Patient Reported Outcomes at Cancer Care Ontario: The program, the data, the research

DR. LISA BARBERA
MARCH 28, 2017
JOHNS HOPKINS
Objectives

1. To describe the Patient Reported Outcome (PRO) Program at Cancer Care Ontario (CCO)
2. To describe how this is being used to drive quality of care
3. To describe how the data has been used in research
A Patient Reported Outcome (PRO) is a validated measure that provides a comprehensive picture on the impact of cancer and treatment from the patient perspective.

By tailoring the focus on physical symptoms and psychosocial concerns that are relevant to the patient, PROs help the healthcare team deliver care that is more person-centred, responsive and efficient.

PROs are administered electronically at a computer station, on a mobile device or by paper and pencil.
Paradigm shift

Physician knows best
Providing services
Survival

Person centred care
Symptom management
Quality of life
Patient experience
What is CCO?
Vision
Working together to create the best health systems in the world.

Mission
Together, we will improve the performance of our health systems by driving quality, accountability, innovation and value.
What is Cancer Care Ontario?

- Agency of the government accountable to the provincial ministry of health
- Provincial government’s advisor on the cancer system and access to key services
  - leads multi-year system planning
  - contracts for services with hospitals and providers
  - deploys information systems
  - establishes guidelines and standards
  - tracks performance targets
What is Cancer Care Ontario?

- Ontario population is ~14M
CCO

Screening and Prevention

Clinical Programs and Quality Initiatives

Drugs

Quality

Diagnosis and Treatment

Patient Centred Care

Primary care, palliative care, survivorship

Nursing

Patient Education

PSO

PREMS

PROs
# Ontario Cancer Plan IV

## 2015–2019

**Ontario Cancer Plan IV**

**At a glance**

**Ontario Cancer Plan IV**

**2015–2019**

**OCP.CANCERCARE.ON.CA**

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## Quality of Life & Patient Experience

**GOAL**

Ensure the delivery of responsive and respectful care, optimizing individual’s quality of life across the cancer care continuum.

<table>
<thead>
<tr>
<th>STRATEGIC OBJECTIVES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drive excellence in the development of policies, programs, strategies, and evaluation by partnering with patients and their families to ensure services and care reflect their needs and preferences.</td>
</tr>
<tr>
<td>Expand and integrate access to palliative, psychosocial, and rehabilitation services to improve quality of life and patient experience in cancer centres and the community.</td>
</tr>
<tr>
<td>Capture a range of real-time patient-reported information that is meaningful to patients to improve the patient experience.</td>
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<tr>
<td>Increase understanding of wait times from the patient’s perspective and identify opportunities to improve the patient experience.</td>
</tr>
<tr>
<td>Support healthcare providers, patients, and families with training, tools and resources to improve communication, decision-making, self-management and quality of life.</td>
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## Safety

**GOAL**

Ensure the safety of patients and caregivers in all care settings.

<table>
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<tr>
<td>Expand the use of technologies and tools for providers that drive adherence to evidence-based guidelines across care settings, including the home.</td>
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<tr>
<td>Develop and implement patient safety tools in collaboration with patients and families that enable safe care in settings outside the hospital, including the home.</td>
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<tr>
<td>Identify opportunities for system-level oversight for safety related to cancer services.</td>
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<tr>
<td>Advance peer review of care plans to ensure concurrence with evidence-informed practice and appropriateness of care that will lead to improved patient safety and clinical effectiveness.</td>
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<tr>
<td>Describe cancer-specific requirements for regulated healthcare providers delivering cancer care.</td>
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</table>

## Equity

**GOAL**

Ensure health equity for all Ontarians across the cancer system.

<table>
<thead>
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<tr>
<td>Develop and implement the First Nations Metis and Inuit (FNMI) Cancer Strategy, building on successes of previous FNMI Cancer Strategic Plans, as well as the established relationship protocol agreements between Cancer Care Ontario and FNMI communities.</td>
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<tr>
<td>Assess, expand, enhance and utilise data to better understand and improve equity issues in the regions.</td>
</tr>
<tr>
<td>Develop locally relevant policies and programs in partnership with community service providers to improve access to services for specific populations and support healthcare providers with training, data and tools to deliver equitable services.</td>
</tr>
<tr>
<td>Advise governments in the development of provincial policies and programs to improve access to services for specific populations, including equitable access to specialized services.</td>
</tr>
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## Integrated Care

**GOAL**

Ensure the delivery of integrated care across the cancer care continuum.

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<td>Identify patients by risk, based on clinical factors, comorbid conditions and social determinants of health, to determine the supports that patients and families require to navigate their care pathways.</td>
</tr>
<tr>
<td>Ensure that standardized care plans are developed and communicated to all members of the care team, across the cancer care continuum, to facilitate an integrated approach to care that is centered on the patient.</td>
</tr>
<tr>
<td>Enhance communication among all providers across the cancer care continuum and care settings to facilitate smooth care transitions.</td>
</tr>
<tr>
<td>Increase the availability of relevant patient clinical information to patients and providers across care settings to support informed decision making.</td>
</tr>
<tr>
<td>Determine opportunities for improving the transition of adolescents and young adults, when appropriate, from the pediatric to adult cancer system.</td>
</tr>
</tbody>
</table>

## Sustainability

**GOAL**

Ensure a sustainable cancer system for future generations.

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<td>Develop and execute on a chronic disease prevention strategy that focuses on reducing the incidence of the major chronic disease modifiable risk factors and exposures.</td>
</tr>
<tr>
<td>Continue to implement organized cancer screening programs for breast, cervical and colorectal cancer.</td>
</tr>
<tr>
<td>Assess value from a patient experience, population health and cost perspective to inform decision-making across the cancer system.</td>
</tr>
<tr>
<td>Optimize the model of care delivery to achieve the greatest benefit for patients and the cancer system.</td>
</tr>
<tr>
<td>Strengthen and expand system capacity planning to ensure resources are most optimally allocated and utilized.</td>
</tr>
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## Effectiveness

**GOAL**

Ensure the provision of effective cancer care based on best evidence.

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<td>Expand measurement of clinical and patient reported outcomes to enable effective, high-quality care.</td>
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<td>Expand our performance management model to include non-hospital healthcare organizations and performance at the provider level in order to be more effective with our quality and access programs across the system.</td>
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<tr>
<td>Leverage and expand the use of evidence-based guidance to improve the appropriateness of care.</td>
</tr>
<tr>
<td>Develop a unified strategy for personalized medicine for cancer care including personal and tumour genetics, and incorporates recommendations into clinical practice.</td>
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Quality of life & patient experience

GOAL
Ensure the delivery of responsive and respectful care, optimizing individuals’ quality of life across the cancer care continuum.

STRATEGIC OBJECTIVES
- Drive excellence in the development of policies, programs, strategies and evaluation by partnering with patients and their families to ensure services and care reflect their needs and preferences.
- Expand and integrate access to palliative, psychosocial and rehabilitation services to improve quality of life and patient experience in cancer centres and the community.
- Capture a range of real-time patient-reported information that is meaningful to patients to improve the quality of care.
- Increase understanding of wait times from the patient’s perspective and identify opportunities to improve the patient experience.
- Support healthcare providers, patients and families with training, tools and resources to improve communication, decision-making, self-management and quality of life.

Effectiveness

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Ensure the provision of effective cancer care based on best evidence.

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- Leverage and expand the use of evidence-based guidance to improve the appropriateness of care.
- Develop a unifying strategy for personalized medicine for cancer care including personal and tumour genetics, and incorporate recommendations into clinical practice.

Ontario Cancer Care Ontario
What is the CCO PRO Program?
Over the years:
Ontario’s Progress in Patient Reported Outcomes and Symptom Management

- Palliative care program established
- Symptom management identified as a gap

2005-2006

- ESAS introduced
- ISAAC released—the electronic engine for standardized symptom assessment

2007

- Psychosocial Oncology program established
- Clinician symptom management tools/guides developed
- The PHQ-9 and GAD-7 identified by CCO’s PROs Working Group (2012)

2008 - 2012

- Second PRO introduced: Patient Reported Functional Status (Patient ECOG)
- Patient-Reported Outcomes Advisory Committee formed (2013)
- Pilot projects launched (2014)
  - EPIC
  - iPEHOC
- Clinical lead for PRO program

2013-2015

- Program Strategic Framework to guide work
- EPIC implementation

2016-2019

- Clinical lead for PRO program
## Your Symptoms Matter

Edmonton Symptom Assessment System Revised (ESAS-R)

Please circle the number that best describes how you feel NOW:

<table>
<thead>
<tr>
<th>Symptom Desc</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<th>7</th>
<th>8</th>
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<th>Worst Possible</th>
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<tbody>
<tr>
<td>No Pain</td>
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<td>Pain</td>
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<td>No Tiredness</td>
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<td>Tiredness</td>
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<td>(Tiredness = lack of energy)</td>
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<td>Drowsiness</td>
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<td>(Drowsiness = feeling sleepy)</td>
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<td>No Lack of Appetite</td>
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<td>Lack of Appetite</td>
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<td>No Shortness of Breath</td>
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<td>Shortness of Breath</td>
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<td>Best Wellbeing</td>
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<td>Wellbeing</td>
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Activities & Function:
Over the past month I would generally rate my activity as:

- 0 - Normal with no limitations
- 1 - Not my normal self, but able to be up and about with fairly normal activities
- 2 - Not feeling up to most things, but in bed or chair less than half the day
- 3 - Able to do little activity & spend most of the day in bed or chair
- 4 - Pretty much bedridden, rarely out of bed
### Screening Assessments

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<td>Tiredness</td>
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<td>Depression</td>
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<tr>
<td>Anxiety</td>
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<td>Wellbeing</td>
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</table>

- **Low (0-3)**
- **Medium (4-6)**
- **High (7-10)**

### Trend View

**Pain**

**Tiredness**

**Drowsiness**

- **Low (0-3)**
- **Medium (4-6)**
- **High (7-10)**
Please remember to talk to your doctor or nurse about any concerns you may have no matter how small they may seem.
Please remember to talk to your doctor or nurse about any concerns you may have no matter how small they may seem.
Your Symptoms Matter Stats

Where is symptom screening happening?
- 14 Regional Cancer Centers
- 78 Partner Sites
- 28 sites use EMR integration

What is the volume of surveys in ISAAC?
- 6,733,903 total surveys (includes ESAS, PRFS, and PPS)
- 3,812,156 ESAS surveys
- 551,290 unique patients

What are the most common symptoms?
- Tiredness or fatigue: 75%
- Issues of wellbeing: 71%
- Depression: 50%

What do patients report?
- 83% of patients reported that their health team treats/manages their physical symptoms
- 78% of patients reported that their health team responds to their worries, concerns, or feelings of sadness
- 86% of patients reported that their health team includes them in decisions about how to treat/manage their symptoms
Figure 1: Information Pyramid—Integrated Health Outcomes Information

- Policy Level
- Administrative Level
- Clinical Level

Time
Collected data from numerous sources:
- Extensive document review
- Interviews with key informants
- Strategic planning workshop with multiple stakeholders

First draft was shared with key stakeholders to capture a **unified** vision:
- Patient and Family Advisors (PFAs)
- Ontario Collaborative for Symptom Management Committee

Framework is well aligned with PFA vision and goals for program

"It is important through the journey for the patient and caregiver to understand what to expect, how to mitigate, how to cope, and when it's necessary to seek immediate medical attention (i.e., what is normal vs. what is life threatening). Cancer can make one feel powerless; if one is at least able to manage one's symptoms, it returns some control and power back to the patient."

- Jean L., CCO Patient and Family Advisory Council member

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**Strategic Framework**

Cancer Care Ontario
Goal: Ensure that patients receive responsive and respectful care that is based on best evidence and optimizes their quality of life across the cancer care continuum.

Mandate: To support the implementation of patient reported outcomes and symptom management to improve person-centred care across Ontario.
**Goal:** Ensure that patients receive responsive and respectful care that is based on best evidence and optimizes their quality of life across the cancer care continuum.

**Mandate:** To support the implementation of patient reported outcomes and symptom management to improve person-centred care across Ontario.

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<th>Symptom Management &amp; Interdisciplinary Teams</th>
<th>Technology</th>
<th>Research &amp; Improvement</th>
</tr>
</thead>
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<td>The defined method and oversight of how new PROs will be introduced and maintained in the Ontario cancer system</td>
<td>How patients and families will be educated, engaged and activated during the implementation of PROs</td>
<td>Support and engagement of the clinical team for the adoption of PROs and improvement in symptom management</td>
<td>The technology and information management tools and systems used to facilitate PROs data collection and analysis</td>
<td>How PROs and Symptom Management data are harnessed and leveraged to learn and improve</td>
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# PROs and Symptom Management in Ontario

## Strategic Framework

**Goal:** Ensure that patients receive responsive and respectful care that is based on best evidence and optimizes their quality of life across the cancer care continuum.

**Mandate:** To support the implementation of patient reported outcomes and symptom management to improve person-centred care across Ontario.

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<td>How PROs and Symptom Management data are harnessed and leveraged to learn and improve</td>
</tr>
<tr>
<td>Outcome</td>
<td>Sustained adoption of suitable PROs in Ontario’s cancer system</td>
<td>Patients and families who are activated to participate in the assessment and management of their symptoms</td>
<td>Clinical teams using PROs and symptom assessments to effectively respond to the symptoms of patients</td>
<td>Effective analytics capabilities and collaboration between IM/IT (information management/Information technology) partners to ensure an excellent user experience</td>
<td>Using data effectively for research, quality improvement initiatives, outcome evaluation and planning</td>
</tr>
</tbody>
</table>
| Initiatives | • Develop a pipeline to support the selection, implementation and sustained adoption of suitable PROs | • Support patients in self-management of their symptoms by implementing an approach to promote patient education that:  
- Allows patients and families to understand the value of PROs  
- Provides patients with the skills, resources and confidence to be activated in symptom management  
- Creates a patient-safe environment where patients can discuss their symptoms  
• Create a strategy to effectively engage patient and family advisors in the implementation and evaluation of new and existing PROs to ensure a person-centred focus | • Implement a strategy to measure the clinical teams’ response to PROs  
• Implement relevant clinical toolkits that are adaptable to local settings  
• Recruit and leverage Clinical Champions to promote the implementation of PROs  
• Collaborate with internal partners to define roles and responsibilities to support symptom management  
• Create a strategy to clearly articulate the value of PROs to clinician teams | • Develop IM/IT requirements for PROs through engagement with internal and external stakeholders  
• Collaborate with IM/IT partners to define roles and responsibilities to support PROs implementation and facilitate symptom management  
• Develop and enhance reporting and analytics capabilities to evaluate and report on PROs | • Leverage CCO data assets to inform and improve the PROs implementation pipeline  
• Develop a research strategy in collaboration with internal and external partners  
• Embed an evaluation framework into appropriate initiatives  
• Support local quality improvement projects and planning |
Pipeline

Prioritization
- Identify focus area
  - i.e. disease type, symptom type
- Conduct literature review

Identification
- Identify relevant PRO measures

Selection
- Select PROs based on agreed upon criteria

Pilot
- Phase 1 – small single site
- Phase 2 – larger multi-site

Implementation
- Site readiness assessment
- Develop guidelines and tool kits
- Develop patient education strategy
- Create a gradual and planned approach to implementation
- Create a change management and communication plan

Evaluation/Refinement
- Evaluate implementation
- Identify improvement opportunities
Pipeline – EPIC (prostate cancer)

**Prioritization**
- Identify focus area i.e. disease type, symptom type

**Identification**
- Identify relevant PRO measures
- Conduct literature review

**Selection**
- Select PROs based on agreed upon criteria

**Pilot**
- Phase 1 – small single site
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CCO Cancer Care Ontario
EPIC-CP Background and Context

- Currently, ESAS-r is being used in cancer centres as the standard for symptom screening to inform clinical care
  - While ESAS-r is a useful tool for *generic* symptom screening, it does not capture disease-specific concerns or the effects of specific treatments
- EPIC was selected to address the *unique needs* of men with prostate cancer
- EPIC-CP is a 16-item instrument specifically designed for men with prostate cancer that measures symptoms such as:
  - Urinary incontinence
  - Urinary irritation
  - Bowel incontinence
  - Sexual health dysfunction
  - Hormonal
  - Health-Related Quality of Life (HRQOL)
• Conducted in 2012 to test the long-form EPIC measure (26 items) for feasibility and acceptability in one Ontario cancer centre (Kingston)

• Results indicated that:
  • EPIC was endorsed and accepted by both patients and clinicians in radiation review clinics,
  • and that the prostate-specific domains of EPIC were seen as a strength
EPIC-CP Phase II Pilot

- In 2014, funding was provided by Cancer Care Ontario to fund an expanded Phase II Pilot evaluation of EPIC-CP

- EPIC-CP was implemented in four cancer centres across Ontario:
  - Princess Margaret Cancer Centre
  - Cancer Centre of South Eastern Ontario
  - Carlo Fidani Peel Regional Cancer Centre
  - Grand River Regional Cancer Centre

- EPIC-CP was implemented in consult and follow-up clinics in radiation oncology and surgical oncology, as well as treatment review

- Results were extremely positive, with 90% of patients reporting a favourable experience with EPIC-CP
1. Implement EPIC-CP across Ontario in surgical and radiation outpatient consult and follow-up clinics, as well as radiation review clinics.

2. EPIC-CP was superior to ESAS-r in capturing prostate-specific symptoms and treatment impacts for the early stage prostate population. ESAS-r should not be used concurrently for early stage patients. A system should be designed through the technology platform that allows prostate patients to be directed to EPIC-CP in place of ESAS-r.

3. Review and adapt (if necessary) clinic flow processes to integrate EPIC-CP into practice and facilitate its uptake for routine use.

4. Develop training and resources for patients and clinicians that facilitate the interpretation of Patient-Reported Outcome Measures (PROMs) and improve comfort with completing PROMs using technology.
- Official launch date was in October
- New patient, provider, and volunteer resources
  - Includes new Symptom Management Guides for patients and providers
- Implementation package
  - Detailed resource, customizable to each region to prepare sites for launch
- Community of Practice
  - Opportunity for sites within wave to share information and lessons learned
  - Sites preparing to launch in next wave will join the CoP a month before go-live

- Resources solicited input from 95 multidisciplinary representatives and informed the development of 21 training materials
How to Manage Urinary Problems

This guide is for men who have had treatment for prostate cancer. The information here is not meant to replace medical advice. For medical advice, consult your doctor.

Urinary problems are common after treatment for prostate cancer.

This is because:
- Surgery can physically change your urinary system.
- Radiation therapy can:
  - Irritate your bladder and urethra; and
  - Make your prostate gland inflamed or swollen.

Urinary problems can cause:
- An intense (strong) need to urinate often
- Pain or burning while you pee
- A weak urine stream
- You to feel like you cannot fully empty your bladder

Talk to your healthcare team if you have any of these problems. They can help you make a plan to manage them.

Your healthcare team will try to find the cause of your urinary problems.

You may be asked to:
- Keep a journal of when, how often and how much you pee
- Get a urine test to check for infection
- Have other tests to measure the pressure in your bladder, how much urine your bladder can hold, and the flow of your urine

There are some things that you can do at home to help your urinary problems.

**Strengthen your pelvic floor muscles**

These muscles help to hold pee inside your body. Strengthening them will help you be able to hold your pee and put off going to the bathroom.

To strengthen your pelvic floor muscles do this exercise:

1. Squeeze your pelvic floor muscles—a squeeze the muscles like you are holding in your pee or like you are trying not to pass gas.
2. Hold the squeeze for 10 seconds.
3. Relax for 10 seconds.
4. Repeat steps 1 to 3, 10 times.
5. Do a set of 10 exercises 3 to 5 times a day.

Ask your healthcare team for help with these exercises in your next visit.

**Schedule your bathroom breaks**

Try to schedule trips to the toilet every 2 to 3 hours while you are awake.

As this gets easier, slowly increase the time to every 3-4 hours.

**Change your diet**

Avoid drinks or food that can irritate your bladder, like:
- Caffeine (in tea, coffee, cola drinks)
- Alcohol
- Citrus fruits and juices
- Drinks with artificial sweeteners
- Tomatoes and tomato-based products
- Spicy foods

**Plan your fluids**

You may need to plan when you drink your fluids.

For example, if you find that you have to get up in the night to pee, cut back your fluids in the evening.

**Take your medication**

You may need medications for some of your urinary problems.

Medications can help to:

- Relax the muscles around your bladder to make it easier to empty fully.
- Reduce your bladder irritation and make it easier to control how often you have to pee.
- Treat an infection

For more information visit the sites below:

**Prostate Cancer Foundation of Australia**
Website: https://www.prostatefoundation.org.au
Search term: “Understanding urinary problems”

**Prostate Cancer Canada**
Website: https://www.prostatecanada.ca
Search term: “Managing urinary difficulties”
Prostate Cancer (EPIC Questionnaire)

Urinary Irritation/Obstruction

Urinary irritation/obstruction symptoms following prostate cancer treatment include:

- High urinary frequency (including at night)
- Blood in the urine
- Burning with urination
- Urinary retention (difficulty urinating)

Step 1:
Check the patient’s EPIC scores for questions 5a-c. If patients report these symptoms to any degree (score of 1-4), proceed to Step 2.

- Voiding Symptom: Any indication of pain or burning with urination (2-5)
- Storage Symptom: Any indication of a frequent need to urinate (2-5)

Step 2:
Conduct an initial assessment of the nature and severity of symptoms.

A. Take a clinical history (1-4).
   - Symptomatically assess symptoms using the EPIC Acronym (0-3). Obtain a detailed history including:
     - Medical history
     - Comorbidities
     - Current medications
     - Diet and fluid intake (hydration)
     - Physical activity and mobility
     - Environmental factors (privacy, toilet accessibility)
     - Functional activity (activities patients partake in)

B. Conduct a physical examination (1-4).
   - Perform an abdominal examination (palpation, suprapubic distention that may indicate urinary retention,; tenderness)

C. Ask patients to complete a frequency volume chart (1, 3, 4).
   - For patients unable to provide accurate intake/voiding information, the chart assists in obtaining information on:
     - Incontinence episodes
     - Fluid intake
     - Frequency
     - Urgency
     - Typical voiding pattern

D. Do a urine dipstick test (1, 2, 3, 7, 8).

E. Conduct post void residual if equipment is available (2, 3).

Step 3:
Identify treatment steps specific to the patient’s urinary symptoms.

For pain/burning with urination:
- If UUT is confirmed, consider general antibiotics (Expert Opinion).
- Consult an urologist early when a UTI has been ruled out (1, 2, Expert Opinion).

STOP & CONSULT

For a weak urine stream / incomplete bladder emptying:
- Consult an urologist for further assessment and/or treatment (1-3).

STOP & CONSULT

For urinary frequency:
Suggest conservative behavioral or lifestyle interventions as first-line treatment:
- Bladder training (1-4, 6-8): voiding according to a fixed voiding schedule, using distraction and relaxation.
- Fluid management or modification (1-4) for patients with high blood flow with fluid intake.
- Limited caffeine intake may improve symptoms of urgency and frequency (6).
- Consult an urologist if:
  - Symptoms persist or worsen and/or
  - Infection occurs

STOP & CONSULT

Annotated Reference List

Step 2:
Conduct an initial assessment of the nature and severity of symptoms.

a. Take a clinical history.
   - Recommendation 1.1.1 (p. 9)
   - Table 4 (p. 67)
   - Guideline Statement 1 (p. 4)
   - Section 2.1 (p. 106)
   - Section 3.2.1 (p. 31) (Rationale)

b. Conduct a physical examination.
   - Recommendation 1.1.2 (p. 9)
   - Table 4 (p. 67)
   - Guideline Statement 1 (p. 4)
   - Section 2.1 (p. 106)

b. Ask patients to complete a frequency volume chart.
   - Recommendation 1.1.2 (p. 8)
   - Table 4 (p. 67)
   - Section 4.5 (Rationale)
   - Section 2.1.3 (p. 14)

d. Do a urine dipstick test.
   - Recommendation 1.1.4 (p. 9)
   - Table 5 (p. 64)
   - Section 2.4.5 (Expert Opinion)

STOP & CONSULT

Step 3:
Identify treatment steps specific to the patient’s urinary symptoms.

a. Bladder training.
   - Recommendation 1.6.1 (p. 12)
   - Section 3.3.1 (p. 40)

b. Fluid management/modification.
   - Recommendation 1.3.4 (p. 12)

References

Clinical Guide on Bowel Function

How to Use This Guide

Clinical Guide Bowel Function

CancerCareOntario
Future world of PROs in Ontario

- Patients will have symptoms addressed in clinic with a standardized approach
- Symptoms that may have been avoided/missed will be discussed more commonly
- Patients will be able to view their own symptoms over time and compare themselves with patients like them
- We will have PRO data that is reflective of cancer symptoms and treatment toxicity across province which will be a strong driver of quality improvement
How is this program driving quality?
Each regional cancer centre is evaluated on many performance indicators on a quarterly basis.

Compared to their own historical performance and the province as a whole.

\[
\text{# of cancer patients screened with ESAS at least once in a given month} = \frac{\text{# of cancer patients eligible for symptom screening in a given month}}{\text{# of cancer patients screened with ESAS at least once in a given month}}
\]
Public Reporting

Symptom Assessment and Management

Key findings

Cancer Care Ontario collects data on patient symptom screening and the patient experience with symptom management using the Edmonton Symptom Assessment System (ESAS).

The percentage of patients who are screened for symptoms using ESAS has increased from 50% in 2011 to 60% in 2015. Four of 14 regional cancer centres are exceeding Cancer Care Ontario’s target ESAS screening rate of 70%. In total, 361,991 unique patients were screened using ESAS in 2015.

Fifty-five percent (55%) of patients surveyed in 2015 said that their healthcare team always discussed their ESAS scores with them (compared to 31% in 2014).
Symptom Screening Rates

Figure 1: Percentage of cancer patients who were screened at least once per month for symptom severity, by regional cancer centre (RCC), 2011–2015

Cancer Care Ontario program target: 70%

Regional Cancer Centre

2011 2013 2015

Report Date: February 2016
Source: Ontario Cancer Symptom Management Reporting Database. Activity Level Reporting
Prepared by: Analytics and Informatics, Cancer Care Ontario
Public reporting

Figure 4: Percentage of patients who report that their healthcare team talked to them about symptoms of concern on their ESAS, by regional cancer centre (RCC), 2015

- Regional Cancer Centre
  - 2015: Sometimes (%) - 2015: Always (%)

Report Date: February 2016
Source: Symptom Management Patient Experience Survey
Prepared by: Cancer Care Ontario
Chart Audits

Figure 1. Chart Audits conducted using initial Chart Audit Tool

- 7,952 Charts Audited Since 2012
- 2,489 Charts Audited in FY 2015/16
- 72 – 93% of Patients Received Assessments*
- 48 – 79% of Patients Received Interventions

*varies by Regional Cancer Centre (RCC)

Key Shortcomings of the Initial Chart Audit Process

1. Time consuming and burdensome
2. Results are not always actionable
3. Intervention and Assessment data not specific
4. Point-in-time measurement provides a snapshot, not longitudinal data
5. Incomplete data in chart audits submitted to Cancer Care Ontario
6. Some subjective items, which are not relevant and require clinical expertise
7. Unclear if symptom was addressed on previous visit or prioritized by the patient
8. Sampling processes inconsistent across regions, which impacts regional comparison and the robustness of aggregate data
# Chart Audits

<table>
<thead>
<tr>
<th>Date of ESAS screen</th>
<th>ESAS Score</th>
<th>Disease site</th>
<th>Was this audit completed?</th>
<th>Was this the patient's most important symptom?</th>
<th>Was this symptom addressed on the patient's last visit?</th>
<th>Is the symptom mentioned in the provider's documentation?</th>
<th>Which provider gave documentation?</th>
<th>If a conversation with the patient took place, what components of the patient's symptom experience were assessed?</th>
<th>Were additional tests suggested?</th>
<th>Intervention/Management Plan</th>
</tr>
</thead>
</table>

## Refinements to the Chart Audit Tool

1. More succinct and less time consuming
2. Multiple-item drop down menus for each category
3. Specific information on types of Assessments and Interventions
4. Mandatory data fields ensure complete datasets
5. Shift from subjective items requiring clinical expertise to more objective items
6. Addition of question examining the patient’s previous assessments and interventions
7. Addition of question examining whether the patient prioritized the symptom
8. Stipulate that the sampling of charts should be as close to random as possible (e.g., All disease sites), and this deliverable is not to be co-opted for Region-specific purposes that seek to only audit certain patient populations
9. Chart audit no longer measures concordance to Cancer Care Ontario’s Symptom Management Guides
Better supports

**Pain in Adults with Cancer: Care Map**

**Mild Pain Care Pathway 1**

**Moderate Pain Care Pathway 2**

**Severe Pain Care Pathway 3**

**PHARMACOLOGICAL Treatment with non-opioids**
- Acetaminophen and NSAIDs including COX-2 inhibitors should be considered at the lowest effective dose.
- The need for ongoing or long term treatment should be reviewed periodically, if no significant response in one week, drugs should be stopped.
- Long term use of NSAIDs should require gastric mucosa protection.
- There is insufficient evidence to recommend bisphosphonates for first line therapy for pain management.

**Treatment with opioids**
- For mild to moderate pain, weak opioids such as codeine or tramadol could be given in combination with a nonopioid.

**PHARMACOLOGICAL Treatment with opioids**

- If the person is opioid naive:
  - Morphine starting dose is usually 5mg Q4h with 2.5-5mg QH prn for breakthrough pain. For elderly or debilitated patients consider a starting dose of 2.5mg Q4h.
  - Hydromorphone starting dose is 1mg Q4h with 0.5-1mg QH prn for breakthrough pain. For elderly or debilitated patients consider a starting dose of 0.5 mg Q4h.
  - Oxycodone starting dose is 2.5 mg or one half tablet Q4H with 2.5 mg or one half tablet Q2H prn for breakthrough. The lowest dose oxycodone tablets available, either in combination with acetaminophen or alone, contain 5mg of oxycodone, equivalent to ~3-5mg of morphine.
- If the person is taking an opioid:
  - As an immediate release preparation with q4h dosing, increase the regular and breakthrough doses by 25%.
  - As a sustained release opioid, increase this dose by 25%. Change the breakthrough dose to 10% of the regular 24h dose, either q1-2h PRN PO or q30 min PRN subcut.
  - Patients with stable pain and analgesic usage, receiving oral morphine, oxycodone or hydromorphone should

**PHARMACOLOGICAL Treatment with strong opioids**

- If the person is opioid naive: Oral: Morphine 5-10 mg PO q4h and 5mg PO q1h PRN OR Hydromorphone 1.0-2.0 mg PO q4h and 1.0 mg PO q1h PRN OR Subcutaneous: Morphine 1.0 mg subcut q4h & 2.5 mg subcut q30min PRN OR Hydromorphone 0.5 - 1.0 mg subcut q1h & 0.5 mg x PRN.
- If the patient is taking an opioid with q4h dosing, increase regular and breakthrough doses by 25%. Changes from the breakthrough to q1h PRN if PO and q30min PRN.
- If the patient is taking a sustained release opioid, increase dose by 25%. Change the breakthrough dose to 10% of the regular 24h dose, either q1-2h PRN PO or q30 min PRN.
- Titrate the dose every 24h to reflect the previous 24h received.
- If unmanageable opioid-limiting adverse effects are present, dose reduces, myalgias, consider switching opioid and re-titrate or consult palliative care.
- For patients with severe uncontrolled pain consider a switch to an equivalent daily dose of immediate release to allow more rapid titration of dose or switch to a preparation/mln infusion.
- Meperidine and pentazocine should generally not be cancer patients with chronic or acute pain.
- If there is difficulty getting the pain under control consult palliative care.

**SEVERE PAIN CRISIS**
- A severe pain crisis requires prompt use of analgesics.

**How to Manage Your Fatigue**

This patient guide will help you understand:

- What is cancer-related fatigue? pg 2
- What causes cancer-related fatigue? pg 3
- What can I do to manage my fatigue? pg 4
- When should I talk to my health care team? pg 12
- Where can I get more information? pg 14
What have we learned from ESAS data?
Symptom burden in cancer

- Fatigue: 70%
- Anxiety: 55%
- Pain: 50%
- Dyspnea: 45%
- Depression: 40%
- Nausea: 20%

CSQI Index: 2013 CCO Rating
Fig 1. Mean Edmonton Symptom Assessment System (total symptom distress score [TSDS]) and Palliative Performance Scale (PPS) score. (*) Values below data points represent the total number of complete assessments available at a given week. Bars represent 95% CIs for the respective mean scores.
Fig 2. Mean Edmonton Symptom Assessment System (ESAS) symptom scores over time. Number of assessments is maximum number available among all nine symptoms. Missing ESAS values for a given symptom were not included when calculating the mean.
Outcomes from High Symptom Burden

Odds Ratio of Visiting an ER within 7 Days of an ESAS Assessment by Symptom Severity

Figure 1. Pain and shortness of breath outcomes for all patient visits. ESAS, Edmonton Symptom Assessment Scale. (*) Sample size by ESAS score category: pain: 0 (n = 263), 1-3 (n = 236), 4-6 (n = 221), 7-10 (n = 192); shortness of breath: 0 (n = 242); 1-3 (n = 228); 4-6 (n = 226); 7-10 (n = 216).
Opioid use in cancer patients with pain

Search for opioid prescriptions in provincial formulary database

Table 1. Proportion of Patients Receiving an OP by Pain Score Severity

<table>
<thead>
<tr>
<th>OP Use</th>
<th>Pain Score (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 (n = 9,044)</td>
</tr>
<tr>
<td>OP 0-7 days after assessment</td>
<td>2.8</td>
</tr>
<tr>
<td>OP 30-0 days before assessment</td>
<td>7.2</td>
</tr>
<tr>
<td>No OP 30 days before or 7 days after</td>
<td>90.0</td>
</tr>
</tbody>
</table>

Abbreviation: OP, opioid prescription.
Did routine ESAS symptom screening decrease ED visits in breast cancer patients on adjuvant chemotherapy?

**Objective**

- RCTs have demonstrated improved patient satisfaction and communication
- Being adopted by many large centres
- In breast cancer many regimens are toxic and high rates of ED visits have been reported (42-60%)

**Hypothesis**

- to evaluate the impact of screening with ESAS through OCSMC on ED visit rates in women with breast cancer receiving adjuvant chemotherapy
- that when women are screened with ESAS as part of the screening program, they would experience fewer ED visits, presumably on the basis of improved symptom control
Inclusion criteria
Adult
Stage I-III Breast cancer
2007-2009
On adjuvant chemotherapy

Control for
• Age
• stage
• comorbidity
• chemo regimen
• neighbourhood income
• region
• total number of clinic visits

Exposure
ESAS

Outcome
ED visits

Recurrent event model
The rate of ED visits was 43% lower among women screened with ESAS compared to those who were not.

Each additional ESAS assessment decreased the ED visit rate by 17%.

Table 3: Univariate and adjusted model results for relative rate of ED visit

<table>
<thead>
<tr>
<th>Variable</th>
<th>Value</th>
<th>Univariate</th>
<th>Adjusted ESAS (Y/N)</th>
<th>Adjusted ESAS (Continuous)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>RR</td>
<td>LCL</td>
<td>UCL</td>
<td>RR</td>
</tr>
<tr>
<td>Age</td>
<td>Continuous</td>
<td>1.00</td>
<td>1.00</td>
<td>1.01</td>
</tr>
<tr>
<td>Income quintile</td>
<td>1</td>
<td>1.26</td>
<td>1.13</td>
<td>1.40</td>
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<td></td>
<td>2</td>
<td>1.16</td>
<td>1.04</td>
<td>1.28</td>
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<td>3</td>
<td>1.24</td>
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<td>1.11</td>
<td>1.01</td>
<td>1.22</td>
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<tr>
<td></td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>1</td>
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<td>0</td>
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<td>1.22</td>
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<td>1.14</td>
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<td>1.99</td>
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<td>0.49</td>
<td>0.52</td>
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<tr>
<td>CP visit</td>
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<tr>
<td>Prior ED</td>
<td>Continuous</td>
<td>1.41</td>
<td>1.35</td>
<td>1.46</td>
</tr>
<tr>
<td>ESAS exposure</td>
<td>Yes</td>
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<td>0.55</td>
<td>0.64</td>
</tr>
<tr>
<td></td>
<td>No</td>
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<td>1</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Continuous</td>
<td>0.84</td>
<td>0.82</td>
<td>0.86</td>
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</tbody>
</table>

Exposure to ESAS during chemotherapy is defined alternately as either as a dichotomous (Y/N) or continuous variable (model also adjusted for region). RR relative rate, LCL lower confidence limit, UCL upper confidence limit, RO radiation oncologist, CT chemotherapy, CP chemotherapy provider.

Source: Barbera et al, 2015 Support Care Cancer
Limitations of the data

- Repeated measures, but do not occur at set times
- Almost exclusively in the ambulatory setting
- Not every patient reports on every visit, bias probably exists, but direction could be either way

Future research directions

- Opioid prescribing in long term survivors
- Impact of screening program on service use
- Symptom profiles by disease type, stage, treatment
- Implication of missing data and inconsistent data timing on using ESAS as an outcome measurement
Conclusions

PROs represent a paradigm shifting approach to facilitate patient centered care

• They can be used at the bedside to identify problems, trigger discussions and help prioritize certain areas
• At a population level they have administrative and policy applications

PROs are embedded within CCO’s strategic planning
Future vision to have all patients screened with generic and disease specific measures

Data available has been used to understand symptom burden, how it predicts for service use
Need to understand how to use this data better as an outcome