Childhood Cancer Data Initiative Webinar Series

Measuring Quality and Experience of Advanced Childhood Cancer Care

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NIH NATIONAL CANCER INSTITUTE

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Today's Speaker and Moderators

Speaker

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Moderators

Brigitte C. Widemann, M.D.
Special Advisor to the Director for Childhood Cancer
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Senior Associate Scientist
National Cancer Institute

Agenda

1. *Background & Rationale*
2. *Patient-Centered Approaches to Measuring Quality and Experience of Care*
3. *Improving Care*

Background & Rationale

Why amplify patient and caregiver voices?

Background

- Children with advanced cancer experience substantial suffering.
- Most children with advanced cancer in the U.S. receive intensive services near the end of life.

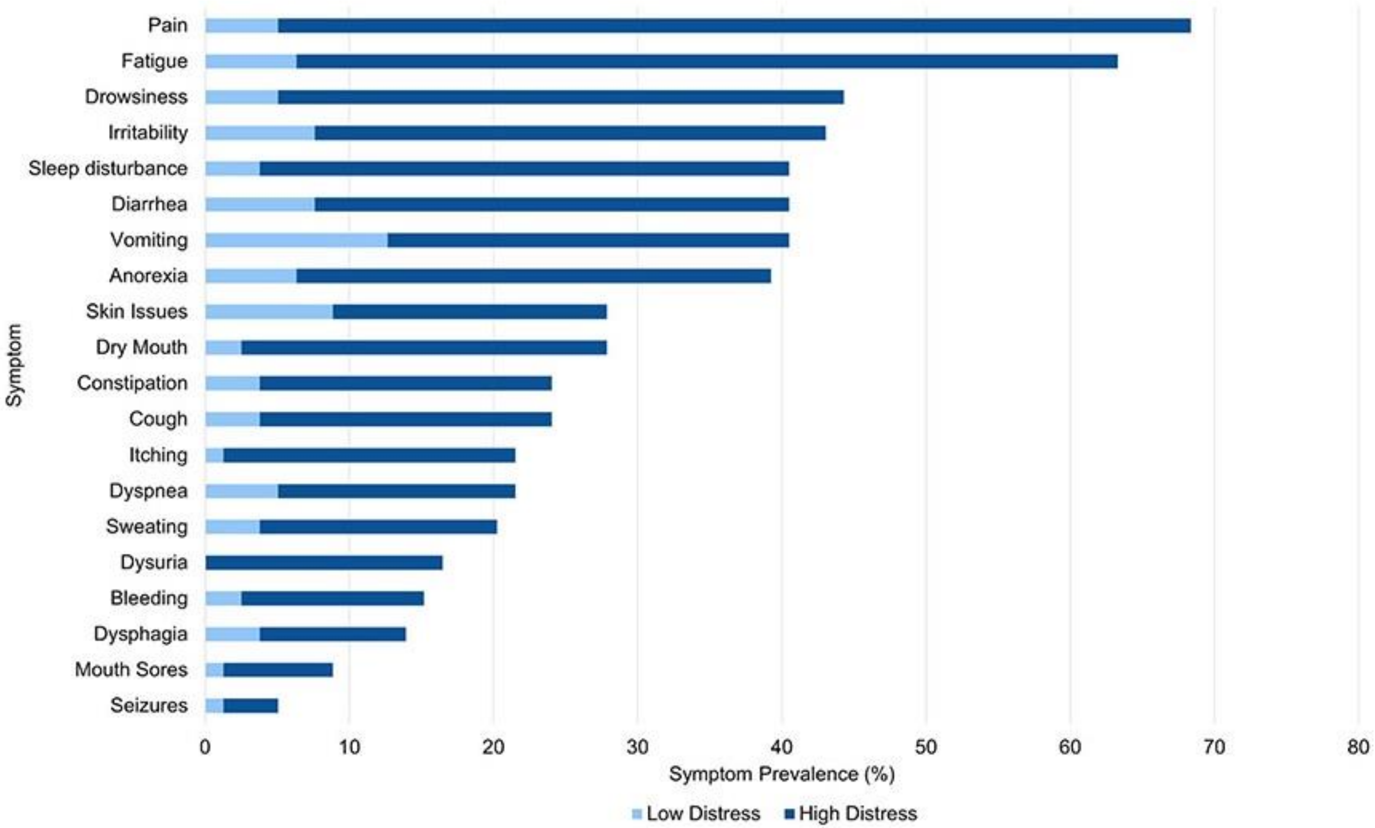
Ananth et al., *Pediatrics,* 2015
Johnston et al., *Pediatrics,* 2017
Kassam et al., *JCO*, 2017
Mack et al., *JAMA Oncology*, 2015
Mun et al., *Cancer, 2021*
Snaman et al., *J Pall Med,* 2017
Wolfe et al., *NEJM*, 2000

Hospital Use in the Last Year of Life

	Median (Interquartile Range)
Admissions	2 (1-5)
Hospital Days	27 (7-84)
Intensive Care Unit Days	7 (1-21)

Ananth et al., *Pediatrics,* 2015

Room for Improvement



Ananth et al., *Pediatr Blood Cancer,* 2023

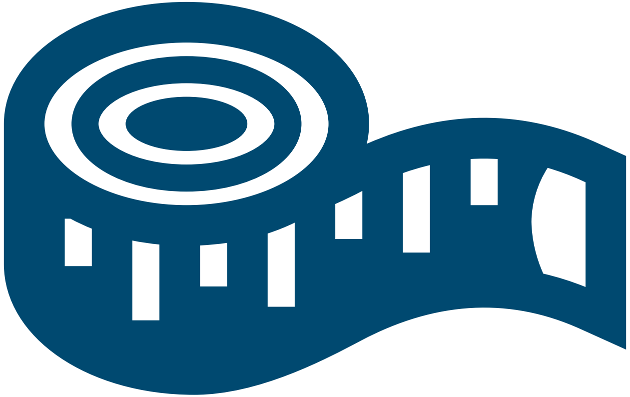
Why Measure Quality?

- “If you can’t measure it, you can’t improve it.”

  -Lord Kelvin

- “Not everything that counts can be measured; not everything that can be measured, counts.”

  -Albert Einstein

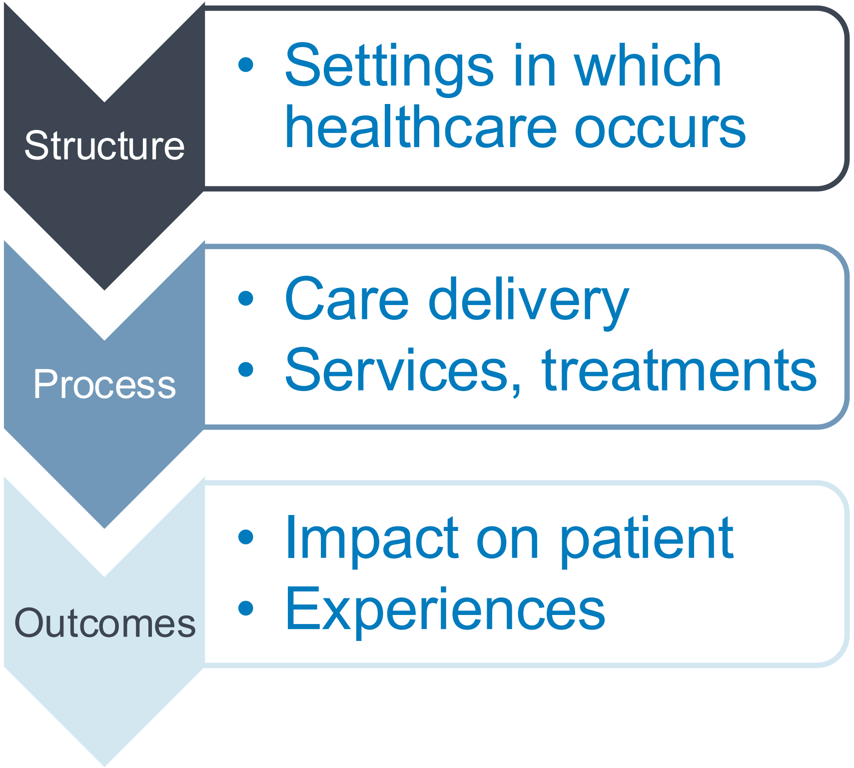


Current State of Quality Measurement

- We do not systematically measure quality of care across the illness trajectory for children with cancer.
- Many programs have instituted approaches to assess patient and family satisfaction.
- This absence of quality measurement stymies efforts to improve delivery of pediatric palliative and end-of-life care.

Quality Measures

- Tools to evaluate health care structure, processes, outcomes
- Goal of delivering equitable, safe, efficient, patient-centered care



Structure
- Settings in which healthcare occurs

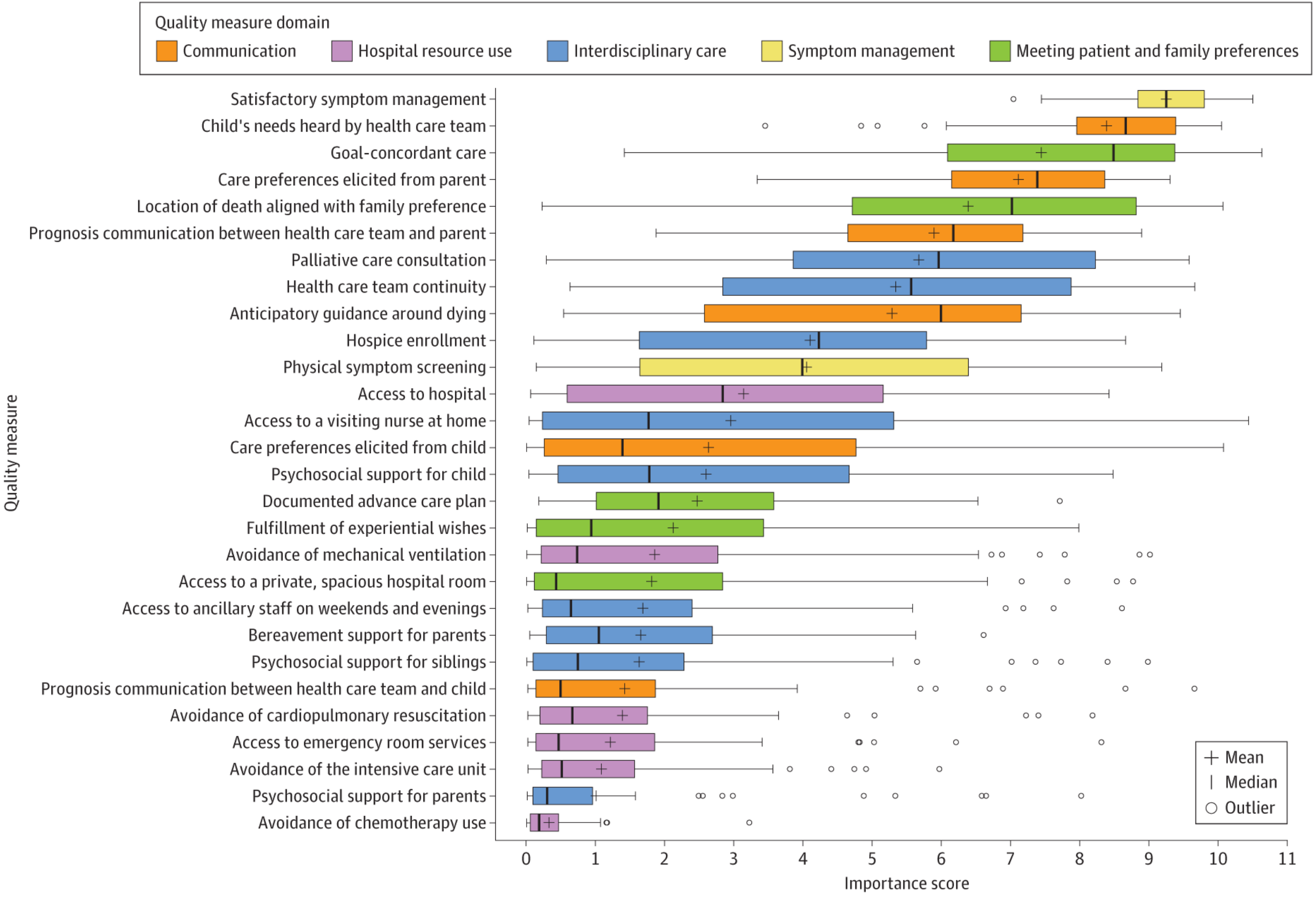
Process
- Care delivery
- Services, treatments

Outcomes
- Impact on patient
- Experiences

Donabedian, *Milbank Q*, 2005

Examples of Existing Quality Measures

Adult Quality Measure	Special Considerations for Children
Avoidance of death in an acute care hospital	Patients and parents may prefer in-hospital death for comfort or respite.
Avoidance of chemotherapy in last 30 days of life	Patients or parents may prefer chemotherapy near the end of life if it alleviates symptoms.
Avoidance of emergency department visits in last 30 days of life	Emergency department may be only location where children can receive immediate care, especially in rural areas.



Ananth et al., *JAMA Network Open*, 2023

What is Most Important

- Symptom management
- Feeling child’s needs are heard
- Having an end-of-life care experience that matches goals and preferences
- Interdisciplinary care

What is Least Important

- Avoidance of
  - Chemotherapy use
  - Intensive care unit
  - Cardiopulmonary resuscitation

Patient-Centered Approaches to Measuring Quality and Experience of Care

How can we amplify patient and caregiver voices?

Patient-Reported Outcomes vs. Patient-Reported Experience

- Patient-reported outcomes (PRO)
  - Symptoms
    - PROMIS
    - MSAS
  - Health-related quality of life
    - PedsQL
  - Adverse events
    - PRO-CTCAE

- Patient-reported experience
  - CAHPS

Bull et al, *JAMA Health Forum*, 2022
Evans et al, *JAMA Health Forum*, 2025
Reeve et al, *ASCO Educ Book*, 2023

Using PROs in Research and Clinical Care

- Quality benchmarking
- Clinical trial endpoint
- Monitoring adverse events
- Intervention itself
- Clinical care
    - Improves communication, satisfaction with care

Anhang Price et al, *Med Care Res Rev,* 2015
Dupuis et al, *JAMA*, 2024
Wolfe et al, *JCO*, 2014, 2015, 2025

Pediatric CAncer Care Experience (PACE)

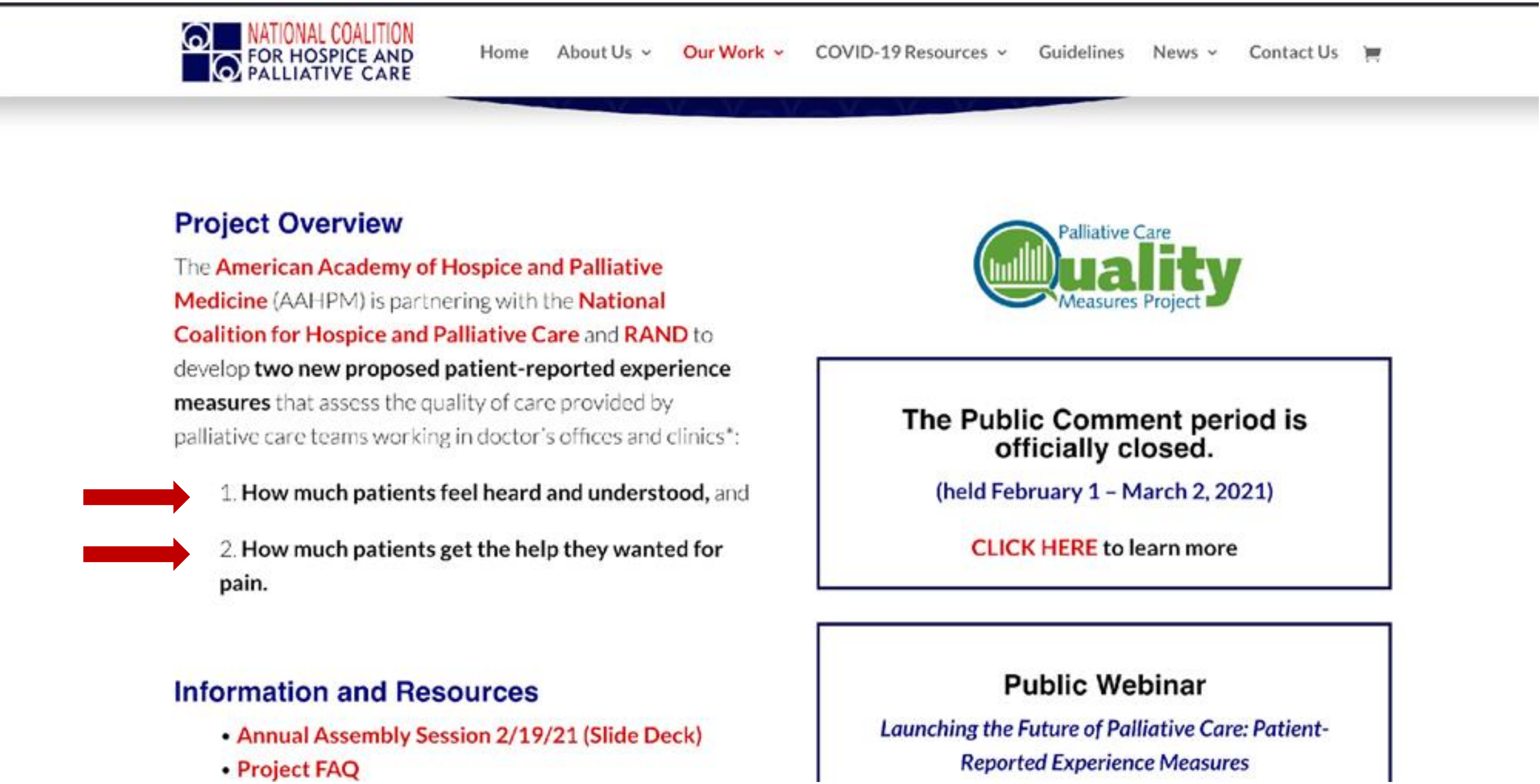
- Questionnaire for caregivers of children with advanced cancer
- Pilot study
    - 8 centers in U.S.

Therapeutic Alliance

Collaborative Care

Prognostic Communication & Shared Decision-Making

Kocinsky et al, *JPSM,* 2026



Project Overview

The **American Academy of Hospice and Palliative Medicine** (AAHPM) is partnering with the **National Coalition for Hospice and Palliative Care** and **RAND** to develop **two new proposed patient-reported experience measures** that assess the quality of care provided by palliative care teams working in doctor's offices and clinics*:

1. **How much patients feel heard and understood,** and
2. **How much patients get the help they wanted for pain.**

Information and Resources

- Annual Assembly Session 2/19/21 (Slide Deck)
- Project FAQ

The Public Comment period is officially closed.

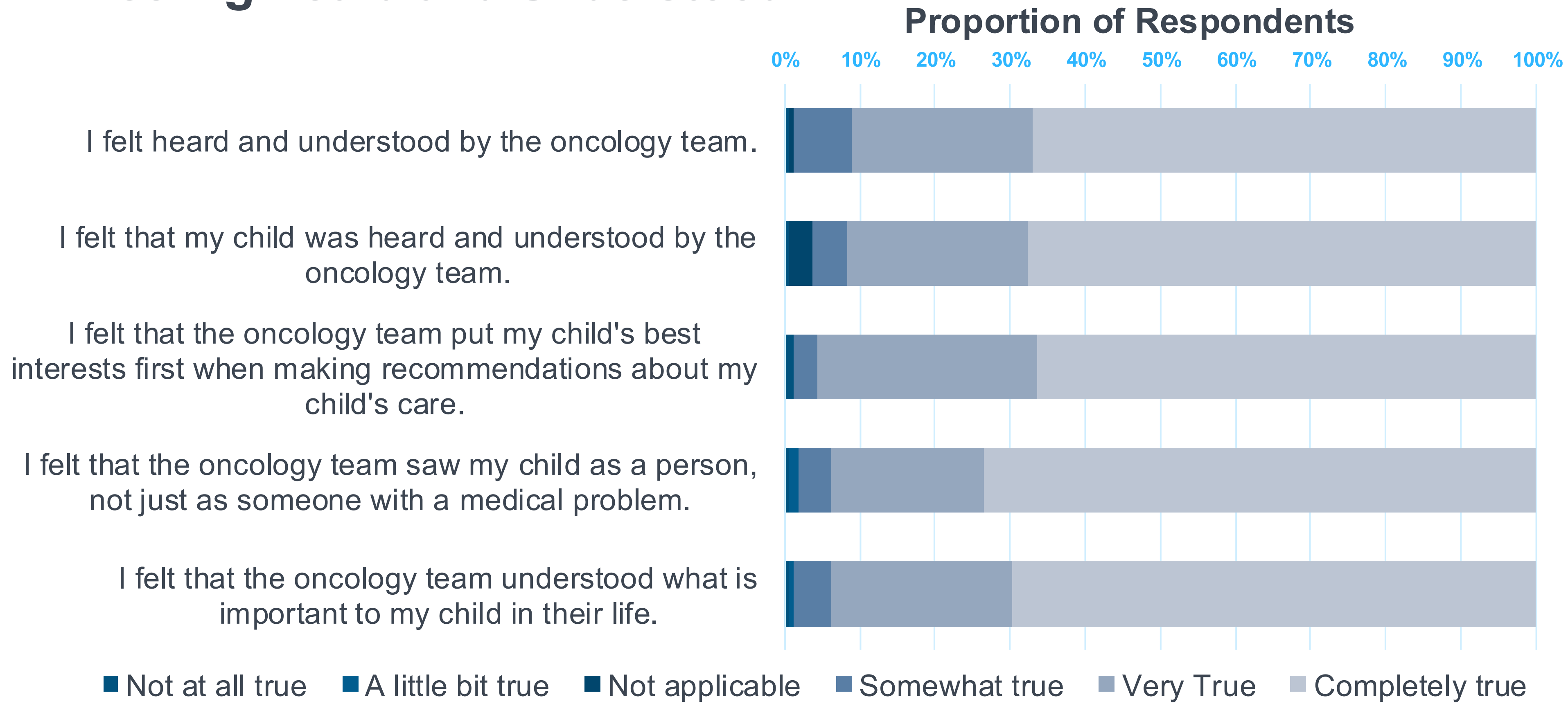
(held February 1 – March 2, 2021)

CLICK HERE to learn more

Public Webinar

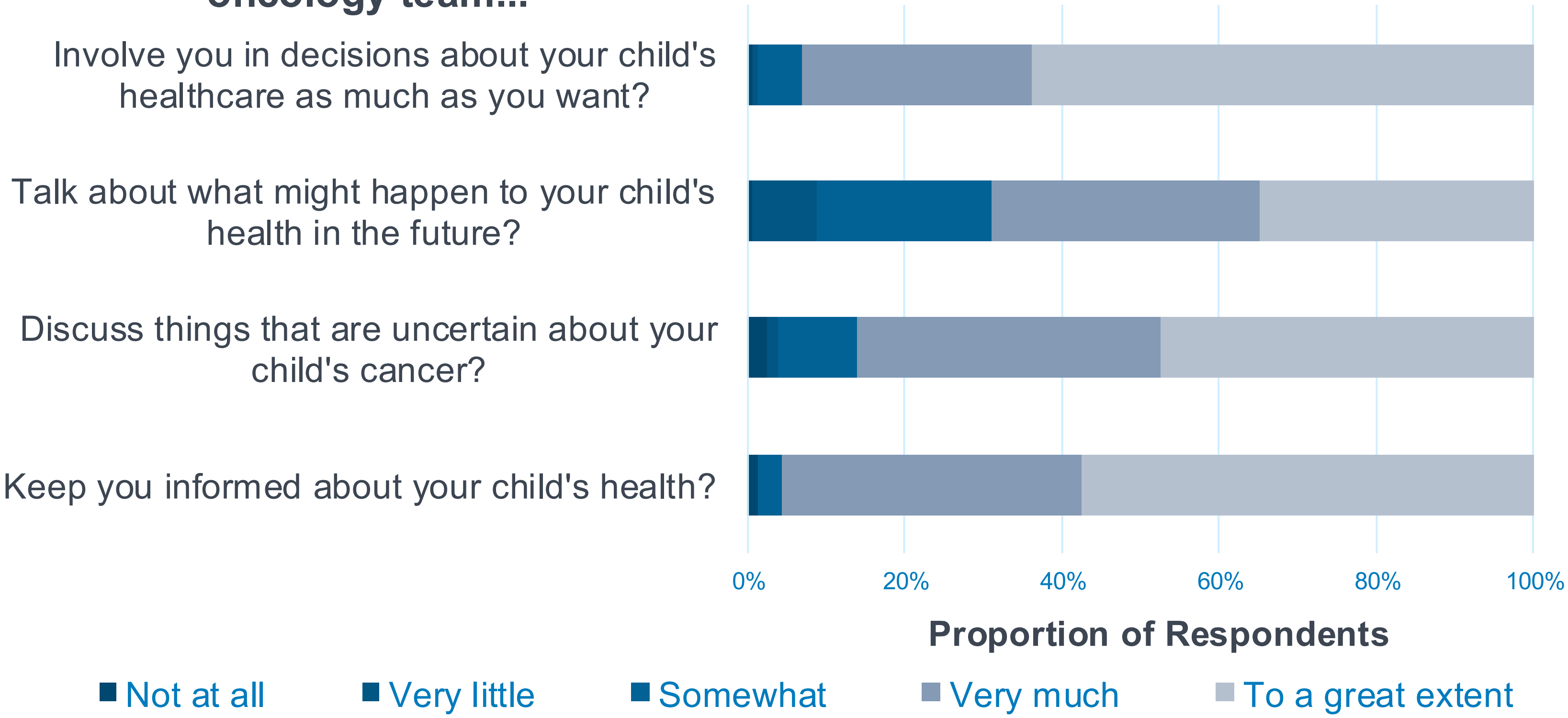
Launching the Future of Palliative Care: Patient-Reported Experience Measures

Feeling Heard and Understood

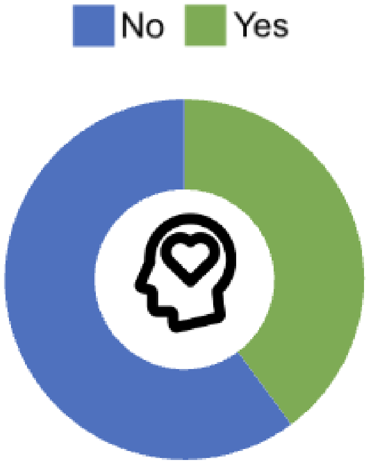


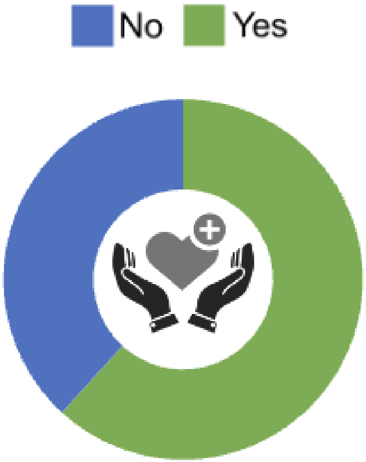
Prognostic Communication and Shared Decision-Making

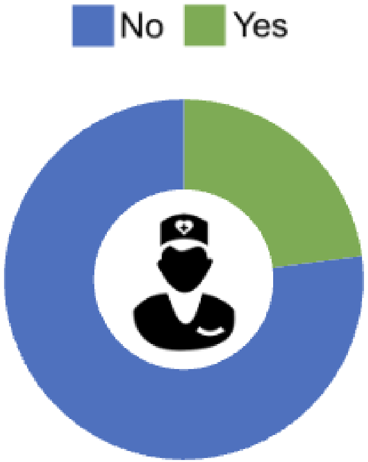
To what extent does your child's oncology team...

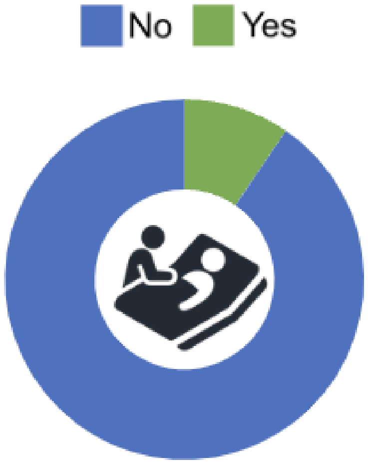


Interdisciplinary Team Involvement

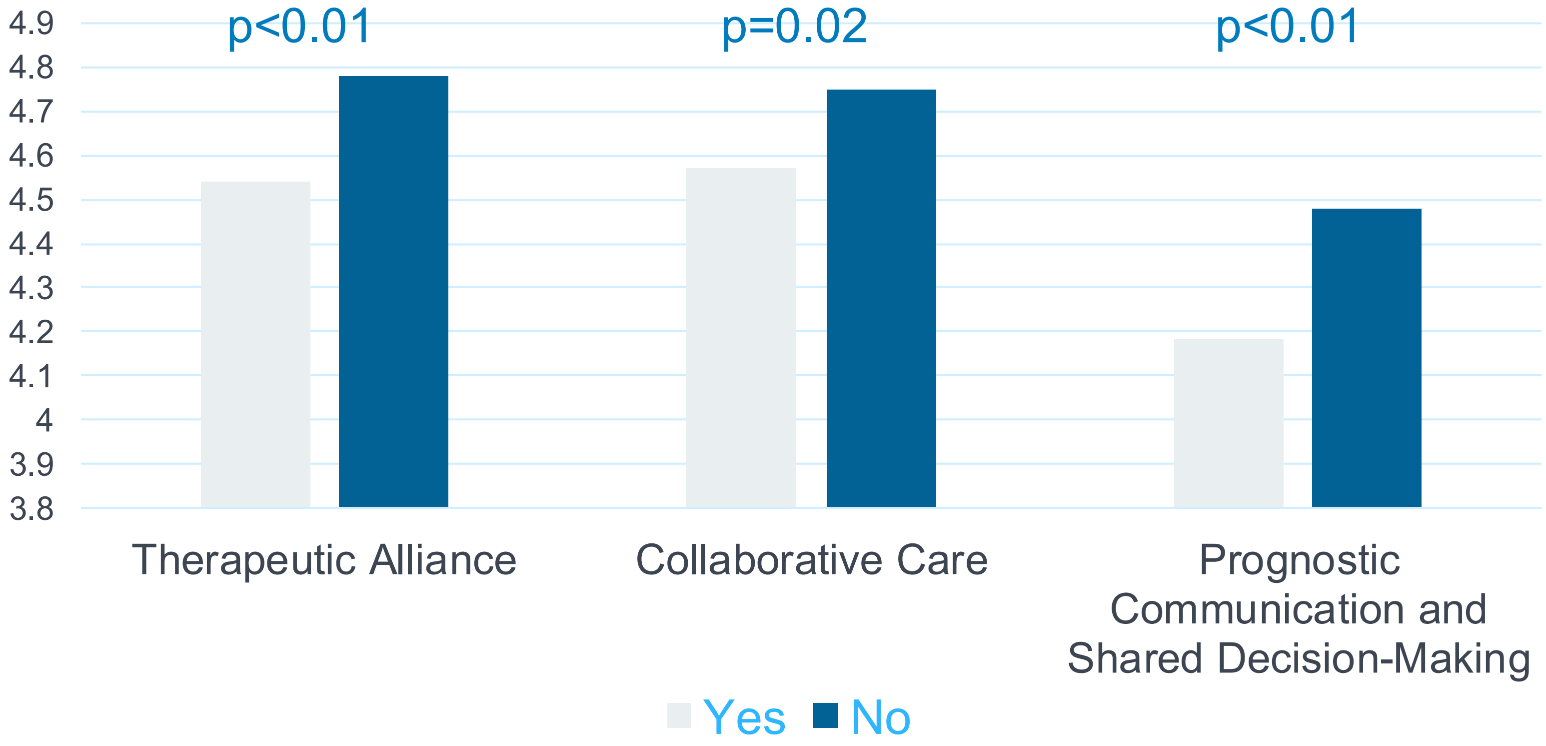

Psychosocial Care


Palliative Care


Visiting Nurse


Hospice Care

Limited Health Literacy



Leveraging Quality and Experience Data to Improve Care

How to move from data to action?

From Data to Action

The NEW ENGLAND JOURNAL of MEDICINE

CURRENT ISSUE ∨ SPECIALTIES ∨ TOPIC

SOUNDING BOARD

Creating a Learning Health System through Rapid-Cycle, Randomized Testing

Authors: Leora I. Horwitz, M.D., M.H.S., Masha Kuznetsova, M.P.H., and Simon A. Jones, Ph.D. Author Info & Affiliations

Published September 18, 2019 | N Engl J Med 2019;381:1175-1179 | DOI: 10.1056/NEJMsb1900856

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- Learning health systems
- Dashboard/scorecard
  - Patient/family-facing
  - Decision support
- Cross-program comparison

Horwitz et al, *NEJM*, 2019
Ludlow et al, *BMJ Open*, 2021

What Can We Add to the Childhood Cancer Data Initiative?

- **Sharing multi-center data**
- **Data types and elements for inclusion in the CCDI Data Ecosystem:**
  - Area-based measures
  - Clinical trials
  - Clinical information systems
  - Medical and pharmacy claims
  - Population-based cancer registries
  - Virtual pooled registry
  - Radiation oncology, and more!

Acknowledgements

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- Funding
  - K08CA259222
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  - U54AG093230
- Collaborators

Q&A

How You Can Engage with CCDI

Learn about CCDI and subscribe to our monthly newsletter:
cancer.gov/CCDI

Access CCDI data and resources:
ccdi.cancer.gov

Questions? Email us at:
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Thank you for attending!

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