



Cancer Care Ontario

# Creating Patient Education to Help Patients understand the Value of Patient-Reported Outcomes:

The application of the 3Ws and H Framework

# Disclosures

- Clinical Lead, Patient-Reported Outcomes and Symptom Management

# Who is Cancer Care Ontario (CCO)?

- The Ontario government's advisor on the cancer system.
- CCO drives continuous improvement in disease prevention and screening, the delivery of care and the patient experience for chronic diseases.
- CCO leads multi-year system planning, contract for services with hospitals and providers, develops and deploys information systems, establishes guidelines and standards, and tracks performance targets to ensure system-wide improvements.

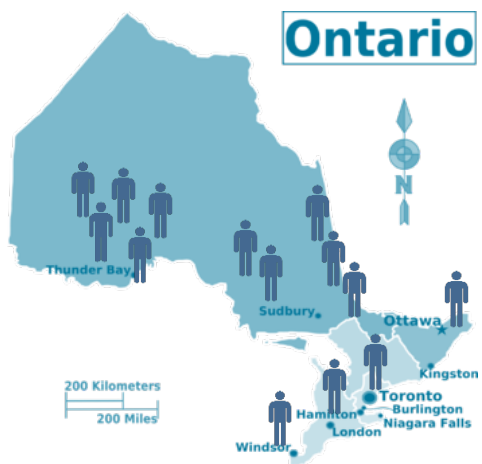


# CCOs Patient Reported Outcomes and Symptom Management Program

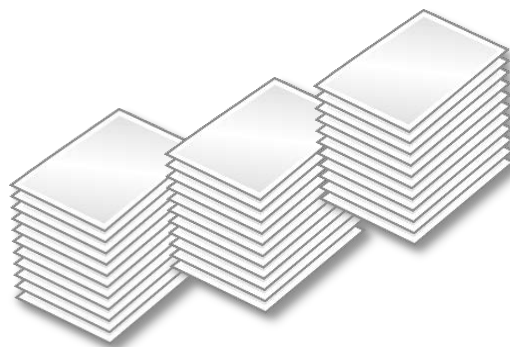
- **The Patient Reported Outcomes (PROs) and Symptom Management Program** is responsible for the expansion of PROs in the province of Ontario.
- A Patient Reported Outcome (PRO) is a **validated measure** that provides a comprehensive picture on the symptoms of cancer and treatment from the **patient perspective**.
- Using PROs, patients self-report on physical symptoms and psychological concerns to prompt providers to identify and respond to issues early on.
- PROs in the context of cancer within Ontario are referred to as **Your Symptoms Matter**.

# Cancer Patient Reported Outcomes in Ontario

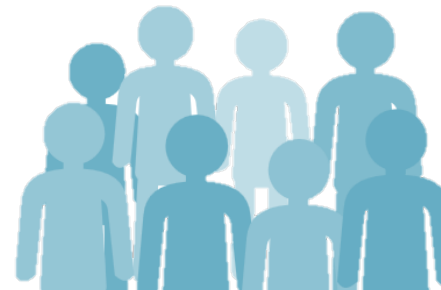
Symptom screening occurs at **14** Regional Cancer Centres & **70** partner sites across Ontario.



PROs implemented province-wide include: ESAS (general cancer symptoms), PRFS (functional status), and EPIC (prostate cancer-specific).

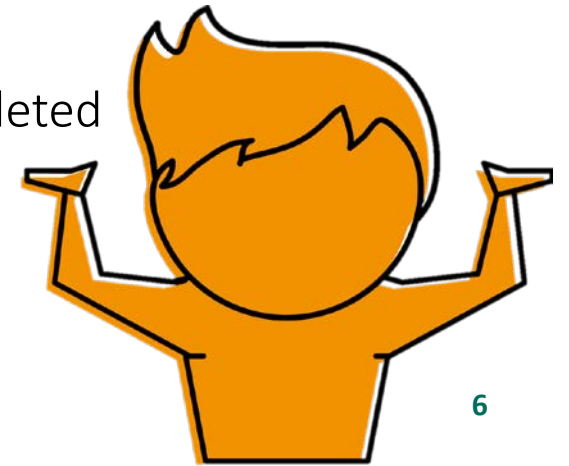


Totalling **8,969,749** PROM symptom reports collected from **587,849** unique patients across Ontario since 2007.



# Barriers to PROs Uptake

- Barriers include: lack of time, lack of awareness, clinician engagement, patient buy-in, among others.
- Over the last fiscal year, only around **54-58%** of patients completed a PROs measure at least once a month.
- Feedback from the hospitals and clinics suggest that patients buy-in is one of the primary obstacles to improving the rate of PRO completion at their sites.
- Factors impacting patient buy-in include:
  - Doubts about the value-add of PROs
  - Misperceptions regarding the purpose of PROs
  - Confusion over who should complete PROs and when they should be completed



# Your Symptoms Matter Patient Education Resource

In response to this feedback, the program convened a working group of clinicians, hospital managers, patient education specialists, CCO program staff and patient family advisors to develop a patient education resource.

Goals of the resource:

1. Help patients understand the value of PROs in their care.
2. Increase buy-in and uptake of PROs completion by the cancer patient population.
3. Help foster regular PROs completion as a cultural norm for cancer patients.

The group decided to use the 3Ws and H methodology to develop the resource.

# The 3 Ws and an H Methodology

The 3 Ws and an H methodology is aimed to help healthcare providers and administrators in the production of effective patient education resources.

To accomplish this, the working group had to answer the following questions:

1. Who specifically is this resource for?
2. Why should they read it?
3. What exactly do they want and need to know?
4. How can the content best reach and engage the learner?



# The Who and the Why

- The first question determines “who” the resource is specifically for.
  - Identifying the “who” at the start ensures that resource is designed around that target audience’s needs.
  - The working group defined the “**who**” for this resource as the following:
- The “why” defines the purpose of the resource.
  - The “why” is determined after the “who” to ensure we design the purpose of the tool with the target audience in mind.
  - The working group defined the “**why**” as the following:

*For patients before, during and after cancer treatment*

*Learn how “Your Symptoms Matter” can help you!*



# The Who and the Why

- Together the who and the why make up the title of the resource.
- The working group must determine that the title is sufficient enough to compel the readers to pick up the resource.

*Learn How “Your Symptoms Matter” Can Help You:  
For patients before, during, and after cancer treatment*

# The What

- Determining the “what” helps outline what content should be included in the resource.
- The methodology requires the engagement of both experts (normally the working group members) and patient and families.
  - The experts first come up with a list with what they believe the target audience **needs** to know.
  - A patient and family needs assessment is then conducted to determine what the target audience **wants** to know.
- For this resource, a small convenience sample survey was conducted to better understand what patients and families want to know.

# Content Samples

## 2. Why should I complete Your Symptoms Matter?

Filling out Your Symptoms Matter can help you and your healthcare team to:

- Notice and treat symptoms early on
- Talk about symptoms that matter to you
- Track your symptoms over time to figure out what may be causing them or any changes in them
- Choose the best treatment and medications for your symptoms

When your symptoms are well managed you can:

- Keep more of your regular routines
- Do the things that are important to you
- Keep up your strength so that you can continue with your treatments

## 3. How do I complete "Your Symptoms Matter"?

- When you open Your Symptoms Matter you will see 9 symptoms listed with the numbers 0-10 below each of them.
- For each symptom, choose the number between 0 and 10 that best describes how you are feeling.

No Pain

Example: Pain question on Your Symptoms Matter

0 1 2 3 4 5 6 7 8 9 10

Worst Possible Pain

- A score of 0 means you do not have any symptoms. A score of 10 means that your symptom is at its very worst.

# The How

- The “how” determines what modality should be used to produce the resource such as a pamphlet, video, presentation, etc.
- The more senses involved in learning the more effective it is and the more like it will be retained. (1)
- A modality usage algorithm helps to inform the working groups choice in modality:
- The working group decided on a **pamphlet** based on spending restrictions and lack of resources.
- However, as content has already been created other modalities - such as an educational video - will be considered in the future should resources become available.

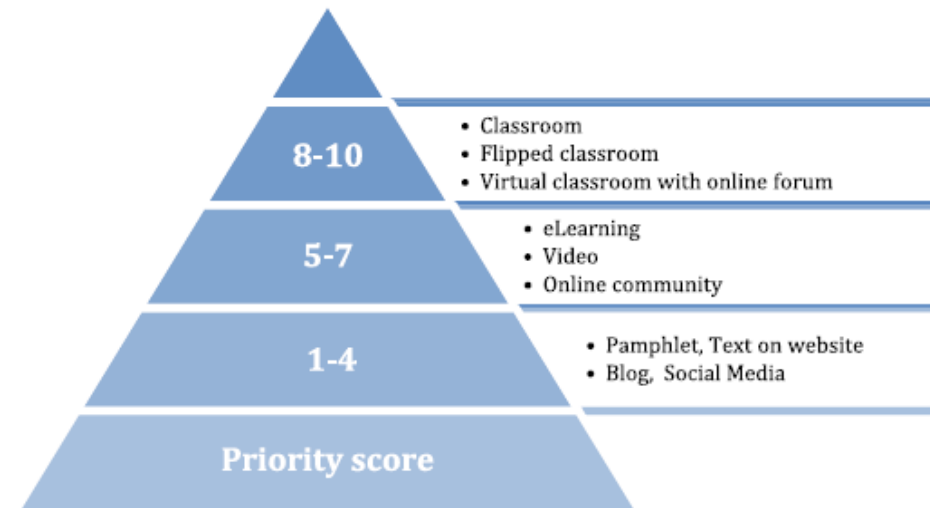


Fig. 1 Modality usage algorithm

# Results

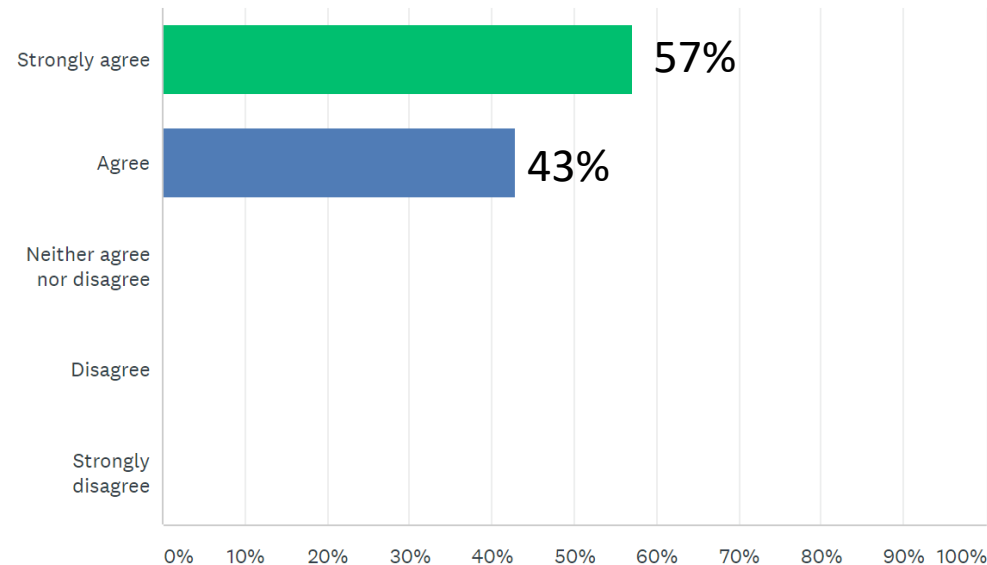
- After utilizing the 3 Ws and an H methodology, CCO staff believed that the final resource was:
  - Was compelling, effective and engaging
  - Addressed what experts felt patients needed to know and what patient wanted to know
- In order to understand if the working group members also felt that the methodology contributed to a high quality patient education resource, CCO conducted a short evaluation survey.

# Working Group Survey Results

- All respondents agreed or strongly agreed the resource covered the most important information to help patients understand the value of Your Symptoms Matter.

The completed pamphlet covers the most important information to help patients understands the value of Your Symptoms Matter.

Answered: 7 Skipped: 0

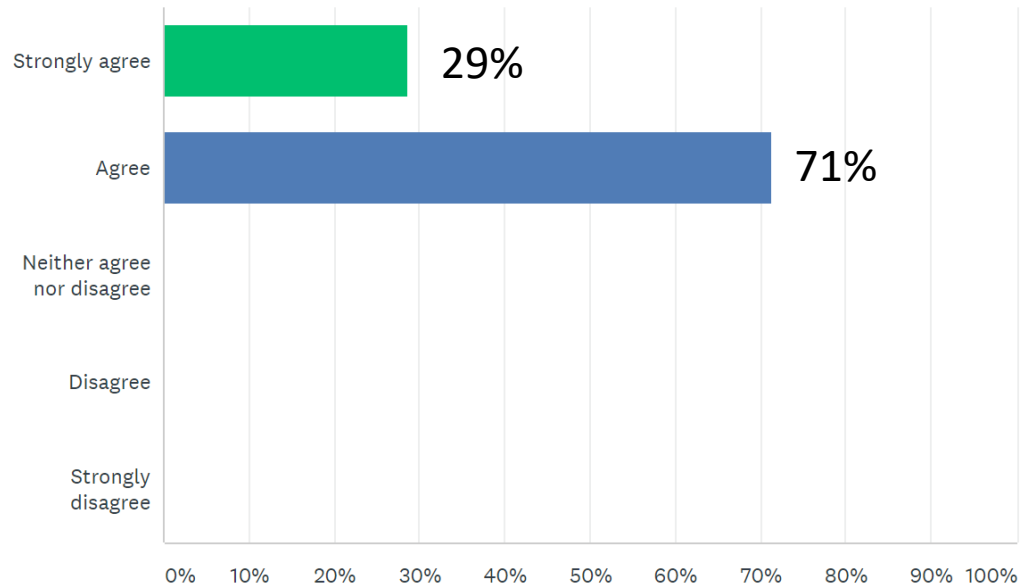


# Working Group Survey Results

- All respondents agreed or strongly agreed the 3Ws and an H methodology created a useful content outline for the pamphlet.

The 3 Ws and an H process helped to create a useful content outline for the Your Symptoms Matter Pamphlet.

Answered: 7 Skipped: 0

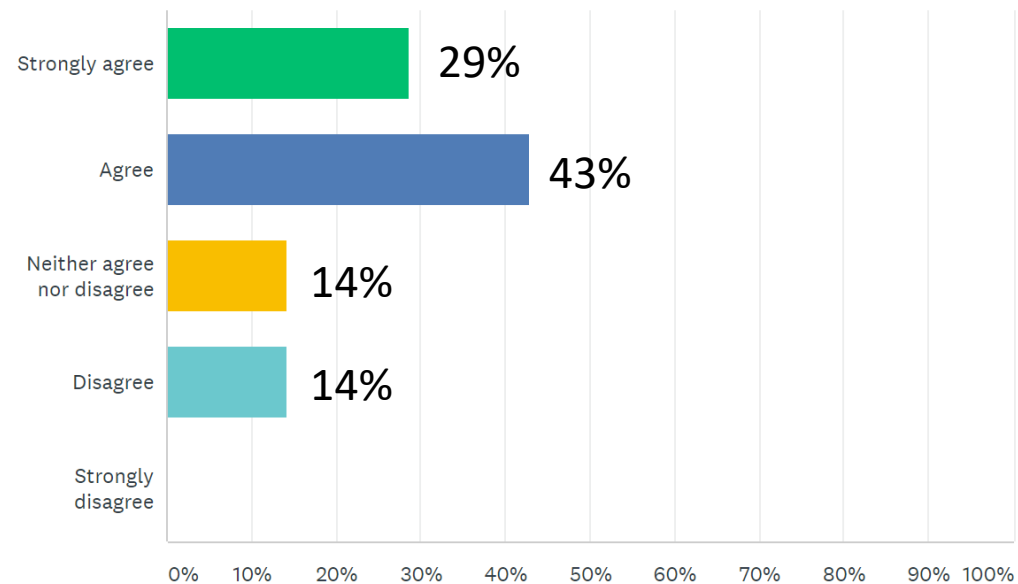


# Working Group Survey Results

- There were mixed reviews about whether or not the methodology helped streamline the creation of the pamphlet.

The 3 Ws and an H process helped to streamline the creation of the pamphlet.

Answered: 7 Skipped: 0



# Working Group Survey Results

- The working group provided comments about working with the methodology:

Defined the 'who, and why'. Identified 'what' the information needed to look like... and the 'how' supported the best way to reach the intended audience. Kept the group on point and easy to reference to ensure the group stayed on task.

It engaged patients at the beginning of developing a patient education material. It addressed some of the challenges with material development - too much information and how to prioritize the information.

The downside of a framework is that it needs tweaks to adapt it to the situation at hand, which included making adjustments and being more fluid for YSM.

# Conclusions

- Overall, the 3 Ws and an H methodology was helpful in the creation of an effective patient education resource which teaches the value of PROs for cancer patients in their care.
- The working group felt the methodology was helpful in identifying and targeting the pamphlet on the information patients need and want to know.
- The survey results were shared with the 3Ws and H framework developers for potential process improvements.

# Acknowledgements

- Sarah McBain, CCO
- Monika Duddy, CCO
- Janet Papadakos, CCO and Princess Margaret Hospital
- Zahra Ismail, CCO
- Natalie Coburn, CCO and Sunnybrook Hospital
- Joanne MacPhail, Patient Family Advisor
- Patricia Pottie, Patient Family Advisor
- Ruth Barker, Stronach Regional Hospital
- Upasana Saha, Princess Margaret Hospital
- Sangeetha Navaratnam, Trillium Health Partners
- Angela Djuric-Paulin, Juravinski Cancer Centre
- Debbie Devitt, Durham Regional Cancer Centre
- Christine Peters, Grand River Hospital
- Lianne Dupras, Patient Family Advisor



Thank You

