

AAHPM Patient-Centered Measures for Outpatient Palliative Care

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AMERICAN ACADEMY OF
HOSPICE AND PALLIATIVE MEDICINE



Looking Back...

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

Our Partnerships

- [American Academy of Hospice and Palliative Medicine](#) (AAHPM) was awarded a three-year cooperative agreement from CMS, with subrecipients the [National Coalition for Hospice and Palliative Care](#) and [RAND Health Care](#), to develop *patient-reported* quality measures for community-based palliative care. (September 2018-September 2021)
- Through partnership with the [National Patient Advocate Foundation](#), we incorporated the perspectives of patients, families, and caregivers as an essential aspect of developing quality measures that would be meaningful.

Project Outcome: Patient-centered Measures

Two patient-reported quality measures of outpatient palliative care experience were developed *that matter to people receiving care*.



Communication

Palliative care outpatients' experience of *feeling heard and understood*



Symptom Management

Palliative care outpatients' experience of *receiving desired help for pain*



Measure Development and Details

Information Gathering



- Literature scan
- Focus groups with palliative care providers
- Interviews with patients and caregivers



- Meetings with technical expert panels
- Cognitive testing with patients 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



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.

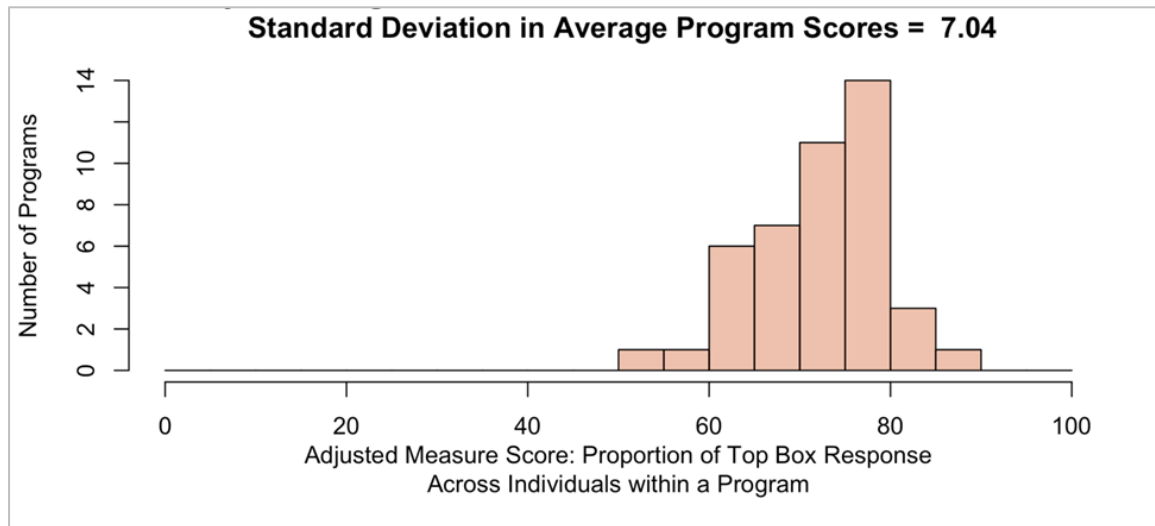
Numerator: The number of patients aged 18 years and older who report getting the help they wanted for their pain by their palliative care provider and team within 6 months of the ambulatory palliative care visit.

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

Test Results: Feeling Heard and Understood



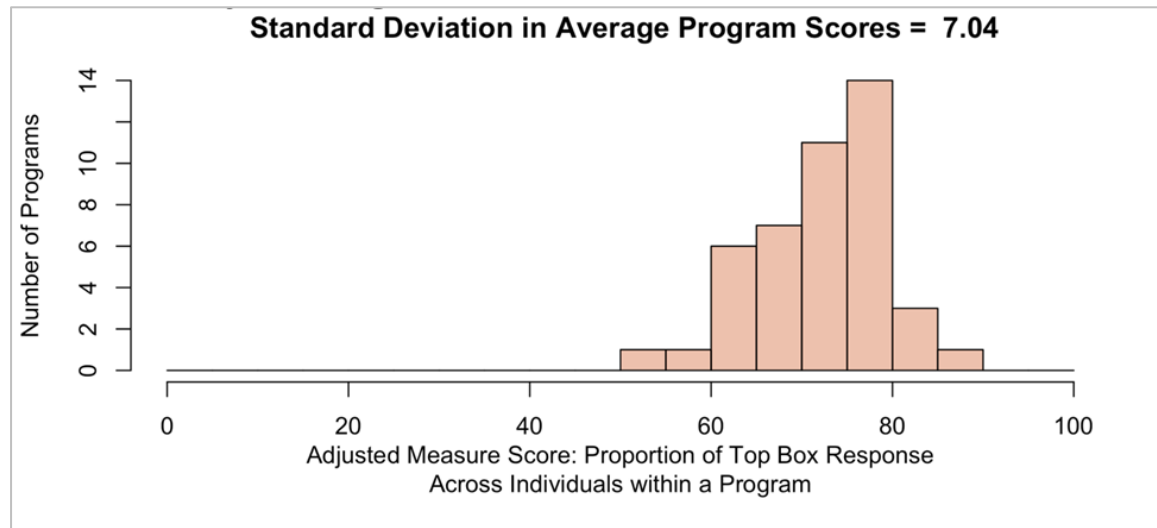
- Reliability and convergent validity of the four-data element scale score was excellent
- Survey mode and proxy-assistance are included in the model as risk-adjustment variables
- We estimated that an average sample size of **37 respondents** is required for a desired measure reliability of 0.7.




Test Results: Receiving Desired Help for Pain



- Test-retest reliability and convergent validity of the pain question was excellent
- Survey mode and proxy-assistance are included in the model as risk-adjustment variables
- We estimated that an average sample size of **33 respondents** is required for a desired measure reliability of 0.7.



A photograph showing a group of people's hands clasped together in a supportive gesture. The background is blurred, showing the faces of several individuals, including a woman with blonde hair and a man with glasses. The overall tone is warm and collaborative.

Feedback from (and for) the Field

Feedback from Patients, Caregivers, and Family Members



Sa'Brina Davis
NPAF Volunteer



Faye
Hollowell
NPAF Volunteer

"Elevating voices of patients and caregivers has been prioritized in every aspect of this initiative. NPAF applauds the inclusive and innovative approach of this remarkable partnership."

Rebecca Kirch, JD
NPAF Executive Vice President, Policy and Programs

Feedback from 207 Stakeholders

- **Providers were 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 were enthusiastic about the two measures, with 87% Very or Somewhat Likely to complete the surveys**
 - **Patients primarily excited about the opportunity to drive change and improve the experience for future palliative care patients**
 - **Patients pleased with these measures because they align with what they are seeking from providers**



How to Use the Measures

Providers and Payers 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

Project Website



www.nationalcoalitionhpc.org/qualitymeasures

Learn more:

- Measure descriptions
- Journal publications
- Patient-centered approach
- Why use the measures
- How to use the measures
- Measure development process

For more information...

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Introducing the Serious Illness Survey for Home-Based Programs

*Medi-Cal Palliative Care Convening
March 17, 2022*

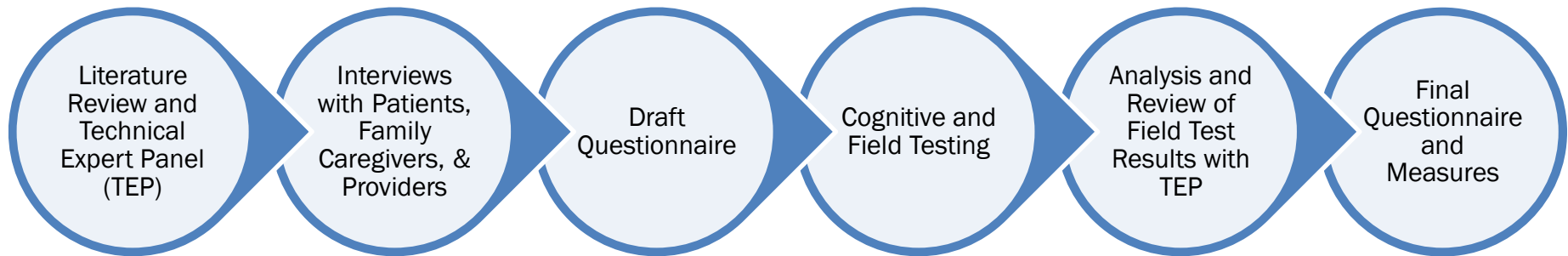
Rebecca Anhang Price, PhD
Senior Policy Researcher, RAND



Overview

- RAND was commissioned by the Gordon and Betty Moore Foundation to develop a set of surveys to assess the care experiences of seriously ill individuals.
 - Serious Illness Survey for Home-Based Programs *(complete)*
 - Serious Illness Survey for Plans and Payers *(underway)*
- Survey responses are used to create measures that can be used for quality improvement and in accountability initiatives.

We incorporated input from patients and families at every step of survey development



- Interviews and testing were conducted among patients with different types of health insurance coverage, including Medicaid

Draft survey was tested among patients of 32 home-based serious illness programs prior to the pandemic

- Participating programs operate all over the United States
 - Based in hospices, health systems, medical groups
 - Number of patients in care ranged from 7 to 1,481 (average: 202)
- 2,263 adult patients (or informal family caregivers) responded
 - 21% less than high school education
 - 10% Hispanic, 10% Black or African American
 - 7% Medicaid

Survey materials are now available free online at www.rand.org/Serious-Illness-Survey

- Full and abridged survey versions
 - English and Spanish
 - Mail and telephone
- Guidelines for use, including information on:
 - Contents of the survey
 - Patient eligibility criteria
 - Sampling
 - Survey administration
 - Calculating measure scores and adjusting scores for patient mix

Final survey covers up to five content domains, plus overall assessments and background questions

Communication

How often people from the program:

- Spend enough time with patient
- Explain things in way patient could understand
- Listen carefully
- Care about patient as a whole person
- Make patient feel heard and understood (similar to MACRA Heard & Understood measure)

Care Coordination

How often people from the program seemed to know medical history

Whether someone from the program talked about:

- Care from other health care providers
- All medications
- How to get help with everyday activities

Patient got needed help between visits

Help for Symptoms

Patient got help wanted for:

- Pain (similar to MACRA Pain measure)
- Trouble Breathing
- Anxiety or sadness

Care Planning

Whether someone from the program ever talked with patient about:

- What to do in case of a health emergency
- What is important in patient's life
- What health care options would be if patient got sicker

Support for Family and Friends

Family members or friends:

- Involved in discussions about care as much as the patient wanted
- Got desired amount of emotional support

There are two versions of the survey: full and abridged

Content Domains / Quality Measures	Full Survey (36 questions)	Abridged Survey (21 questions)
Communication	X	X
Care Coordination	X	X
Help for Symptoms	X	X
Care Planning	X	X
Support for Family and Friends	X	
Overall Rating	X	X
Willingness to Recommend the Program	X	

Survey is designed for adult patients who receive care from a serious illness program at home or in an assisted living facility

- DO include in the survey sample:
 - Patients who may not be able to answer for themselves – a family caregiver can act as their proxy
 - Patients enrolled in the serious illness program for at least six weeks at the time of sampling
- Do NOT include in the survey sample:
 - Patients known to have been discharged to hospice
 - Patients known to have died

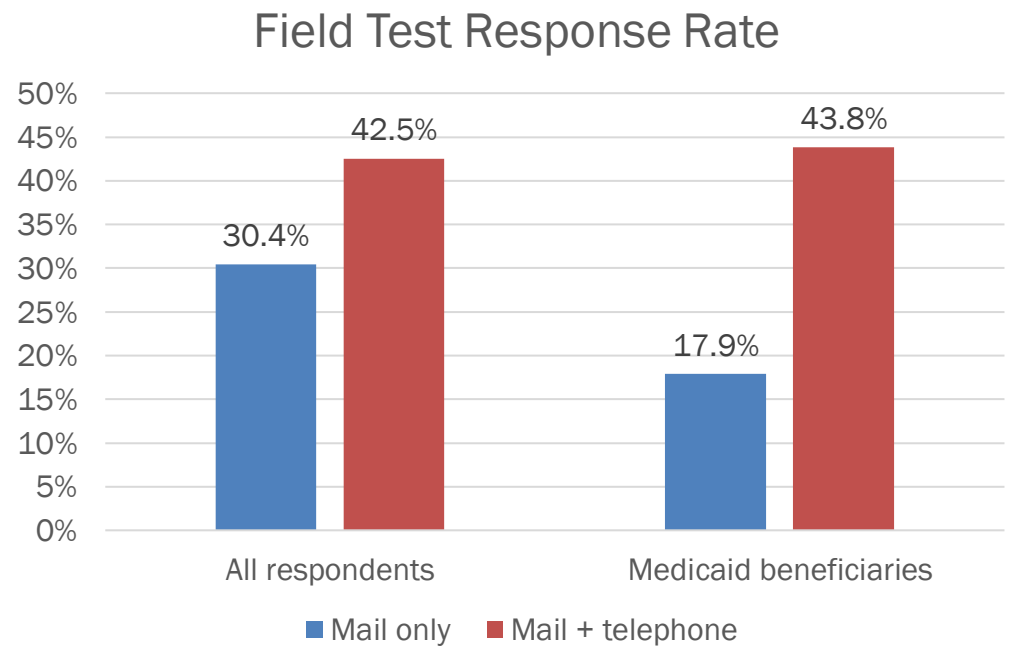
We tested two recommended modes of survey administration

Mail only mode

- Prenotification letter
- Two survey mailings three weeks apart

Mail + telephone (mixed mode)

- Prenotification letter
- One survey mailing
- Three weeks later, 5 to 7 telephone calls to those who have not responded



“Top-box” scoring is recommended to promote interpretability

- Scores are calculated only for respondents who are eligible to complete a given question.
 - Respondents who indicate that the question is not relevant to them (e.g., those without a given symptom) are NOT included.
- Top-box scores are calculated as the % of responses in the most positive response category.

Always / Sometimes / Usually / Never
Yes, definitely / Yes, somewhat / No
9 and 10 on 0 to 10 scale

Case mix adjustment is recommended if survey data will be used to compare programs' performance or track performance over time

- Recommended adjustment variables include:
 - Age
 - Education
 - Primary diagnosis
 - Use of a proxy respondent
 - Self-rated physical health
 - Self-rated mental health
 - Self-rated functional status (full survey only)
 - Response percentile
 - Mode of survey administration

Next up: Field test of the Serious Illness Survey for Plans and Payers

- Plans can participate in a 2022 field test of a revised version of the Serious Illness Survey designed for plans and payers
 - To participate, plans must serve at least 100 patients meeting the study's criteria for serious illness
- Survey will be administered in mixed mode
 - Mail with telephone follow-up; web offered if feasible
 - ~25 questions
 - Spanish and English language
- Participating plans will receive free data collection, a report of results, and a \$1000 payment as a token of appreciation

For more information, to share feedback, or to inquire about participating in the 2022 field test...

- Serious Illness Survey website: www.rand.org/Serious-Illness-Survey.
- Key contacts at RAND:
 - Serious Illness Survey project team: seriousillness@rand.org
 - Rebecca Anhang Price, PhD, Principal Investigator: ranhangp@rand.org
 - Melissa Bradley, Co-Principal Investigator: mbradley@rand.org

