NCCN **NCCN Virtual Nursing Program:**
Advancing Oncology Nursing™

Patient-Reported Outcomes: Assessment and Interventions to Improve Symptom Management

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Objectives

- Recognize the challenges of symptom management in patients with cancer.

- Describe what PROs and ePROs are, and settings in which they may be used.

- Discuss how PROs and ePROs may affect cancer care delivery, patient health outcomes, and health care utilization and associated costs.

The Problem: Symptom Management

Patients with Cancer Receiving Chemotherapy:

From Chemotherapy Complications:

PER YEAR

Hospital admissions: 1
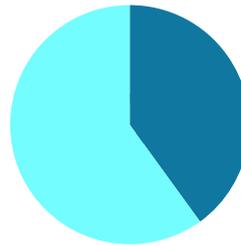
ED Visits: 2

Admissions
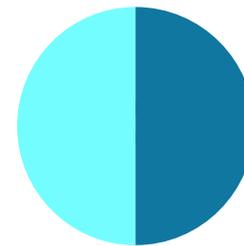
ED Visits

Department of Health and Human Services, *Federal Register*, August 22, 2016. Klodziej M, Hoverman JR, Garey JS, et al. Benchmarks for value in cancer care: an analysis of a large commercial population. *Journal of Oncology Practice*. 2011;7(5):301-306.

Attributing "The Gap"

Patients manage symptoms at home

Patients may assume little can be done and may not seek assistance

Variation in patient-clinician communication

Department of Health and Human Services, *Federal Register*, August 22, 2016; Mathematica Policy Research, *Admissions and Emergency Department Visits for Patients Receiving Outpatient Chemotherapy Measure Technical Report*, March 2016

Patient and Provider Perception

Assume symptoms inevitable

Do not remember how to contact care team

Often feel unsupported in the days after treatment

Assume "no news is good news"

Underestimate impact of symptoms on patient's quality of life

Vidall, C., Sharma, S., & Amlani, B. (2016). Patient–practitioner perception gap in treatment-induced nausea and vomiting. *British Journal of Nursing*, *25*(16), S4-S11.

What are PROs?

"A PRO is any report of the status of a patient's (or person's) health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else."

U.S. Department of Health and Human Services Food and Drug Administration

Uses for PROs

PROs capture:
- Health-related quality of life (including functional status)
- Symptoms and symptom burden
- Experience with care
- Health behaviors

PROs and quality care:
- Provide accountability for healthcare claims
- Allow for cost-benefit analysis

"Patient and family engagement is increasingly acknowledged as a key component of a comprehensive strategy … to achieve a high quality, affordable health system"- National Quality Forum

Patient-Reported Outcome Measures (PROMs)

PROMs are the tools or instruments used to measure PROs
- Usually patient-completed questionnaires
- Can be general or disease-specific
- General PROMs allows for comparison across conditions
- Disease-specific PROMs allow for identification of symptoms and their impact

History of PROMs
- Initially developed for use in pharmacological and healthcare research
- Expanded into clinical care as a measure of quality
- Increasing use of these tools has led to new outcome measures and models of care

Transitioning from Paper to ePROs

Traditionally, PROs were paper forms that were either completed in clinic or at home and brought to clinic for review (e.g. pill diaries or a symptom log).

The prevalence of smartphones, tablets, and computers have enabled the development of ePROs, which are NOT just electronic versions of paper PROs.

COVID-19–related growth in telehealth has increased reliance on ePROs.

Why ePROs?

Pen-and-paper patient forms are frequently:
- Incomplete
- Illegible
- Untimely
- Poorly utilized/not included in EHR

ePROs allow for:
- Improved accuracy
- Improved compliance
- Symptom reporting in real time
- Automated entry to EHR

Types of ePROs

Interactive voice response systems
- Automated calls
- Allow for response on keypads

Screen-based reporting devices
- Patients answer questions on devices
- Responses are digitally recorded
- Requires consistent internet access

SMS texting
- Use of SMS texts to collect ePROs has increased dramatically in recent years

ePROs in Oncology: Basch Study

Patients engaged in:

Proactive Self-reporting

Standard of Care Symptom Management

Quality of Life

30%
Better

ER Visits

7%
Fewer

Survival

5 mo.
Longer

Basch E, Deal AM, Dueck AC, et al., *JAMA*, 2017

Symptom Monitoring & Control: Improving Survival

Proactive monitoring promotes early intervention

Symptom control improves quality of life

Monitoring allows patients to be on chemotherapy longer

Need for Proactive Symptom Management
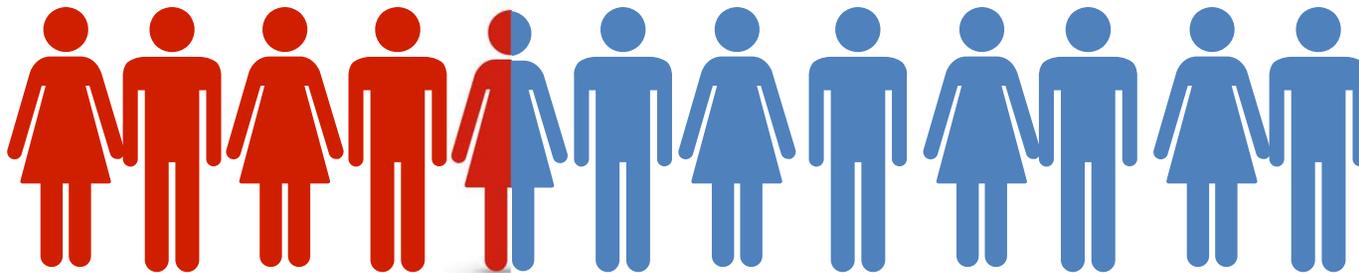
**36% of new start antineoplastic patients at MSK present to the UCC
for symptoms that could be safely managed outpatient
if identified early & managed proactively**

Vision for InSight Care

To extend the reach of our care, we will focus on keeping patients and their caregivers connected using ePROs, symptom alerts, and a dedicated care team.

By keeping our patients in our line of sight at all times—as well as building on data-driven insights—we will be better able to deliver predictive, anticipatory, and proactive care.

Patients will spend more time at home, thereby maximizing physical, psychological, and emotional comfort.

Program Goals

1. Identify cohorts of patients most at risk

2. Evaluate & implement the right structure & resources to ensure the best care

3. Monitor & provide proactive management & interventions 24/7

4. Enhance patient engagement & involvement in their own care

5. Continuously use & develop technology to augment & improve our ability to monitor, assess, engage, & intervene

Identify Early, Manage Proactively

Identify those most at risk

Proactive care 24/7

Collaborative care team

Enabled by Digital Platform

Extend Our Reach to Transform Our Care

Dedicated team reviews alerts in context of patient's care

Patient completes daily symptom assessment via patient portal

Collaborates with primary oncology team to determine appropriate intervention

Eligibility for InSight Care

✓ Inclusion

18 years or older

New IV antineoplastic order

New visit (NV or IR) with one of the included doctors in Westchester

✗ Exclusion

Had IV or oral chemo in the 6 months prior to the current chemo order

Had Leukemia or a BMT

Had an IRB other than specimen banking or genetic trials

ePRO Summary and Cadence

	Question Topic	Cadence
1	Pain	Daily
2b	Pain – Location (conditional)	Daily
2b	Pain - Severity(conditional)	Daily
2c	Pain - Interference (conditional)	Daily
3	Activity	Daily
4	Fatigue/Weakness	Daily
5	Nausea	Daily
5b	Nausea – Severity (conditional)	Daily
6	Emesis/Vomit	Daily
7	Diarrhea	Daily
8	Constipation (conditional per Diarrhea response)	Daily
9	Dyspnea/Shortness of Breath (conditional)	Daily
10	Depression	Weekly
11	Anxiety	Weekly
12	Any Other Symptoms (free text)	Daily
13	Who Completed This Survey?	Daily
14	Missed Work	Daily
15	Non-MSKCC ED or UCC Visit	Daily

Positive Symptom Responses Elicit More Detail

Have you had any of the following symptoms in the past 24 hours?

Pain *   ⊙ Yes   ○ No

How often did you have pain in the last 24 hours? *

○ A little of the time

○ Some of the time

○ A lot of the time

○ Almost all the time or all the time

One question expanded view if "Yes" selected in a binary question

Alerts Based on ePROs

| ALERT LEVEL	SEVERITY	INTERVENTION	DESCRIPTION
No Alert	No symptom reported	None	No required action
Yellow	Mild/moderate symptoms	Assessment, coaching, management	Team response determined by clinician judgment, symptom trends, clinical history
Red	Severe symptoms	Assessment call by team	Alert requires team to call patient to assess symptoms within the hour

ePROs- Part of the Equation

Signal: Daily ePROs   →   **Alerts based on thresholds**   →   **Evaluation of ePROs**   →   **Intervention**
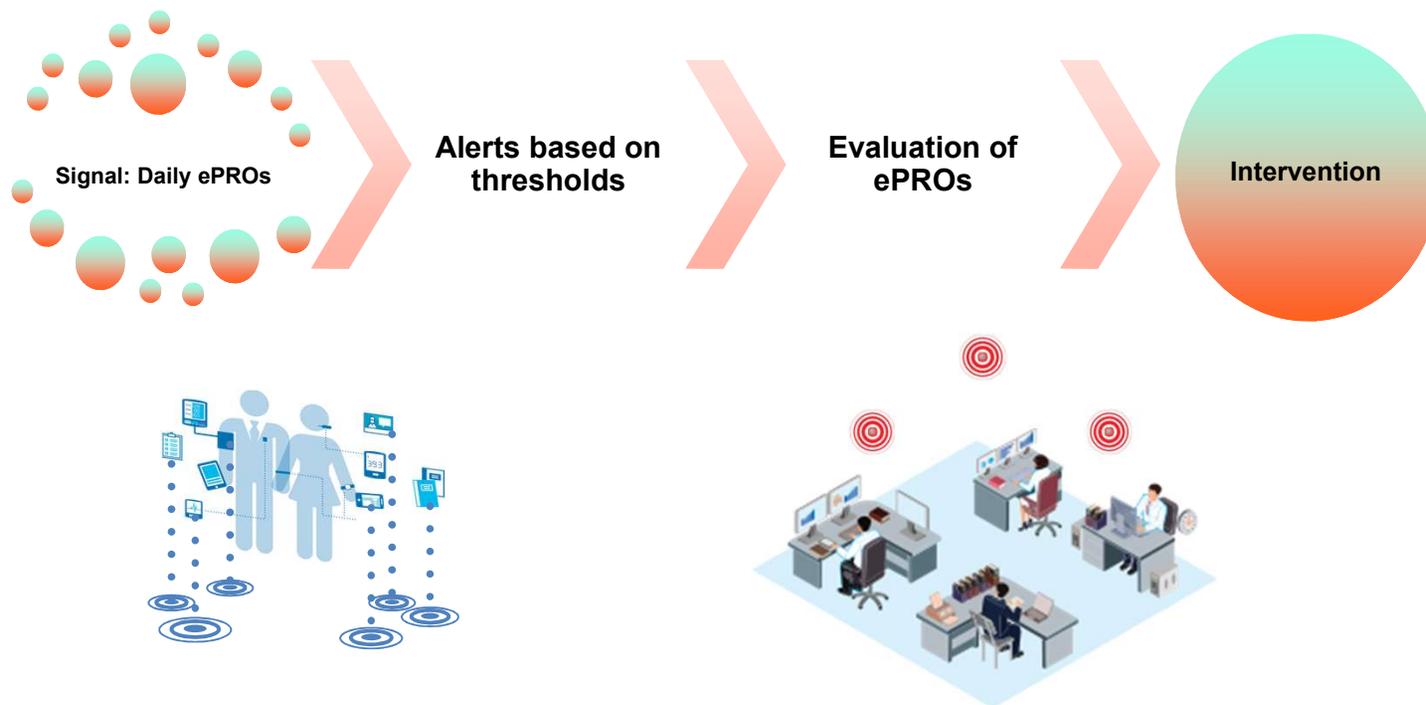
Nursing Interventions in Response to ePROs

Legend:
- Education/Coaching
- Diagnostic Testing
- Referral/Consult
- Prescription
- Acute Care Appointment
- Care Coordination

Analysis of the response to alerts from ePROs showed that the overwhelming majority required nurses to provide coaching or education

2%
2%
5%
5%
3%

Education/Coaching
83%
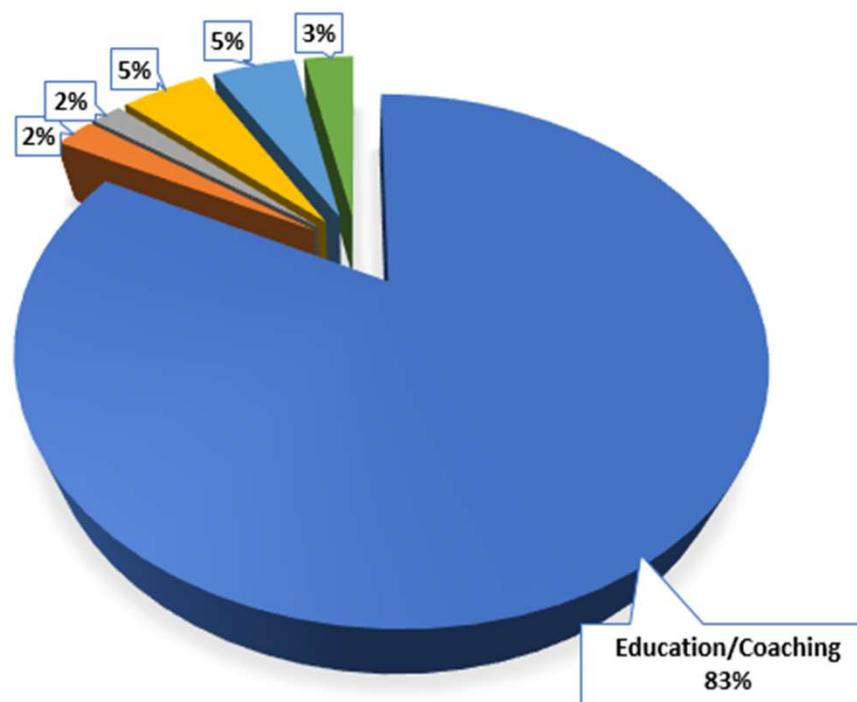
Pilot Program Evaluation: Patient Interviews

1 Speedy responses: Patients appreciated rapid response after submitting a survey reporting issues.

"One time I included this issue in my survey, they reached out in five minutes. Nothing but good."

2 The feeling of having a safety net: Patients were reassured by having 24/7 access to clinicians.
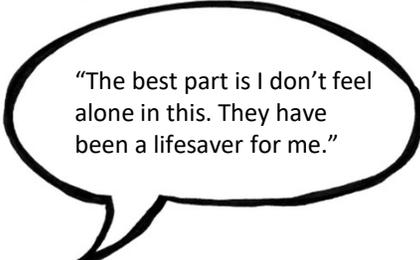
"The best part is I don't feel alone in this. They have been a lifesaver for me."

3 Convenience: Patients appreciated the ability to address issues without an in-person visit.

"That was good. I didn't have to get dressed and go to another doctor's appointment."

Daly B, Kuperman G, Zervoudakis A, et al. *JCO Oncology Practice*, Accepted for simultaneous publication with ASCO annual meeting

Pilot Program Evaluation: Response Rate

Response Rate: Time in Program + ePRO Completion Rate

Days in Program	Response rate
1 – 30 days	67%
31 – 90 days	60%
91 – 180 days	56%

Average length of enrollment: 99 days
Median length of enrollment: 84 days

Pilot Program Evaluation: Alerts

Prevalence Symptoms Reported at Moderate and Severe Levels on 1 or More Days

Symptom	Moderate (%)	Severe (%)
Pain	73	74
Anxiety	71	21
Depression	70	14
Activity	66	53
Diarrhea	62	12
Oral intake	61	18
Nausea	58	25
Dyspnea	38	22
Additional	94	NA

93%
of patients generated at least 1 red alert

Pilot Program Evaluation: UCC Utilization

High-risk patients followed for at least 6 months presenting to UCC

Unenrolled, high risk

n = 28
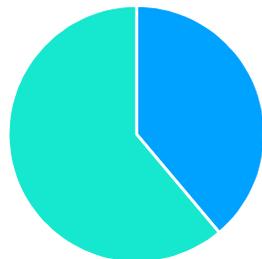
InSight Care

n = 100

**39%**

11 of 28 patients presented to UCC
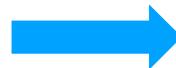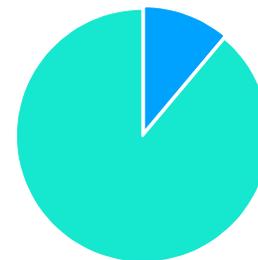
22%

22 of 100 patients presented to UCC

Daly, Bobby, Kuperman, Gilad, Zervoudakis, Alice, et al. InSight Care Pilot Program: Redefining Seeing a Patient. *JCO oncology practice*. 2020;16(10):675-e1059.

Lessons Learned

- Patient Inclusion
  - Most patients enrolled using clinician override, not model prediction

- ePRO Cadence
  - Response rate to daily ePRO lowered over time but remained > 50% at 6 months

- Workforce
  - Disease-specific knowledge and responsiveness essential

- Interventions
  - Education and coaching were the majority of interventions

COVID-19 Cohort Monitoring Program (CCMP)
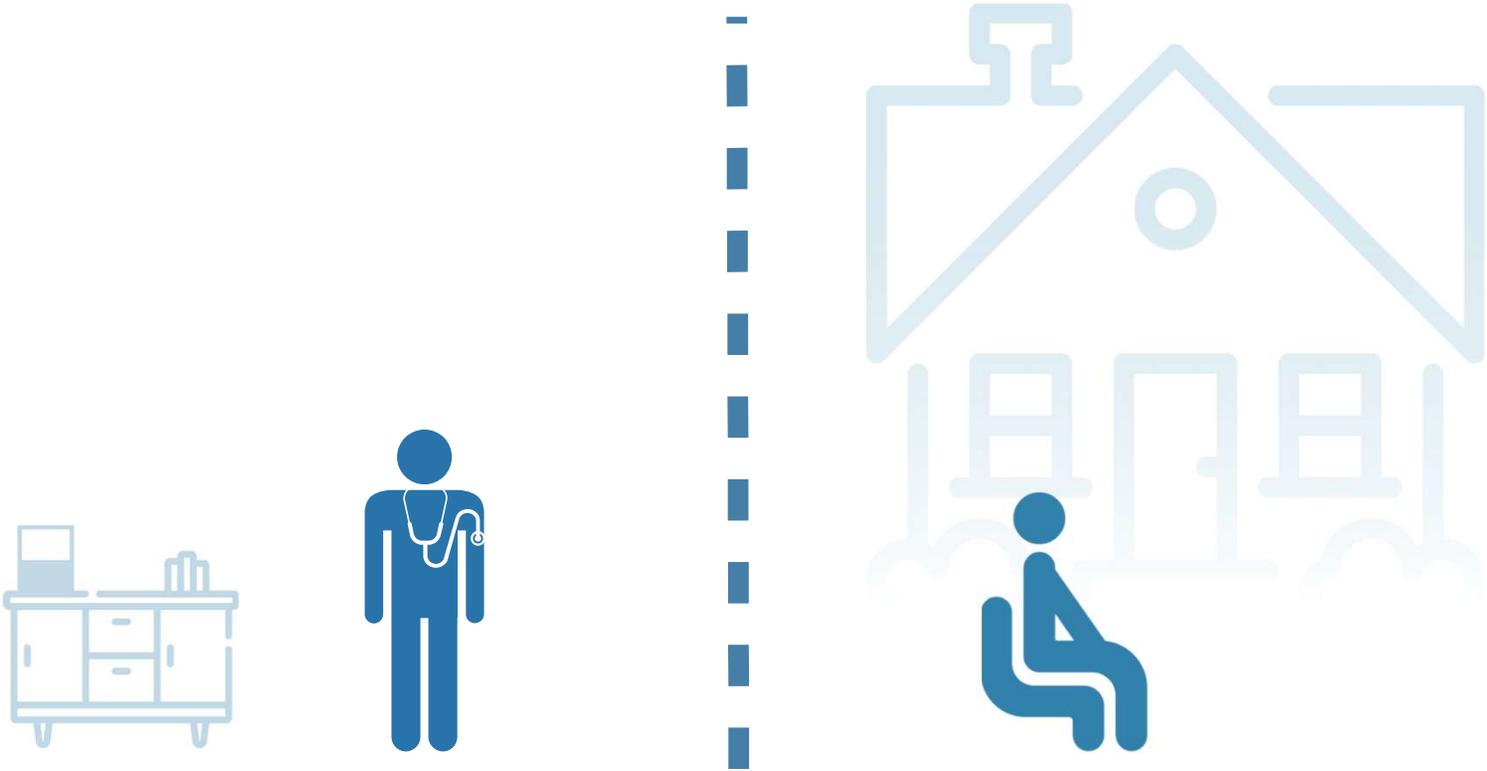
CCMP Goals and Objectives

 Monitor patients with cancer who are COVID-19+ and managing at home

 Identify and direct patients that require immediate escalations in care

 Ensure patients are continuing to recover post-discharge

CCMP Phases

Onboarding

Identify patients that meet inclusion criteria and enroll them

Monitoring

Monitor patients' symptoms and recovery

Exit

Discharge patients who have recovered or transitioned to a higher level of care

CCMP Onboarding Process

Onboarding
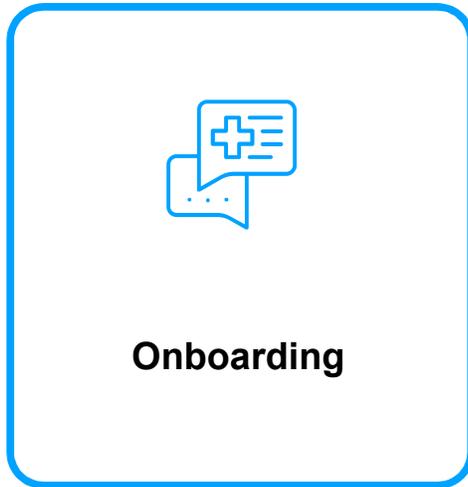
📢 CCMP automatically notified based on the inclusion criteria

📢 CCMP assesses if patient is eligible to be onboarded

📢 CCMP calls patient to inform them of the result and provide education and introduction to the program

CCMP Inclusion Criteria

COVID-19 Lab Result Positive

Initially, all patients who tested positive were enrolled

Over time, we stopped enrolling asymptomatic patients

Recent Inpatient Discharge

Discharged, high-risk patients received a pulse oximeter for remote monitoring

COVID-19 Lab Result Positive, Externally

+

+IP

+E

CCMP Exclusion Criteria

COVID-19 Lab Result Negative

Pediatric patients and caregivers

Employees
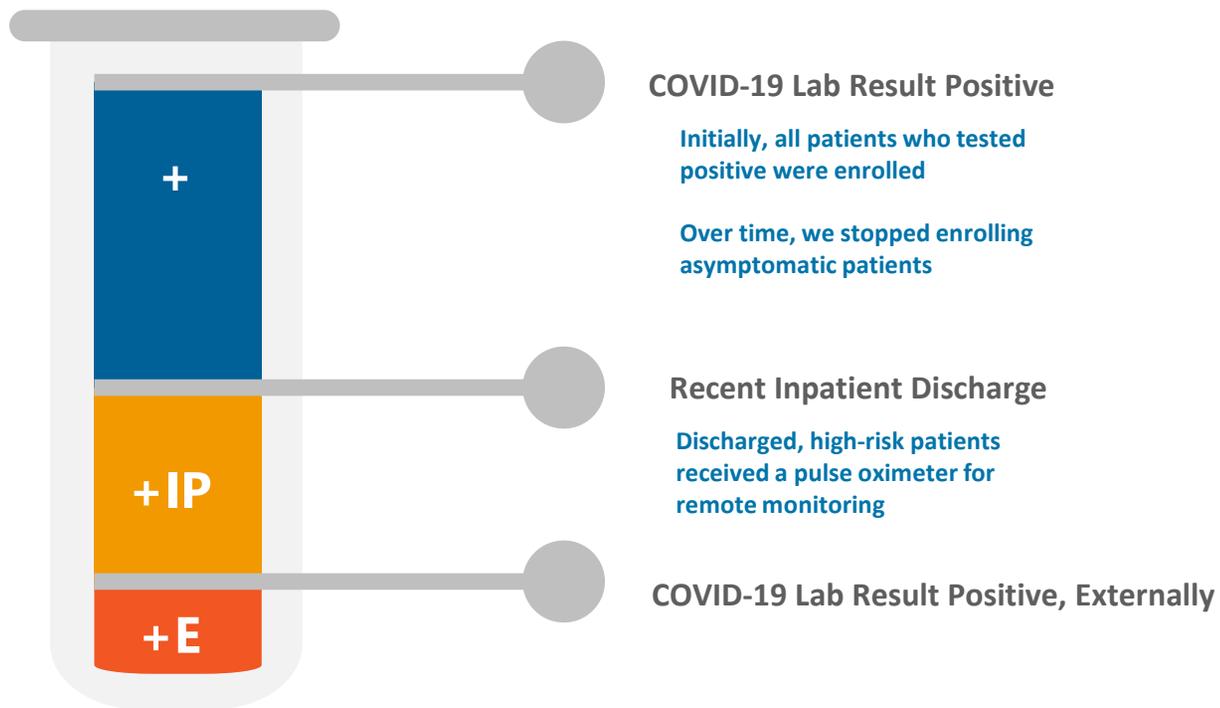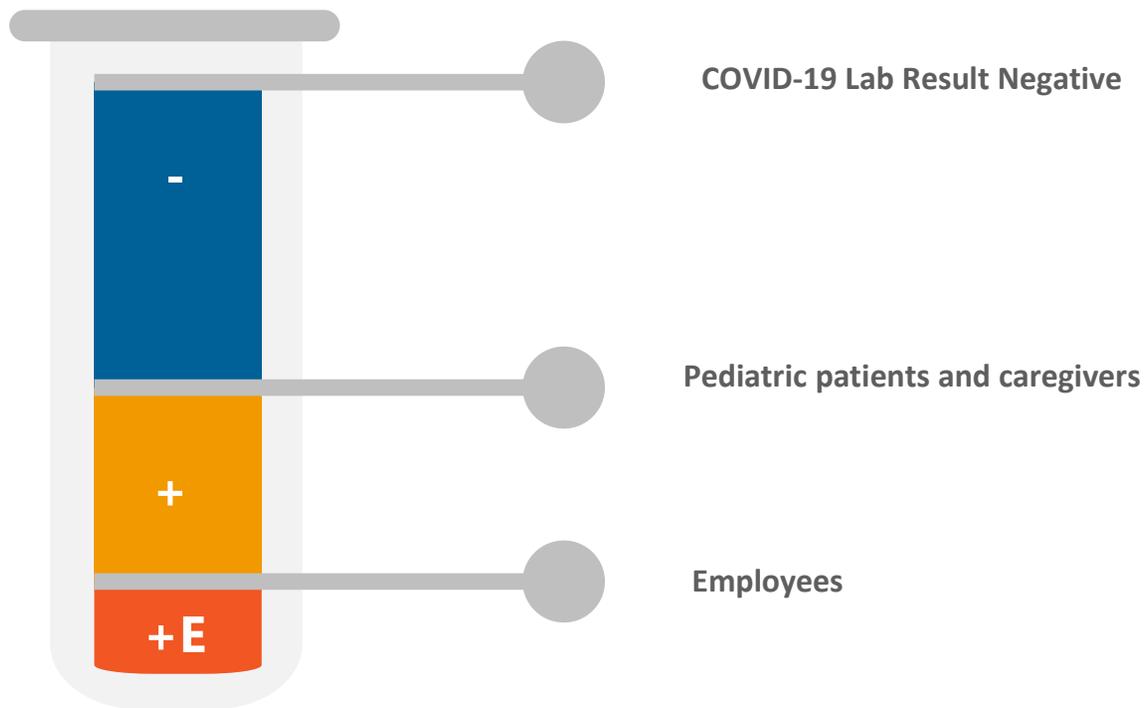
Monitoring Process

Monitoring
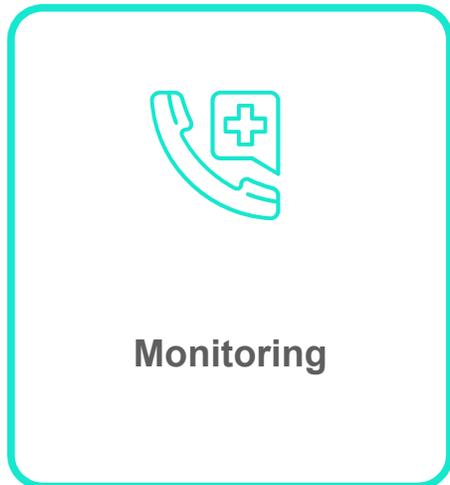
❤ **Patients fill out ePROs daily**

⏻ **Patients with pulse oximeters transmit readings twice a day**

🎧 **CCMP calls patients in response to alerts and triages symptoms**

CCMP Symptom Alert Thresholds

CCMP Exit Process

Exit

- Identify patients that are ready for exit based on criteria

- Notify patients that they will be exiting the program

- Notify patient's oncology team when the patient is exited from the program

Exit Criteria

Symptomatic

Asymptomatic

Discharged

Initial exit criteria

**The patient is admitted as inpatient,
or subacute rehab
OR
3 responses in a row afebrile
AND
14 days since positive result
AND
No cough on today's questionnaire
AND
No responses today that trigger an alert**
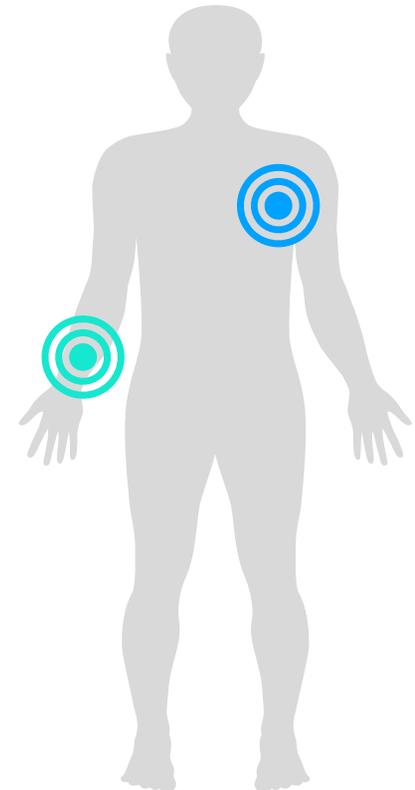
Iterate, Iterate, Iterate

- **Inclusion**
  Initially, all COVID-19+ patients were enrolled. In December, we stopped enrolling patients who were asymptomatic at the time of testing. If patients develop symptoms, the primary team notifies CCMP for onboarding.

- **Unanswered questionnaires**
  Initially all patients who did not submit their daily questionnaire received a call from the CCMP. Based on feedback from the RNs, we now allow the team to determine who needs a call.

- **Exit criteria**
  The exit criteria has evolved multiple times based on CDC guidelines and recommendations from our Chief Medical Epidemiologist. Symptomatic, asymptomatic, and discharged patients have all been considered separately.

CCMP Metrics

- **1,721 patients enrolled in CCMP (March 25 - December 22, 2020). 100% received a daily ePRO**

  - **27% triggered an alert from the questionnaire**

- **12% of enrolled patients had been discharged from the hospital with a pulse oximeter device**

  - **63% triggered an alert from the device**

- **Among patients who triggered an alert of any kind, 3% were triaged to a higher level of care**

CCMP Satisfaction Survey

The COVID-19 Management Program was an important part of my care for COVID-19.

I would recommend the COVID-19 Management Program to other patients like me.

N=240

N=240

88% strongly agree or agree

92% strongly agree or agree

Strongly agree   Agree   Neither agree or disagree   Disagree   Strongly disagree
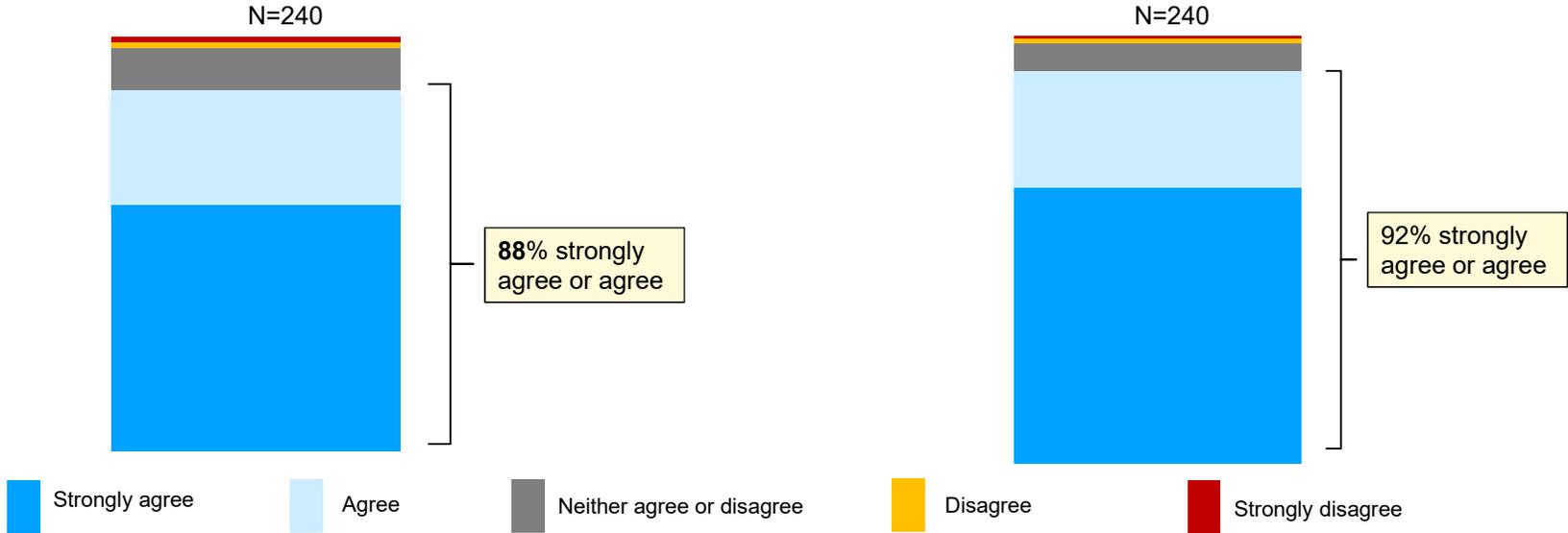
CCMP Satisfaction Survey

The time and effort it took to report my symptoms was worth it.

N=240

92% strongly agree or agree

Strongly agree Agree Neither agree or disagree Disagree Strongly disagree
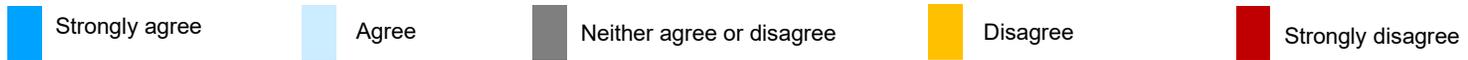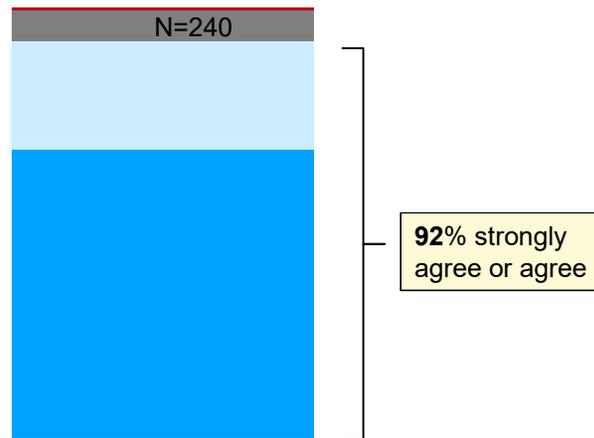
Establishing a Program

Purpose	**Drives cadence, thresholds, response time**
Patients	**Establish inclusion and exclusion criteria and revisit as needed**
Workforce	**Centralized v. decentralized**
PROs	**Evaluate PROMs and determine cadence and how data will be used**
Symptom data	**Determine how symptom data will be acted on and shared with patients**
Exit strategy	**Consider criteria and strategy for exiting patients if appropriate**

Patient-Reported Outcomes: Assessment and Interventions to Improve Symptom Management

QUESTIONS?
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NCCN Member Institutions

Who We Are
An alliance of leading cancer centers devoted to patient care, research, and education

Our Mission
To improve and facilitate quality, effective, efficient, and accessible cancer care so patients can live better lives

Our Vision
To define and advance high-quality, high-value, patient-centered cancer care globally

Fred Hutchinson Cancer Research Center/ Seattle Cancer Care Alliance

Mayo Clinic Cancer Center

University of Wisconsin Carbone Cancer Center

Dana-Farber/Brigham and Women's Cancer Center Massachusetts General Hospital Cancer Center

Roswell Park Comprehensive Cancer Center

University of Michigan Rogel Cancer Center

Yale Cancer Center/ Smilow Cancer Hospital

Huntsman Cancer Institute at the University of Utah

Case Comprehensive Cancer Center/University Hospitals Seidman Cancer Center and Cleveland Clinic Taussig Cancer Institute

Memorial Sloan Kettering Cancer Center

Fred & Pamela Buffett Cancer Center

Robert H. Lurie Comprehensive Cancer Center of Northwestern University

Fox Chase Cancer Center

Abramson Cancer Center at the University of Pennsylvania

UCSF Helen Diller Family Comprehensive Cancer Center

Stanford Cancer Institute

University of Colorado Cancer Center

The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute

The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins

Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine

Duke Cancer Institute

UCLA Jonsson Comprehensive Cancer Center

City of Hope National Medical Center

Vanderbilt-Ingram Cancer Center

UC San Diego Moores Cancer Center

Mayo Clinic Cancer Center

St. Jude Children's Research Hospital/ The University of Tennessee Health Science Center

O'Neal Comprehensive Cancer Center at UAB

UT Southwestern Simmons Comprehensive Cancer Center

Mayo Clinic Cancer Center

The University of Texas MD Anderson Cancer Center

Moffitt Cancer Center

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