

Canadian Partnership for Quality Radiotherapy

Guidance on the use of Patient Reported Outcomes for Canadian Radiation
Treatment Programs

A document 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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CPQR
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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 will be approximately 225, 800 new cases of cancer in 2020 (Canadian Cancer Society, 2020) 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 enhance and optimize the collection and use of patient reported outcomes (PRO)s in routine clinical practice. A PRO is defined as any report of a patient's health status that comes directly from the patient without interpretation by clinicians or others. Examples of common PROs used in Canada include ESAS, EPIC, EORTC and Brief Pain Inventory. The document is one in a suite of guideline documents created by the CPQR that include:

- *Quality Assurance Guidelines for Canadian Radiation Treatment Programs* 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* that 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 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.

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- *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 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
CCO	Cancer Care Ontario
COMP	Canadian Organization of Medical Physicists
CPAC	Canadian Partnership Against Cancer
CPQR	Canadian Partnership for Quality Radiotherapy
EORTC	European Organization for Research and Treatment of Cancer
EPIC	Expanded Prostate Cancer Index Composite
ESAS	Edmonton Symptom Assessment System
IT	Information Technology
PROs	Patient Reported Outcomes
PROMs	Patient Report Outcome Measures
POSI	Prospective Outcomes and Support Initiative (POSI)
QRT	Quality Assurance Guidelines for Canadian Radiation Treatment Programs
ROPs	Radiation Oncology Programs
RT	Radiotherapy
Definitions	
Cancer Program	The multidisciplinary cancer program that encompasses the radiation treatment program
Organization	The hospital, cancer centre, or institution in which the radiation treatment program resides
Radiation Treatment Facility	The physical location where radiation treatment is administered
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

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1. Introduction

A patient-reported outcome (PRO) is defined as any report of a patient's health status that comes directly from the patient without interpretation by clinicians or others. PROs are typically determined by instruments or measures (often referred to as PRO Measures or PROMs) in the form of questionnaires of which patients respond. PROMs may measure domains of quality of life, such as physical or social functioning, anxiety and depression, symptom checklists, or other aspects of health status. PROMs have been used for many years in clinical trials, testing new clinical interventions to enable comparisons in PROs between groups. More recently, PROs have been introduced into routine clinical practice.

Introducing PROs into clinical practice originated as a means of improving the quality of patient care, initially in the setting of cancer patients with advanced disease receiving systemic therapy where patients often have many potentially concerning issues. In prospective studies, the use of PROs has been shown to improve patient-clinician communication, assist with problem detection, influence patient management, and improve outcomes; such as symptom control, health-related quality of life, and level of functioning. More recent studies have shown a survival benefit associated with use of PROs in advanced cancer settings. PROs relevant to RT can also be relevant to other disciplines, which can maximize effectiveness. In the context of routine clinical radiotherapy practice, several applications of PROs address pertinent outcomes for curative local therapies, sometimes with adjuvant systemic treatments, as well as treatment and general symptom management in the palliative setting; thus addressing symptom management, communication, and outcomes assessment unique to radiotherapy. In addition to their role in improving quality of care, PROs in RT can be linked to corresponding patient treatment data, allowing comparative studies that have the potential to inform clinical practice and health policy decisions more broadly.

Guidance on the use of Patient Reported Outcomes for Radiation Treatment Programs provides guidance and insights for radiation treatment programs that seek information on the appropriate use and implementation of PROs. It promotes local, provincial and pan-Canadian partnerships in the use and implementation of PROs in radiation treatment programs. This document was developed by the PRO Working Group at the CPQR, which comprised radiation therapists, radiation oncologists, physicists and patient representatives.

The PRO working group advises that radiation treatment programs also utilize existing resources on the use and implementation of PROs in clinical practice; in particular, the *User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice*, as well as, the *Users' Guide to Integrating Patient-Reported Outcomes in Electronic Health Records*, produced by world experts on patient reported outcomes (on behalf of the International Society for Quality of Life Research and Johns Hopkins University, respectively). These documents are designed to aid clinicians and other health care providers in the use of PROs in clinical practice. Rather than recommending one right way of implementing PROs in clinics, these documents present various options and thoroughly describe their respective advantages and disadvantages. These resources can be used by Canadian radiation treatment programs as a guide to meaningfully incorporate PROs into clinical practice working toward the ultimate goal of improving both

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the quality and safety of the radiation treatment being delivered to their patients.

2. Summary of Guidance Statements

1	Given the established benefits of implementing PROs in clinical practice, the CPQR strongly encourages radiation treatment programs to collect PROs from patients managed with radiotherapy. It is reasonable to take a step-wise approach to PRO introduction.
2	Prior to implementing PROs in clinical practice, the radiation treatment program should set and communicate clear goals for the use of PROs in the local context.
3	The CPQR recommends that programs use a PRO measure endorsed nationally by the CPQR where relevant. If no nationally endorsed PRO measure exists, or if it is inappropriate in the given context, the PRO selection process should be rigorous, or programs should adopt PROs rigorously evaluated elsewhere. For radiation therapy, body-region and/or disease specific PROs are preferred to general PROs as they can be more sensitive to symptoms experienced by patients. Ideally, the PRO should also address content relevant to multi-modality management.
4	Prior to implementation, the radiation treatment program should establish the target patient population(s) to assess with PROs and determine the local resources required to do so. It is recommended that programs consider starting PRO collection on populations most likely to benefit because of high symptom burden (e.g. HN, gynecology, palliative). The program should strive to increase the number of patients from which these data are collected to be in keeping with the program goals. "Hard to reach" populations should be explicitly considered.
5	The radiation treatment program should establish the frequency of PRO completion. It is preferred to have PRO assessment for a patient at multiple time points in order to monitor changes over time and promote patient-centered care.
6	It is recommended that the timing of PRO administration be such that PRO data are available for the clinical encounter. Ideally, PROs will be completed and PRO scores available to the health care team prior to a clinician encounter to aid in the communication during the visit.
7	The interpretation of PRO scores by the health care team requires guidance and education to ensure proper understanding of the PRO score and detection of problems (e.g. higher score indicates worse symptom). Programs should ensure that this guidance is available as part of the PRO implementation process.
8	A process for follow-up on concerning PRO scores should be established to ensure that issues uncovered by PROs can be addressed promptly and appropriately by the health care team. The CPQR encourages direct discussion with the patient to gain full insight of issues identified through PROs.
9	The health care team must have a plan to respond and properly attend to problems that are discovered from PROs to ensure symptoms are addressed appropriately.
10	Confidentiality and privacy in the completion of PROs and PRO data requires explicit consideration. Adopted processes should ensure that the patient has privacy when completing PROs and that their personal information remains confidential.
11	An evaluation of the impact of PROs locally is recommended to ensure the established goals (as per Guidance Statement #2) are met.

3. Why PROs are Important?

The utilization of PROs provides a means to incorporate the voice of patients treated with radiotherapy in clinical practice. The importance and benefits of PROs extends to patients, physicians, and other health care providers, as well as the entire health care system.

PROs can be used to assess the impact that specific cancer treatments have on a patient's quality of life and well-being, at either the individual or population level. Within the context of radiotherapy treatments, the data obtained from PROs can identify symptoms and toxicity experienced throughout a patient's treatment and follow-up.

At the individual patient level, PROs can improve clinical encounters by enhancing communication between patients and their care provider(s) which, in turn, can uncover issues that may not have been discovered otherwise, or can aid the prioritization of issues that need to be clinically addressed. When measured over time, PRO scores can be used to assess the impact of an intervention such as analgesia or nausea management, and thereby improve these outcomes. When PROs are relevant to multiple disciplines (e.g., chemo-radiation), they have been shown to increase communication between multidisciplinary health care teams and can enable the treating health care providers to work together to achieve common treatment goals.

Given these clinical applications and potential impacts, it is critical that medical professionals, as well as patients, understand the processes and benefits of PROs in order to optimize the impact of PRO measurement and to capitalize on the resources required to implement a PRO program. These arguments form the basis of the first guidance statement of this document.

Guidance Statement #1
Given the established benefits of implementing PROs in clinical practice, the CPQR strongly encourages radiation treatment programs to collect PROs from patients managed with radiotherapy. It is reasonable to take a step-wise approach to PRO introduction.

4. CPQR's Approach to PROs in Radiotherapy

The CPQR recognizes the importance and benefits of PROs in radiotherapy clinical practice to understand the experiences of patients treated. As a result, the CPQR considers PROs essential in radiotherapy clinical practice to enable improved quality of care, quality of life and survivorship for those that are undergoing cancer treatment. The CPQR recommends that, in routine clinical practice, PROs be relevant to radiotherapy patients and the disease of which they are undergoing treatment.

To support an increase in the use of PROs in routine clinical radiotherapy practice, the CPQR launched a pan-Canadian initiative in 2017. The general principle of the initiative is to support local uptake and facilitate pan-Canadian learning and knowledge mobilization of PROs. A multidisciplinary PRO Working Group within the CPQR has been assembled with a goal to provide guidance on the collection and use of

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RT specific PRO measures in radiation oncology programs (ROPs) across Canada. Ultimately, the CPQR strives to promote quality and consistency in the use of PROs within centres locally, provincially and nationally.

To determine the current landscape of PROs across Canada, an interview framework was developed by the PRO working group and an environmental scan was conducted (Jul-Nov 2018) with select members of ROPs across Canada using semi-structured telephone interviews. Findings from these interviews include an inventory of PRO measures that are in use across the country, barriers and facilitators to PRO implementation locally, as well as the programs' levels of interest in obtaining guidance from the CPQR on the clinical use of PROs. These interview findings, as well as a review of the current literature, provide the foundation for this guidance document.

5. Implementation Considerations

Prior to implementation, there is a wide breadth of subjects that should be taken into consideration. As a first step in the process, the goals of instituting the PRO measure locally should be discussed. In support of these goals, additional considerations include:

- The target patient population;
- What PROMs will best meet needs;
- The method of administration;
- Which medical professional(s) will have access to the PROs;
- Who will be responsible for reviewing and responding to the findings;
- How the results are reported within the medical record; and
- If there are tools to aid in interpreting the results.

Finally, there should be a plan in place to determine the impact of PROs in local clinical practice to ensure the initial goals are set prior to implementation.

Guidance Statement #2
Prior to implementing PROs in clinical practice, the radiation treatment program should set and communicate clear goals for the use of PROs in the local context.

6. Buy-in

The PRO implementation literature makes clear that establishing stakeholder buy-in to PRO implementation is critical to success of the initiative. To facilitate buy-in of the use and/or implementation of PROs, it is important to communicate with all medical professionals, as well as patients, the rationale for using PROs in clinical practice in the centre. Stakeholders should be included in the discussion of goals prior to PRO implementation to ensure that concerns are addressed and barriers mitigated. If PROs are already instituted in clinical practice, a method for stakeholder feedback can also increase buy-in.

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A local champion of PROs can facilitate PROs in clinical practice and was noted as beneficial to a number of centres during the environmental scan. Local champions will not only be able to promote the use of PROs in clinical practice but may be able to respond to PRO related inquiries or concerns.

Prior to implementing PROs, a scan of the local environment to review local systemic or hospital PROs currently in place, as well as provincial PRO guidance, should be reviewed.

7. PRO Tools Selection

PRO tools selection should be a rigorous process; however, it is important to note that the process need not duplicate previous efforts from other colleagues within or outside the institution. General quality of life PROs has been implemented provincially by governing bodies in Ontario, Alberta, British Columbia and Quebec. Although all programs at the local level will need to decide what PROM to use, that decision could be to adopt an already validated measure selected formally by other clinics, or to use their own rigorous selection process.

The CPQR has partnered with Cancer Care Ontario (CCO) in their PRO tool selection strategy; an exceptional example of a rigorously designed process. It involves multiple stakeholders including patients, clinicians, methodologists and administrators that participate in a step-wise process with a goal to facilitate selection of PRO instruments including their prioritization, identification, selection, and implementation. The CPQR endorses this process and, in partnership with CCO, will continue to identify PROMs to recommend to the RT community.

Since most local programs do not have the resources to duplicate this type of process, sharing this information on a pan-Canadian basis is one of the goals of the CPQR platform. Goals for the collection of PROs should be fully recognized and articulated to aid in selecting the most appropriate PROM for each program's use. When outlining goals, it is important to consider PROs that are also relevant to other disciplines in addition to RT (multidisciplinary) in order to maximize effectiveness. Goals to consider include the potential roles of PROs for screening, monitoring, treatment evaluation, treatment planning, shared decision making with patients and families, and improved patient or provider communication. A thorough evaluation of resources required (e.g. human resources, technical support, space and cost) for a given PRO tool should also be undertaken as part of tool selection to ensure that local resources will be able to support the proper implementation and use of the tool in RT clinical practice.

In addition to general PROs suitable for use across diseases and treatment modalities, (e.g., the Edmonton Symptom Assessment Scale) there are PROs specific to patient groups (e.g. EPIC for men with prostate cancer) that are currently in use across Canada. In the debate between generic and disease or treatment specific PROMs, a disease or treatment specific questionnaire can be more sensitive to specific symptoms related to the disease or treatment rather than the more common. The CPQR has begun to investigate opportunities to support a consistent approach to which PROs should be collected for specific types of cancer. Building on a robust measure selection process developed by CCO, the CPQR has developed a list of CPQR recommended PRO tools that can be found at www.cpqr.ca and will continue to be updated.

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Guidance Statement #3

The CPQR recommends that programs use a PRO measure endorsed nationally by the CPQR where relevant. If no nationally endorsed PRO measure exists, or if it is inappropriate in the given context, the PRO selection process should be rigorous or, programs should adopt PROs rigorously evaluated elsewhere. For radiation therapy, body-region and/or disease specific PROs are preferred to general PROs as they can be more sensitive to symptoms experienced by patients. Ideally, the PRO should also address content relevant to multi-modality management.

Patient-specific considerations should be incorporated into PRO tool selection. Target patient population(s) must be set including age and ability (mentally and physically) to complete. Within any patient population, there are vulnerable patients that may be difficult or impossible to reach with PROs; however, the advantages and disadvantages of including/excluding certain populations should be considered. On a pan Canadian level, language barriers are likely to exist and should be considered. In addition, the following patient specific population considerations should be discussed to determine if the selected PROs will incorporate the following: patients that are able to self-report, patients who may or do require assistance, all ambulatory patients, ambulatory patients with specific conditions, and acute care inpatients. Independent patients in the outpatient setting may have a greater ability to complete PROs but may not be as in need of monitoring, whereas obtaining PROs from inpatients may require more hospital resources, as assistance completing PROs is more likely to be required. The hospital environment may also influence PROs in the inpatient setting and assessing acute inpatients may be short term rather than long term monitoring. The assessment of PROs in radiotherapy inpatients is more complex and beyond the intended scope of this document.

Guidance Statement #4

Prior to implementation, the radiation treatment program should establish the target patient populations(s) to assess with PROs and determine the local resources required to do so. It is recommended that programs consider starting PRO collection on populations most likely to benefit because of high symptom burden (e.g. HN, gynecology, palliative). The program should strive to increase the number of patients from which these data are collected to be in keeping with the program goals. "Hard to reach" populations should be explicitly considered.

As previously noted, the environmental scan identified a total of 13 different PRO instruments in use across Canada. This provides an opportunity for Canadian cancer centres to knowledge share, and the CPQR welcomes this opportunity. For example, from 2017-2019, the CPQR supported the translation of BC Cancer's Prospective Outcomes and Support Initiative (POSI) to other radiation therapy programs across the country. POSI was seen as a program for others to emulate due to its nimble "real time" approach to the collection and review of PROs during patient encounters. The POSI model is being integrated into centres affiliated with Dalhousie University Department of Radiation Oncology and being considered by centres in the prairies. This piloting will continue to be undertaken through centre leadership and monitored by the CPQR. If your centre is interested in learning more about POSI, please contact us (administration@cpqr.ca) for more information.

8. Patient Completion of PROs

It should be clear to the patient why they are completing a PROM and who will be looking at the results. Prior to implementation, it is important to determine how often patients will be expected to complete PROMs, as there are many options to consider: every visit, frequent administration, one-time only assessment, or between visits. When weighing these options, it is important to consider the advantages and disadvantages of each and the resources required. Administration at every visit or multiple administrations of a PROM will require more resources than PROs completed in an acute setting, but will allow a patient to be monitored over time. In radiotherapy, monitoring patients over time with PROs - prior to, during or following treatment - can be linked to RT treatment and outcome data.

Guidance Statement #5
The radiation treatment program should establish the frequency of PRO completion. It is preferred to have PRO assessment for a patient at multiple time points in order to monitor changes over time and promote patient-centered care.

The method of administering a PRO to a patient must also be considered. Methods of administration in clinic include: self-administered, live interview, or computer based. PRO administration within clinic requires different resources than PRO administration outside of the clinic. For example, space within the clinic would be required for clinic administration; whereas, outside the clinic there could be numerous resources required to manage the administration process.

Within the clinic setting, trained personnel are essential for interviews, but they can be costly; however, they enable more in-depth questioning. Completion on paper is initially less costly, but also requires personnel for data entry, and it may be difficult or impossible for some patients to complete a paper form due to physical barriers, language barriers, literacy issues, etc. IT infrastructure costs for a computer-based PROM can be high upfront, but this method allows more efficient data collection and has the potential to be electronically integrated with other elements of the medical record.

Outside of the clinic setting, modes of administration can include: self-administration via mail, telephone interview (live or voice activated) or a web-based platform. Administration via mail requires personnel to send/receive, as well as personnel for data capture, which can result in low participation rates. Telephone PROMs can be convenient, but having a trained interviewer is costly, and in most instances, inefficient. Automated telephone response interviews can be effective, but also may be ill-received by some patients, and may require patient training. Data security, privacy, and implementation costs are a main concern for a web-based platform, but this strategy can be convenient for many patients. When PROs are to be completed outside the regular clinic visit, a process to review the results and deal with patient issues in real time can also be resource intensive but absolutely vital.

Guidance Statement #6
It is recommended that the timing of PRO administration be such that PRO data are available for the clinical encounter. Ideally, PROs will be completed and PRO scores available to the health care team prior to a clinician encounter to aid in the communication during the visit.

9. Interpreting PROs

A patient's score may be reviewed by their nurse, physician or another health care professional. The flow of PRO information should be clear to patients, (roles of nurses, radiation therapist, physicians, etc.) and the health care professionals involved in their care. Physicians may review the scores personally, or they may be presented to the physician after being interpreted by another medical professional. In RT, there is an opportunity to include radiation therapists in the interpretation or administration of PROs; radiation therapists interact with patients undergoing treatment frequently, resulting in strong rapport. The positive impact radiation therapists could have on a PRO program in RT should not be overlooked when determining the flow of PRO information.

The interpretation of PROs varies depending on whether there is a current patient score or if the patient has completed a PROM at other times during treatment. If previous scores are available, physicians may only be alerted when a change in score is noted during interpretation. Multiple tools can aid in PRO interpretation and often combinations of these tools are used together. Some guidelines give a general description of what a score means (e.g. higher scores indicate better functioning) but do not indicate clinical importance, or if the score is meaningful to the patient. A cut-off or threshold score can also be implemented, meaning that, if a certain score is obtained in a given category, action may be required. A cut-off score can be relatively easy to apply and is often used in categories related to anxiety and depression; however, its usefulness depends on the sensitivity of the cut off and if it has been thoroughly established for the PRO measure in use. Scores can also be compared to similar research populations, or the general population with the same condition, or a healthy population. This approach can be used for general PROs or site-specific PROs but may not be available for all instruments. Patients can vary greatly, (e.g. comorbidity and preferences) so patients on clinical trials, or in the general population, may be quite different from patients whose PRO scores are being reported. Comparisons with benchmarks can also be problematic because there is a greater chance of error of measurement at the individual patient level compared to a group.

A structured review of completed PROs with patients can significantly aid interpretation and provide patients the opportunity to clarify their score and provide more detail. The main disadvantage to this method of interpretation is ensuring trained personnel have the resources required.

Scores can be linked to management guidelines (when available) describing how clinicians should respond to issues uncovered by PROs. Linking guidelines to PROs may increase the chance of PROs having a positive effect on patient care and outcomes; however, some clinicians have expressed that a link to guidelines may challenge their expertise.

Guidance Statement #7, 8, 9
The interpretation of PRO scores by the health care team requires guidance and education to ensure proper understanding of the PRO score and detection of problems (e.g. higher score indicates worse symptom). Programs should ensure that this guidance is available as part of the PRO implementation process.

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A process for follow-up concerning PRO scores should be established to ensure that issues uncovered by PROs can be addressed promptly and appropriately by the health care team. The CPQR encourages direct discussion with the patient to gain full insight of issues identified through PROs.

The health care team must have a plan to respond and properly attend to problems that are discovered from PROs to ensure symptoms are addressed appropriately.
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10. Confidentiality

When implementing PROs, patient confidentiality must be considered in the process for the patient's completion of PROs, and how the information is stored. A balance must be sought to ensure that patients have the help they need to complete PROMs, but also the confidentiality to ensure that it is answered honestly, particularly in sensitive cases (e.g. questions regarding incontinence or sexual functioning). As with all clinical interactions, confidentiality is also required when discussing the PRO scores with the patient in the clinical encounter.

Guidance Statement #10

Confidentiality and privacy in the completion of PROs and PRO data requires explicit consideration. Adopted processes should ensure that the patient has privacy when completing PROs and that their personal information remains confidential.

11. Evaluation of PROs

Following PRO implementation and roll out in clinical practice, programs may want to assess the impact of PROs on the quality of care to determine if goals have been met. This evaluation can shed light on whether processes should be altered to meet the goals, and if stakeholders are benefiting from the use of PROs. There are numerous approaches that can be used to determine the value of PROs in clinical practice including: experimental, quasi-experiment, observational, survey or quality improvement designs and methods. The resources required to do a randomized controlled trial will likely be prohibitive for many programs. A quality improvement design (e.g. plan-do-study-act) is typically easier to initiate and implement. Process outcomes (e.g. how many patients completed planned PROs, how many problematic scores resulted in clinical action) may be more feasible for most programs than definitive outcomes such as survival.

Guidance Statement #11

An evaluation of the impact of PROs locally is recommended to ensure the established goals (as per Guidance Statement #2) are met.
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12. PRO Data and Future Opportunities

There are multiple uses of PRO data including for use in a clinical encounter, to map over time, and/or for research purposes. Regardless of the intended use, the timing of PRO data presentation and how the data will be presented, both require consideration and are beyond the scope of this document. The environmental scan indicated that most Canadian Cancer centres present PRO data to the patient at the time of clinical encounter, and within the clinical workflow, although there were examples of PROs being

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used between clinic visits. When presented at a clinical encounter, PROs act as a means to notify physicians about patient concerns, and to aid in the communication during the visit.

The environmental scan highlighted a strong desire to store and share PRO data. Given the interest in collaboration, there are multiple opportunities in the future to do this on a pan-Canadian level. The CPQR will continue to work with centres across Canada to support collaboration and implementation of PRO in radiotherapy routine clinical practice.

13. Opportunities for Growth

Our pan-Canadian environmental scan identified numerous challenges to implementing PROs, which have mostly been addressed within this document. Buy-in (by patients and health care providers) is critical to the use of PROs in routine clinical practice and has been noted as a barrier for many centres across Canada. Lack of buy-in can be a result of the perceived time required to complete PROs for a patient, or to review PROs for medical professionals. Patients can encounter PRO burnout when required to fill out multiple PROMs. Patients can also fear that completing PROs affects timely care, or they may perceive that the PROs are not being utilized by their health care providers. In addition to lack of time and resources, physicians have identified concerns about the ability to provide appropriate patient care for issues reported on PROs, particularly in relation to mental health concerns or symptoms that have few active interventions (such as fatigue). Although obtaining buy-in from patients and health care providers can be challenging, it is an opportunity to have open dialog with these stakeholders.

Feasibility and timely implementation can be difficult to determine and overcome when deciding what PRO instrument to implement. There are numerous PROs in place throughout radiation treatment programs across Canada, and vast amounts of knowledge regarding PRO use and implementation that can and should be utilized. There is a strong desire among Canadian radiation oncology programs to learn from each other, and from other health care programs, to prevent duplication. The CPQR embraces partnerships and pan-Canadian learning, and strives for quality and consistency in the implementation and use of PROs. Ideally, the CPQR envisions a platform which allows for knowledge-sharing among radiation treatment programs.

A lack of resources is by far the most common challenge to the use and implementation of PROs. These resources can include: time, funding, IT infrastructure, or human resources. Although multiple challenges present themselves within the use and implementation of PROs in clinical practice, it is vital to keep in mind the importance of PROs and their benefits as these far outweigh the barriers to implementation

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