

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



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Kathleen Bickel, Jeanie Youngwerth

Disclosures

- **Katherine Ast has no disclosures.**
- **Amy Melnick has no disclosures.**
- **Sangeeta Ahluwalia has no disclosures.**
- **Kathleen Bickel has no disclosures.**
- **Jeanie Youngwerth has no disclosures.**

Polling Question #1

What is the best description of your palliative care practice?

A stand-alone/independent palliative care program

Part of one of the following entities:

- Hospice
- Inpatient hospital
- Outpatient primary care
- Outpatient specialty care (non-oncology)
- Oncology
- Home care
- Other

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Session Objectives

- **Learn how you can use newly developed patient reported experience measures in your practice, quality improvement (QI) programs and quality reporting programs**
- **Understand patient-centered quality measurement and why it's important**
- **Participate in discussions around measurement workflow and implementation issues, barriers, and why all this even matters**
- **Discover how you can share your voice and influence the quality of care patients receive in QI and measurement programs**



AMERICAN ACADEMY OF
HOSPICE AND PALLIATIVE MEDICINE



INTRODUCTION AND OVERVIEW

CMS Awards \$5.5M to Develop Palliative Care Measures



- **AAHPM**, in partnership with the **National Coalition for Hospice and Palliative Care (Coalition)** and the **RAND Corporation**, was awarded a 3-year cooperative agreement from Centers for Medicare and Medicaid Services (**CMS**) to develop patient-reported quality measures
- The measures are intended for use in CMS's Quality Payment Program (**QPP**), including Merit-Based Incentive Payment System (**MIPS**) and Alternative Payment Models (**APMs**)

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Project Team Members

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Thank you!



**is providing valuable support and representatives
to ensure patient and caregiver inclusion
in the measure development process**

Polling Question #2

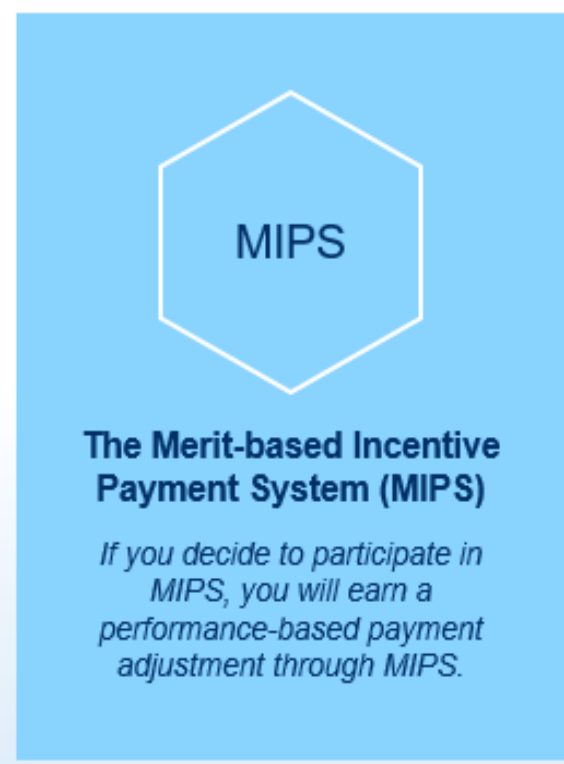
How familiar are you with the Merit-based Incentive Payment System (MIPS)?

- Not familiar at all**
- A little familiar**
- Very familiar**

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CMS Quality Payment Program

The Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) requires CMS by law to implement an incentive program, referred to as the Quality Payment Program (QPP), that provides for two participation tracks:

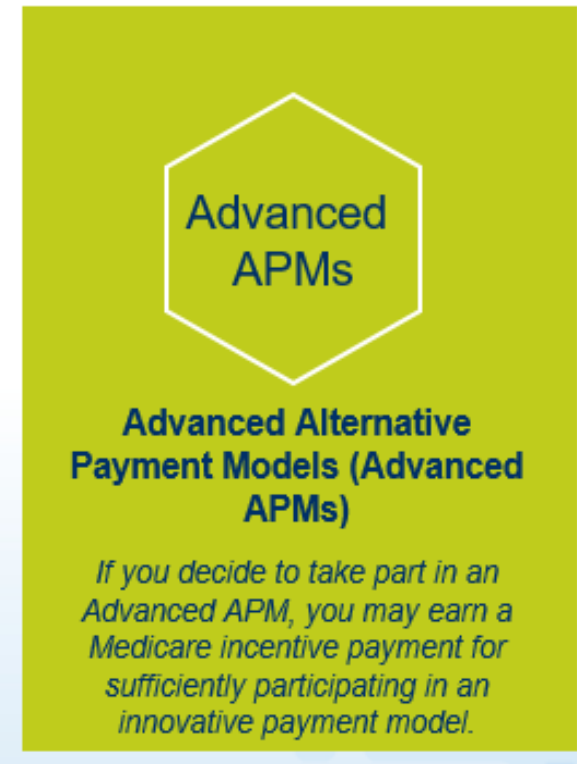


MIPS

The Merit-based Incentive Payment System (MIPS)

If you decide to participate in MIPS, you will earn a performance-based payment adjustment through MIPS.

OR



Advanced APMs

Advanced Alternative Payment Models (Advanced APMs)

If you decide to take part in an Advanced APM, you may earn a Medicare incentive payment for sufficiently participating in an innovative payment model.

MIPS: Quick Overview



- Comprised of **four** performance categories
- So what? *The points from each performance category are added together to give you a MIPS Final Score*
- The MIPS Final Score is compared to the MIPS performance threshold to determine if you receive a **positive, negative, or neutral payment adjustment**

• Requirements for programs: 6 measures, including 1 outcome measure

Measures Under Development

Palliative care outpatients' experience of feeling heard and understood

Heard and Understood –

The percentage of patients aged 18 years and older with at least 1 outpatient palliative care visit in 3 months, who complete a patient experience survey within 6 months of the outpatient palliative care visit and report feeling heard and understood by their palliative care provider and team.

Palliative care outpatients' experience of receiving desired help for pain

Help Wanted –

The percentage of patients aged 18 years and older with at least 1 outpatient palliative care visit in 3 months, who complete a patient experience survey within 6 months of the outpatient palliative care visit, who report having pain and wanting help for their pain, and who report getting the help they wanted for their pain by their palliative care provider and team.

Why These Measures?

- **The Palliative Care field has prioritized these measure concepts**
- **These measures address significant gaps in care, namely in nuanced symptom management (pain), and meaningful communication**
- **Patient Experience Measures are absent except for the CAHPS survey which some say is long and burdensome**
- **Eligible providers who report to MIPS need measures that matter to patients, caregivers and family members**
- **New alternative payment models (APMs) need a way to distinguish good performance from poor performance**

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Timeline/Process for Quality Measure Development

✓ CMS MACRA Cooperative Agreement to AAHPM



✓ Identification of Co-chairs and TECUPP/MSP Members



✓ ENVIRONMENTAL SCAN AND LITERATURE REVIEW



✓ FOCUS GROUPS WITH PATIENTS AND PROVIDERS

✓ COGNITIVE INTERVIEWS



✓ DRAFT PATIENT REPORTED OUTCOME TOOL/SURVEY DEVELOPMENT



✓ TECUPP IN PERSON MEETING

Discussion of Tools and Patient Reported Outcome Performance Measure Concepts



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Timeline/Process (continued)

✓ MSP IN PERSON MEETING

- Discussion of detailed Tool Information
- Refinement of PRO-PM Measure Specification Details



MEASURE TESTING (Summer 2019 – Fall 2020)

- Alpha Testing (Feasibility, Cognitive Testing, Tool Refinement)
- Beta Testing (Validity, Reliability, Tool Refinement)



PUBLIC COMMENT (WINTER 2021)



CONSENSUS-BASED ENTITY ENDORSEMENT AND IMPLEMENTATION

- NQF Endorsement Process
- CMS Measures Under Consideration/Measures Application Partnership Review
- Implementation in MIPS/Quality Improvement Programs

A photograph showing a group of people's hands clasped together in a circle, symbolizing teamwork and collaboration. The background is blurred, showing the faces of several people smiling. The image is overlaid with a semi-transparent white horizontal band containing the text.

Stakeholder Engagement

What's Unique: Patient-Centered Approach



“FOR US, BY US”

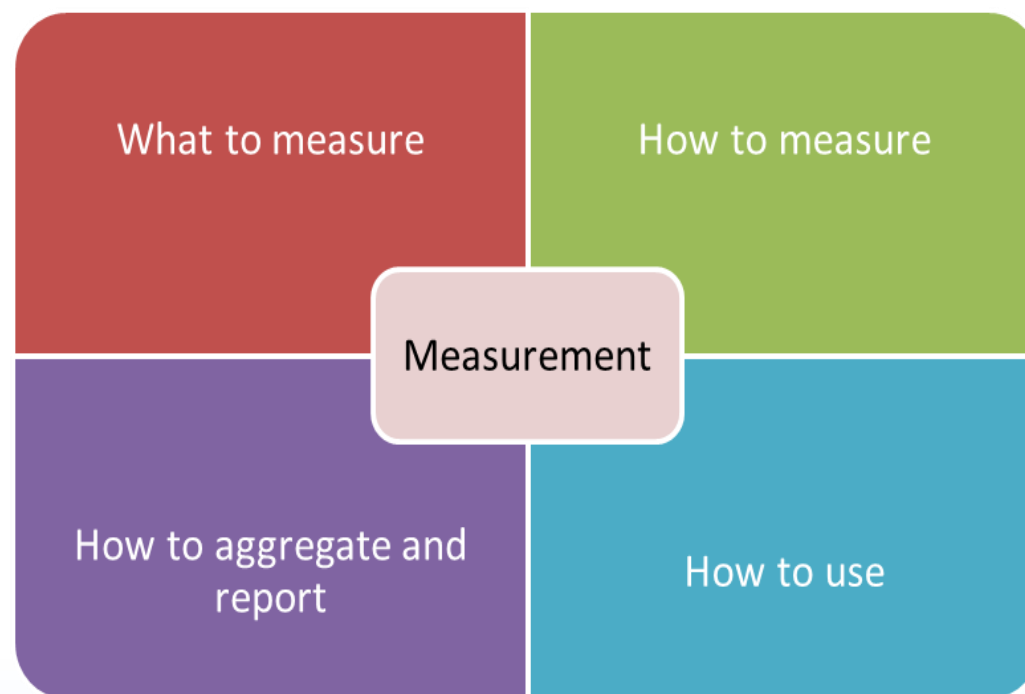
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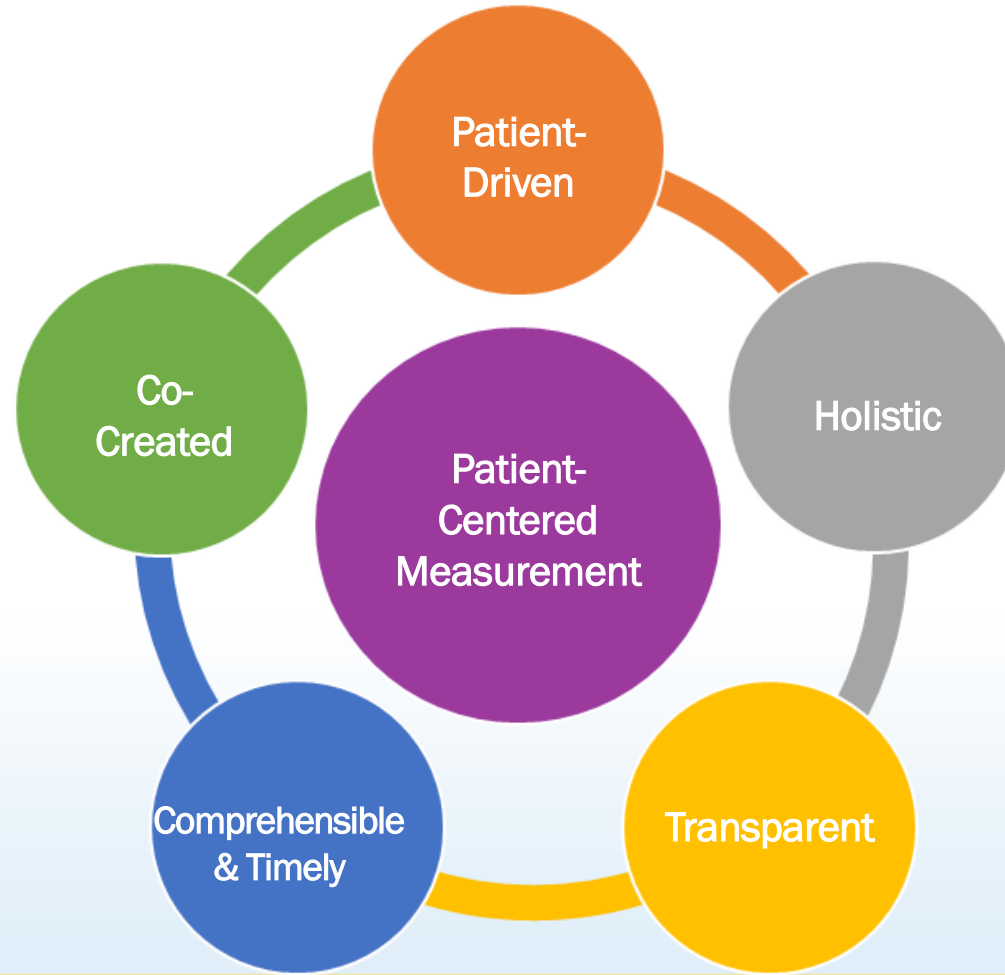
Patient-Centered Measurement*



*Measurement driven by **patients' expressed preferences, needs, and values** that informs progress toward better health, better care, and lower costs.*

*Source: American Institutes For Research (AIR)

Principles of Patient-Centered Measurement*



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*Source: American Institutes For Research (AIR)



Stakeholder Engagement Deliverables



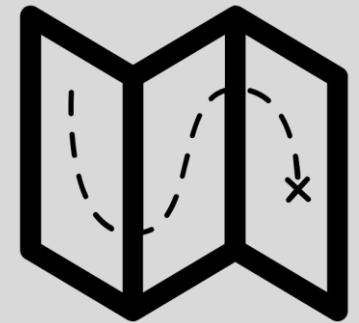
**Convene a
Technical Expert
Clinical End User
Panel (TECUPP)**



**Solicit diverse
care settings**



**Provide
opportunities for
public comment**



**Deploy strategic
communications**

Technical Expert Clinical User Patient Panel (TECUPP)

Group of clinical experts, patients, caregivers and other stakeholders who:

- Provides direction and guidance throughout development process
- Improves measure development processes
- Provides input on key decisions regarding data elements, testing design, and the proposed quality measures

All perspectives and experiences are critical and highly valued.



Organizations Represented on the TECUPP

- **AMDA – The Society for Post-Acute and Long-Term Care Medicine**
- **American Association of Family Physicians (AAFP)**
- **American College of Physicians (ACP)**
- **American Geriatrics Society (AGS)**
- **American Society of Clinical Oncology (ASCO)**
- **Center to Advance Palliative Care (CAPC)**
- **Coalition to Transform Advanced Care (C-TAC)**
- **HealthCare Chaplaincy Network (HCCN)**
- **Hospice & Palliative Nurses Association (HPNA)**
- **National Hospice and Palliative Care Organization (NHPCO)**
- **National Patient Advocate Foundation (NPAF)**
- **Physician Assistants in Hospice and Palliative Medicine (PAHPM)**
- **Social Work Hospice & Palliative Network (SWHPN)**
- **Society of Pain and Palliative Care Pharmacists (SPPCP)**
- **Supportive Care Coalition (SCC)**

Patient, Caregiver, and Family Member (PCFM) Inclusion



Sa'Brina Davis



Faye Hollowell

What's Important to Patients, Caregivers, and Family Members (PCFM)



PCFM: “My brother didn’t care that his pajama bottoms fell down – he just wanted to drive his car”



PCFM: “If patients support the new measures, the providers will use the measures”



NPAF: “We have evidence that patients care more about financial distress than symptoms, and that ties to emotional distress”



Clinicians say: “At least ½ the time I’m addressing the patient’s emotional pain; helping the patient feel heard and understood, addressing pain, and providing emotional support”



Public Comment Opportunities (Winter 2021)

- **Webinar**
 - **Results of the measure development testing will be shared**
- **Online Feedback**
 - **Key audiences will be invited to provide specific input through an online portal**

How You Can Get Involved

- **Learn more:**
 - Listen to the public webinar about the project, held June 2019; the recording and handout are posted on the project website.
- **Stay up to date:**
 - Visit the project website periodically, and
 - Follow @Coalitionhpc on Twitter.
- **Provide input:**
 - Join our public comment period that will be held January-February 2021.
 - *Stay tuned for more information.*

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A photograph of a group of people, likely a team, with their hands clasped together in a circle. The image is slightly blurred, focusing on the hands in the center. The background shows the faces and upper bodies of several individuals, some smiling. The overall tone is warm and collaborative.

Project Testing Overview

Project Goal

To develop two patient-reported quality measures of outpatient palliative care experience for CMS's Merit-Based Incentive Payment System (MIPS) under the Quality Payment Program (QPP) created by MACRA.

Brief Description of Proposed Measures

Palliative care outpatients' experience of feeling heard and understood

The percentage of patients aged 18 years and older who had at least one outpatient palliative care visit and report feeling heard and understood by their palliative care provider and team during their care in the last six-months. The measure will be aggregated over a one-year period.

Palliative care outpatients' experience of receiving desired help for pain

The percentage of patients aged 18 years and older who had at least one outpatient palliative care visit and report having pain, wanting help for pain, and receiving the help they wanted for their pain by their palliative care provider and team during their care in the last six-months. The measure will be aggregated over a one-year period.

TECUPP/MSP: Key questions discussed


- **Measure attribution**
- **Measure eligibility**
- **Data element considerations**
- **Proxy response**
- **Case-mix adjustment**



Survey Instrument

- **Care from provider and team in last 6 months**
 - CAHPS communication composite
 - Pain/Help wanted for pain
 - Emotional support
- **Overall experience with provider and team in last 6 months**
 - Heard and understood
 - Trust/Comfort
 - Whole person orientation
 - Overall rating
- **Patient Characteristics**
 - Overall health status
 - Cognition, mood, pain interference
 - Respondent demographics
- **Proxy Information**
 - Who is the proxy?
 - How did the proxy help?
 - Why did the proxy help?
 - How well does the proxy know the patient?

Alpha Field Test

- **The purpose of the formative alpha test was to understand program capabilities, establish data collection processes, and identify/resolve challenges to testing and implementation**
 - **August 8th 2019 – October 3rd, 2019**
 - **300 patients sampled from 5 outpatient palliative care programs**
 - **Mixed-mode survey design led by RAND**
 - **English-language only**
- 
- A decorative graphic consisting of several short, thick yellow dashes arranged in a curved, upward-sloping path in the bottom right corner of the slide.

A photograph showing a group of people with their hands clasped together in a supportive gesture. The focus is on the hands in the center, with the faces of the people blurred in the background. The lighting is warm and soft. A semi-transparent white horizontal bar is overlaid across the middle of the image, containing the text.

Alpha Findings and Lessons Learned

Measure eligibility

- **Goal was to balance recall/recency of patient experience with number of patients eligible for the measure**
- **996 patients identified with ≥ 1 eligible visit in 6 months; 662 (66%) with ≥ 1 visit in 3 months**
- **However, 318 patients out of the 662 patients had only 1 eligible visit in 3 months**
 - **Setting eligibility at 2 visits in 3 months might increase relevant exposure upon which to base one's experience, but would likely limit reliability of the measure.**
- **Measure eligibility set at 1 outpatient palliative care visit in 3 months**

Email/web-based surveys could be a feasible implementation option

- **1 out of 5 alpha sites collected email contact information with 65% coverage**
- **Larger, better-resourced programs utilizing other electronic means of communication (e.g., patient portals) may have email information**
- **Looking forward, electronic surveys may be a more convenient option for an increasingly web-savvy population**



Additional materials with survey mailing can be helpful



Pre-notification letter:
Communicates survey intent and adds legitimacy to survey efforts



Cover letter: Communicates high-level instructions for completing survey as well as data safeguarding and use information

Findings from alpha test identified improvements to both documents; including additional information regarding privacy and data security, use of protected health information, and clarification of project intent

Additional materials with survey mailing can be helpful

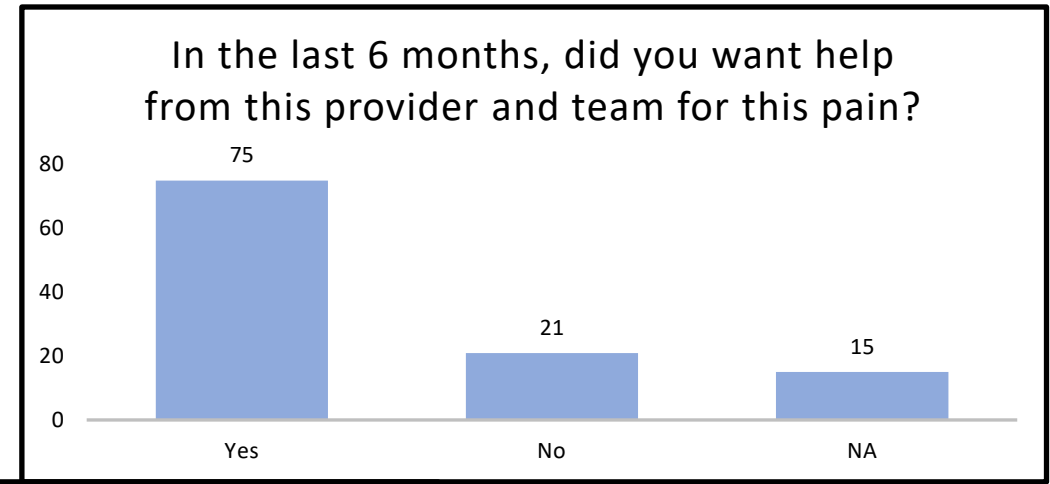
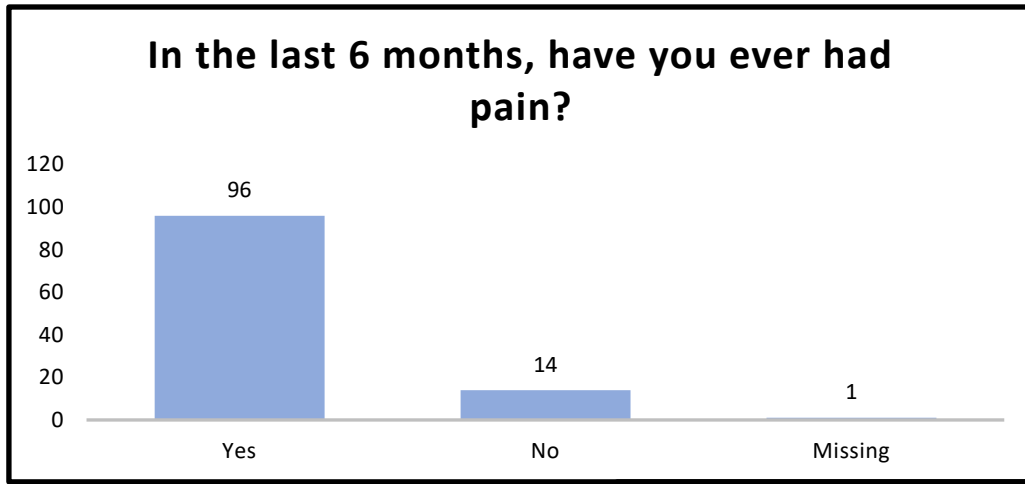
- **Stamped postcard sent with pre-notification letter allowed respondents to “opt-out” of receiving the survey due to patient death, or to update address information.**
 - **5 postcards were returned indicating patient had died, avoiding survey mailing**
 - **During telephone follow-up, an additional 14 patients were confirmed deceased**



Most patients reported feeling heard and understood by their outpatient palliative care provider and team

DE #	Data Elements	Very true	Mostly true	Somewhat true	A little bit true	Not at all true	Missing
Q12	I felt heard and understood by this provider and team	89	16	2	1	2	1
Q13	I trusted this provider and team	99	8	1	1	1	1
Q14	I felt comfortable asking this provider and team questions	97	9	1	2	1	1
Q15	I could tell this provider and team anything, even things I might not tell anyone else	77	23	4	0	2	2
	I felt this provider and team...						
Q16	put my best interests first when making recommendations about my care	95	9	3	1	1	2
Q17	always told the truth about my health, even if there was bad news	96	9	1	1	1	3
Q18	saw me as a person, not just someone with a medical problem	100	4	4	0	1	2
Q19	knew what worried me most about my health	85	20	3	0	1	2
Q20	understood what is important to me in my life	90	15	1	2	1	2
Q21	would know what I would want done if I was unconscious or in a coma	74	19	9	2	3	4

Most patients who wanted help for their pain received the help they wanted



Patients have positive experiences with outpatient palliative care

- **Patients typically rated communication data elements very high**
 - e.g., 92% rated “I felt heard and understood by my provider and team” as very or mostly true.
- **Patients typically report appropriate pain management**
 - 92% reported definitely or somewhat getting the help they wanted for pain
- **On the one hand – good (and not surprising) news!**
- **On the other hand – concerns about measures “topping out” arise**
 - Patients may struggle with distinguishing their generally positive experience
 - Is there continued room to improve?

Proxy respondents

- **17 patients (14%) received some proxy assistance, typically from spouses (n=7; 41%)**
- **Most common assistance was answering questions on behalf of the patient (n=8; 47%), due to reported trouble with memory (n=5; 29%), illness (n=3; 18%), or difficulty seeing or reading (n=3; 18%)**
- **Most proxies were “extremely” familiar with patient’s condition/care (n=12; 71%) and “always” provided help with treatment decision making (n=13; 77%)**

Beta Field Test

- **The purpose of the beta field test is to establish measure reliability, validity, feasibility**
 - **November 2020 – November 2020**
 - **~41 participating palliative care programs**
 - **Enhanced mixed-mode survey design led by RAND**
 - **English- and Spanish-language**
- **Our goal is 6,000-7,500 sampled patients for 2,400-3,000 completed surveys (40% response rate)**
 - **3 tracks and 5 fielding rounds**

Beta Field Test

- **Survey Completion to date:**

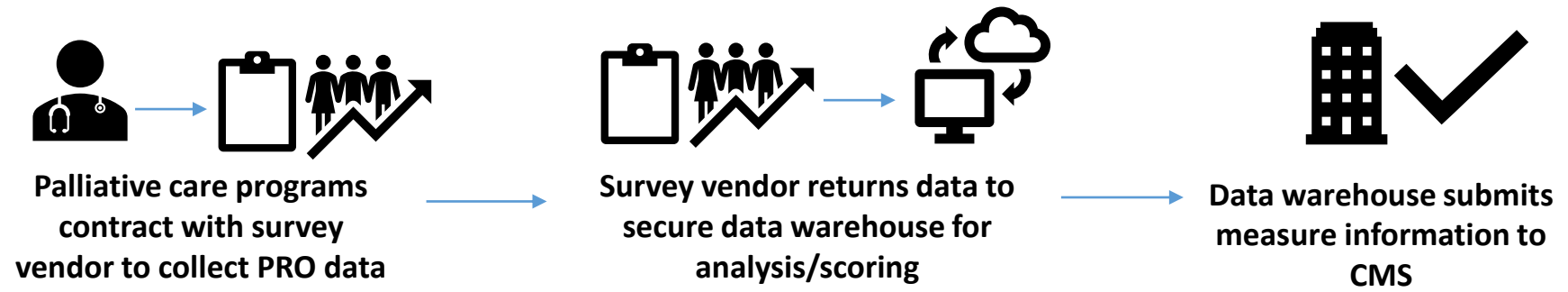
	Track 1 Round 1	Track 2 Round 1	Track 3 Round 1	Track 1 Round 2	Track 2 Round 2	Total To Date	Beta Target
Sample size	650	467	101	812	800	2830	6000 - 7500
Closing date	1/15/20 [closed]	2/5/20 [closed]	3/3/20 [closed]	3/24/2020	4/27/2020		--
Total complete	284	185	43	315	22	849	2400 - 3000
By phone	127	96	17	102		342	--
By mail	129	83	17	140		369	--
By web	28	6	9	73	22	138	--
Response rate (if closed)	44%	40%	42%	--	--	--	

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Considerations for Measure Implementation



*Palliative Care Quality Collaborative (PCQC) unified registry to open in summer 2020

Considerations for Measure Implementation

- **Data management and patient identification**
- **Cost of survey fielding and data collection**
- **Burden to patients and proxy respondents**
- **Ability for proxy respondents to appropriately reflect patient experience**
- **Ability to act on measure information; how best to improve palliative care experiences?**

Why

Measuring what matters

- Providers
- Patients
- Field of HPM

How

Tap into Resources

1. Make new friends

- E.g., quality, population health, C-suite, outpatient admin, billing company, patient experience, EHR/IT

a. It's all about relationships!

b. Doors open to new opportunities

2. Get a report built

3. Voilà



Discussion Questions

- How do you think outpatient palliative care clinics will use these measures?
- To what extent do these measures balance patient and provider burden with information that will improve care?
- Who experiences the value and who bears the cost?
- Will practices have the ability to act on measure information in order to improve palliative care experiences?
- Are you willing to implement these measures in your program when they are completed?

Questions?

Q & A

Moderator:
Amy Melnick

**Follow-up
Questions?**

Contact
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Thank you!



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Why measure quality in hospice and palliative care?

Purpose	Example measures
Justify need for a palliative care program	Extended hospitalizations, intensive care unit stays near the end of life
Demonstrate where improvements are needed (patients deserve the best care)	Pain scores Documentation of end-of-life discussions
Evaluate impact of new programs or quality improvement	Patient/family perceptions of care
Monitor care for deficiencies, worsening care	Patient safety reporting on pain issues Scorecard including pain scores
Help patients, families, providers make informed choices	Hospice quality reporting, including patient/family perceptions of care

Dy S. Measuring the quality of palliative care and supportive oncology: principles and Practice. J Support Onc. Dec. 2013.



Measuring What Matters (AAHPM & HPNA)

Top 10 Indicators

Comprehensive assessment

Screening for physical symptoms

Pain treatment

Dyspnea screening and management

Discussion of emotional or psychological needs

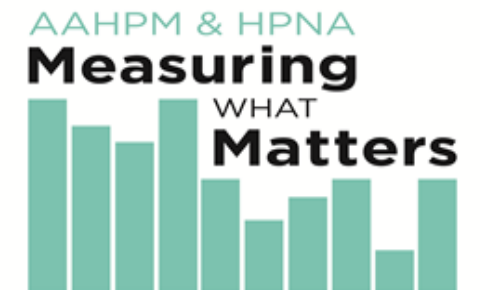
Discussion of spiritual/religious concerns

Documentation of surrogate

Treatment preferences

Care consistency with documented care preferences

Patient/family care quality global assessment



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