{44,45}. The percentage of patients who used information obtained from the internet was much higher, almost 50%, as they had been supplied the information by a family member.

In a longitudinal study of 135 women with breast cancer, all specific information needs except for one changed over time. Participants rated the importance of various types of information at baseline, 3 months and 6 months later. The importance of

information related to medical tests and exams did not change significantly between measurement points. Statistically significant changes were found with the importance of aftercare information, with the highest rating at 6 months, followed by baseline and then 3 months⁸⁶.

A meta-analysis of 12 studies showed that the younger the adult is with cancer the greater was their information need⁵. A more active role in decision making was associated with higher information needs. Both stage of illness and time since diagnosis were found not to affect information need; that is, the amount of information needed seems to be constant throughout the cancer trajectory. Results from an on-line survey of young adult cancer survivors found unmet information needs related to: age-appropriate web-based cancer resources, nutrition, exercise and infertility⁹¹.

Satisfaction with and Completeness of Information

Findings from the previous literature search indicated patients are very satisfied with care when they receive timely, appropriate and adequate information^{9,24,31,36,38,44,48,54,56,61,70,90}. The ability of the patient to recall the information provided however, is less than optimal^{84,88}. Patients appear to immediately forget between 40-80% of the medical information provided by their HCPs⁸⁴.

An audit of 394 cancer patients in the United Kingdom by Cox et al. highlights areas for improvement in information provision²⁹. This was a retrospective study, based on patients recalling a discussion with a HCP about various topics. Results indicated that all patients could recall receiving information about tests, diagnosis

and treatment. In contrast, less than half of the patients could recall receiving information related to: clinical trials; family history; sexual well-being or social well-being. Only 58% recalled receiving information related to emotional well-being. A large cross-sectional survey from France found that information related to treatment-induced infertility was not recalled by 30% of women and 13% of men with self-reported treatment-induced infertility⁵⁷. Similar gaps in information provision were found for people with head and neck cancer⁵⁵. Many people in this study had not recalled information related to support groups, financial assistance and long term effects of treatment. This was a longitudinal study and it was observed that for many of these patients their information needs continued unmet at least one month after the end of treatment. In a retrospective study of 20 breast cancer survivors, less than half could recall receiving any information on what to expect after treatment²³. Similarly, of 231 breast cancer survivors, surveyed at least 3 months after completion of therapy; only 30% were highly satisfied with survivorship information³⁹. Results of a satisfaction survey amongst radiation oncology patients in Australia found that the majority of patients were satisfied with the information they received about their illness and radiation but less were satisfied with information related to lifestyle and practical issues such as parking and treatment cost⁹³. When studying the practical needs of rural families in Australia, Wilkes et al. found that the greatest unmet practical need was for comprehensive information before travelling to an urban treatment centre⁸⁹. Through questionnaires and focus groups, 111 patients and 67 family members were surveyed about information they needed

and had recalled. Only a minority (less than 50%) of patients and family members received information (which was judged inadequate by those who did receive it) about particular assistance programs, clothing needs, travel choice and the potential disruption to domestic arrangement⁸⁹.

Family

Family members coping with the cancer experience of a loved one may have greater informational needs than the person with cancer⁴. Spouses of patients with breast cancer look to the patient for information and are hesitant to ask the doctor for information, they want to know how to meet their partners care needs and communicate with them about their illness²⁷. Caregivers were found in one qualitative study to more likely be information seekers and continuously sought new information to help cope with their cancer experience⁴⁵.

Provision of Information

Consistent with the previous literature search findings, the most preferred method of receiving information is through a discussion with their doctor^{27,45}. In some studies, the term HCP was used rather than identifying particular providers; HCPs were then identified as the most preferred source of information⁵⁸.

Similarly, the previous literature search identified print material as the second most preferred source of information and written materials continue to be provided frequently and are generally found to be satisfactory^{42,45,80}. The provision of written information during teaching can supplement and reinforce information, increase knowledge and retention, increase satisfaction and decrease distress^{27,88}. The use of pictographs or pictures closely

related to the text may further improve recall and help overcome low literacy levels⁸⁸.

The internet has been shown to be a trusted and useful source of information for both patients and family/caregivers^{45,58}. It is important to note that both of these studies found that people affected by cancer would prefer their doctor/HCP to provide information related to the internet, such as trustworthy websites. Benefits of internet use for health-related education (not specific to cancer care) were identified by the previous literature search and include: tool for information seeking; means to enhance information offered by the HCP; provides access to resources depleted in the doctor's office; allows rapid update of information; allows information seeking to occur at the individual's preferred time and pace; and, as a communication tool between peers^{8,44,48,60,64,71,77,81,92}.

Other forms of information delivery such as computer-assisted learning (e.g., computer games, decision aids) telephones and audiotapes have been shown to be effective in a variety of patient groups^{27,49}.

The use of decision aids was reviewed through the Cochrane Database of Systematic Reviews and found to help people take an active and informed role in decision making related to values-based treatment or screening decisions^{33,67}. Noted findings include: improvement in knowledge of options, realistic expectations of benefits and risks, decreased difficulty with decision making and increased involvement in decision-making. Effects on satisfaction with decision making or anxiety were not found.

The use of audio-recordings of consultations for people with cancer has

been the focus of many RCTs and recent systematic reviews. All three systematic reviews found that there was evidence that providing the person with an audio-recording of his/her medical consultation improved recall^{73,84,88}. Pitkethly, MacGillivray & Ryan concluded that recordings or written summaries may benefit most adults with cancer and that practitioners should consider providing these⁷³. Recordings or summaries are used as a personal reminder and as a tool to inform family, friends and their family doctor^{40,73,83}. Anxiety or depression were not increased and quality of life was not affected by the use of recordings or summaries^{73,84}. Studies show that the patients found the audio-recording helpful even if they did not actually listen to the audio-recording post consultation^{40,83}.

Interventions pre-consult to help people address their information needs such as question prompt sheets or coaching have also been studied. The results of a meta-analysis of 33 randomized controlled clinical trials by the Cochrane Database of Systematic Reviews found small and statistically significant increases in question asking and satisfaction from interventions immediately prior to the consult⁵³. Upon further analysis coaching produced a smaller increase in consultation time and a larger increase in satisfaction. The authors concluded that these interventions were of limited benefit to patients. Dimoska, et al., conducted a review of the literature on question prompt lists, specifically by people with cancer³². This review included a total of 15 studies (controlled and noncontrolled). Findings were equally inconsistent on various outcome measures, such as number of questions asked, anxiety or for facilitating communication. The key finding

of the review was that all studies found either a significant effect or trend in favour of the person asking a question related to prognosis. Two additional systematic reviews (inclusive of only RCTs, randomized trials or controlled clinical trials) found limited evidence of the value of question prompt sheets and only when the doctor actively reviewed the sheet with the patients was recall improved^{84,88}. This was based on one RCT judged to be of high quality.

Summary

In summary, *most* people affected by cancer want as much information as possible about their illness. The detail and timing of particular information is best individualized for each person. Patients and families have a variety of information needs throughout the cancer continuum. Many studies have identified top priorities as related to diagnosis, treatment and prognosis however, it has also been well documented that supplying people with only this information is not adequate and the exact detail related to each category of information varies with each person affected by cancer. Psychosocial concerns and/or long term physical effects of their disease and treatment may be overlooked by HCPs.

Using an individualized approach to information provision, which is sensitive to a person's coping style and validates that the person has understood the important points of the discussion and has no further concerns can help ensure information needs are met. HCPs should continue to supply appropriately written materials to support the education process, including audio-recordings or summary letters if available. HCPs could further assist individuals and family members by

recommending internet websites should they wish to seek out additional information.

Specific to the Nova Scotia experience, further considerations are drawn from the recommendations detailed in qualitative studies commissioned by *Cancer Care Nova Scotia (CCNS)*.

Results from the 2007 Ambulatory Oncology Patient Satisfaction Survey identified the following gaps in information as top priorities; meaning improvements in these areas would have the greatest impact on overall patient satisfaction:

- Information related to emotional changes
- Changes in work/activities
- Information related to nutritional needs
- Information related to energy changes
- Information related to changes in sexual activity
- Discussion of cancer treatments¹³

Results from three studies: *Navigating the Cancer Care System African Nova Scotians' Experience*¹⁶; *Our Journey: First Nations Experience in Navigating Cancer Care*¹⁷; and *Immigrant Needs Assessment*¹⁵

identified several concerns related to information needs of diverse communities. The following summarizes key findings/recommendations related to education for people affected by cancer from those communities:

- Culturally specific materials are needed;
- HCPs need to be culturally sensitive;
- Value for existing community based resources and indigenous health practices;
- Information provided needs to address psychosocial concerns;
- Language barriers and mistrust of professional interpreters was a concern for people of immigrant communities;
- Videos from a First Nation perspective are needed to supplement written material and offer support to people of First Nations.

Encouragingly, many people are satisfied with the information they have received from their HCP and this can likely be improved with a more comprehensive and culturally sensitive approach to education to help ensure that all information needs are addressed.

STANDARD 1. Collaborative Person-Centred Practice

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.

The literature review identified a range of educational needs related to diagnosis, treatment, side-effects and quality of life⁵⁸. A variety of information gaps were identified in several studies such as survivorship information and practical issues (e.g., parking, travel information, financial information and support groups)^{39,55,89,93}. The knowledge and expertise required to meet these informational needs involves a variety of HCPs. This is echoed in the recommendations from the Patient Navigation Qualitative Study commissioned by CCNS in 2000 which called for a multi-disciplinary approach to cancer care service that would attend to the medical, emotional and financial concerns of the person affected by cancer¹⁸. In particular, the family doctor was recognized as a key participant throughout the cancer continuum. The literature review also found that the specific information needs of individuals affected by cancer varies considerably and that HCPs should identify with each person's unique information needs^{26,27,35,46,47}.

Guidelines:

An interprofessional team delivers cancer care and oncology services:

- 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}.

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 educational needs.

The way that information is delivered affects the person's ability to understand and utilize the information (eg., to make decisions and manage self-care)⁸⁴. Using an individualized approach to information provision, with clear and specific language, which is sensitive to a person's coping style and validates that the person has understood the important points of the discussion and has no further concerns can help ensure information needs are met^{47,49,76,84,88}. One particular method of information provision has not been recommended over another, a combination of approaches is likely to be most effective, particularly within the context of a systematic education plan^{20,21,49}. Effective communication skills (e.g., active listening, establishing a rapport) provide the foundation for this interaction, but are not the focus of these standards and guidelines.

Barriers to quality health-care and cancer care specifically, include but are not limited to: Language and literacy (e.g., lack of fluency in English or French, low literacy level); geography (e.g., access to resources is limited by local availability); and culture (e.g., HCPs level of cultural competence when working with members of diverse communities) (Cancer Journey Action Group Canadian Partnership Against Cancer^{20,21}. The teaching-learning process may be directly affected by these barriers through misunderstandings and miscommunication of cancer related information⁵². Commonly used medical terms (e.g., impotent, erection) were understood by less than 50% of survey participants from an underserved population in the U.S.⁵². This was statistically significantly associated with literacy level.

To overcome language barriers, professional interpreters or same language encounters are recommended^{20,21}. Recognizing that there is diversity within groups it is important for HCPs to use a person-centred approach throughout the teaching-learning process and not make assumptions based on the person's cultural background (e.g., role of family, personal beliefs around health and illness, preferences for information)^{3,20,21,72}.

The ability of the person affected by cancer to recall the information provided by the HCP is less than optimal^{84,88}. Patients appear to immediately forget between 40-80% of the medical information provided by their HCPs^{84,88}. The use of audio-recordings of consultations for people with cancer has been the focus of many RCTs and recent systematic reviews. All three systematic reviews found that there was evidence that providing the person with an audio-recording of his/her medical consultation improved recall^{73,84,88}. Pitkethly et al. concluded that recordings or written summaries may benefit

most adults with cancer and that practitioners should consider providing these⁷³. Recordings or summaries are used as a personal reminder and as a tool to inform family, friends and their family doctor^{40,73,83}. Anxiety or depression were not increased and quality of life was not affected^{73,84}.

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^{1,2,27,33,34,36,56,76}.
- People affected by cancer may be offered a summary of the consultation (letter or audio-recording), as permitted by the policies institution^{40,73,76,83,84,88}.
- The Health Care Professional:
 - Assists the person to identify their learning needs; considering prior knowledge, level of understanding and preferences for information^{1,2,35,76}.
 - 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^{1,2,12,21,49,69}.
 - Respects a person's choice not to learn^{1,2}.
 - Encourages the presence of a support person; recognizing that this is a personal preference^{72,76}.
 - Establishes an effective learning environment, where the person affected by cancer feels safe and comfortable expressing themselves and is ready to learn⁶⁹.
 - 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 objectives 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^{49,69}.

- Obtains feedback from the person to assess understanding and to evaluate the learning experience^{49,69,76}.
- Modifies the education plan if needed based on the outcome/evaluation⁶⁹.

Resources provided by CCNS:

- Patient Education Fundamentals, available via cancercare.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.

Most people with cancer want as much information as possible about their illness^{3,26,27,29,46,47,68,72,93}. Examples of the types of information needed include: diagnosis, treatment, and goals of treatment, side effects, quality of life^{3,58,72}. People affected by cancer often have unmet information needs related to psychosocial concerns (e.g., information about support groups, finances, effects on body-image/sexuality concerns) and long term physical effects from treatment^{23,29,55}.

Individuals may have additional areas of concern and want either more or less detail on particular topics based on their coping style and particular situation. Young adults with cancer may have specific informational needs related to age-appropriate resources (e.g., websites and support programs)⁹¹. Many cancer survivors who currently smoke may benefit from smoking cessation advice or information related to smoking cessation²⁸. A survey of people diagnosed with cancer at least one year ago found that two-thirds wanted to quit smoking and 40% had tried to quit²⁸.

Results from the 2007 CCNS Ambulatory Oncology Patient Satisfaction Survey identified the following gaps in information as top priorities¹³:

- Information related to emotional changes
 - Changes in work/activities
 - Information related to nutritional needs
 - Information related to energy changes
 - Information related to changes in sexual activity
 - Discussion of cancer treatments
-

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^{1,2,12,21,91}.
- 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^{1,29,35,69}.
- Timely, complete and accurate information is provided related to:
 - Cancer prevention and screening^{22,69}

- Diagnosis and prognosis ^{1,2,22,69}
- Treatment plan and alternatives to treatment ^{1,2,13,22,69}
- Tests: reason for and results from ^{13,86}
- Preparation for medical procedures ^{1,2,76}
- Evaluating the credibility of information/cancer therapies ^{69,85}
- Evidence, research, and best practice ^{1,2}
- Resolving issues/concerns, decision-making, and self-management ^{1,2, 69}
- Healthy lifestyle and cancer prevention strategies ^{28,69,91}
- Management of potential physical symptoms, pain and psychosocial responses (e.g. anger, fear, uncertainty, body image and/or sexuality concerns) to cancer and/or its treatment ^{1,2,13,22}
- Nutrition ^{1,2,13,43,91}
- Complimentary and Alternative Medicine ^{85,91}
- Financial supports and practical issues (e.g., accommodation, parking, orientation to cancer centre, system navigation) ^{89,91,93}
- Recovery, rehabilitation, return to work, follow-up and survivorship ^{13,22,69}
- Support for families and caregivers ^{1,2,10}
- Palliative care, end of life care and bereavement ^{1,2,10,13,22}
- Patient rights and responsibilities including their role in patient safety ^{1,2,22}
- Resources and services available both within the healthcare setting(e.g., counseling/support, occupational therapy and/or physiotherapy) and the community, including recommended websites ^{1,2,22,44,45, 69,58,91}
- Information is provided according to institutional policies and procedures (e.g., chemotherapy administration, consent, blood/blood product administration) ^{25,63}.

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 NSCPEC.¹

Rationale:

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

It seems well established that *most* people affected by cancer want as much information as possible about their illness^{3,26,27,29,47,68,72,93}. The most preferred method of receiving information is through a discussion with the person's doctor/HCP^{27,49,50}. Secondary to a discussion with their doctor, printed materials seem to be the next most valuable source of this information. The provision of written information during teaching can supplement and reinforce information, increase knowledge and retention, increase satisfaction and decrease distress²⁷. The use of pictographs or pictures closely related to the text may further improve recall and help overcome low literacy levels⁸⁸. The internet has also been shown to be a trusted and useful source of information for both patients and family/carers^{44,45,58}. It is important to note that both of these studies found that people affected by cancer would prefer their doctor/HCP to provide information related to the internet, such as trustworthy websites. Other forms of information delivery such as computer-assisted learning (e.g., computer games, decision aids), telephones and audiotapes have been shown to be effective in a variety of patient groups^{27,49,50}.

According to the principles of adult learning, adults are generally self-directed learners⁵¹. Environments that assist learners to identify and access appropriate resources enable this self-directed approach.

Results from three CCNS studies: Navigating the Cancer Care System African Nova Scotians' Experience¹⁶; Our Journey: First Nations Experience in Navigating Cancer Care¹⁷; and Immigrant Needs Assessment¹⁵, identified several concerns related to the information needs of diverse communities. The following summarizes key findings/recommendations related to education for people affected by cancer from those communities:

- Culturally specific materials are needed;
- HCPs need to be culturally sensitive;
- Value for existing community based resources and indigenous health practices;
- Information provided needs to address psychosocial concerns;
- Language barriers and mistrust of professional interpreters was a concern for people of immigrant communities;

¹ Refer to the Patient Education Resource Approval Process, defined within the Guidelines for the Development of Patient Education Materials, available via cancercares.ns.ca

- Videos from a First Nation perspective are needed to supplement written material and offer support to people of First Nations
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Guidelines:

- An effective learning environment is maintained where the person affected by cancer feels safe and comfortable expressing themselves and is ready to learn.
63,69
- Make every effort to provide sufficient, private, and comfortable space to accommodate individual or group education services²⁵
- Facilities and resources are available to support self-directed learning (e.g., access to computers and training)²⁵
- Make every effort to provide access to audiovisual support (e.g., printing and graphic support and audiovisual equipment)^{25,63}.
- 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.
1,2,15,16,17,20,21,50,66,69,91
- Additional personnel resources are available to support learning (e.g., interpreters, librarians)^{20,21,66,69,87}.

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.
- 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 – outline medications a NS cancer patient may experience during their cancer journey, 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 HCPs, 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, toll-free 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, provide print resources and connect people to support services in their community, website cancer.ca.
- Canadian Virtual Hospice provides information and support on palliative and end-of-life care, loss and grief, via virtualhospice.ca
- Cancer Care Ontario's guideline "Provider-Patient Communication: A Report of Evidence-Based Recommendations To Guide Practice in Cancer", available via the CCO website, cancercare.on.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: cancercare.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 resources.
- Cultural Competence resources, Nova Scotia Department of Health and Wellness, available via gov.ns.ca
- Cancer Institute's Physician Data Query (PDQ)/Patient Information File (PIF), website: cancer.gov. This site provides HCPs, people affected by cancer and the public with 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.

In addition to meeting institutional policies for documentation, recording what information has been provided to individuals allows others to reinforce the information and fill in gaps. Cancer education is provided by members of an interprofessional team working in the context of a collaborative patient-centred practice as described in Standard 1; Collaborative Patient-Centred Practice. Australian medical guidelines stress the importance of documentation as a means to provide continuity of communication, a necessary component of continuity of care⁶.

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 in place 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 for Establishing Comprehensive Cancer Patient Education Services were developed by The National Cancer Institute's (NCI), Cancer Patient Education Network (CPEN) to act as a model for the delivery, management and quality of cancer patient education services⁶³. The guidelines were originally developed in 1993 and last updated in 2002. These guidelines were adopted with some revisions by Cancer Care Ontario's Patient Education Committee in 2006²⁵. Revisions were made to reflect the Ontario context, professional experience and consensus. The guidelines advise that a Patient Education Program be created within the Regional Cancer Centre/Program to be accountable for patient education services. Quality/Performance Improvement, Evaluation and Research are one of nine components of the program. The following criteria have been adapted from the CCO and NCI CPEN documents to provide direction to each organization/facility providing cancer care and oncology services within Nova Scotia.

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^{25,63}
- The approach to quality/performance improvement considers “patient satisfaction, effectiveness of services and expected outcomes, and quality indicators”²⁵.
- A system is in place to obtain feedback from people affected by cancer^{1,2,25,63}.
- A process is in place to evaluate and approve new education services/resources prior to implementation¹⁴.
- Education services/resources/materials are evaluated regularly using a variety of methods (e.g., focus groups, pre and post tests)^{25, 49,63}.
- Expected learning outcomes are measured as part of the evaluation process for education programs^{25,63}.
- Educational activities are evaluated by the people who participated^{25,63}.

- Education services/resources (e.g., pamphlets, OIES, group learning programs and individual structured learning programs) are modified based on results from the evaluation process ^{25,63}.
- To determine a change in attitudes, understanding or behaviour a follow-up evaluation of participants may be appropriate ^{25,63}.
- 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 ^{1,2,63}.
- Policies and procedures are in place to guide the provision of education to people affected by cancer ^{25,63}.

Resources provided by CCNS via cancercares.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.

The development of knowledge, skills and judgment related to patient education and the maintenance of currency with these knowledge and skills is a shared responsibility between the organization/facility providing cancer care and the HCP. It is an expectation that HCPs are “educated, trained, qualified and competent” for their roles and responsibilities^{1,2}. Further to this, the team checks that the ongoing learning and development needs of the interprofessional team are met. It is also suggested that an interprofessional approach to education may help develop collaboration amongst various team members^{1,2}.

The need for HCPs to receive education about cultural competence, cancer care and the cancer care system was identified through the following CCNS reports: Our Journey: First Nations Experience in Navigating Cancer Care; Immigrant Needs Assessment; and Navigating the Cancer Care System - African Nova Scotians' Experience^{15,16,17}. HCPs need to tailor information to the person's unique situation (e.g., cultural background, coping style and preferences for information) for education to be most effective^{20,21,59}. In one systematic review of information provision and decision-making in people with advanced cancer, misunderstandings were repeatedly found regarding the stage of disease, prognosis and/or goals of treatment³⁷.

Within the Cochrane Database of Systematic Reviews, a systematic review by Moore, et al. found evidence to suggest that specific types of communication skills training were effective for the specific HCPs studied; however, the generalized use of these programs with other instructors and participants may not have the same benefit to HCP communication⁶².

Guidelines:

- HCPs demonstrate competency related to the education of people affected by cancer consistent with professional standards⁶³
- 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^{1,2,63}.

- 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 Communication ⁴⁹
 - Coping styles (blunter versus monitor) ⁴⁹;
 - Principles of adult learning⁴⁹
 - Teaching strategies and available educational resources⁴⁹
 - Literacy level & health literacy⁴⁹
 - Cultural competence ^{12,14,15,16,17,49,65}
 - Gender-based learning considerations⁴⁹
 - Institutional policies and procedures related to education (e.g., chemotherapy administration, consent, documentation)
 - Observation, modeling and coaching by competent, proficient or expert teachers ⁷⁵.

Resources provided by CCNS via cancercare.ns.ca:

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

Appendix 1 Guideline Development Process

These standards were written following a review of accreditation standards, oncology specific practice standards, education guidelines, clinical practice guidelines and qualitative and quantitative research related to cancer patient education. A writer was contracted by CCNS to write a first draft of standards with review by Members of the Standards sub-committee of the Nova Scotia Cancer Patient Education Committee. The standards sub-committee members included representatives from Nursing, the Diverse Communities Cancer Coordinator, the Cancer Patient Family Network Coordinator and the Provincial Manager Education and Patient Navigation. Twice during the development process the standards were reviewed for critical appraisal by the full NSCPEC with representatives from patient and family members and the disciplines of: Medicine, Nursing, Nutrition, Pharmacy and Social Work and supported by A. Murray, Provincial Manager Education and Patient Navigation. Specific recommendations were based upon existing standards of practice and evidence reviewed by the writer and by consensus development among the standards sub-committee and the NSCPEC.

Specifically, the following standards, guidelines and CCNS documents informed the development of these standards:

- Accreditation Canada. Qmentum Program Standards: Cancer Care and Oncology Services¹.

- Accreditation Canada. Qmentum Program Standards: Cancer Populations²
- Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer⁶
- Cultural Competence Assessment Tool for Provincial Program Clinical Guidelines⁶⁶
- Effective Teaching Strategies and Methods for Patient Education²⁵
- Establishing Comprehensive Cancer Patient Education Services - A Framework to Guide Ontario Cancer Education Services²⁵.
- Guidelines for Establishing Comprehensive Cancer Patient Education Services⁶³.
- Patient Navigation Study¹⁸.
- Practice Standards and Competencies for the Specialized Oncology Nurse²².
- Provider-Patient Communication: A Report of Evidence-Based Recommendations to Guide Practice in Cancer²⁵.
- Navigating the Cancer Care System: African Nova Scotians' Experience¹⁶.
- Our Journey: First Nations Experience in Navigating Cancer Care¹⁷.
- Standards of Oncology Education: Patient/Significant Other and Public⁶⁹.
- The 2007 Ambulatory Oncology Patient Satisfaction Survey¹³.

These standards were written for HCPs in all relevant disciplines and administrators that manage the resources and make decisions affecting the ability of HCPs to meet these standards.

Once the draft document was approved by the NSCPEC, it was distributed to a group of community reviewers from health care districts in Nova Scotia, New Brunswick, Newfoundland, and Prince Edward Island. Responses to the draft review were collected on a standard guideline review questionnaire.

The standards were revised based on feedback from reviewers, an updated review of the literature and were returned to the standards sub-committee and NSCPEC for final review and approval.

The approved standards are published in both a Full Version and a Quick Reference Version available for download from the CCNS website (www.cancercare.ns.ca). The Quick

Reference Version will be circulated to DHAs and HCPs as part of the implementation process. Hard copies of the Full or Quick Reference version may be requested by contacting *Cancer Care Nova Scotia (CCNS)* at 1-866-599-2267 or download from the CCNS website (www.cancercare.ns.ca).

The development of these standards was funded indirectly by CCNS via a stipend for the standard writer. CCNS staff also supported the standards development process. CCNS directly funded the design, printing and dissemination of the standards survey as well as the approved standards. The views and interests of CCNS have not influenced the Standards Writing Team's recommendations in the standards or guidelines.

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