
Your Symptoms Matter



Volunteer Training Resources for LRCP

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London Health Sciences Centre



Ontario Health
Cancer Care Ontario

LRCP YSM/Kiosk Contact Information

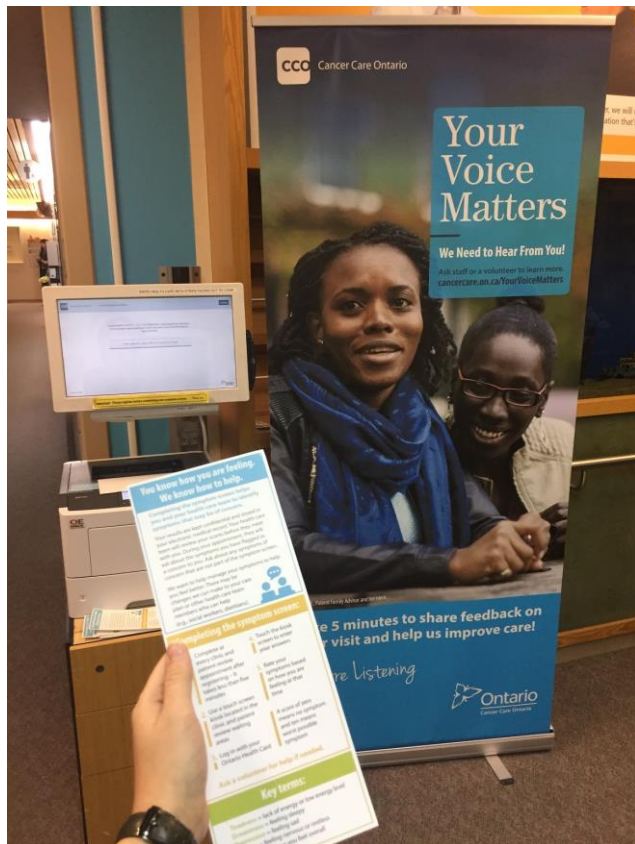
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Your Symptoms Matter



Importance and purpose of symptom screening or a Patient Reported Outcome (PRO)



- Throughout the cancer care journey, a patient may experience a **wide range of side effects and symptoms** from either their cancer or treatment
- These symptoms, such as fatigue, pain, and anxiety, can have a significant impact on a patient's **quality of life**
- A Patient Reported Outcome (PRO) is a validated measure that provides a complete picture on the impact of cancer and treatment from the patient perspective.
- Using PROs, patients self-report on physical symptoms and psychological concerns to prompt conversations with their healthcare providers around symptom management early on

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- Symptom screening lets patients and their caregivers **assess and track their symptoms** online. This tool makes it easier for healthcare providers to identify those in need of care and monitor changes in their patients' symptoms over time
- Research has shown that routinely asking patients to self report their symptoms in a systematic way
 - Helps identify **symptoms** that might not have been identified otherwise
 - Improves the **communication** between patients and their health care team
 - Improves **patient satisfaction** with care

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How patients are directed to Your Symptoms Matter kiosks

- Patients check in with reception and are directed to the kiosks
- Greet patients by the computer and introduce Your Symptoms Matter
 - Example: “Your Symptoms Matter helps your health care team know how you are doing at every appointment”
- Patients will then swipe their health card at the kiosk and be directed to the appropriate questionnaire
- Kiosks are located in New Patient Referral, Clinic 1, Clinic 2, Clinic 3, Clinic 4/Pharmacy, Radiation Patient Review and Baines(3rd floor)

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- If you need a 'test' number to work with enter: aaaaaaaaaa (10 a's)
- For many patients this will be the first time they see or use a touch screen computer. Welcome them to the kiosk.
- The first training session for the kiosk could take approximately 10 to 15 minutes.
- Some patients may need continued help with the screen at return appointments but this should take less time.

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- When logging into **Your Symptoms Matter**, patients will have the option to complete the following questionnaires:
 - **Your Symptoms Matter – General Symptoms** (formerly known as “ESAS r+”)
 - **Your Symptoms Matter – Prostate Cancer** (also known as “EPIC”)
 - **Your Symptoms Matter – Daily Activities** (formerly known as “pECOG/PFRS”)
- There is logic built-in that will help select the appropriate questionnaire for patients

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Your Symptoms Matter – General Symptoms

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- Most patients will complete **Your Symptoms Matter – General Symptoms** (formerly known as ESAS r+) screening tool
- There are **12 multiple choice questions** with each symptom rated on a scale of “0 to 10”
 - ESAS r+ added 3 new questions regarding sleeping, diarrhea and constipation
 - A score of “**0**” means **you do not have the symptom**, whereas a score of “**10**” means that **your symptom is at its very worst**
 - It is important for patients to answer the questions from **their own perspective**. Refrain from offering your own perspective (e.g. giving examples of personal experience)
- The General Symptoms questionnaire is also available in paper form in over 30 different languages. Copies of each language are available in the clinics.
- Some kiosks allow for printing of the questionnaire, please remind patients to pick up their printed copy of their survey report from the printers and bring it with them to their appointment (double check initials). Also remind patients that a printed copy is Not necessary as the information immediately goes to the patients medical record and the health care provider can see it in the exam room

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Your Symptoms Matter – Prostate Cancer

ALSO KNOWN AS EPIC



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- Cancer Care Ontario (CCO) introduced a new disease-specific survey for patients with **prostate cancer** called Your Symptoms Matter – Prostate Cancer. Also known as “EPIC”
- This disease-specific survey was introduced in response to **patient feedback**
- Patient’s provided feedback that completing the survey would be **more valuable if the questions were specific** to their type of cancer
- EPIC is the **first survey tailored to a specific type of cancer**. The goal is that additional surveys, specific to other types of cancer, will be introduced in the future.

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Your Symptoms Matter – Prostate Cancer

- Through the self-selection questions described previously, men with early stage prostate cancer will be selected to complete the **Your Symptoms Matter – Prostate Cancer** questionnaire
 - There are a total of **17 multiple choice questions** with four or five possible answers
- The questionnaire discusses symptoms in the following domains:
 - Bowel symptoms
 - Urinary irritation/obstruction symptoms
 - Urinary incontinence symptoms
 - Vitality/hormone symptoms
 - Sexual function symptoms

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Sensitive nature of some questions Your Symptoms Matter – Prostate Cancer

- Since the Prostate Cancer questionnaire addresses **sensitive topics** like sexual function and vitality/hormone symptoms, it is important to be aware of the content of these questions.
- It is also important for you to know that patients will be familiar with these types of questions prior to their clinic visit
- These questions cover topics such as:
 - Orgasms
 - Erections
 - Hot flashes
 - Urinary incontinence
- Patients may also feel uncomfortable asking questions or answering in front of you

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Sensitive nature of some questions Your Symptoms Matter – Prostate Cancer

- Tips about assisting patients with the Your Symptoms Matter – Prostate Cancer questionnaire:
 - Do not read the question **or response** out loud
 - Bring the patient aside to explain what the question is asking (if space permits)
 - Encourage patients to ask questions of their health care provider
If a patient is uncomfortable or unsure about answering the questions, they can complete the symptom screening in the clinic appointment
 - Step aside once the patient has begun the survey to provide them with privacy
- Please remind patients to pick up their printed copy of their survey report from the printers (if available) and bring it with them to their appointment (double check initials on the printout)

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Screenshots: Your Symptoms Matter – Prostate Cancer

Example of question

Please note, should patients realize they have selected the wrong questionnaire, the **“Start Over”** button is available with all questions.

CCO Cancer Care Ontario Your Symptoms Matter Français Quit

Pre-assessment questionnaire

Bloody Stool
How big a problem, if any, has rectal bleeding been for you in the **LAST FOUR WEEKS?**

No problem

Very small problem

Small problem

Moderate problem

Big problem

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Your Symptoms Matter – Daily Functions

ALSO KNOWN AS pECOG/PRFS



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Your Symptoms Matter – Daily Activities

- All patients will be asked to complete Your Symptoms Matter – Daily Activities
- This formerly known as pECOG or PRFS
- This questionnaire will be probed at the end of Your Symptoms Matter – General Symptoms and Your Symptoms Matter – Prostate Cancer
- This questionnaire consists of one question and asks patients to rate their daily functions and activity levels

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Your Symptoms Matter – Daily Activities

Question

CCC Cancer Care Ontario Your Symptoms Matter Français Quit

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

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Ensuring Privacy

- Avoid situations of reading questions or responses out loud
- It is important to be mindful that patients may feel uncomfortable having anyone close by while filling in the questionnaire. Let them know you are there if they would like any help and stand away to the side.
- Patients have the option to complete symptom screening in their clinic appointments.
- Patients have the option of completing the screening on their own device; either at home or in the waiting room.
- It can be completed by QR code or by URL [Your Symptoms Matter - Start \(ontariohealth.ca\)](https://www.ontariohealth.ca/your-symptoms-matter)
- Please remind patients to be sure and pick up their printed copy of their survey report from the printers (if available) and bring it with them to their appointment. *Check initials on the printout*

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Thank you for all that you do!

If you have any questions, please do not
hesitate to reach out to any of the
contacts listed on Slide 2.