

Canadian Partnership for Quality Radiotherapy
Patient Education Guidance for Canadian Radiation Treatment Programs

Guidance on behalf of:

Canadian Association of Radiation Oncology

Canadian Organization of Medical Physicists

Canadian Association of Medical Radiation Technologists

Canadian Partnership Against Cancer

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Canadian Partnership for
Quality Radiotherapy

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Preface

Approximately 50% of all incident cases of cancer require radiation treatment at some point during the management of the disease (Delaney et al., 2005). In Canada, it is estimated there were approximately 220,400 new cases of cancer in 2019 (Canadian Cancer Society, 2019) and around 103,551 courses of radiation treatment were administered in 2017 (data from the Canadian Association of Radiation Oncology (CARO) biannual human resource survey of Canadian radiation oncology programs). There are currently 48 radiation treatment facilities in Canada.

The Canadian Partnership for Quality Radiotherapy (CPQR) is an alliance amongst the three key national professional organizations involved in the delivery of radiation treatment in Canada: CARO, the Canadian Organization of Medical Physicists (COMP), and the Canadian Association of Medical Radiation Technologists (CAMRT), together with financial and strategic backing from the Canadian Partnership Against Cancer (CPAC), which works with Canada's cancer community to reduce the burden of cancer on Canadians. The vision and mandate of the CPQR is to support the universal availability of high quality and safe radiotherapy for all Canadians through system performance improvement and the development of consensus-based guidelines and indicators to aid in radiation treatment program development and evaluation.

This document provides guidance for radiation treatment programs on how they can incorporate patient education techniques, tools and resources into their programs to ensure that patients and family members are adequately and appropriately educated in their care. The statements included are intended to be tools that, if implemented, will provide regional centres with a sense of the degree of accountability and success with which they are approaching patient education.

The *Patient Education Guidance for Canadian Radiation Treatment Programs* document compliments, and should be considered in conjunction with, the CPQR's *Patient Engagement Guidelines for Canadian Radiation Treatment Programs* (PEG), a set of guidelines advocating for patient engagement at the patient care, programs, and systems levels. The document is one in a suite of guideline documents created by the CPQR that include:

- *Quality Assurance Guidelines for Canadian Radiation Treatment Programs*, which outlines the overarching elements of quality that are important in all radiation treatment programs, together with key quality indicators (KQI)s for periodic programmatic self-assessment and quality improvement.
- The suite of *Technical Quality Control Guidelines for Canadian Radiation Treatment Programs*, which outlines key elements of radiation treatment technology quality control;
- *National System for Incident Reporting – Radiation Treatment Minimum Data Set*, which provides guidance for reporting radiation treatment incidents nationally and helps users navigate the National System for Incident Reporting – Radiation Treatment (NSIR-RT) database managed by the Canadian Institute of Health Information;

Patient Education Guidance for Canadian Radiation Treatment Programs

- *Patient Engagement Guidance for Canadian Radiation Treatment Programs*, which outlines overarching elements of quality that are important to ensure that patients and family members are engaged in the care process and satisfied with both the process and outcomes of care;
- *Patient Education Guidance for Canadian Radiation Treatment Programs*, which provide guidance on activities radiation treatment programs can incorporate to ensure that patients and family members are adequately and appropriately educated in their care;
- *Guidance on the collection and use of Patient Reported Outcomes in Canadian radiation treatment programs*, which provides guidance for radiation treatment programs on how they can enhance and optimize the collection and use of patient reported outcomes (PROs) in routine clinical practice; and
- *Guidance on the use of common nomenclature and data sets in Canadian radiation treatment programs*, which supports the use of common nomenclature and a minimum data set of clinical, dosimetric and PRO data elements to be recorded across radiation treatment programs. The aim is to harmonize community practice and improve quality performance and patient outcomes.

When considered together, these documents address all aspects of quality and safety related to radiation treatment delivery. All CPQR documents are considered living documents and are reviewed and revised at regular intervals by the CPQR to maintain relevance in the Canadian radiation treatment environment.

Ownership of the CPQR documents resides jointly with the national professional organizations involved in the delivery of radiation treatment in Canada – CARO, COMP, CAMRT and CPAC. All documents can be accessed online at www.cpqr.ca.

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Abbreviations and Definitions

Abbreviations	
CAMRT	Canadian Association of Medical Radiation Technologists
CARO	Canadian Association of Radiation Oncology
COMP	Canadian Organization of Medical Physicists
CPAC	Canadian Partnership Against Cancer
CPQR	Canadian Partnership for Quality Radiotherapy
CT	Computed Tomography
PED	Patient Education Guidance for Canadian Radiation Treatment Programs
PEG	Patient Engagement Guidelines for Canadian Radiation Treatment Programs
SBRT	Stereotactic body radiotherapy
Definitions	
Cancer Program	The interprofessional cancer program that encompasses the radiation treatment program
Organization	The hospital, cancer centre, or institution in which the radiation treatment program resides
Radiation Treatment Program	The personnel, equipment, information systems, policies and procedures, and activities required for the safe delivery of radiation treatment according to evidence-based and/or best practice guidelines
Resources	Educational resources such as written materials, online materials or educational classes
Disease site	The anatomical location of a patient's cancer
Health literacy universal precautions	Health literacy universal precautions are the steps that programs take when they assume that all patients may have difficulty comprehending health information and access health services. These precautions are aimed at simplifying communication with and confirming comprehension for all patients, making the system easier to navigate and supporting patients' efforts to improve their health.

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Introduction

Patient education is defined comprehensively by CPAC (2009) as a series of organized, structured educational opportunities, enhancing the relationship between the patient and their health care provider, that actively and consciously improve the health knowledge, behaviour, and outcomes of the cancer patient. Given that the quality and quantity of patient education varies widely in cancer care, and there is an increasing, widespread desire by patients to be more actively engaged and informed about their disease, their treatment options, and their prognosis, it can be a challenge for health care providers to know what materials to provide a patient and at what point in their care journey (Purificacion 2016, CPAC 2009, Gaston 2005, Stacey 2008). This patient education guidance document was created to enhance and bring consistency to the quality and delivery of patient education across radiation treatment programs in Canada.

Patient Education and its Role in the Quality Experience

Radiation oncology is a highly specialized, rapidly developing specialty with increasing demands and complexity, and to date, quality improvement has been largely focused on technical and treatment approaches (Purificacion et al., 2016, Albert & Das, 2012, Torras et al., 2017, Stacey et al., 2008, Woodhouse et al., 2017). However, with the progressive technological advancements, there is more discussion among health care providers, patients and their families around the quality and safety of radiotherapy both pertaining to planning and delivery, as well as the patient and health care provider relationship (Purificacion et al., 2016, Albert & Das, 2012, Torras et al., 2017, Bogusz-Czerniewicz & Kaźmierczak, 2012). This places an increased importance on the interdisciplinary nature of care and on the role that interprofessional health care providers may play in patient engagement and education (Bogusz-Czerniewicz & Kaźmierczak, 2012, Stacey et al., 2008).

Both patient engagement and education are key indicators of a quality radiation treatment program and are addressed in both CPQR's *Quality Assurance Guidelines for Canadian Radiation Treatment Programs* (QRT) document and Accreditation Canada's standards on cancer care. In radiotherapy, quality indicators are broad and continually developing. Traditionally, indicators have consisted of clinical, operational, technical, and administrative aspects. The increasing emphasis on patient-centered care has resulted in more focus on the patient voice and role in the continuous quality assessment process (Cionini et al., 2007, Albert & Das, 2012, Torras et al., 2017, Bogusz-Czerniewicz & Kaźmierczak, 2012).

Patient engagement is an effective approach to meeting clinical patient-centered quality indicators (Purificacion et al., 2016, Woodhouse et al., 2017). Studies indicate that patient engagement and education varies widely across radiation treatment programs and the country and until recently, there existed insufficient commitment and leadership at a systems level (CPAC, 2009, Purificacion et al., 2016 Stacey et al., 2008). Recently, there has been a culture shift and an increase in awareness around the value of patient engagement. Meaningful education programs are being launched, and quality educational resources are being developed. As this work evolves, it is important to ensure resources available to patients reflect best practice around health literacy, plain language and universal precautions while meeting the functional needs

of patients. This encourages patient autonomy in cancer care and improves patient-physician trust and communication (Brega et al., 2015, Purificacion et al., 2016, Haywood et al., 2005, Gaston & Mitchell, 2005). Incorporation of disease-site and treatment specific patient education through an interdisciplinary approach at all levels of care – patient, program, and systems – will facilitate patient-provider communication (Woodhouse et al., 2017). As is the case in other areas of health care, it is acknowledged that radiation treatment programs face barriers to appropriately educate patients in practice, such as time constraints, workload pressures, health care provider awareness, and organizational systems (Purificacion et al., 2016, Woodhouse et al., 2017). Developing and established patient education programs benefit from local clinical audits to help assess the utility and efficacy of current patient education practices. External reporting of such practices can help inform and prioritize further educational efforts or improvements and improve consistency across the country (Albert & Das, 2012, Torras et al., 2017).

2.1. CPQR’s Approach to Patient Education in Radiotherapy

The CPQR recognizes the importance and benefits of patient education in radiotherapy clinical practice to support person-centered care and the overall patient experience. As a result, the CPQR considers patient education an essential component of a high-quality radiation treatment program. To support an increase in the use of high-quality radiotherapy specific patient education materials, and a consistent approach across Canada, the CPQR launched a pan-Canadian initiative in 2017. The general principle of the initiative is to support local uptake and facilitate learning and knowledge mobilization of patient education across the country. The CPQR partnered with the CARO Quality and Standards Committee to establish a Patient Education Working Group with a goal to provide guidance on the development, application and use of patient education programs and materials. Ultimately, the CPQR strives to promote quality and consistency in patient education locally, provincially and nationally.

Patient Education Guidance detailed in this document is summarized below:

Education at the Patient Care Level

1	The radiation treatment program should provide patients and their families with radiotherapy-specific oncology educational resources.
2	Basic educational resources should follow best practices for health literacy and plain language, while supplementary and more advanced level material should be available based on patient need.
3	Educational resources tailored to individual patient need should consider various patient demographics, including, but not limited to, language, gender, socioeconomic background, ethnic background, and cultural differences.
4	The radiation treatment program should provide patients and their families with educational resources on radiation treatment, symptoms and self-management for side-effects and post-treatment.

5	Radiation treatment programs should have patient education available at all points during the patient’s care journey. Patient education should be provided continuously according to individual patient need and their evolving cancer care journey. Patient readiness to learn and their understanding of the education provided should be assessed and documented at various time points.
6	Radiation treatment programs should have disease site specific patient education resources.

Education at the Program Level

7	Radiation treatment-specific education should complement education provided by the oncology program.
8	The development and evaluation of radiation treatment specific education should be done in collaboration with patients and their families.
9	A patient-centered approach is utilized in the delivery of patient education. Educational materials should be available in written form with other forms of education based on patient preference, including verbal, online materials, and educational classes.
10	Radiation treatment programs should take an interprofessional approach to provide comprehensive and consistent patient education. This shared responsibility should maximize the expertise of all members of a patient’s care team.

Education at the Systems Level

11	The radiation treatment program provides educational materials that are reflective of best practice and current medical evidence. These resources are updated in a timely manner as best practice recommendations evolve.
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Patient Education within Patient Care

Patient education is a key component of patient engagement (Purificacion et al., 2016). To ensure patients are knowledgeable about their diagnosis, treatment, prognosis, and that their care is aligned with their individual values and preferences, health care providers should encourage patient involvement in their own care and utilize shared decision-making techniques (Stacey et al., 2008, Woodhouse et al., 2017). While failure to educate patients about their disease and treatment is the primary cause of patient dissatisfaction, finding ways to provide quality education to patients, at their preferred level of detail, enhances patient satisfaction by improving quality of life, their ability to cope, and a reduction in the severity of side effects and hospital admissions (CPAC, 2009, Purificacion et al., 2016, Stacey et al., 2008, Woodhouse et al., 2017, Gaston & Mitchell, 2005, Jones et al., 2006).

3.1. High Quality Radiotherapy Specific Education

There are several different treatment techniques used to treat cancer including radiotherapy, systemic therapy and surgery. These may be used on their own, concurrently or in an adjuvant setting and the approach will each have different toxicities, side effect profiles and care needs depending on how they are implemented. Radiation treatment programs should provide patients and their families with radiotherapy-specific education information and, when possible and appropriate, materials relevant to a patient’s specific cancer type. Care should also be given to ensure that the education materials available are high-quality, developed following best practices for health literacy, plain language and universal precautions, which detail common approaches to infection control (PHSA, 2016). Translated materials should similarly undergo evaluation to ensure high quality, clarity and that intent was not compromised during translation from their original language.

1	The radiation treatment program should provide patients and their families with radiotherapy-specific oncology educational resources.
2	Basic educational resources should follow best practices for health literacy and plain language, while supplementary and more advanced level material should be available based on patient need.

3.2. Educational Resources for Varying Patient Demographics

Educational materials should also meet the needs of a diverse patient population, including but not limited to language, gender, socioeconomic status, ethnicity, and culture. Translation should be available to help ensure patients understand the materials being shared with them. As noted in Section 3.1, quality materials should be available in plain language to meet the health literacy needs of patients and their families. When required, information relevant to the patient’s gender should be considered when determining the best materials to provide. Care should be given to ensure radiation treatment departments have the resources available to meet the needs of underserved populations and any barriers to patient education, including but not limited to ethnicity and/or culture. These should be addressed through patient engagement.

3	Educational resources tailored to individual patient need should consider various patient demographics, including, but not limited to, language, gender, socioeconomic background, ethnic background, and cultural differences.
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3.3. Patient Education Throughout Trajectory of Their Disease and Treatment

Educational resources provided to patients should be multifaceted to consider the complex nature of the disease and treatment-specific information required. Complete education resources should advise patients and their families on various aspects of care: diagnosis, symptoms, treatment, and during and post-treatment care; including radiotherapy details, referrals to multidisciplinary professionals, and expected outcomes in

terms of disease control, quality of life and side effects (acute, subacute and chronic). Information should include self-management techniques for radiotherapy-specific side effects.

4	The radiation treatment program should provide patients and their families with educational resources on radiation treatment, symptoms and self-management for side-effects and post-treatment.
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Patient and family informational needs evolve with the patient's disease, treatment, and prognosis. Patient education is required along various points of the cancer journey, from initial radiation oncology consult to computed tomography (CT) simulation, on treatment review clinics and follow-up post-radiotherapy. Clinicians, members of the care team, patient support groups and written resources all have an important role in providing comprehensive patient education. The provision of education by these different sources should be viewed as a continuous process, rather than an endpoint. The ultimate goal is to provide patients and their families with the right information at the right time in a patient centered approach.

5	Radiation treatment programs should have patient education available at all points during the patient's care journey. Patient education should be provided continuously according to individual patient need and their evolving cancer care journey. Patient readiness to learn and their understanding of the education provided should be assessed and documented at the various time points.
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3.4. Disease-Site Specific Education

Radiation treatment delivery, side-effects, and self-management techniques vary widely depending on the anatomic location of a patient's cancer. Patients want to see their specific cancer site reflected in education resources. Even within a specific disease site (ex. lung), education material may need to be tailored based on radiotherapy technique (ex. stereotactic body radiation therapy). Educational materials should reflect the uniqueness of the disease and treatment, in order to appropriately inform care and manage expectations.

6	Radiation treatment programs should have disease site specific patient education resources.
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Patient Education at the Programmatic Level

Radiation treatment-specific patient education resources are intended to complement patient engagement and education initiatives of the cancer centre. Because of this, the role radiation treatment programs play in leading the development and implementation of modality specific education will vary depending on the comprehensiveness and cohesiveness of the cancer centre's education program. Radiation treatment department leadership should work within the cancer centre to establish processes to monitor and evaluate radiation treatment specific education initiatives to ensure they continue to align with those of the centre.

4.1. Patient-Centered Approach to Education

Radiation treatment specific education is just one component of a comprehensive patient education program. To make sure patients are not overwhelmed with information, receive duplicate or potentially harmful contradictory information, both radiation treatment programs and cancer centres should take a patient-centered approach to the development and delivery of patient education. Collaborating with patients and their families in the development of patient education programs and seeking continuous feedback from them can help radiation treatment programs continuously assess and improve educational resource quality and ensure alignment with initiatives of the cancer centre.

7	Radiation treatment-specific education should complement education provided by the oncology program.
8	The development and evaluation of radiation treatment specific education should be done in collaboration with patients and their families.

4.2. Patient Education Delivery Methods

Print materials are only one component of a comprehensive patient education program, which may also include online literature or webinars, patient education sessions, support groups and education provided verbally by clinicians and members of a patient’s care team.

In fact, written materials should be designed to supplement and enhance the understanding of information provided through in person visits, not to serve as a surrogate. When patient education sessions or support groups form a core component of a radiation treatment program’s patient education, care should be given to schedule events when convenient for patients.

9	A patient-centered approach is utilized in the delivery of patient education. Educational materials should be available in written form with other forms of education based on patient preference, including verbal, online materials, and educational classes.
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4.3. Interprofessional Approach to Patient Education

As noted throughout this guidance document, patient education is a shared interprofessional responsibility within radiation treatment programs. This shared responsibility should maximize the expertise of all members of a patient’s care team. The radiation treatment program should engage other members of the oncology team (ex. medical oncology) to promote consistency of patient education provided. Patients and their families interact with numerous health care providers in their care journey. Utilizing the expertise of the various team members at key points of intervention allows education to be provided in a longitudinal, personalized manner. Often, health care providers do not have formal training in patient engagement, and they may underestimate a patient’s desire to be involved in shared decision making (Stacey 2012, Kane 2014). Moreover, there is a tendency to overestimate the amount of information a patient retains during visits and

a patient’s health literacy. To enable provision of meaningful, consistent education to patients and their families, it is recommended that patient education training be provided to the various health care professionals

10	Radiation treatment programs should take an interprofessional approach to provide comprehensive and consistent patient education. This shared responsibility should maximize the expertise of all members of a patient’s care team.
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Patient Education at a Systems Level

Health care systems play a critical role in supporting patient education practices. However, studies have indicated insufficient commitment and leadership at a systems level in relation to standardization or enhancement of oncology education quality. To help address this, radiation treatment programs can internally review educational practices within both their programs and cancer centres and utilize patient feedback to drive change and to increase patient engagement at their centre. Capitalizing on local, provincial and national opportunities to share best practices within the cancer community can help Canada establish a community of continuous improvement when it comes to patient education. However, without drivers of change originating at the pan-Canadian level, programs are often left to develop their own resources, resulting in a lack of consistent messaging and a clear direction within and among programs. Professional associations and organizations such as the CPQR can help address this disparity by facilitating opportunities for knowledge mobilization and encouraging health care systems to collaborate with external sources to prioritize patient-centered care.

5.1. Patient Education Reflecting Best Practice and Current Medical Evidence

To be truly useful for patients and their families, educational materials need to reflect current practice and be based on best available evidence. As medical practice recommendations evolve in radiation oncology, educational resources shared with patients and their families should be updated to inform practices. Renewing resources every two years, or as significant changes occur in radiation oncology, affords transparency in information sharing and facilitates informed decision making as practice advances. This renewal process should be done in collaboration with patients and their families as well as members of the interprofessional team both within the radiation treatment department and cancer centre. For reliable updating of shared patient educational materials tailored to the specific environment, processes should be implemented at a systems level to promote collaboration across regional and national radiotherapy communities.

11	The radiation treatment program provides educational materials that are reflective of best practice and current medical evidence. These resources are updated in a timely manner as best practice recommendations evolve.
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Conclusion

Pan-Canadian efforts to standardize and enhance the quality of patient education across radiation treatment programs aims to improve patient and family experience, as well as radiotherapy quality and safety. Enhanced patient engagement and education will satisfy patient expectation to acquire information about their disease, treatment, and prognosis that facilitates shared decision making. Through patient empowerment in self-management of treatment side effects, patient education may positively impact patient outcomes. Educational resources meeting diverse population needs and characteristics can facilitate patient engagement at patient care, program, and systems level. The guidance provided in this document is intended to provide radiation treatment programs with a means of assessing the accountability and success of patient education.

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