

# Elevating Patient and Caregiver Voices: Implementing New Patient-Reported Experience Measures

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Declare any relevant financial relationship(s) with ineligible companies:

- Katherine Ast, faculty for this educational event, has no disclosures.
- Ben Hamlin, faculty for this educational event, has no disclosures.
- Laura Hanson, faculty for this educational event, has no disclosures.

# Organization Disclosures

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# Learning Outcomes

Upon Completing this session, participants will be able to:

1. Learn how the newly developed patient reported experience quality measures can be used in practice, quality improvement programs, and quality reporting programs.
2. Understand why new PRO-PMs from AAHPM, RAND and the Coalition are important and how they can help improve care for patients and families.
3. Connect implementation of these measures with what's important and/or mandatory (ie, TJC, “magnet certification” for nurses).
4. Learn ways different programs have found ways to incorporate the measures into workflow and have overcome barriers to measure implementation, including leadership support, patient engagement, data collection, and workflow.

# The Palliative Care Measures Project developed Patient-centered Measures, endorsed in 2022 by National Quality Forum (NQF)

Palliative care outpatients' experience of feeling heard and understood

Palliative care outpatients' experience of receiving desired help for pain

# Why These Measures?

- **The Palliative Care field prioritized** these measure concepts
- These measures address **significant gaps in care**, namely in nuanced symptom management (pain), and meaningful communication
- **Patient Experience Measures** are largely absent except for the CAHPS survey which some say is burdensome and not actionable (CAHPS=26 questions [minus “About Me” section], Heard and Understood=4 questions)
- Eligible providers who report to CMS quality reporting programs need **measures that matter to patients**, caregivers and family members
- **Alternative payment models** (APMs) need a way to distinguish good performance from poor performance

# The Palliative Care Measures Project

## Looking Back...

AAHPM and HPNA's [Measuring What Matters](#) work led the way; Measure concepts were prioritized as essential aspects of quality palliative care



- Unprecedented opportunity from the Centers for Medicare and Medicaid Services (CMS) to fund medical specialty societies to develop quality measures via the [Medicare Access and CHIP Reauthorization Act of 2015 \(MACRA\)](#)
- Meaningful palliative care measures sorely needed for quality reporting in Merit-based Incentive Payment System (MIPS) and alternative payment models (APMs)



## The Project

AAHPM was awarded a three-year cooperative agreement from CMS to develop patient-reported quality measures for community-based palliative care. The project ran from September 2018-September 2021.



## Our Partners



**Subrecipient:** the National Coalition for Hospice and Palliative Care

**Role:** Stakeholder Engagement



**Subrecipient:** RAND Health Care

**Role:** Technical Partner



National Patient Advocate Foundation

**Role:** Incorporation of the perspectives of patients, families, and caregivers

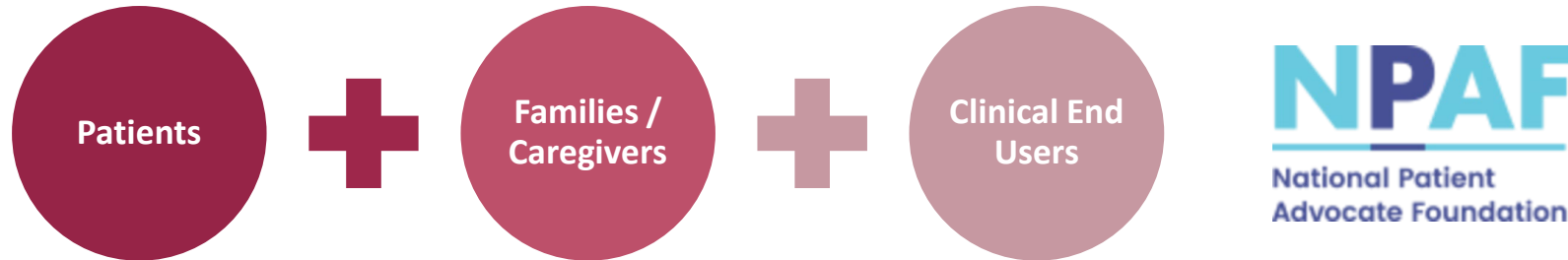


# National Beta Field Test

- Used a web-to-mail-to-phone survey design
- Surveys sent to over 8,800 adult patients receiving care from 44 outpatient palliative care programs across the U.S.
- In total, 3,850 surveys returned (response rate over 40%)
- Data from these surveys used to establish the reliability and validity of the two measures and to finalize measure specifications



# This project put people at the heart of it. At every step.



- Expertise provided by a Technical Expert Clinical User Patient Panel (TECUPP) that included patients, caregivers, and clinical end users
- Applies a person-centered approach that *recognizes the person beyond the disease*
- Prioritizes peoples' health concerns *as they see them*



Sa'Brina Davis  
NPAF Volunteer



Faye Hollowell  
NPAF Volunteer

# Public Comment Feedback from 207 stakeholders

- **Providers** are likely to use both measures and feel that they get to the heart of what palliative care is about
  - Feeling Heard & Understood: **83% Very or Somewhat Likely to Use**
  - Receiving Desired Help for Pain: **72% Very or Somewhat Likely to Use**
- **Patients** are enthusiastic about the two measures, with **87% Very or Somewhat Likely to Complete the surveys**
  - Patients are primarily excited about the opportunity to drive change and improve the experience for future palliative care patients
  - Patients are pleased with these measures because they align with what they are seeking from providers

# Clinicians Can Use the Measures to:

- **Assess** how well patients' needs are being met
- **Implement** as part of a larger quality improvement (QI) effort to understand patient experience
- **Identify and advocate** for resources critical to improving patient care and experience
- **Reward and encourage** those who are providing high-quality care
- **Provide support** for improving care processes
- **Guide education** to effectively manage all types of pain and conduct meaningful conversations with patients
- **Provide education** to patients about pain management to properly set expectations
- **Conduct research** with patients to examine external factors that affect their experience of care

# Implementation Guide

- Resources for gaining organizational buy-in from senior leadership
- Resources to explain to patients why the data is being collected
- Implementation strategies
- Quality Improvement (QI) resources
- Recommended survey administration procedures
- Survey materials and advice for choosing a vendor
- [http://aahpm.org/uploads/AAHPM22\\_PRO-PM\\_IMPLEMENTATION\\_GUIDE.pdf](http://aahpm.org/uploads/AAHPM22_PRO-PM_IMPLEMENTATION_GUIDE.pdf)



ELEVATING PATIENT AND CAREGIVER VOICES





# Are the Measures Culturally Sensitive?

- TECUPP discussed how pain encompasses **physical, mental, emotional, and spiritual pain**
- “Pain” and “desired help” are intentionally undefined in the measure so **patient can define** for themselves
- “**Inclusive and sensitive to the challenges of health disparities** by emphasizing relief of pain from the patient perspective and whether their **goals for pain management** are achieved” –Public Commenter
- The wording of feeling “**heard and understood**” was developed in collaboration with patients/caregivers, family members, clinical experts, and methodologists
- **Cognitive interviews and focus groups** were held with diverse patients/caregivers, including in **Spanish**, to ensure that the surveys conveyed the correct meaning
- **Proxy assistance** on the survey was allowed for measurement purposes, but proxy only responses were not counted in the testing results
- The survey is **risk adjusted** only for survey mode

# Pearls for Palliative Care and Hospice Implementation



- Don't go it alone or reinvent the wheel
- Work as an interdisciplinary team (IDT) with a goal of inviting diverse perspectives
- Know your institution's structures and processes and integrate into them
- The technology currently exists to make this happen where you work
- Commit to becoming educated in implicit bias and DEI efforts, self-awareness, and continual learning

# Improving Goal Concordant Care (IGGC)

The  
**Oncologist**<sup>®</sup>

Commentary

## Improving Goal Concordant Care Among 10 Leading Academic U.S. Cancer Hospitals: A Collaboration of the Alliance of Dedicated Cancer Centers

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The Alliance of Dedicated Cancer Centers (ADCC), representing the 10 freestanding U.S. academic cancer hospitals, has developed a national implementation initiative to enhance goal-concordant care for patients with cancer.



# ADCC Member Institutions

- The James Comprehensive Cancer Center
- City of Hope Cancer Center
- Fox Chase Cancer Center
- Dana-Farber Cancer Institute
- Moffitt Cancer Center
- MD Anderson Cancer Center
- Memorial Sloan Kettering Cancer Center
- Roswell Park Cancer Institute
- Seattle Cancer Care Alliance
- USC Norris Comprehensive Cancer Center

# IGCC Implementing *Feeling Heard and Understood*

- Four centers have integrated *Feeling Heard and Understood*
- Data has been collected for ~14,000 pts from first month
- All 10 centers should be collecting H&U by the end of the CY
- Press Ganey built H&U in IGCC's existing survey using the validated survey items and responses; only difference is survey asks about oncology provider and team, not palliative care team
- Survey uses top box scoring, plus more granular results (ie, top box for each item; mean scores for each item and overall)

# References

- Julia I. Bandini, Lucy B. Schulson, Claude Messan Setodji, Jhacova Williams, Katherine Ast, and Sangeeta C. Ahluwalia. (2022). “Palliative Care Is the Only Medical Field That I Feel Like I’m Treated As a Person, Not As a Black Person”: A Mixed-Methods Study of Minoritized Patient Experiences with Palliative Care. *Journal of Palliative Medicine*. Published Online:16 Aug 2022.  
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Elevating the Patient  
and Caregiver Voice

Project Website:  
[www.nationalcoalitionhpc.org/qualitymeasures](http://www.nationalcoalitionhpc.org/qualitymeasures)

# *Feeling Heard and Understood:* Final Measure Specifications

- **Measure Description:** This is a multi-data element measure consisting of four data elements: Q1: “I felt heard and understood by this provider and team”, Q2: “I felt this provider and team put my best interests first when making recommendations about my care”, Q3: “I felt this provider and team saw me as a person, not just someone with a medical problem”, Q4: “I felt this provider and team understood what is important to me in my life.”\*
- **Denominator:** All patients aged 18 years and older who had an ambulatory palliative care visit.
- **Numerator:** Calculated using top-box scoring which reflects the percentage of patient respondents that give the most positive response across the 4 questions.

\***Response options:** Completely true, Very true, Somewhat true, A little bit true, Not true at all

# *Receiving Desired Help for Pain:* Final Measure Specifications

- **Measure Description:** The percentage of patients aged 18 years and older who had an ambulatory palliative care visit and report getting the help they wanted for their pain\* from their palliative care provider and team within 6 months of the ambulatory palliative care visit.
- **Denominator:** All patients aged 18 years and older who had an ambulatory palliative care visit.
- **Numerator:** The number of patients aged 18 years and older who report getting the help they wanted for their pain by their palliative care provider and team within 6 months of the ambulatory palliative care visit.

**\*Response options: Yes, definitely; Yes, somewhat; No**