CCO Cancer Care Ontario

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

DR. LISA BARBERA
SEPTEMBER 19, 2017
UNC

Ontario
Cancer Care Ontario

Objectives

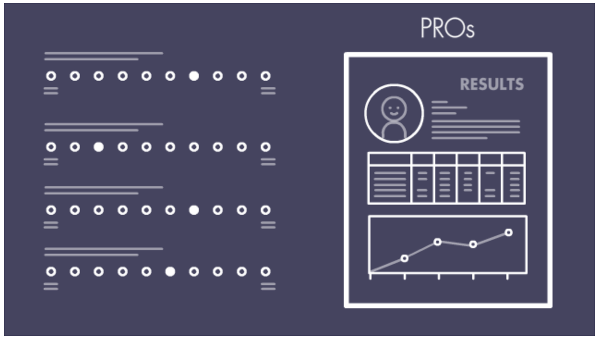
1. To describe the Patient Reported Outcome (PRO) Program at Cancer Care Ontario (CCO)
2. To describe how this is being used to drive quality of care
3. To describe how the data has been used in research

Patient Reported Outcome Measures (PROMs)

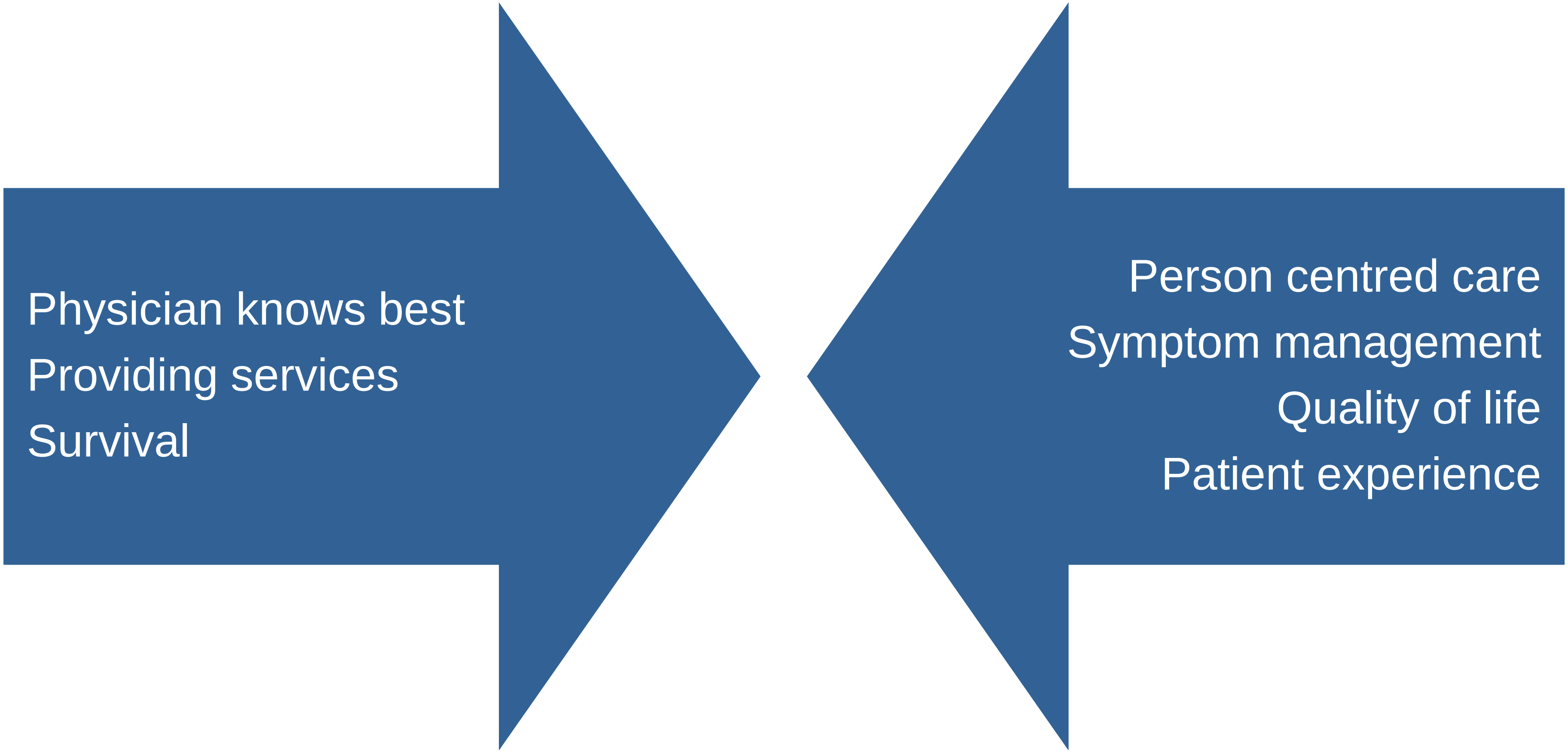
A Patient Reported Outcome (PRO) is a validated measure that provides a comprehensive picture on the impact of cancer and treatment from the patient perspective.

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?

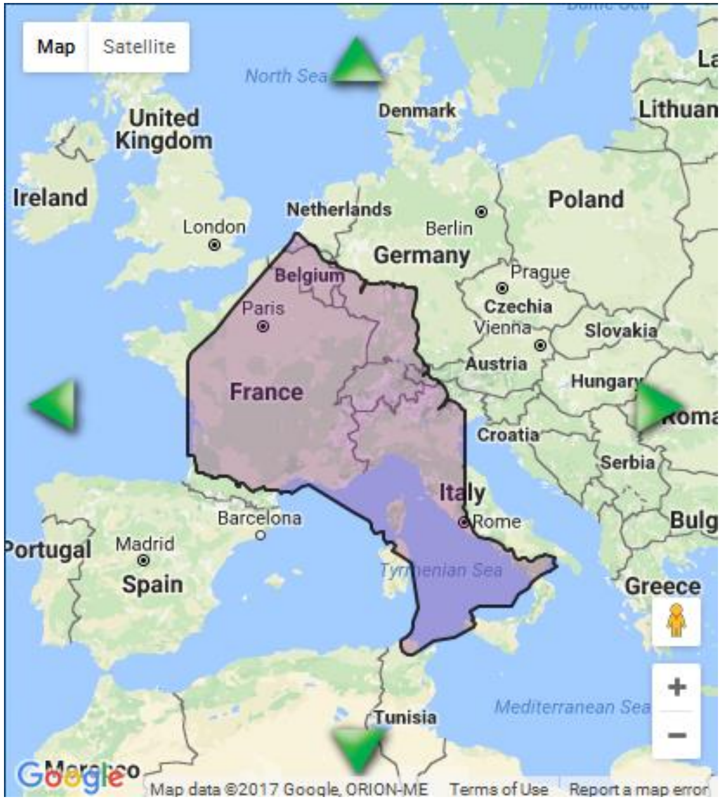
- Agency of the government accountable to the provincial ministry of health

- Provincial government's advisor on the cancer system and access to key services

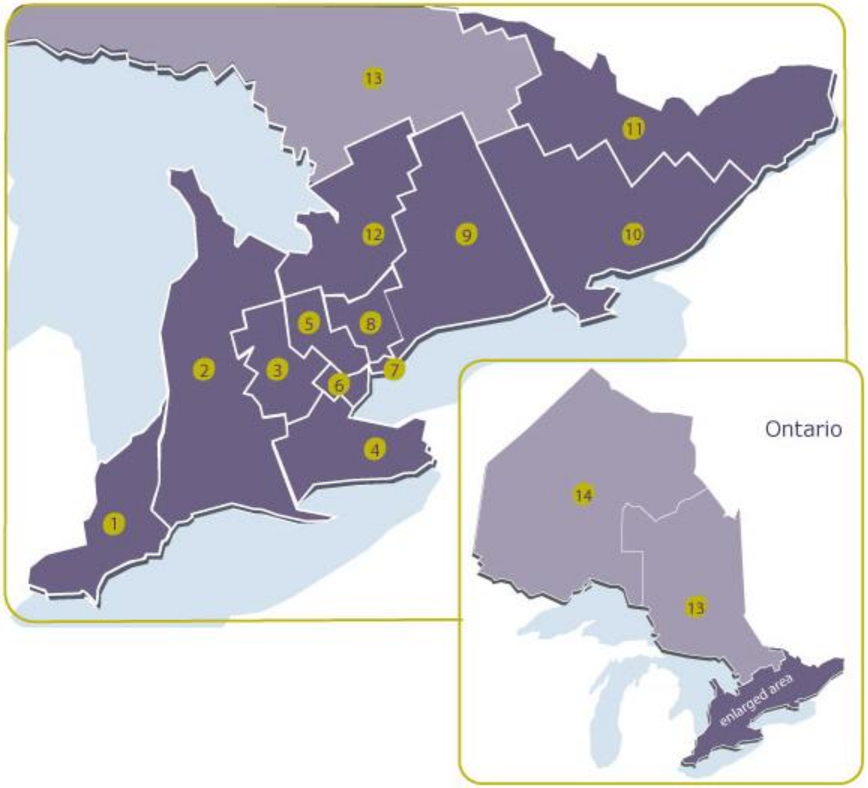
    - leads multi-year system planning
    - contracts for services with hospitals and providers
    - deploys information systems
    - establishes guidelines and standards
    - tracks performance targets

What is Cancer Care Ontario?

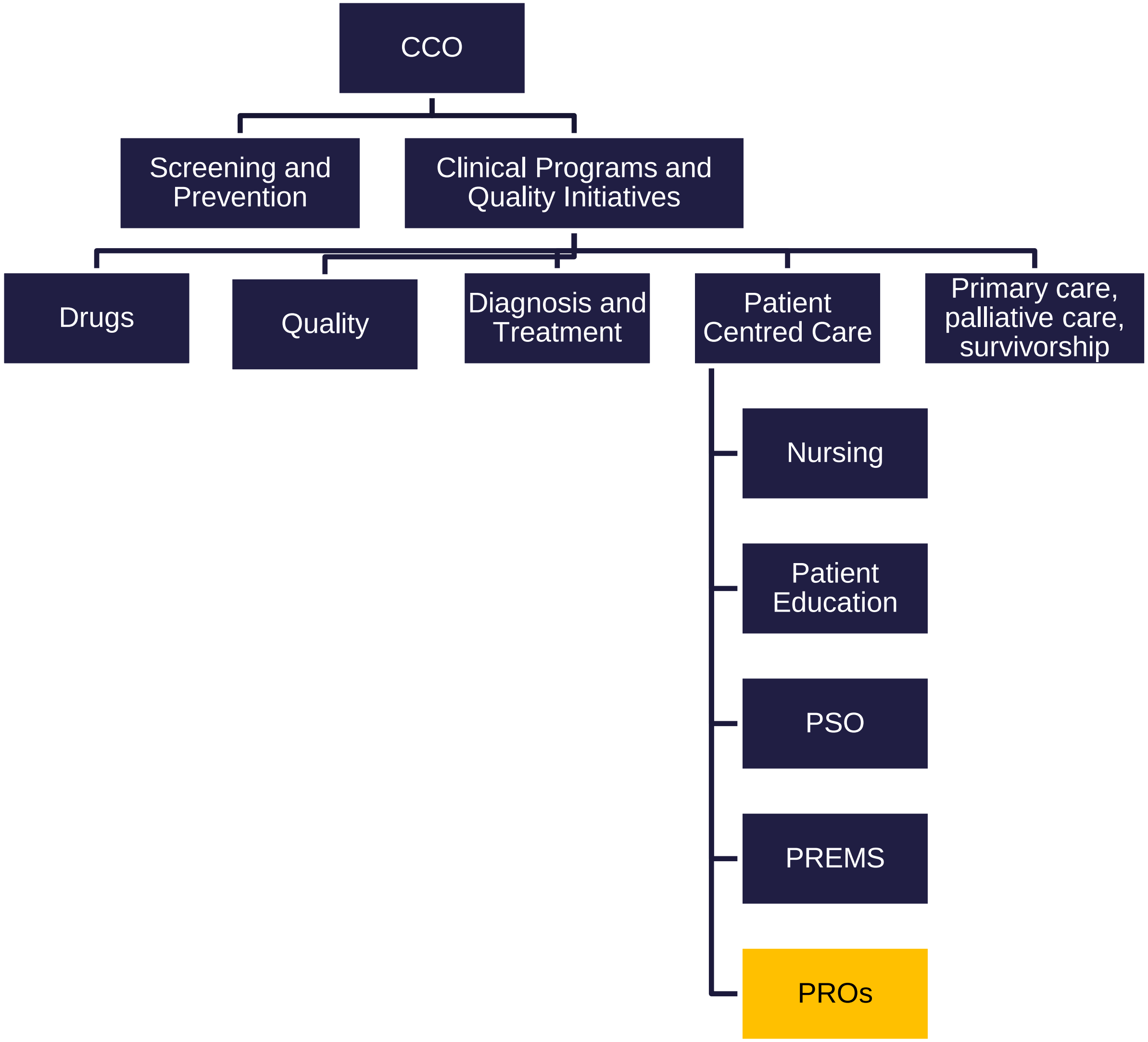
- Ontario population is ~14M



Cancer System Map



1 Erie St. Clair Cancer Program
2 South West Regional Cancer Program
3 Waterloo Wellington Regional Cancer Program
4 Hamilton Niagara Haldimand Brant Regional Cancer Program
5&6 Mississauga Halton/Central West Regional Cancer Program
7 Toronto Central Regional Cancer Program
8 Central Regional Cancer Program
9 Central East Regional Cancer Program
10 South East Regional Cancer Program
11 Champlain Regional Cancer Program
12 North Simcoe Muskoka Regional Cancer Program
13 North East Regional Cancer Program
14 North West Regional Cancer Program



CCO

Screening and Prevention

Clinical Programs and Quality Initiatives

Drugs

Quality

Diagnosis and Treatment

Patient Centred Care

Primary care, palliative care, survivorship

Nursing

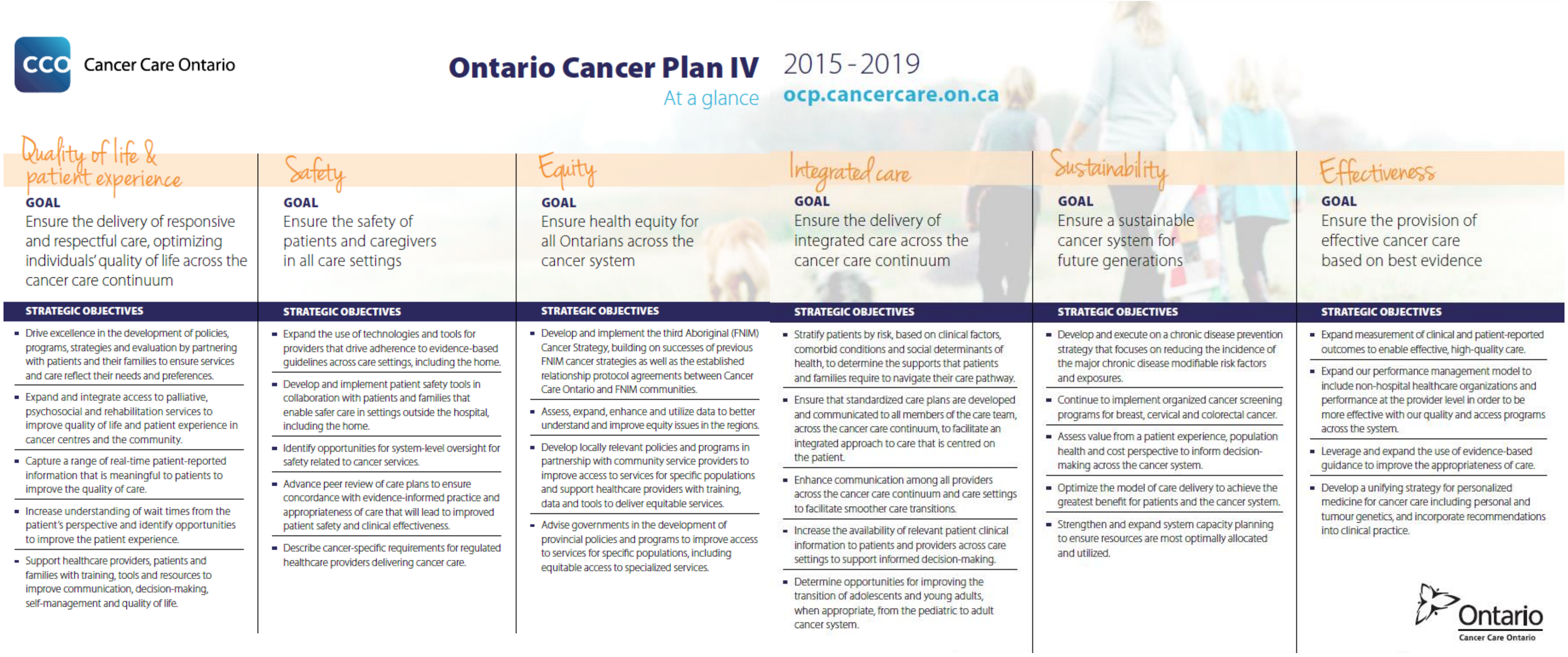
Patient Education

PSO

PREMS

PROs

Cancer Care Ontario



Cancer Care Ontario

Ontario Cancer Plan IV

2015 - 2019

At a glance

ocp.cancercare.on.ca

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.

Safety

GOAL

Ensure the safety of patients and caregivers in all care settings

STRATEGIC OBJECTIVES

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

Equity

GOAL

Ensure health equity for all Ontarians across the cancer system

STRATEGIC OBJECTIVES

- Develop and implement the third Aboriginal (FNIM) Cancer Strategy, building on successes of previous FNIM cancer strategies as well as the established relationship protocol agreements between Cancer Care Ontario and FNIM communities.
- Assess, expand, enhance and utilize data to better understand and improve equity issues in the regions.
- 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.
- Advise governments in the development of provincial policies and programs to improve access to services for specific populations, including equitable access to specialized services.

Integrated care

GOAL

Ensure the delivery of integrated care across the cancer care continuum

STRATEGIC OBJECTIVES

- Stratify 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 pathway.
- 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 centred on the patient.
- Enhance communication among all providers across the cancer care continuum and care settings to facilitate smoother care transitions.
- Increase the availability of relevant patient clinical information to patients and providers across care settings to support informed decision-making.
- Determine opportunities for improving the transition of adolescents and young adults, when appropriate, from the pediatric to adult cancer system.

Sustainability

GOAL

Ensure a sustainable cancer system for future generations

STRATEGIC OBJECTIVES

- 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.
- Continue to implement organized cancer screening programs for breast, cervical and colorectal cancer.
- Assess value from a patient experience, population health and cost perspective to inform decision-making across the cancer system.
- Optimize the model of care delivery to achieve the greatest benefit for patients and the cancer system.
- Strengthen and expand system capacity planning to ensure resources are most optimally allocated and utilized.

Effectiveness

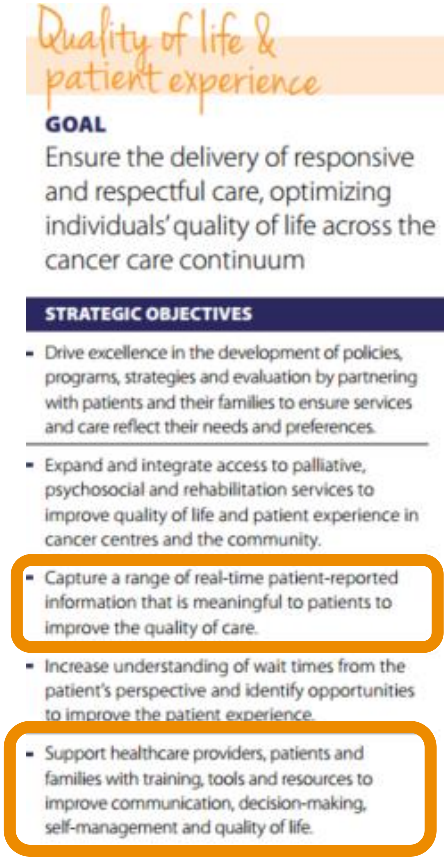
GOAL

Ensure the provision of effective cancer care based on best evidence

STRATEGIC OBJECTIVES

- Expand measurement of clinical and patient-reported outcomes to enable effective, high-quality care.
- 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.
- 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



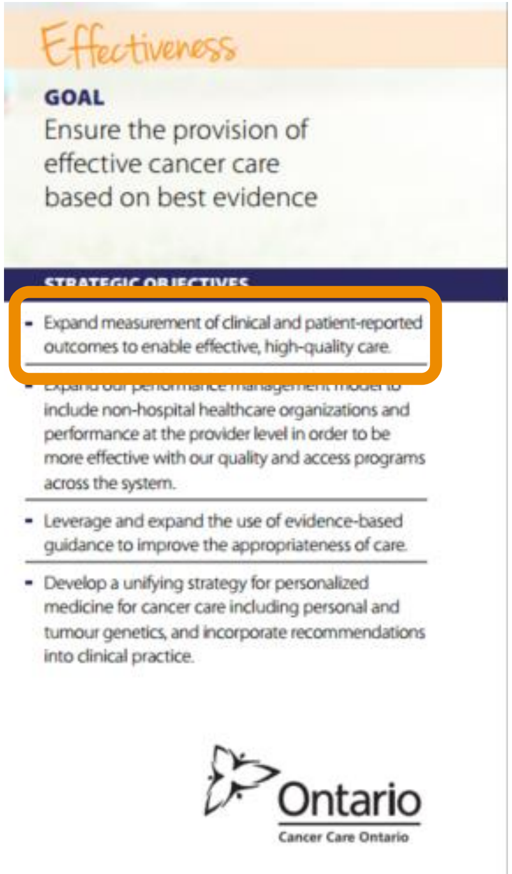
Quality of life & patient experience

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

GOAL

Ensure the provision of effective cancer care based on best evidence

STRATEGIC OBJECTIVES

- Expand measurement of clinical and patient-reported outcomes to enable effective, high-quality care.
- 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.
- 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

Patient-Reported Outcomes and Symptom Management Program

STRATEGIC FRAMEWORK 2016-2019

What is the CCO PRO Program?

Over the years:

Ontario's Progress in Patient Reported Outcomes and Symptom Management

2005-2006

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

2007

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

2008 - 2012

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

2013-2015

- 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

2016-2019

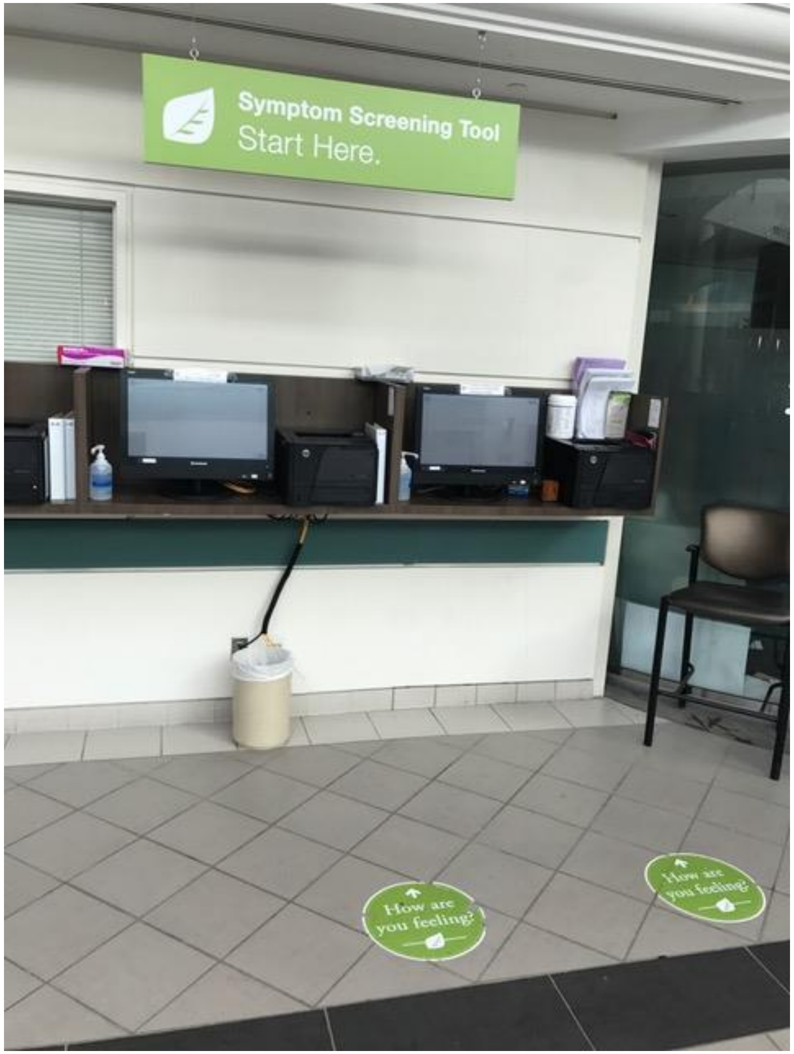
- Program Strategic Framework to guide work
- EPIC implementation

Your Symptoms Matter

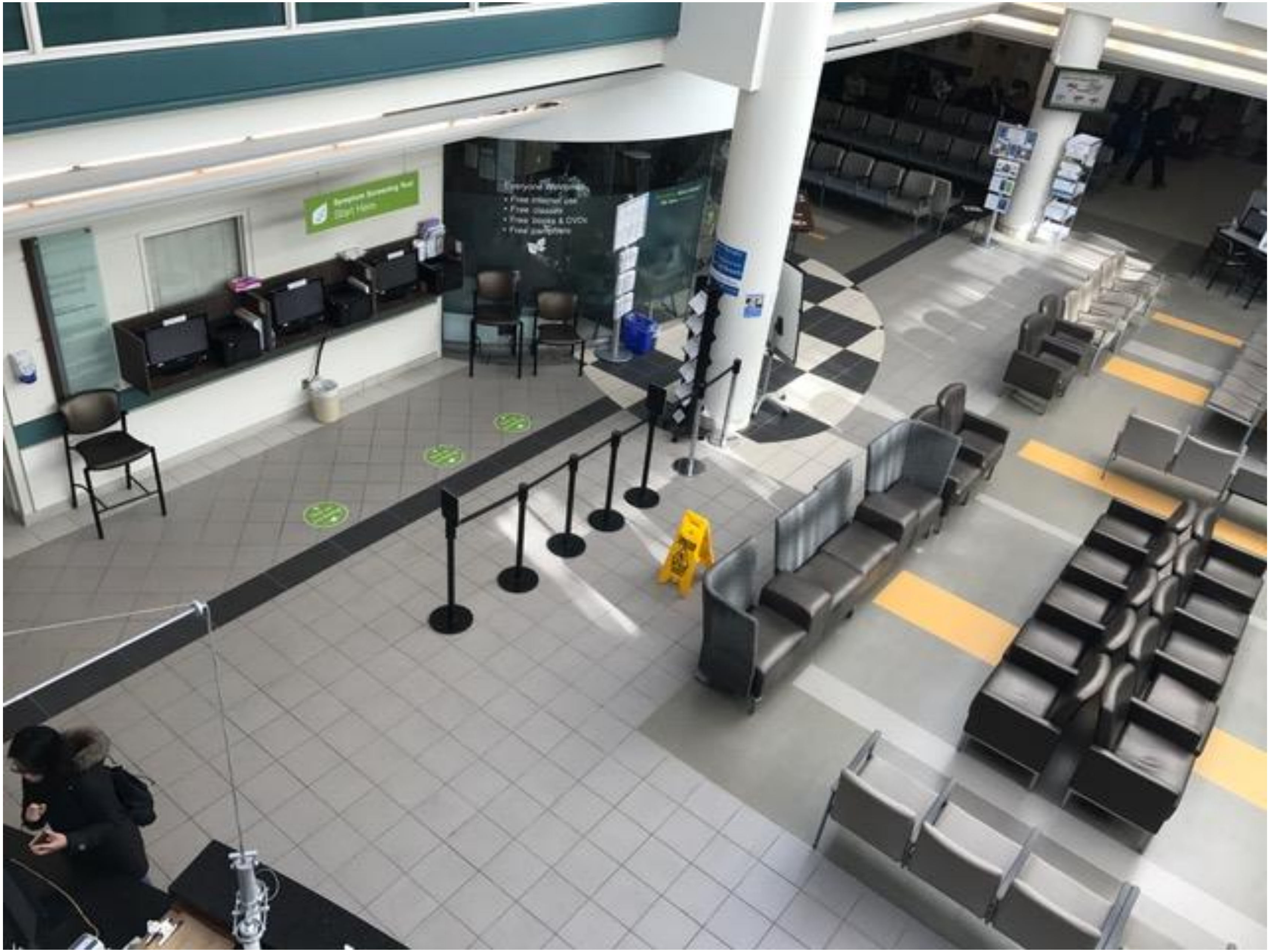
Edmonton Symptom Assessment System-Revised:
(ESAS-R)

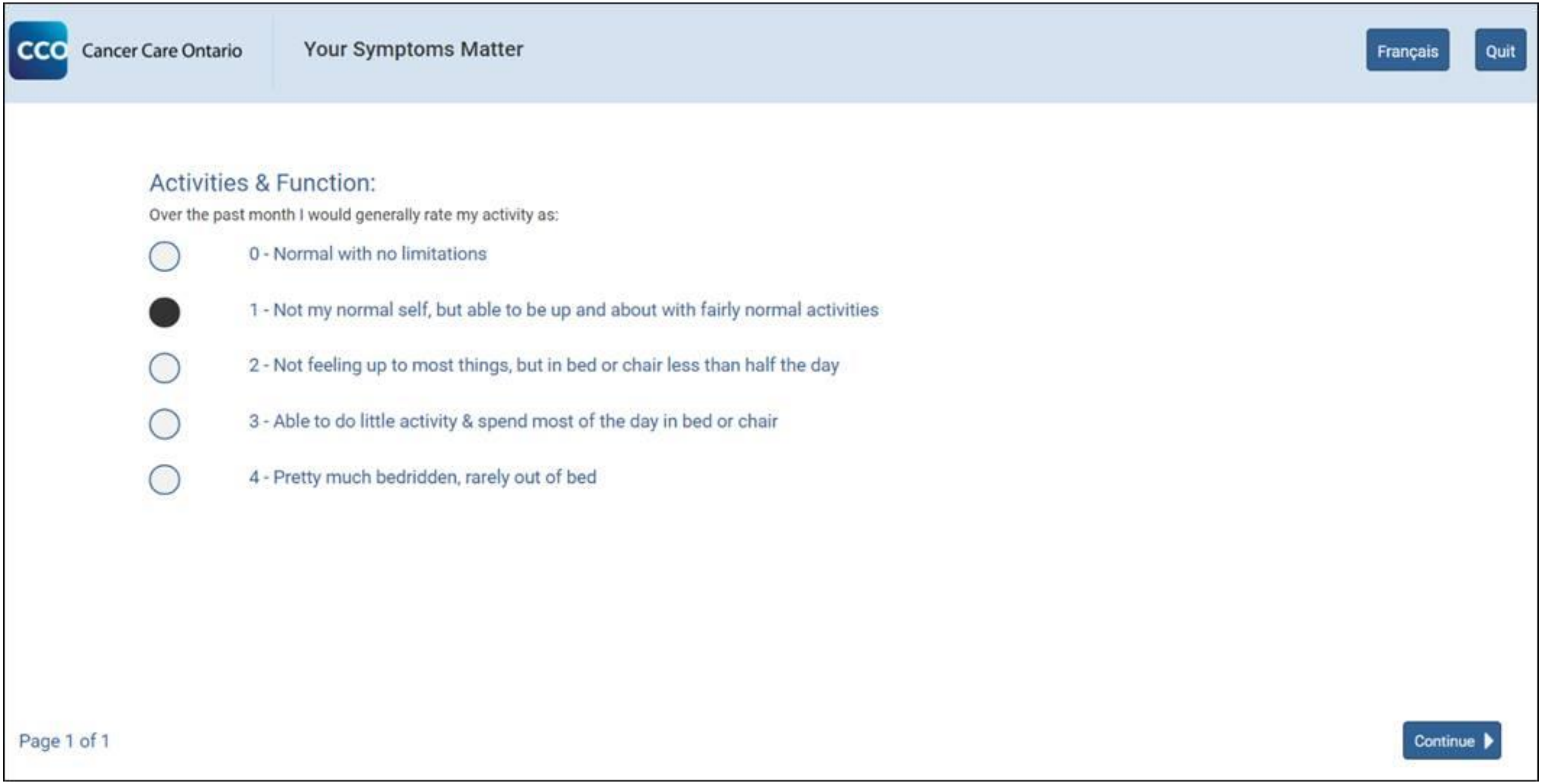
Please circle the number that best describes how you feel NOW:

No Pain	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Pain
No Tiredness *(Tiredness = lack of energy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Tiredness
No Drowsiness *(Drowsiness = feeling sleepy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Drowsiness
No Nausea	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Nausea
No Lack of Appetite	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Lack of Appetite
No Shortness of Breath	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Shortness of Breath
No Depression *(Depression = feeling sad)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Depression
No Anxiety *(Anxiety = feeling nervous)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Anxiety
Best Wellbeing *(Wellbeing = how you feel overall)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Wellbeing
No Other Problem *(for example constipation)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible


Symptom Screening Tool
Start Here.
How are you feeling?
How are you feeling?


Symptom Screening Tool
Cancer Care Ontario


Symptom Screening Tool
Start Here
Everyone Welcome
• Free internet use
• Free classes
• Free books & DVDs
• Free pamphlets



Activities & Function:

Over the past month I would generally rate my activity as:

○ 0 - Normal with no limitations

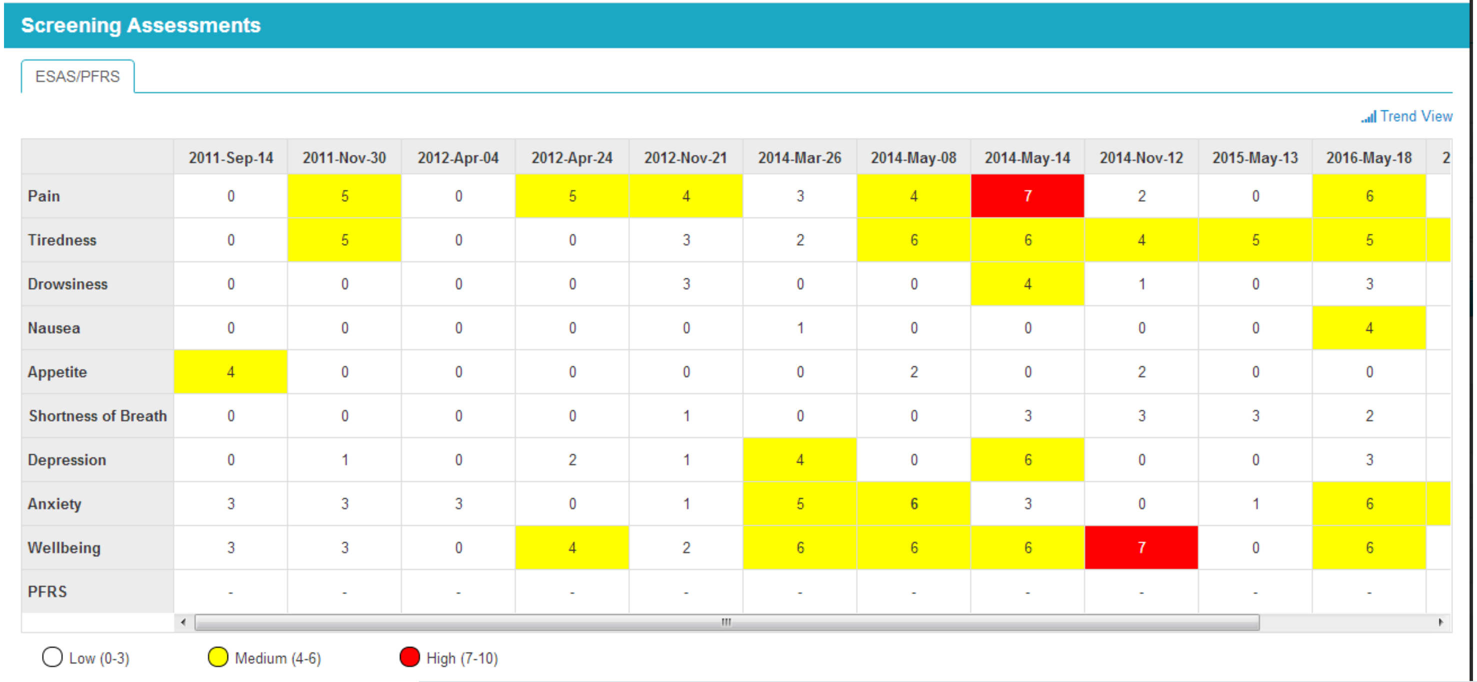
● 1 - Not my normal self, but able to be up and about with fairly normal activities

○ 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

Page 1 of 1



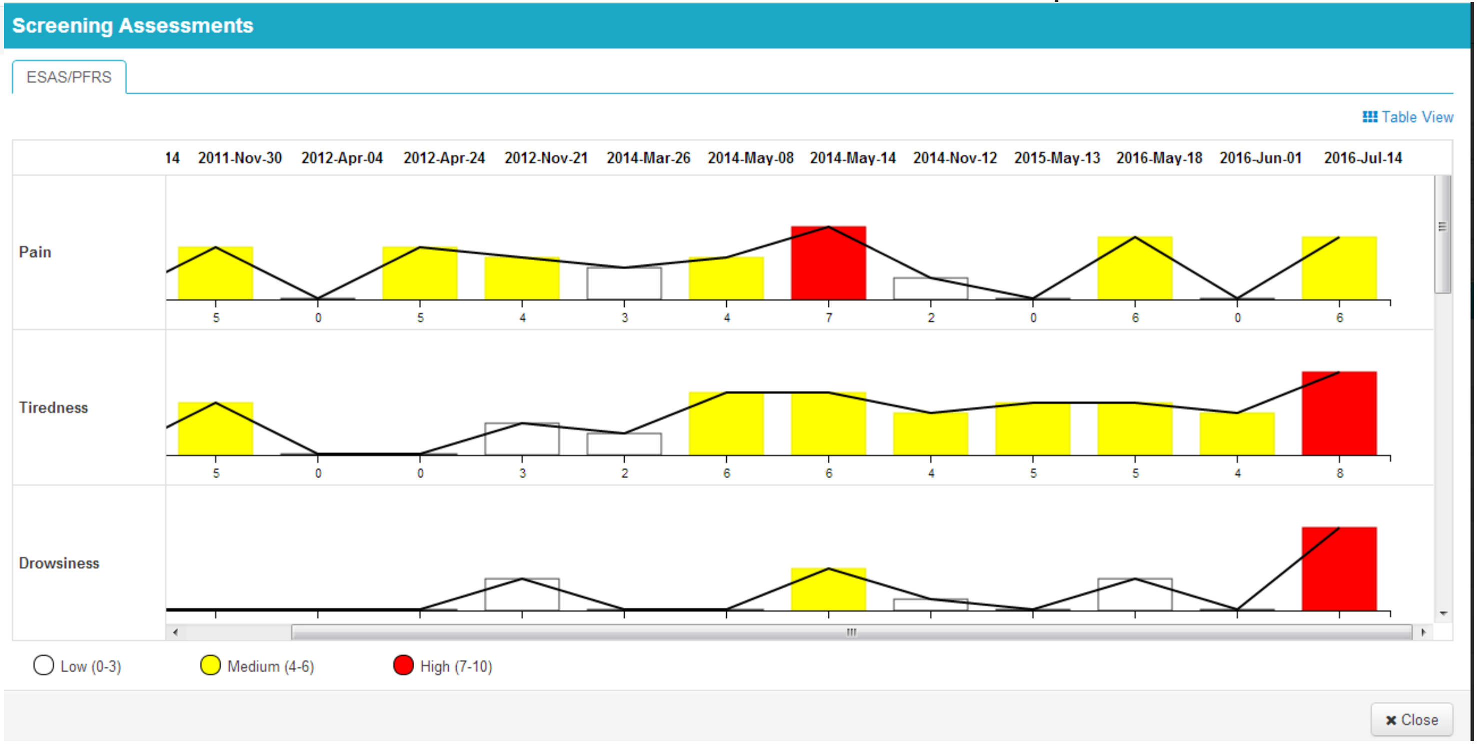
Screening Assessments

ESAS/PFRS

Trend View

	2011-Sep-14	2011-Nov-30	2012-Apr-04	2012-Apr-24	2012-Nov-21	2014-Mar-26	2014-May-08	2014-May-14	2014-Nov-12	2015-May-13	2016-May-18
Pain	0	5	0	5	4	3	4	7	2	0	6
Tiredness	0	5	0	0	3	2	6	6	4	5	5
Drowsiness	0	0	0	0	3	0	0	4	1	0	3
Nausea	0	0	0	0	0	1	0	0	0	0	4
Appetite	4	0	0	0	0	0	2	0	2	0	0
Shortness of Breath	0	0	0	0	1	0	0	3	3	3	2
Depression	0	1	0	2	1	4	0	6	0	0	3
Anxiety	3	3	3	0	1	5	6	3	0	1	6
Wellbeing	3	3	0	4	2	6	6	6	7	0	6
PFRS	-	-	-	-	-	-	-	-	-	-	-

○ Low (0-3) 🟡 Medium (4-6) 🔴 High (7-10)



Screening Assessments

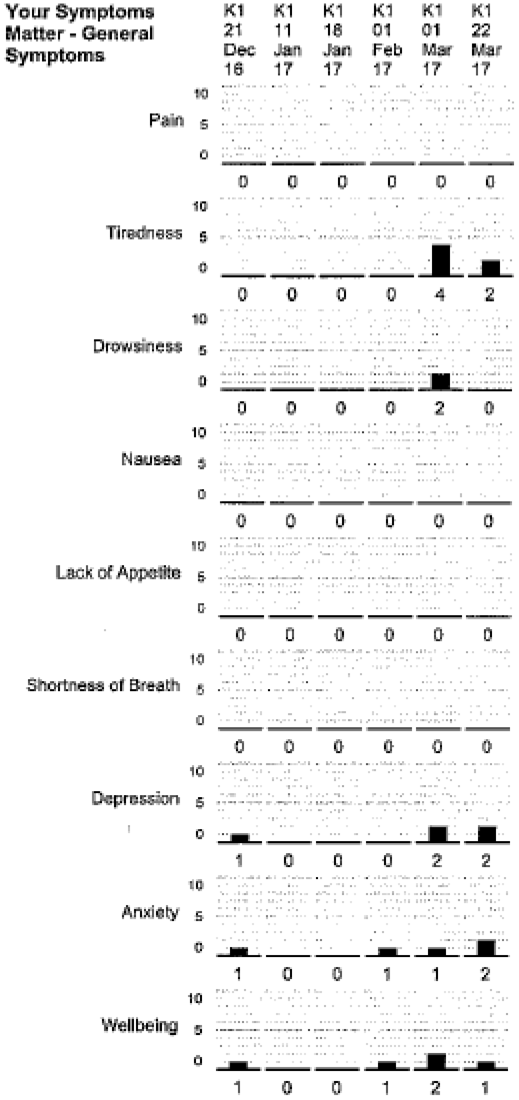
ESAS/PFRS

Table View

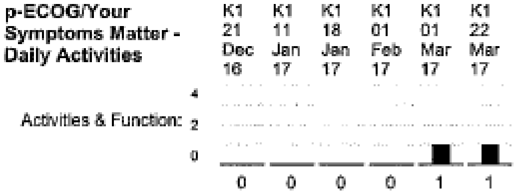
○ Low (0-3) 🟡 Medium (4-6) 🔴 High (7-10)

✖ Close

Your Symptoms Matter - General Symptoms

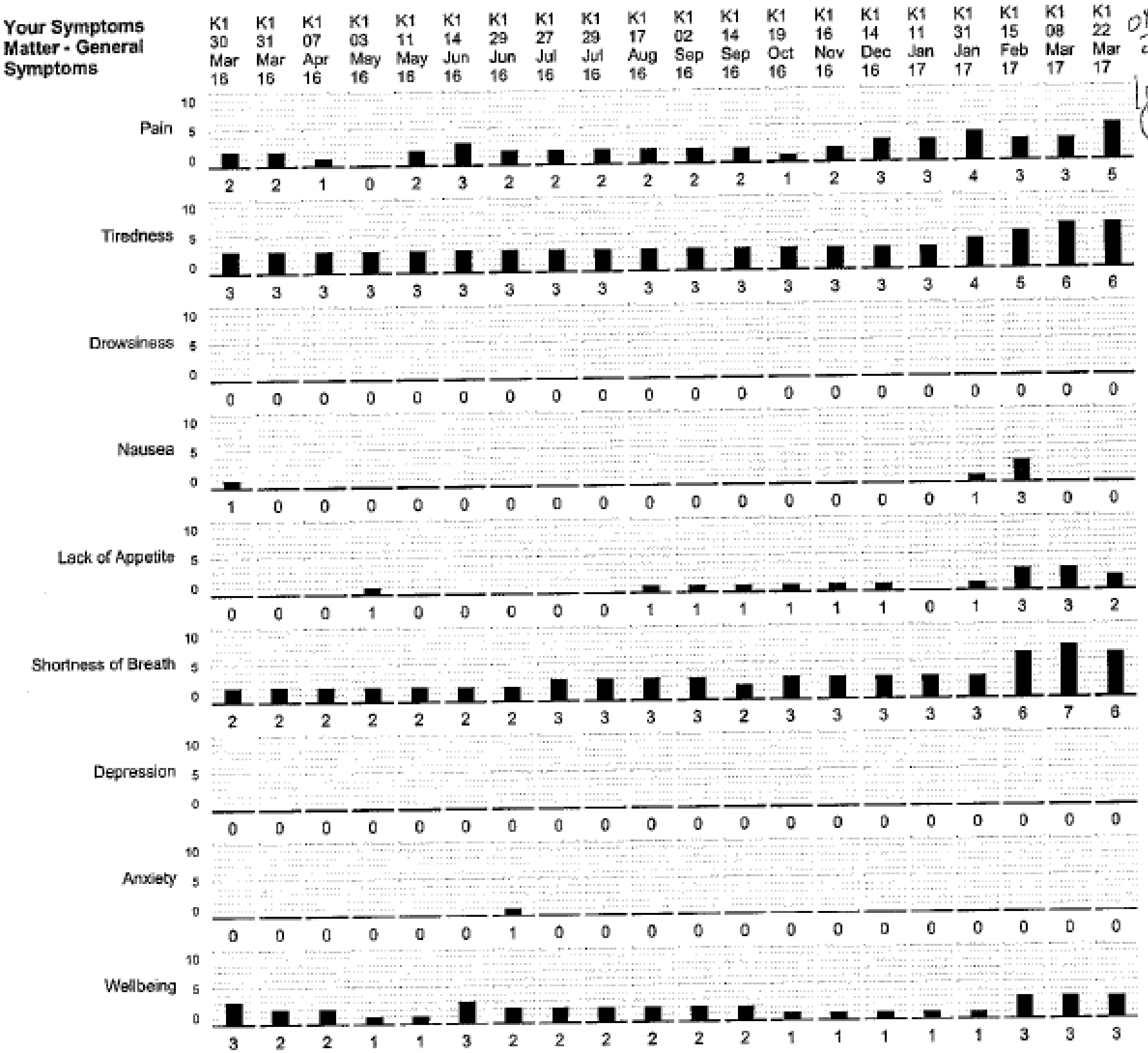


p-ECOG/Your Symptoms Matter - Daily Activities



Please remember to talk to your doctor or nurse about any concerns you may have no matter how small they may seem

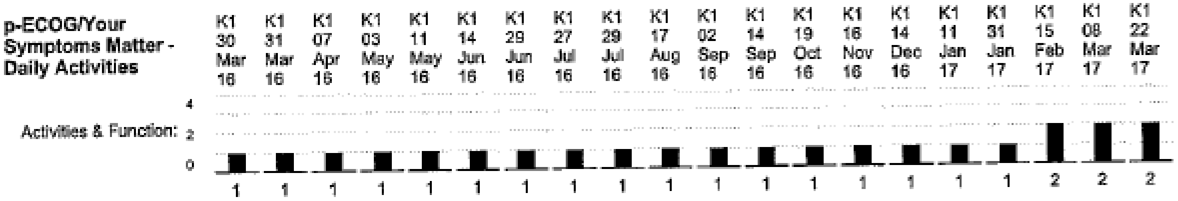
Your Symptoms Matter - General Symptoms



oxy c̄ relief

Lower Ⓛ back + abd

p-ECOG/Your Symptoms Matter - Daily Activities



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	Issues of wellbeing	Depression
75%	**71%**	**50%**

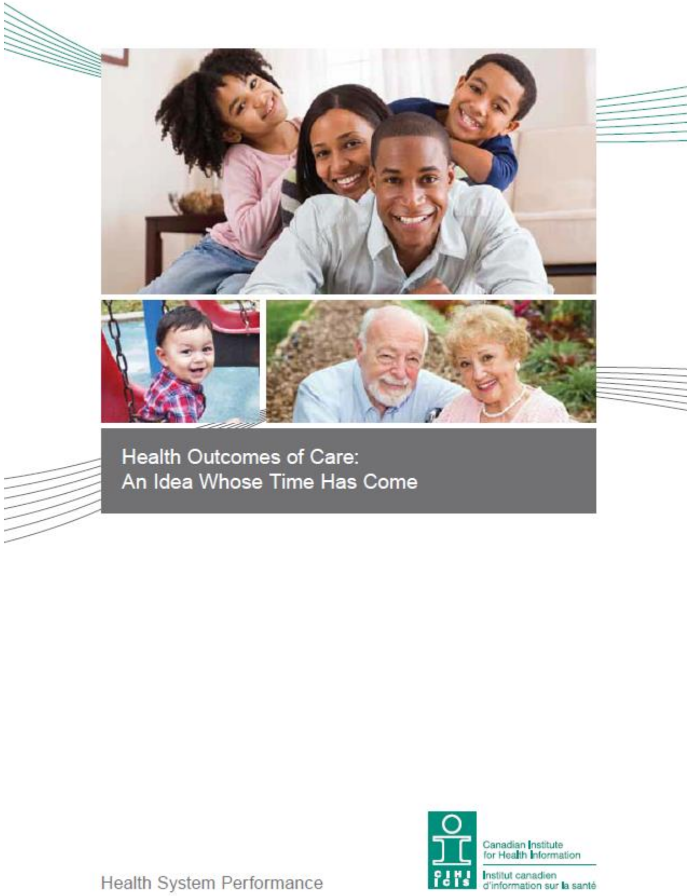
What do patients report?

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

CCO Cancer Care Ontario

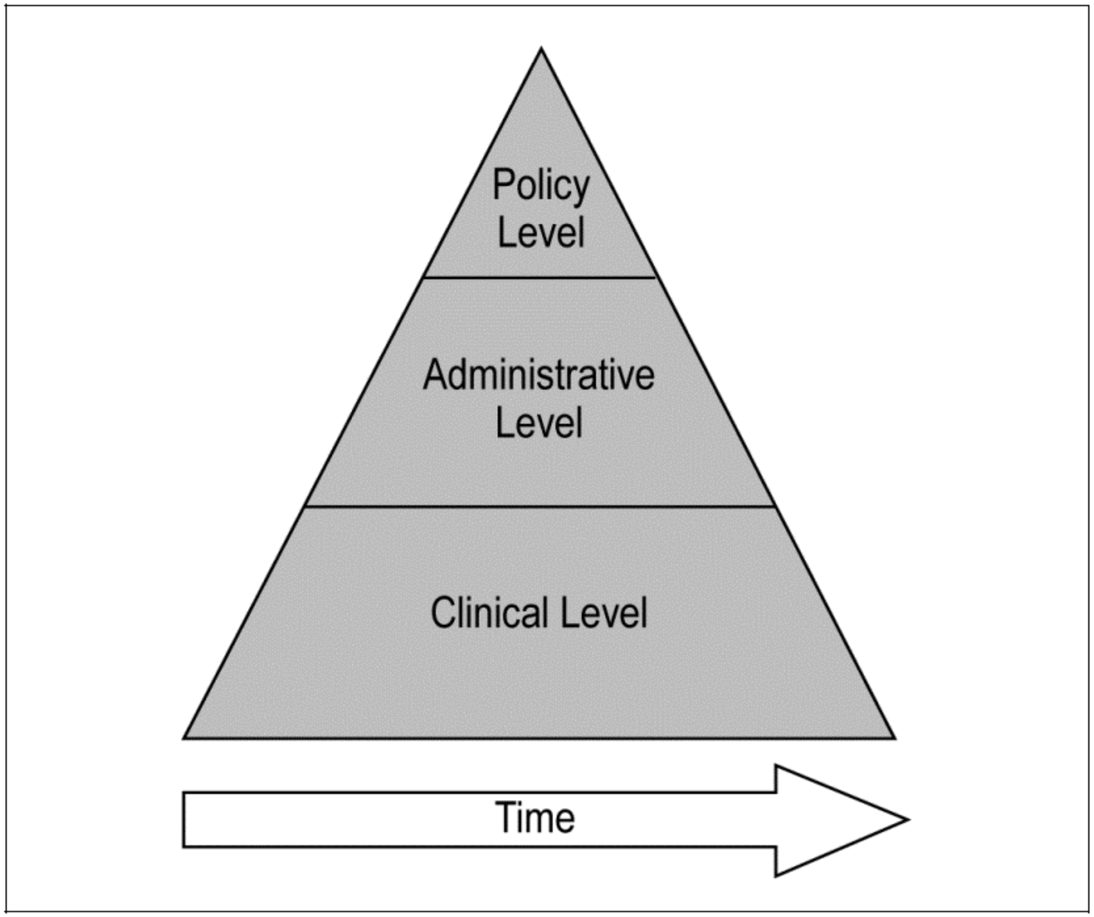


Health Outcomes of Care:
An Idea Whose Time Has Come

Health System Performance

Canadian Institute for Health Information
Institut canadien d'information sur la santé

Figure 1: Information Pyramid—Integrated Health Outcomes Information



Strategic Framework

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

> "My hope is the framework will assist me in the getting the assistance I need to manage lymphedema – I suffer with this on a daily basis. My hope is that someone will pay attention to symptoms for this earlier in the trajectory of treatment for cancers like mine. That services will be offered sooner to the patient. That other patients will not have to wait as long as I have to get the support and services needed to manage their symptoms. That hospitals will partner with the community to give these much needed services to patients when they need them and are affordable."
>
> – Joanne M., CCO Patient and Family Advisory Council member

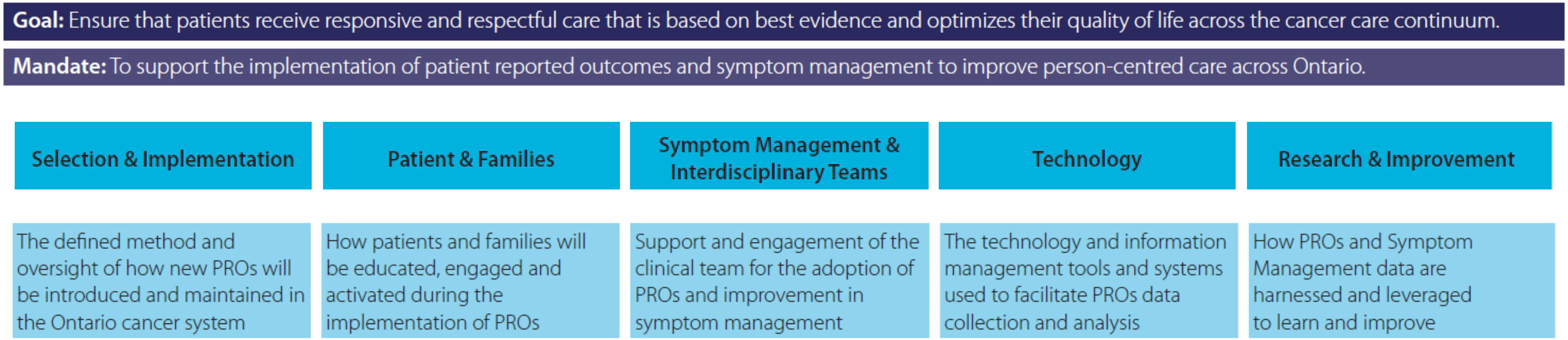
> "It is important through the journey for the patient and caregiver to understand what to expect, how to mitigate, how to cope, and when it's necessary to seek immediate medical attention (i.e., what is 'normal' vs. what is life threatening). Cancer can make one feel powerless: if one is at least able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

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.

Strategic Framework



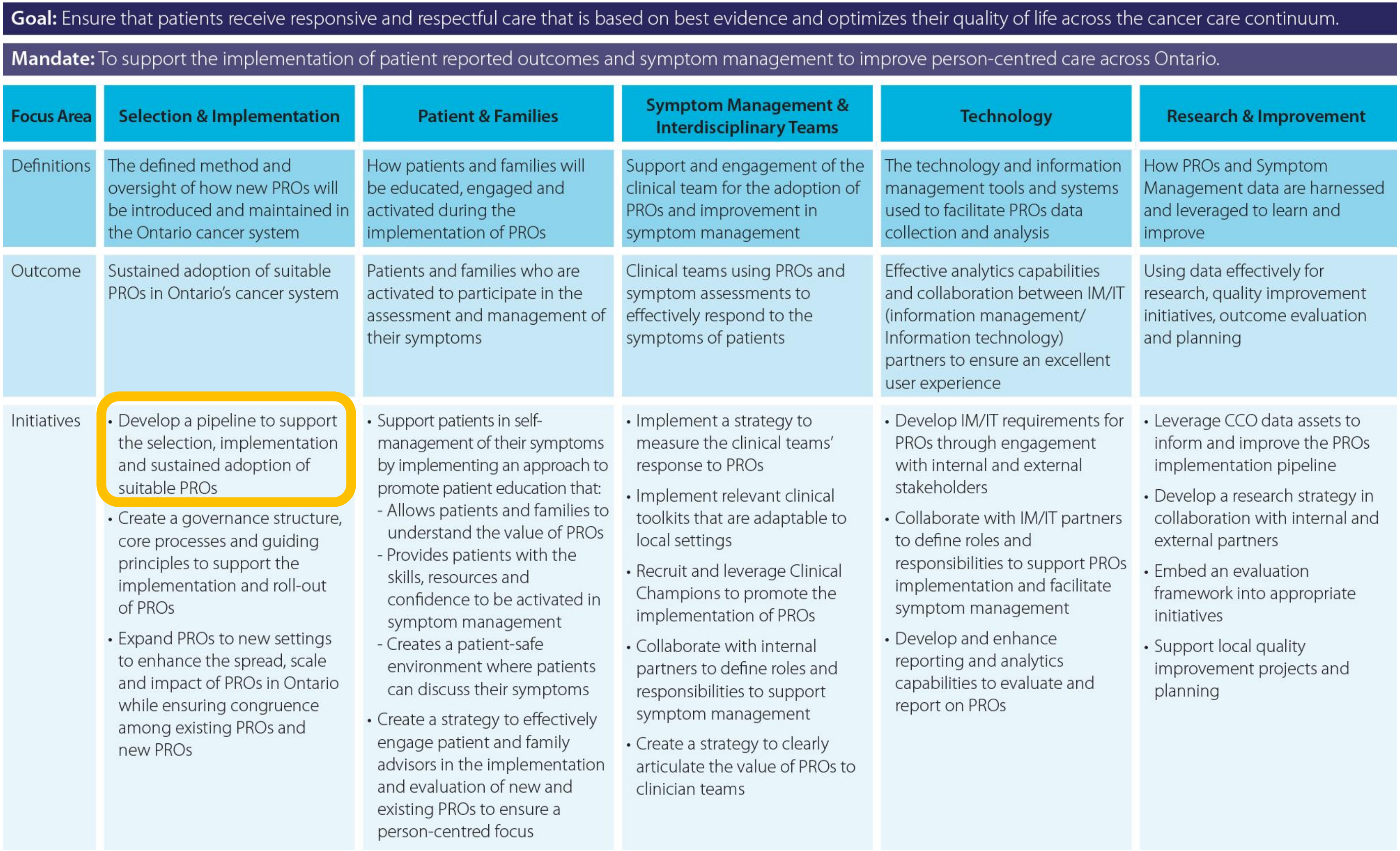
Goal: Ensure that patients receive responsive and respectful care that is based on best evidence and optimizes their quality of life across the cancer care continuum.

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

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

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.

Focus Area	**Selection & Implementation**	**Patient & Families**	**Symptom Management & Interdisciplinary Teams**	**Technology**	**Research & Improvement**
Definitions	The defined method and oversight of how new PROs will be introduced and maintained in the Ontario cancer system	How patients and families will be educated, engaged and activated during the implementation of PROs	Support and engagement of the clinical team for the adoption of PROs and improvement in symptom management	The technology and information management tools and systems used to facilitate PROs data collection and analysis	How PROs and Symptom Management data are harnessed and leveraged to learn and improve
Outcome	Sustained adoption of suitable PROs in Ontario's cancer system	Patients and families who are activated to participate in the assessment and management of their symptoms	Clinical teams using PROs and symptom assessments to effectively respond to the symptoms of patients	Effective analytics capabilities and collaboration between IM/IT (information management/ Information technology) partners to ensure an excellent user experience	Using data effectively for research, quality improvement initiatives, outcome evaluation and planning
Initiatives	• Develop a pipeline to support the selection, implementation and sustained adoption of suitable PROs • Create a governance structure, core processes and guiding principles to support the implementation and roll-out of PROs • Expand PROs to new settings to enhance the spread, scale and impact of PROs in Ontario while ensuring congruence among existing PROs and new 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

Cancer Care Ontario

Pipeline

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

Identification
- Identify relevant PRO measures
- Conduct literature review

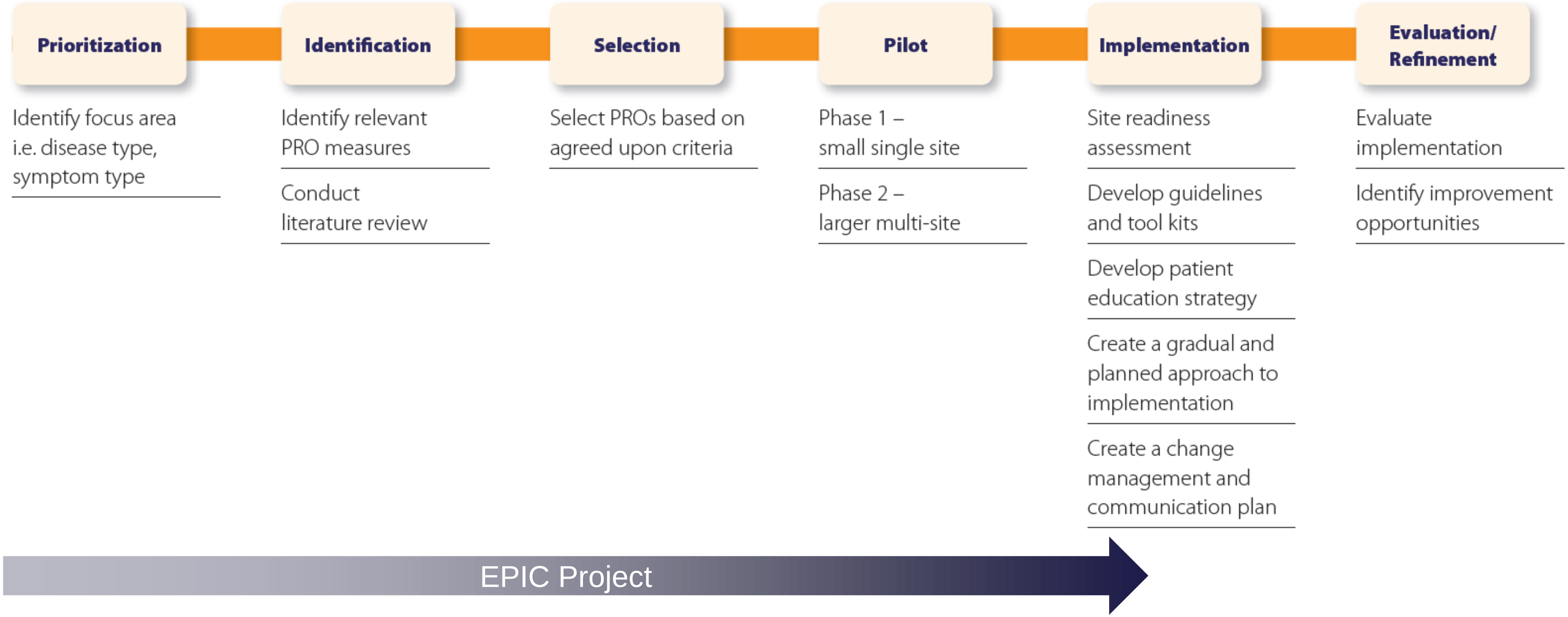
Selection
- Select PROs based on agreed upon criteria

Pilot
- Phase 1 – small single site
- 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
- 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

EPIC Project

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

EPIC-CP Phase II Pilot - Recommendations

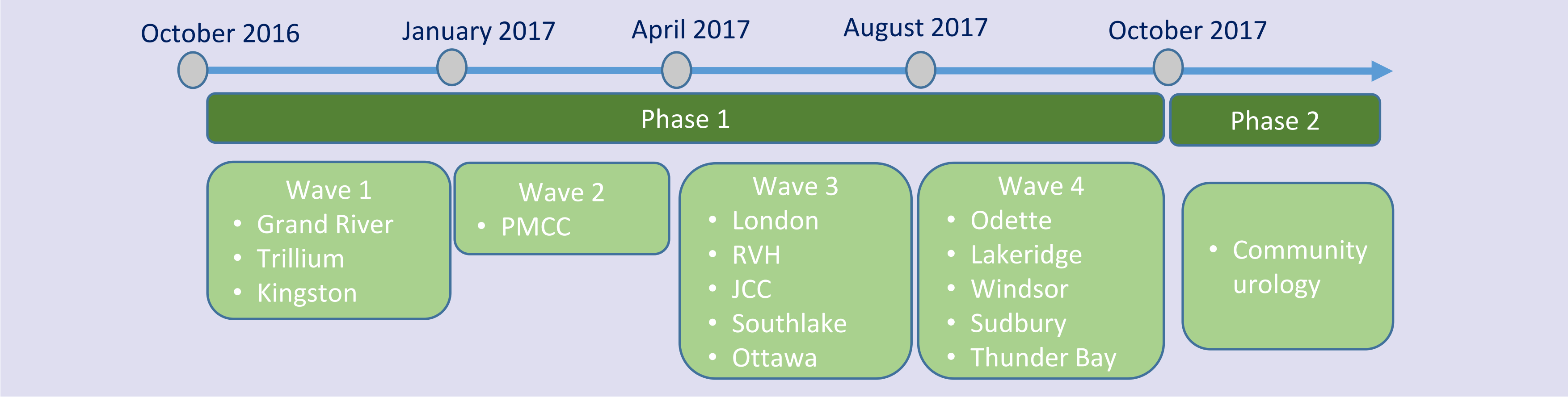
1. Implement EPIC-CP across Ontario in surgical and radiation outpatient consult and follow-up clinics, as well as radiation review clinics.

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.

EPIC (Your Symptoms Matter – Prostate Cancer)



October 2016 · January 2017 · April 2017 · August 2017 · October 2017

Phase 1

Wave 1
- Grand River
- Trillium
- Kingston

Wave 2
- PMCC

Wave 3
- London
- RVH
- JCC
- Southlake
- Ottawa

Wave 4
- Odette
- Lakeridge
- Windsor
- Sudbury
- Thunder Bay

Phase 2
- Community urology

- 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

Cancer Care Ontario

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

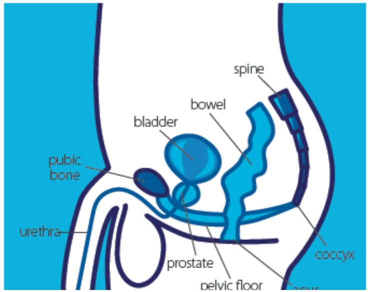
Your healthcare team will try to find the cause of your urinary problems.

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 – 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 your 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

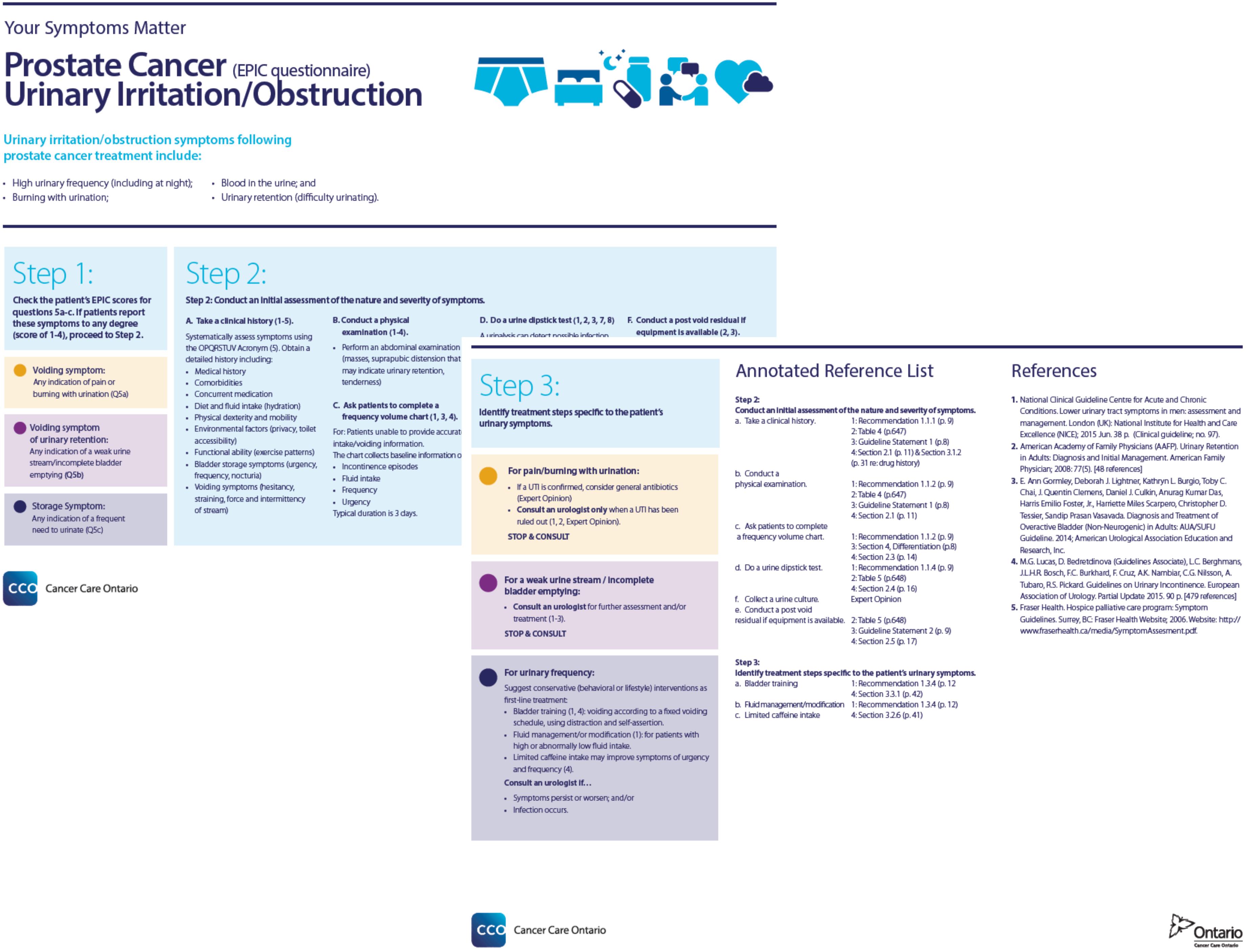
For more information visit the sites below:

Prostate Cancer Foundation of Australia
Website: www.prostate.org.au
Search term: "Understanding urinary problems"

Prostate Cancer Canada
Website: www.prostatecancer.ca
Search term: "Managing urinary difficulties"

Cancer Care Ontario

Ontario
Cancer Care Ontario



Your Symptoms Matter

Prostate Cancer (EPIC questionnaire) Urinary Irritation/Obstruction

Urinary irritation/obstruction symptoms following prostate cancer treatment include:

- High urinary frequency (including at night);
- Burning with urination;
- Blood in the urine; and
- 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 (Q5a)

● **Voiding symptom of urinary retention:**
Any indication of a weak urine stream/incomplete bladder emptying (Q5b)

● **Storage Symptom:**
Any indication of a frequent need to urinate (Q5c)

Step 2:

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

A. Take a clinical history (1-5).

Systematically assess symptoms using the OPQRSTUV Acronym (5). Obtain a detailed history including:

- Medical history
- Comorbidities
- Concurrent medication
- Diet and fluid intake (hydration)
- Physical dexterity and mobility
- Environmental factors (privacy, toilet accessibility)
- Functional ability (exercise patterns)
- Bladder storage symptoms (urgency, frequency, nocturia)
- Voiding symptoms (hesitancy, straining, force and intermittency of stream)

B. Conduct a physical examination (1-4).

- Perform an abdominal examination (masses, suprapubic distension that may indicate urinary retention, tenderness)

C. Ask patients to complete a frequency volume chart (1, 3, 4).

For: Patients unable to provide accurat
intake/voiding information.
The chart collects baseline information o

- Incontinence episodes
- Fluid intake
- Frequency
- Urgency

Typical duration is 3 days.

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

A urinalysis can detect possible infection

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

CCO Cancer Care Ontario

Step 3:

Identify treatment steps specific to the patient's urinary symptoms.

● **For pain/burning with urination:**

- If a UTI is confirmed, consider general antibiotics (Expert Opinion)
- **Consult an urologist only** 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): voiding according to a fixed voiding schedule, using distraction and self-assertion.
- Fluid management/or modification (1): for patients with high or abnormally low fluid intake.
- Limited caffeine intake may improve symptoms of urgency and frequency (4).

Consult an urologist if…

- Symptoms persist or worsen; and/or
- Infection occurs.

Annotated Reference List

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

a. Take a clinical history.	1: Recommendation 1.1.1 (p. 9) 2: Table 4 (p.647) 3: Guideline Statement 1 (p.8) 4: Section 2.1 (p. 11) & Section 3.1.2 (p. 31 re: drug history)
b. Conduct a physical examination.	1: Recommendation 1.1.2 (p. 9) 2: Table 4 (p.647) 3: Guideline Statement 1 (p.8) 4: Section 2.1 (p. 11)
c. Ask patients to complete a frequency volume chart.	1: Recommendation 1.1.2 (p. 9) 3: Section 4, Differentiation (p.8) 4: Section 2.3 (p. 14)
d. Do a urine dipstick test.	1: Recommendation 1.1.4 (p. 9) 2: Table 5 (p.648) 4: Section 2.4 (p. 16)
f. Collect a urine culture.	Expert Opinion
e. Conduct a post void residual if equipment is available.	2: Table 5 (p.648) 3: Guideline Statement 2 (p. 9) 4: Section 2.5 (p. 17)

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

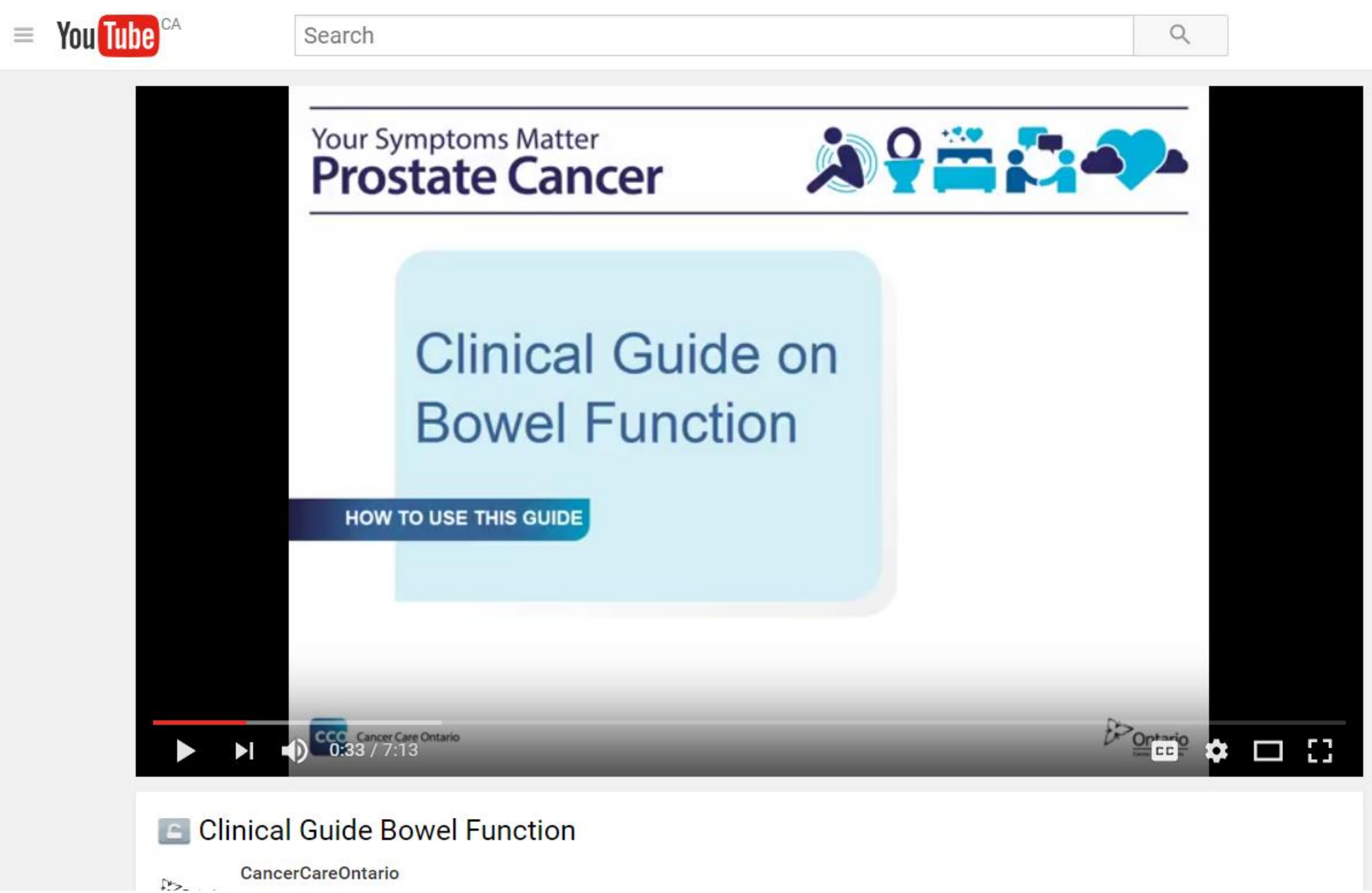
a. Bladder training	1: Recommendation 1.3.4 (p. 12 4: Section 3.3.1 (p. 42)
b. Fluid management/modification	1: Recommendation 1.3.4 (p. 12)
c. Limited caffeine intake	4: Section 3.2.6 (p. 41)

References

1. National Clinical Guideline Centre for Acute and Chronic Conditions. Lower urinary tract symptoms in men: assessment and management. London (UK): National Institute for Health and Care Excellence (NICE); 2015 Jun. 38 p. (Clinical guideline; no. 97).
2. American Academy of Family Physicians (AAFP). Urinary Retention in Adults: Diagnosis and Initial Management. American Family Physician; 2008: 77(5). [48 references]
3. E. Ann Gormley, Deborah J. Lightner, Kathryn L. Burgio, Toby C. Chai, J. Quentin Clemens, Daniel J. Culkin, Anurag Kumar Das, Harris Emilio Foster, Jr., Harriette Miles Scarpero, Christopher D. Tessier, Sandip Prasan Vasavada. Diagnosis and Treatment of Overactive Bladder (Non-Neurogenic) in Adults: AUA/SUFU Guideline. 2014; American Urological Association Education and Research, Inc.
4. M.G. Lucas, D. Bedretdinova (Guidelines Associate), L.C. Berghmans, J.L.H.R Bosch, F.C. Burkhard, F. Cruz, A.K. Nambiar, C.G. Nilsson, A. Tubaro, R.S. Pickard. Guidelines on Urinary Incontinence. European Association of Urology. Partial Update 2015. 90 p. [479 references]
5. Fraser Health. Hospice palliative care program: Symptom Guidelines. Surrey, BC: Fraser Health Website; 2006. Website: http://www.fraserhealth.ca/media/SymptomAssesment.pdf.

CCO Cancer Care Ontario

Ontario
Cancer Care Ontario



Your Symptoms Matter

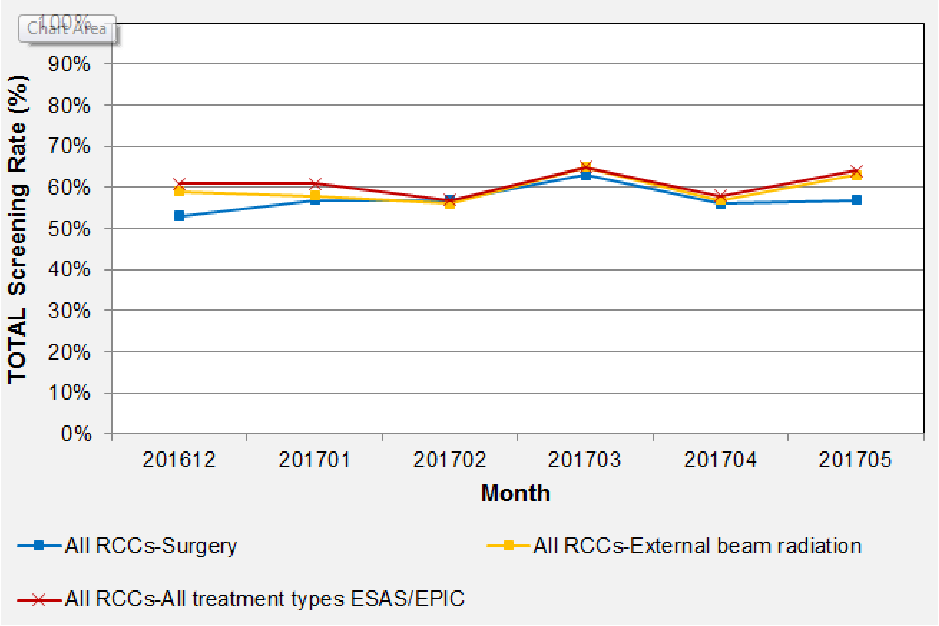
Prostate Cancer

Clinical Guide on Bowel Function

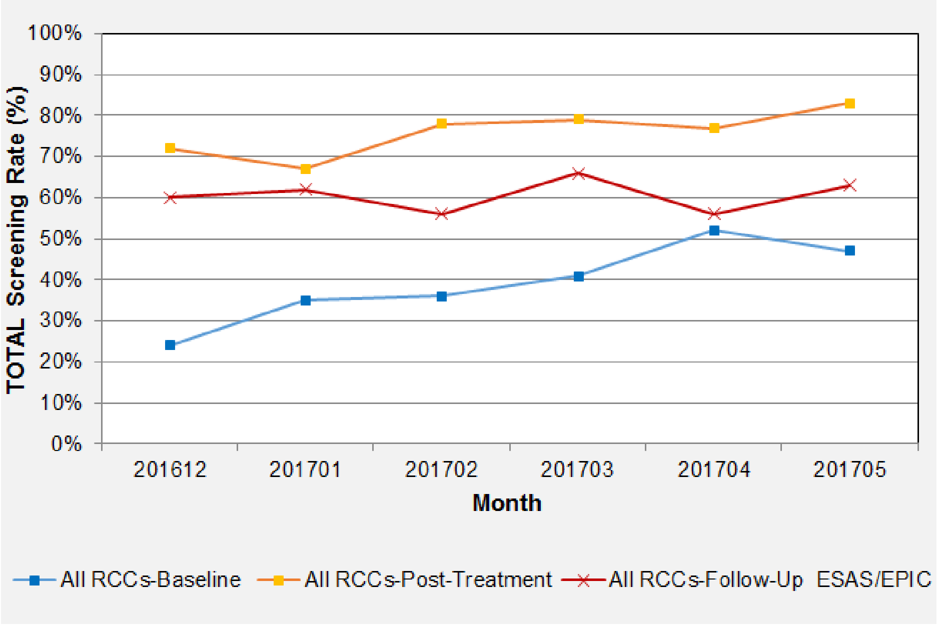
HOW TO USE THIS GUIDE

Clinical Guide Bowel Function

CancerCareOntario



- 8 centres are live
- 7 to follow in upcoming 4-6 months
- ~7000 assessments collected
- Plans to move into community urology



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

Better patient care

- 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

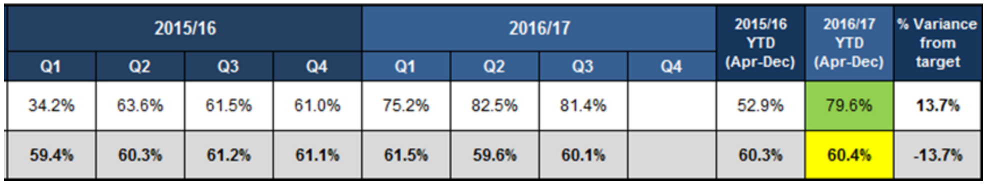
Higher quality system

How is this program driving quality?

Performance Measurement

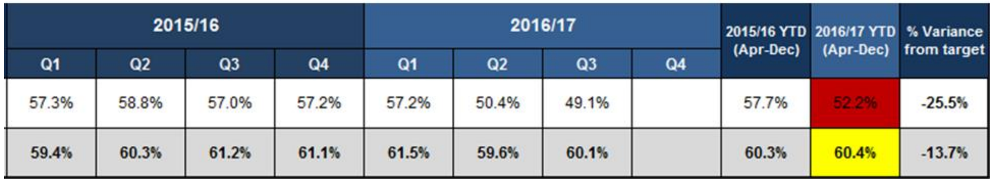
$$= \frac{\text{\# of cancer patients screened with ESAS at least once in a given month}}{\text{\# of cancer patients eligible for symptom screening in a given month}}$$

Each regional cancer centre is evaluated on many performance indicators on a quarterly basis



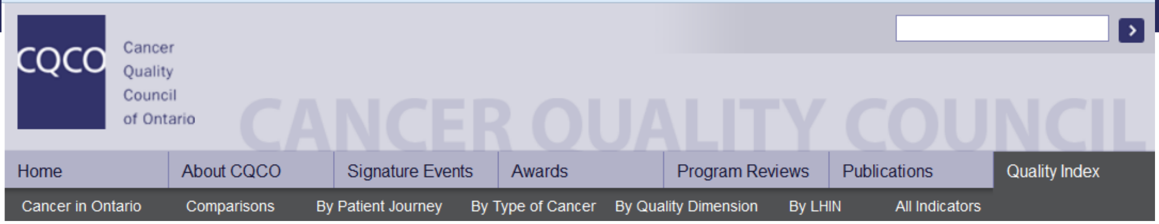
	2015/16				2016/17				2015/16 YTD (Apr-Dec)	2016/17 YTD (Apr-Dec)	% Variance from target
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4			
Centre A	34.2%	63.6%	61.5%	61.0%	75.2%	82.5%	81.4%		52.9%	79.6%	**13.7%**
Province	**59.4%**	**60.3%**	**61.2%**	**61.1%**	**61.5%**	**59.6%**	**60.1%**		**60.3%**	**60.4%**	**-13.7%**

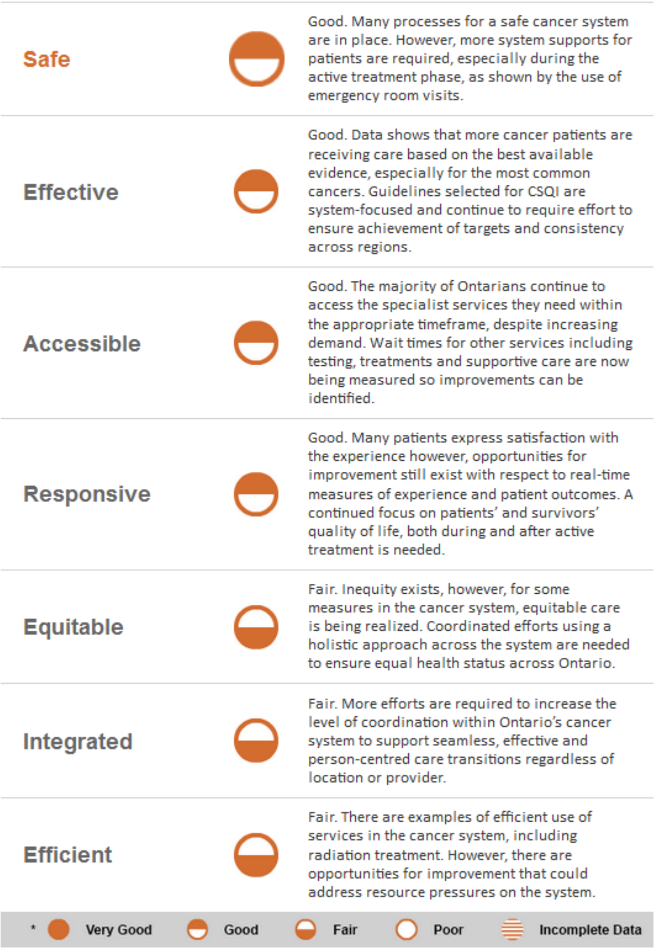
Compared to their own historical performance and the province as a whole



	2015/16				2016/17				2015/16 YTD (Apr-Dec)	2016/17 YTD (Apr-Dec)	% Variance from target
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4			
Centre B	57.3%	58.8%	57.0%	57.2%	57.2%	50.4%	49.1%		57.7%	52.2%	**-25.5%**
Province	**59.4%**	**60.3%**	**61.2%**	**61.1%**	**61.5%**	**59.6%**	**60.1%**		**60.3%**	**60.4%**	**-13.7%**

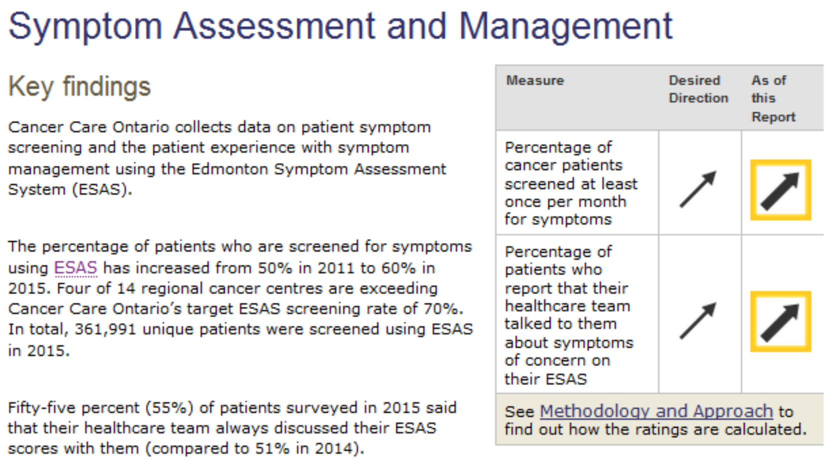
Public Reporting





Safe	◓	Good. Many processes for a safe cancer system are in place. However, more system supports for patients are required, especially during the active treatment phase, as shown by the use of emergency room visits.
Effective	◓	Good. Data shows that more cancer patients are receiving care based on the best available evidence, especially for the most common cancers. Guidelines selected for CSQI are system-focused and continue to require effort to ensure achievement of targets and consistency across regions.
Accessible	◓	Good. The majority of Ontarians continue to access the specialist services they need within the appropriate timeframe, despite increasing demand. Wait times for other services including testing, treatments and supportive care are now being measured so improvements can be identified.
Responsive	◓	Good. Many patients express satisfaction with the experience however, opportunities for improvement still exist with respect to real-time measures of experience and patient outcomes. A continued focus on patients' and survivors' quality of life, both during and after active treatment is needed.
Equitable	◒	Fair. Inequity exists, however, for some measures in the cancer system, equitable care is being realized. Coordinated efforts using a holistic approach across the system are needed to ensure equal health status across Ontario.
Integrated	◒	Fair. More efforts are required to increase the level of coordination within Ontario's cancer system to support seamless, effective and person-centred care transitions regardless of location or provider.
Efficient	◒	Fair. There are examples of efficient use of services in the cancer system, including radiation treatment. However, there are opportunities for improvement that could address resource pressures on the system.

* ● **Very Good** ◓ **Good** ◒ **Fair** ○ **Poor** ▤ **Incomplete Data**



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 51% in 2014).

Measure	Desired Direction	As of this Report
Percentage of cancer patients screened at least once per month for symptoms	↗	↗
Percentage of patients who report that their healthcare team talked to them about symptoms of concern on their ESAS	↗	↗

See Methodology and Approach to find out how the ratings are calculated.

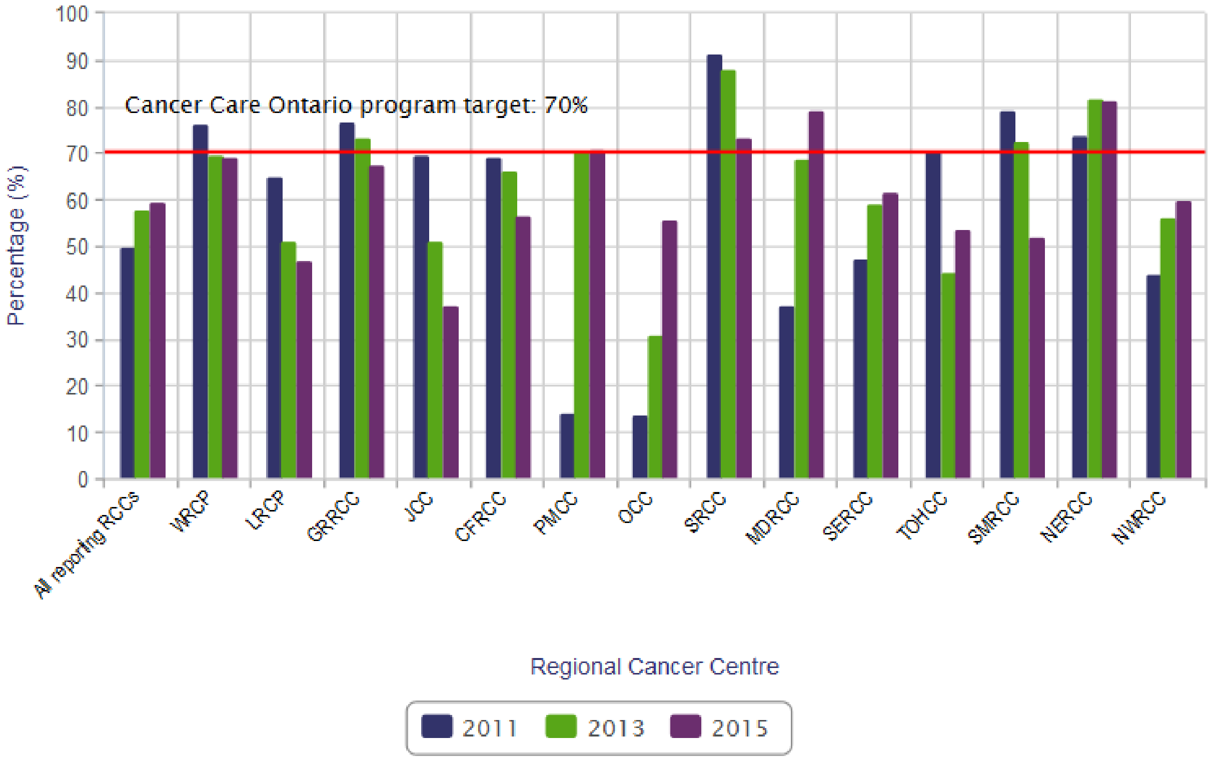
Public Reporting

Back

Next

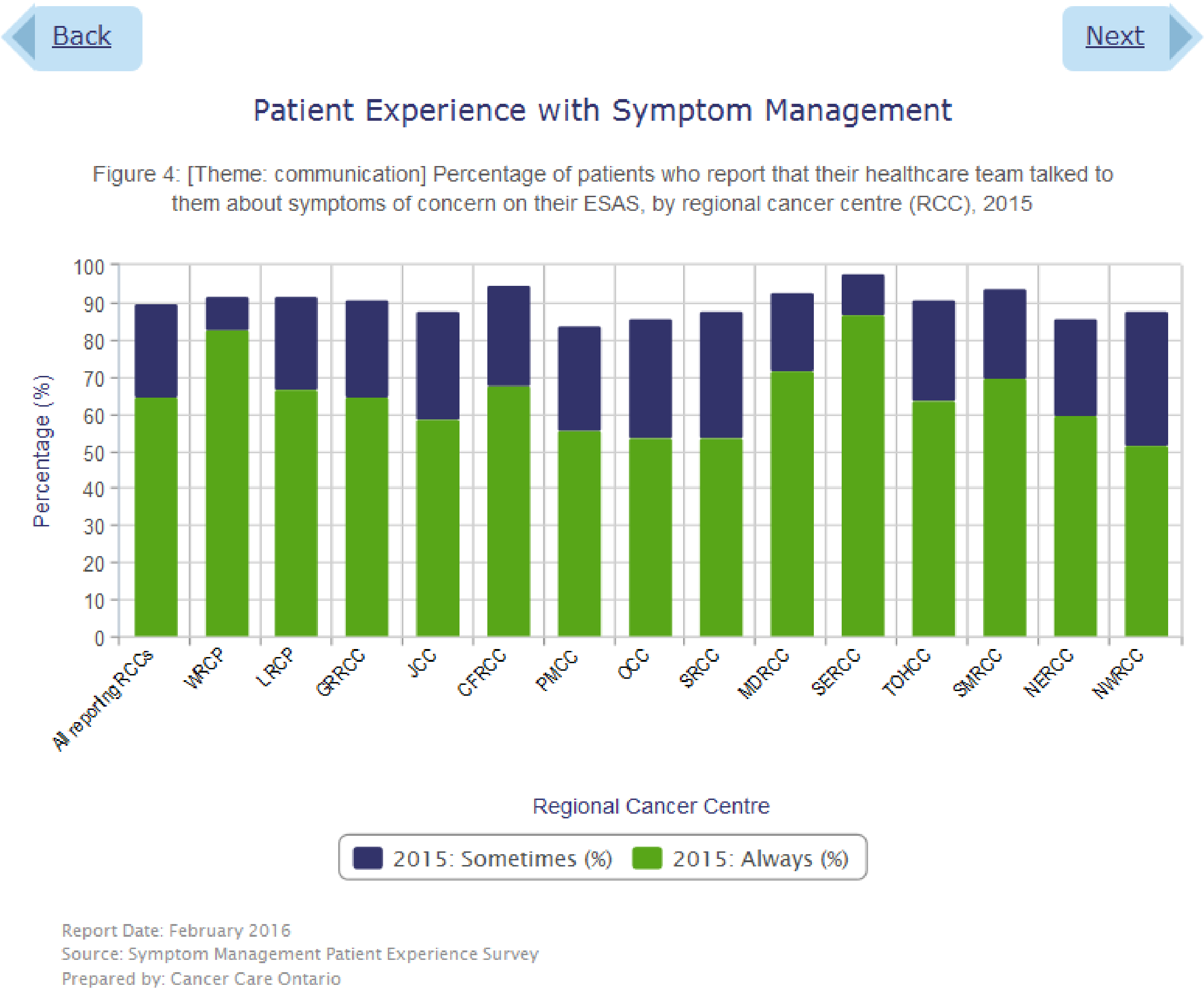
Symptom Screening Rates

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



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

Public reporting



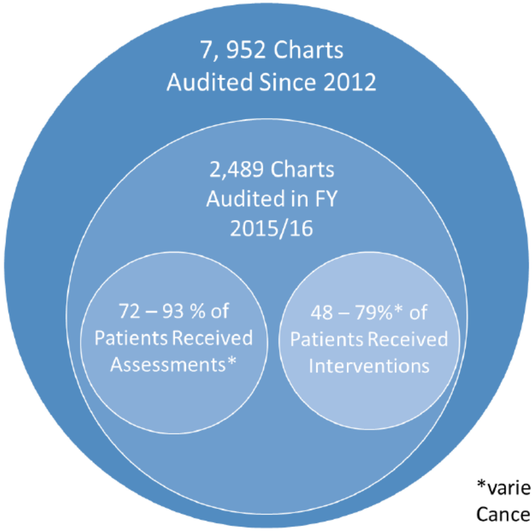
Patient Experience with Symptom Management

Figure 4: [Theme: communication] 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

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

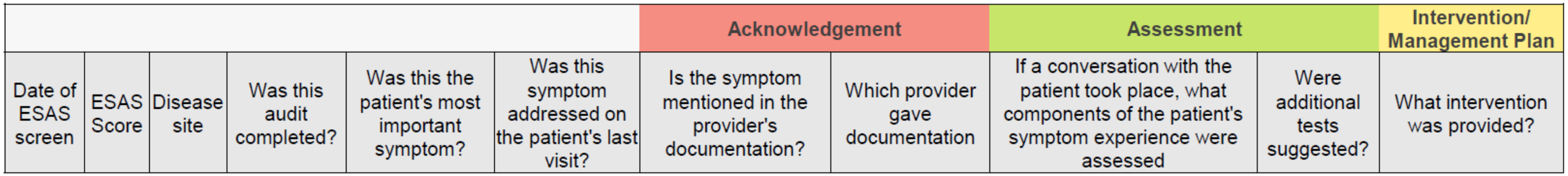


*varies by Regional Cancer Centre (RCC)

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

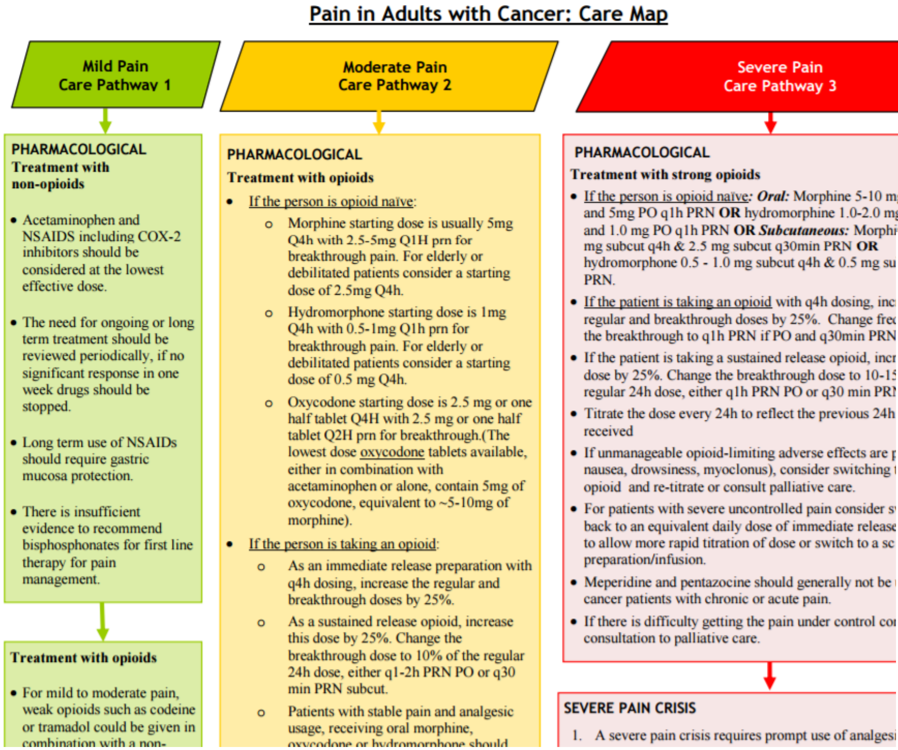


						Acknowledgement		Assessment		Intervention/ Management Plan
Date of ESAS screen	ESAS Score	Disease site	Was this audit completed?	Was this the patient's most important symptom?	Was this symptom addressed on the patient's last visit?	Is the symptom mentioned in the provider's documentation?	Which provider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

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 (eg. 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

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 non-

Moderate Pain
Care Pathway 2

PHARMACOLOGICAL
Treatment with opioids

- If the person is opioid naïve:
  - Morphine starting dose is usually 5mg Q4h with 2.5-5mg Q1H 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 Q1h 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 ~5-10mg 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

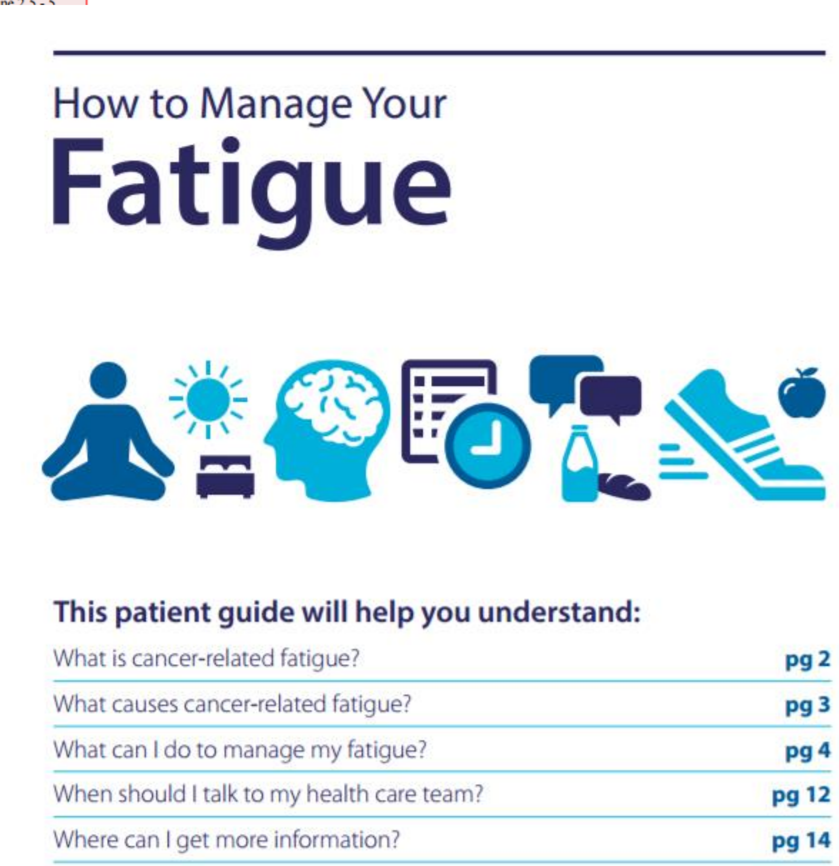
Severe Pain
Care Pathway 3

PHARMACOLOGICAL
Treatment with strong opioids

- If the person is opioid naïve: ***Oral:*** Morphine 5-10 mg PO q4h and 5mg PO q1h PRN **OR** hydromorphine 1.0-2.0 mg PO q4h and 1.0 mg PO q1h PRN **OR** ***Subcutaneous:*** Morphine 2.5 - 5 mg subcut q4h & 2.5 mg subcut q30min PRN **OR** hydromorphone 0.5 - 1.0 mg subcut q4h & 0.5 mg su PRN.
- If the patient is taking an opioid with q4h dosing, inc regular and breakthrough doses by 25%. Change fre the breakthrough to q1h PRN if PO and q30min PRN
- If the patient is taking a sustained release opioid, incr dose by 25%. Change the breakthrough dose to 10-15 regular 24h dose, either q1h PRN PO or q30 min PRN
- Titrate the dose every 24h to reflect the previous 24h received
- If unmanageable opioid-limiting adverse effects are p nausea, drowsiness, myoclonus), consider switching t opioid and re-titrate or consult palliative care.
- For patients with severe uncontrolled pain consider s back to an equivalent daily dose of immediate release to allow more rapid titration of dose or switch to a sc preparation/infusion.
- Meperidine and pentazocine should generally not be cancer patients with chronic or acute pain.
- If there is difficulty getting the pain under control co consultation to palliative care.

SEVERE PAIN CRISIS

1. A severe pain crisis requires prompt use of analgesi



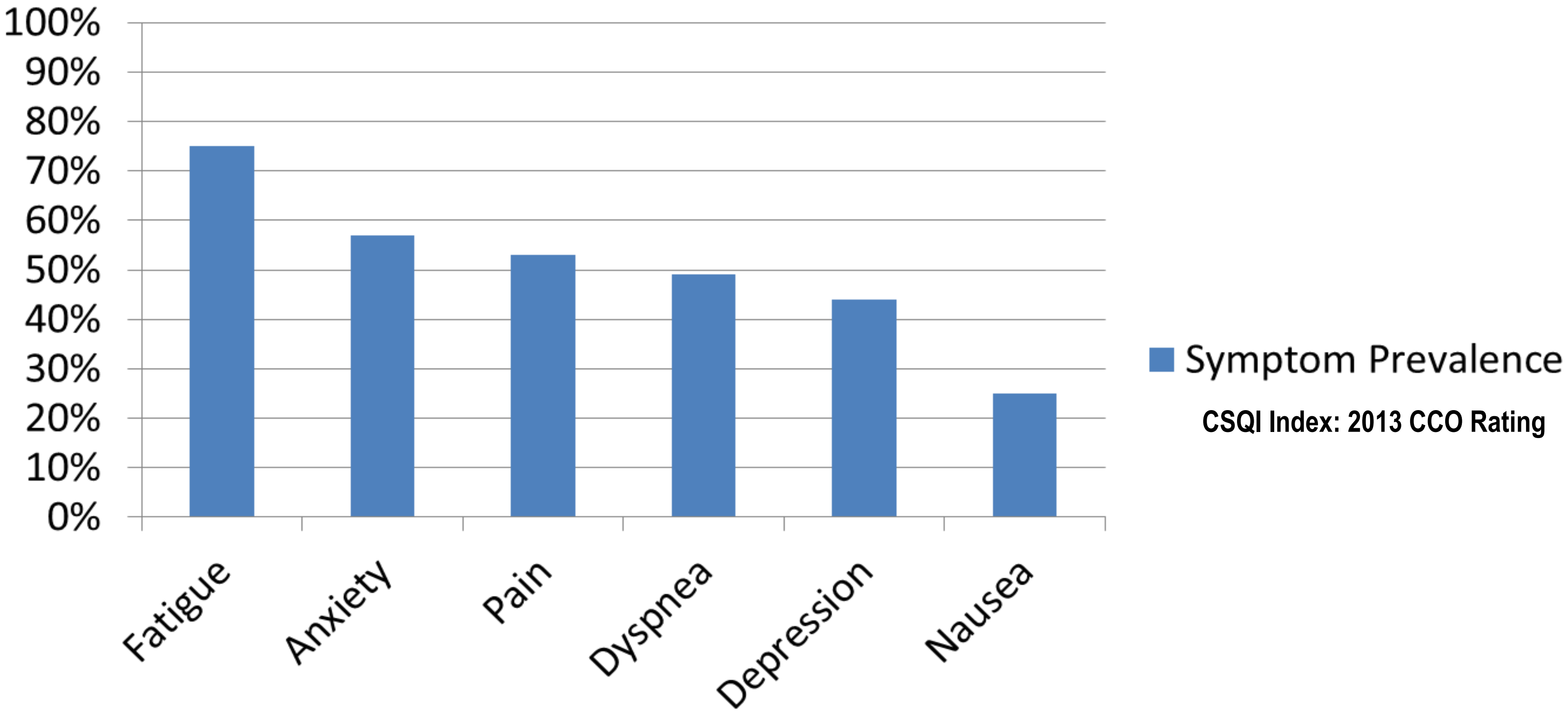
How to Manage Your
Fatigue

This patient guide will help you understand:

CCO Cancer Care Ontario

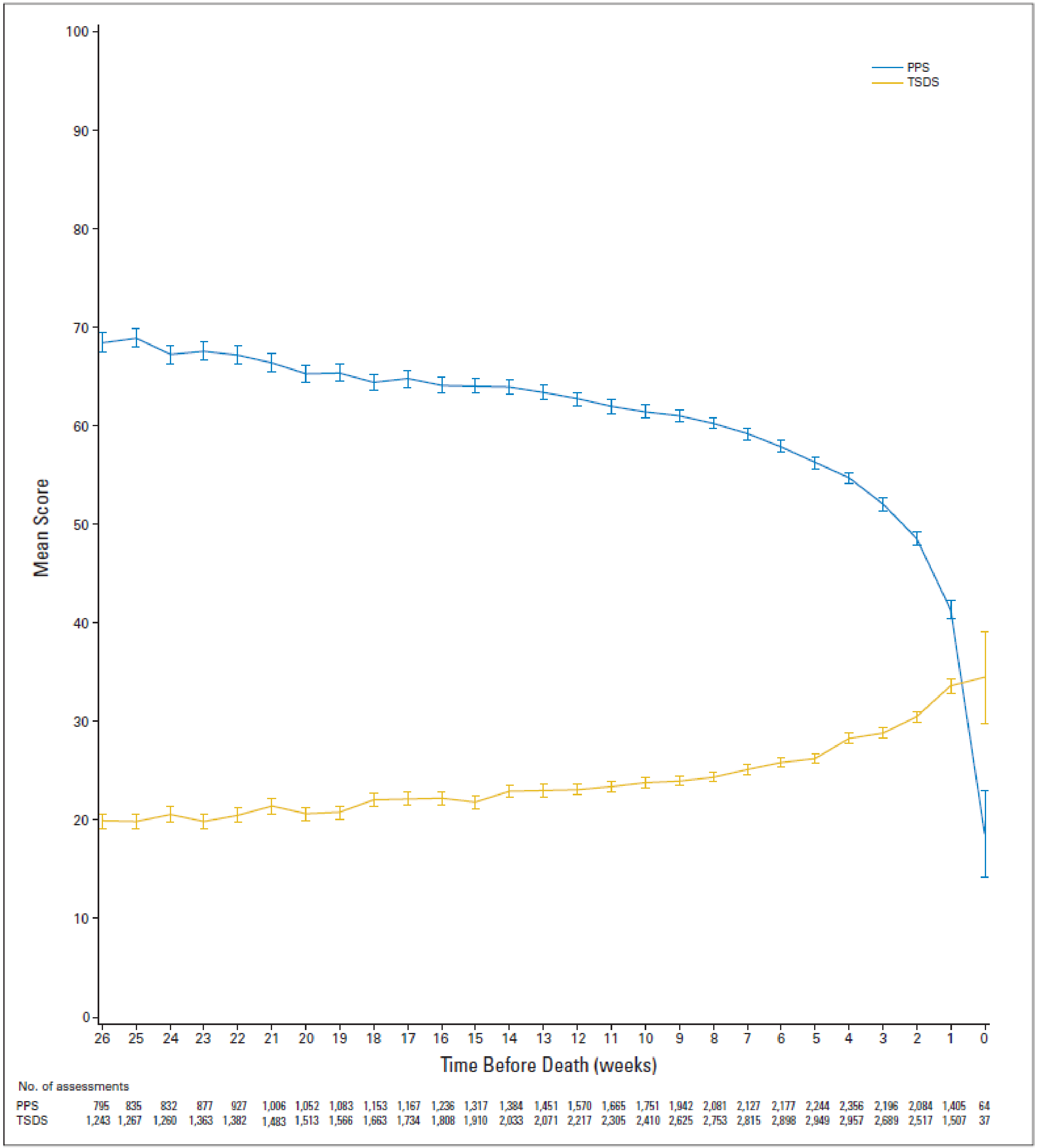
What have we learned from ESAS data?

Symptom burden in cancer



CSQI Index: 2013 CCO Rating

Cancer Care Ontario



No. of assessments

	26	25	24	23	22	21	20	19	18	17	16	15	14	13	12	11	10	9	8	7	6	5	4	3	2	1	0
PPS	795	835	832	877	927	1,006	1,052	1,083	1,153	1,167	1,236	1,317	1,384	1,451	1,570	1,665	1,751	1,942	2,081	2,127	2,177	2,244	2,356	2,196	2,084	1,405	64
TSDS	1,243	1,267	1,260	1,363	1,382	1,483	1,513	1,566	1,663	1,734	1,808	1,910	2,033	2,071	2,217	2,305	2,410	2,625	2,753	2,815	2,898	2,949	2,957	2,689	2,517	1,507	37

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.

Seow, Barbera 2011,
JCO 29 (9) 1151

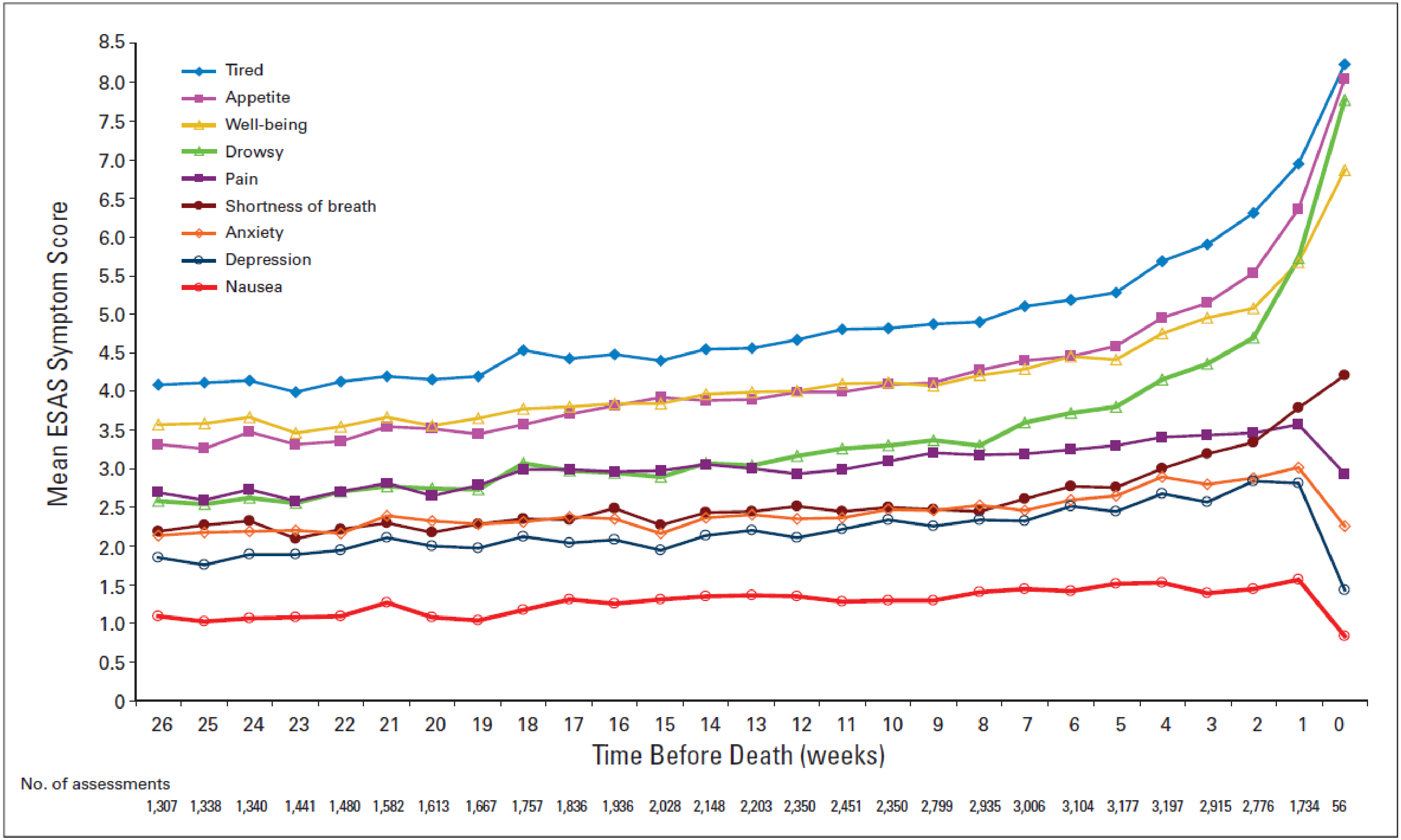
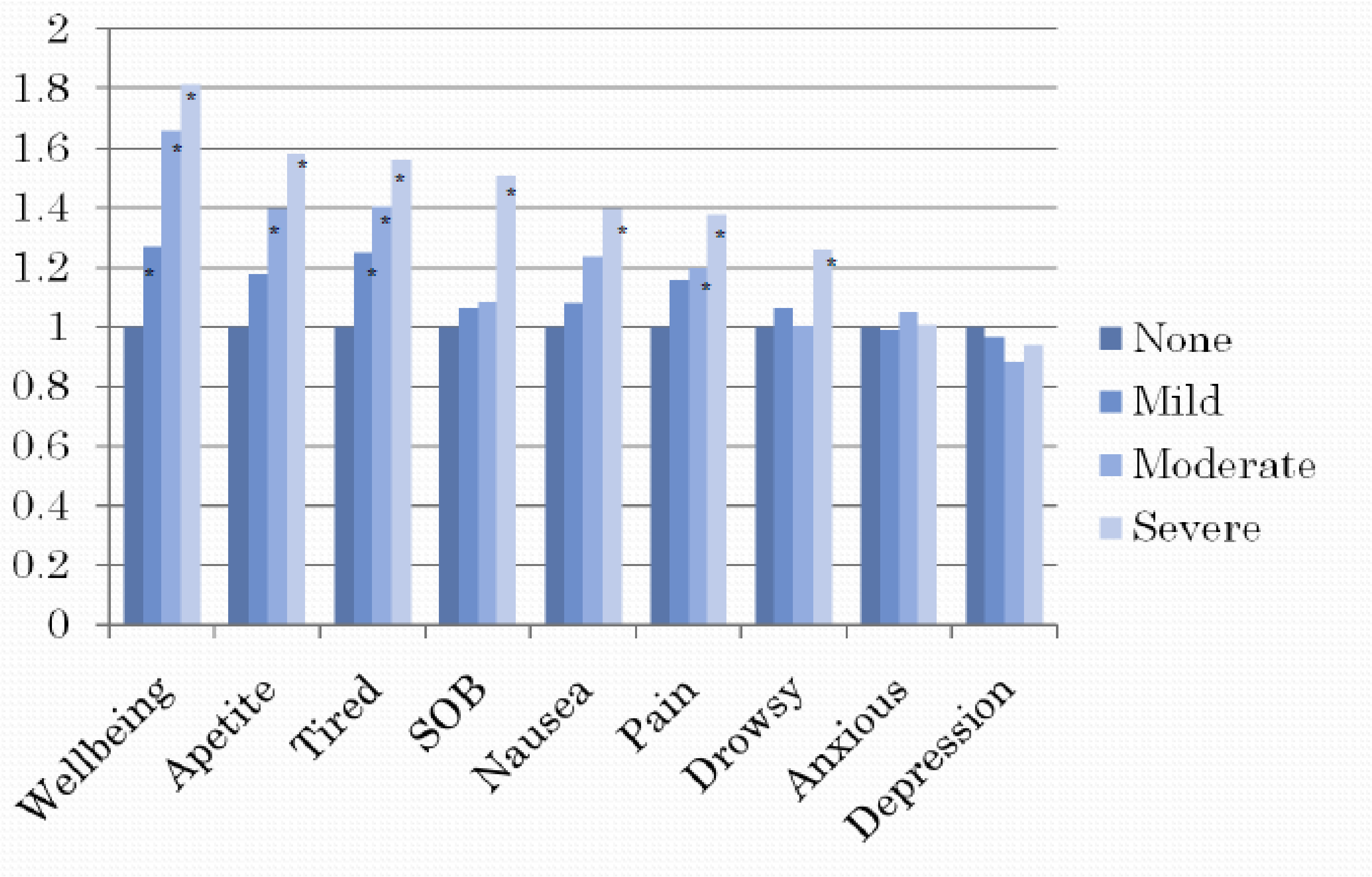


Fig 2. Mean Edmonton Symptom Assessment System (ESAS) symptom scores over time. Number of assessments is maximum number available among all nine symptoms. Missing ESAS values for a given symptom were not included when calculating the mean.

Seow, Barbera 2011, JCO 29 (9) 1151

Outcomes from High Symptom Burden

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



Cancer Care Ontario

Source: Barbera et al, 2012, Ann Emerg Med; 61(4):427-437

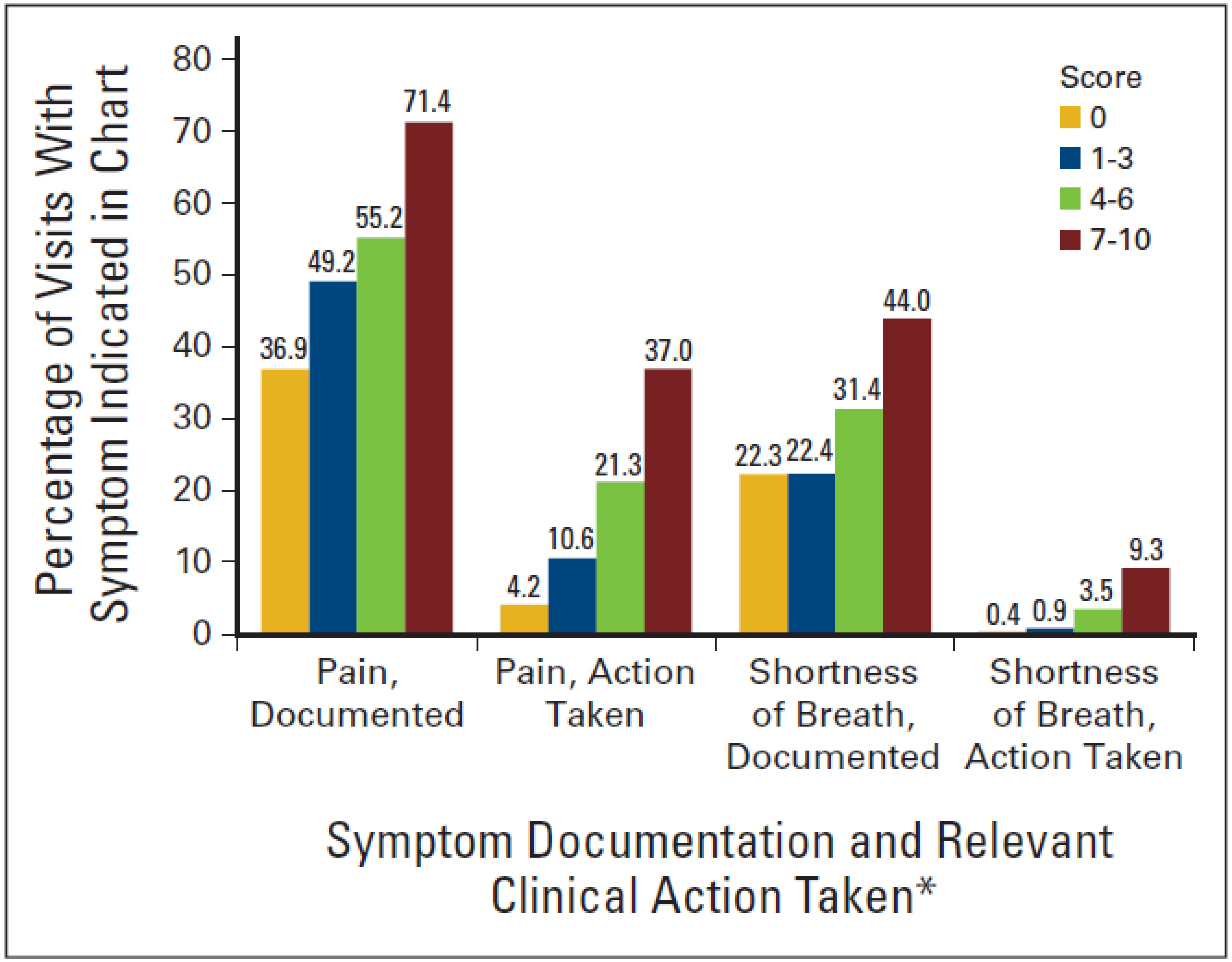


Figure 1. Pain and shortness of breath outcomes for all patient visits. ESAS, Edmonton Symptom Assessment Scale. (*) Sample size by ESAS score category: pain: 0 (n = 263), 1-3 (n = 236), 4-6 (n = 221), 7-10 (n = 192); shortness of breath: 0 (n = 242); 1-3 (n = 228); 4-6 (n = 226); 7-10 (n = 216).

Seow 2012 Journal Oncology Practice

Opioid use in cancer patients with pain

Search for opioid prescriptions in provincial formulary database

Cancer Care Ontario

Barbera et al, 2012, JCO 20(10): 1095-1099

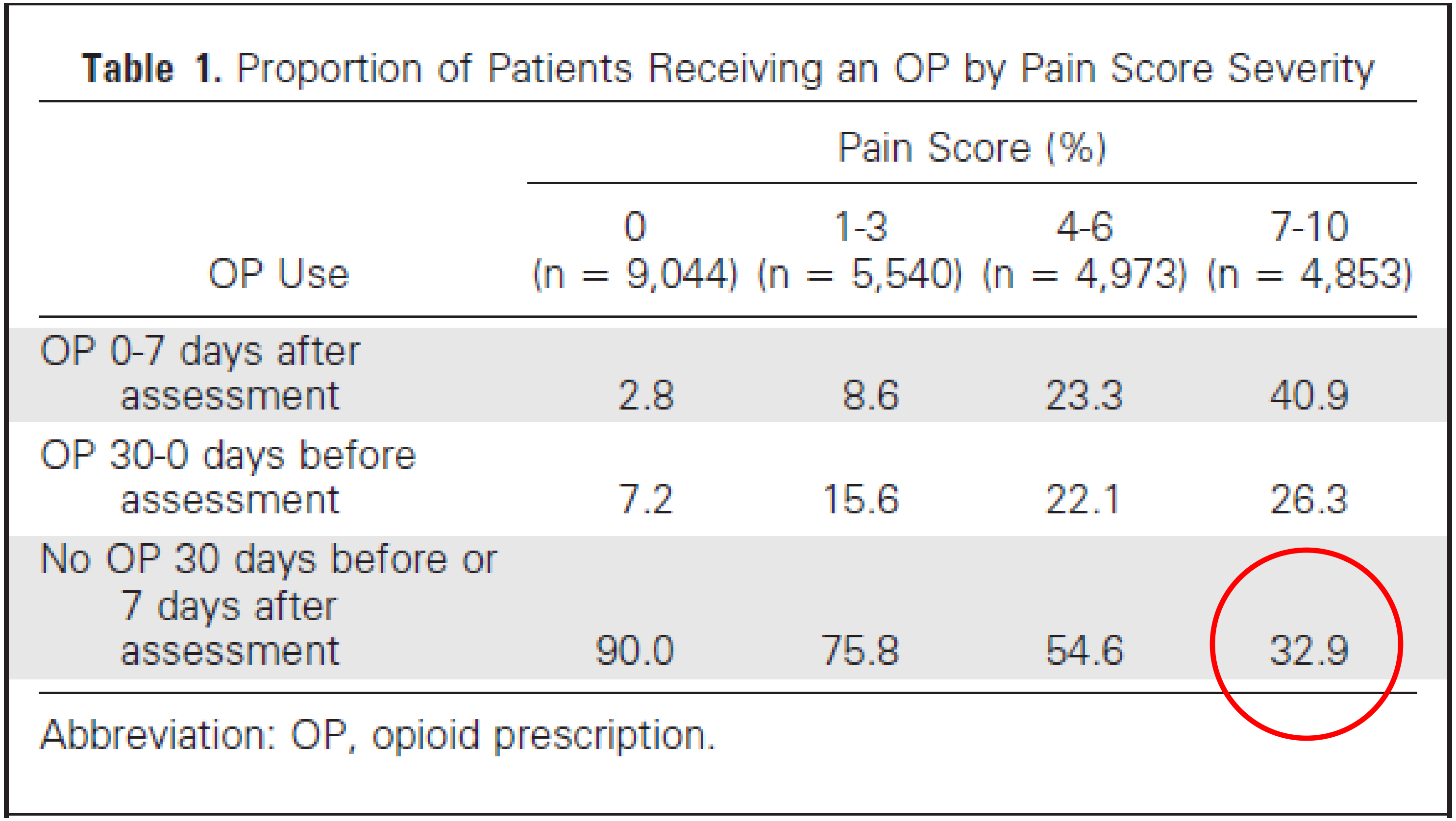


Table 1. Proportion of Patients Receiving an OP by Pain Score Severity

OP Use	Pain Score (%)			
	0 (n = 9,044)	1-3 (n = 5,540)	4-6 (n = 4,973)	7-10 (n = 4,853)
OP 0-7 days after assessment	2.8	8.6	23.3	40.9
OP 30-0 days before assessment	7.2	15.6	22.1	26.3
No OP 30 days before or 7 days after assessment	90.0	75.8	54.6	32.9

Abbreviation: OP, opioid prescription.

Barbera et al, 2012, JCO 20(10): 1095-1099

Observed proportion of patients with a prescription within -30 days to +7 days of index date, by pain severity and year

	Pain severity				
	None	Mild	Moderate	Severe	Overall
2007	11.5	25.0	41.8	60.9	31.7
2008	9.0	19.9	38.0	52.8	23.7
2009	7.5	15.6	29.6	46.7	18.2
2010	6.2	13.8	27.6	45.4	16.1
2011	5.6	11.7	26.2	42.7	14.8
2012	5.4	11.7	25.4	42.6	14.5
2013	4.9	11.7	25.0	39.2	13.6

Barbera et al, 2017, JOP, in press

Did routine ESAS symptom screening decrease ED visits in breast cancer patients on adjuvant chemotherapy?

- 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%)

Objective	• to evaluate the impact of screening with ESAS through OCSMC on ED visit rates in women with breast cancer receiving adjuvant chemotherapy
Hypothesis	• 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

Barbera 2015, Support Care Cancer 23(10) 3025

Method

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

CCO Cancer Care Ontario

Barbera 2015, Support Care Cancer 23(10) 3025

Screening with ESAS decreases ED visits

- 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%.

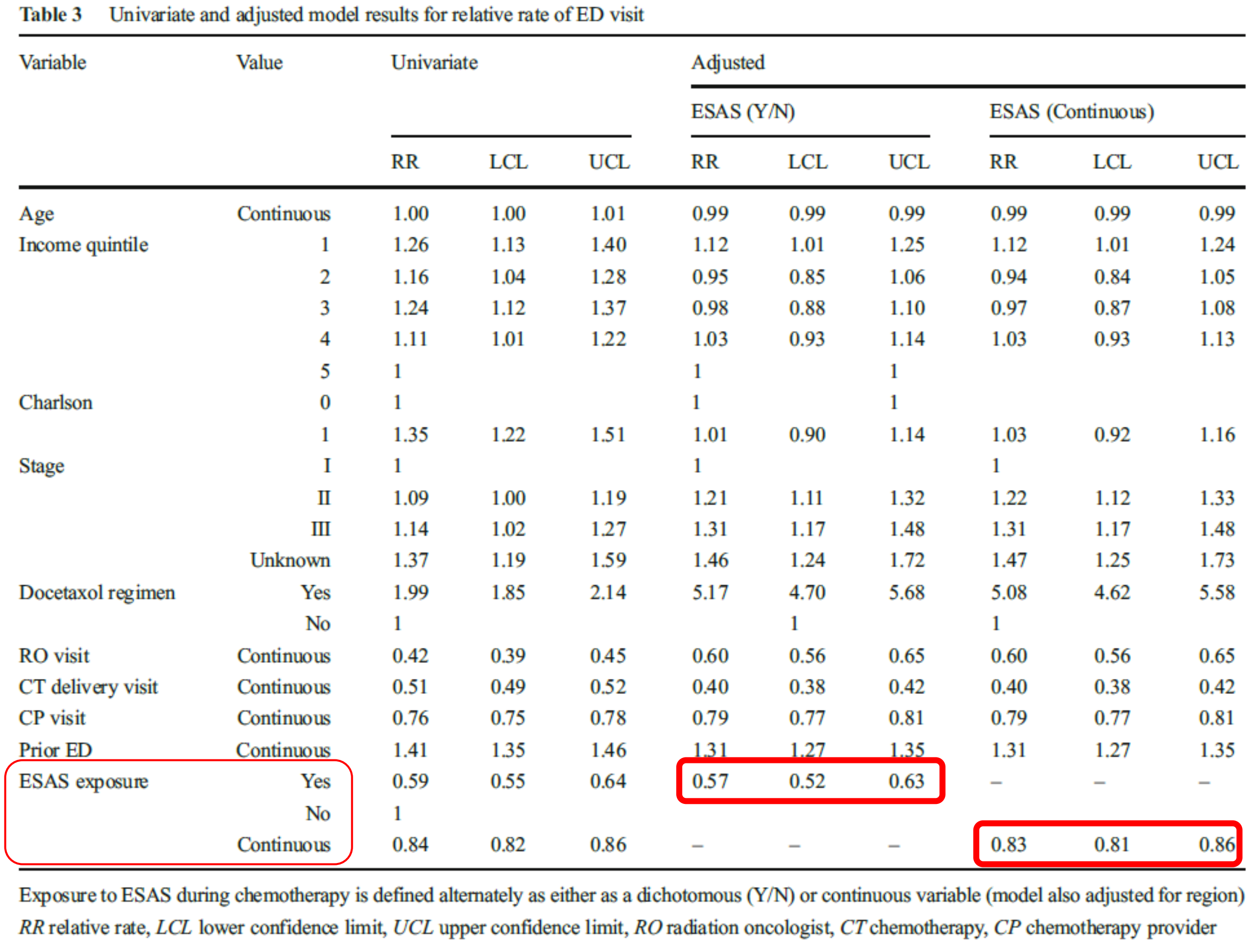


Table 3 Univariate and adjusted model results for relative rate of ED visit

Variable	Value	Univariate			Adjusted					
					ESAS (Y/N)			ESAS (Continuous)		
		RR	LCL	UCL	RR	LCL	UCL	RR	LCL	UCL
Age	Continuous	1.00	1.00	1.01	0.99	0.99	0.99	0.99	0.99	0.99
Income quintile	1	1.26	1.13	1.40	1.12	1.01	1.25	1.12	1.01	1.24
	2	1.16	1.04	1.28	0.95	0.85	1.06	0.94	0.84	1.05
	3	1.24	1.12	1.37	0.98	0.88	1.10	0.97	0.87	1.08
	4	1.11	1.01	1.22	1.03	0.93	1.14	1.03	0.93	1.13
	5	1			1		1			
Charlson	0	1			1		1			
	1	1.35	1.22	1.51	1.01	0.90	1.14	1.03	0.92	1.16
Stage	I	1			1			1		
	II	1.09	1.00	1.19	1.21	1.11	1.32	1.22	1.12	1.33
	III	1.14	1.02	1.27	1.31	1.17	1.48	1.31	1.17	1.48
	Unknown	1.37	1.19	1.59	1.46	1.24	1.72	1.47	1.25	1.73
Docetaxol regimen	Yes	1.99	1.85	2.14	5.17	4.70	5.68	5.08	4.62	5.58
	No	1				1		1		
RO visit	Continuous	0.42	0.39	0.45	0.60	0.56	0.65	0.60	0.56	0.65
CT delivery visit	Continuous	0.51	0.49	0.52	0.40	0.38	0.42	0.40	0.38	0.42
CP visit	Continuous	0.76	0.75	0.78	0.79	0.77	0.81	0.79	0.77	0.81
Prior ED	Continuous	1.41	1.35	1.46	1.31	1.27	1.35	1.31	1.27	1.35
ESAS exposure	Yes	0.59	0.55	0.64	0.57	0.52	0.63	–	–	–
	No	1								
	Continuous	0.84	0.82	0.86	–	–	–	0.83	0.81	0.86

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

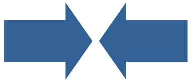
Limitations of the data

- 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

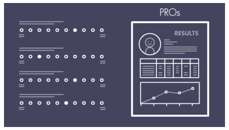
- Opioid prescribing in long term survivors
- Impact of screening program on service use
- Symptom profiles by disease type, stage, treatment
- Implication of missing data and inconsistent data timing on using ESAS as an outcome measurement

Conclusions



PROs represent a paradigm shifting approach to facilitate patient centred 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 measure

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