

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



Katherine Ast, Sangeeta Ahluwalia, Kathleen Bickel, Jeanie Youngwerth

Disclosures

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



Welcome to our session!

- Please write all your questions in the chat.
- Members of our Project Team are monitoring the chat and will answer as well as they can during the session.
- Any questions we don't get to will be answered and made available after the session.



Session Objectives

By the end of the session, participants will be able to:

- **Start to use newly developed patient reported experience measures in your practice, quality improvement (QI) programs, and quality reporting programs**
- **Articulate why patient-centered quality measurement is important**
- **Participate in discussions regarding measure implementation and why all this matters**
- **Discover how you can share your voice and influence the quality of care patients receive in QI and measurement programs**



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



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)

www.nationalcoalitionhpc.org/macra

Brief Description of Proposed Measures

Palliative care outpatients' experience of feeling 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

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**



Project Testing Overview

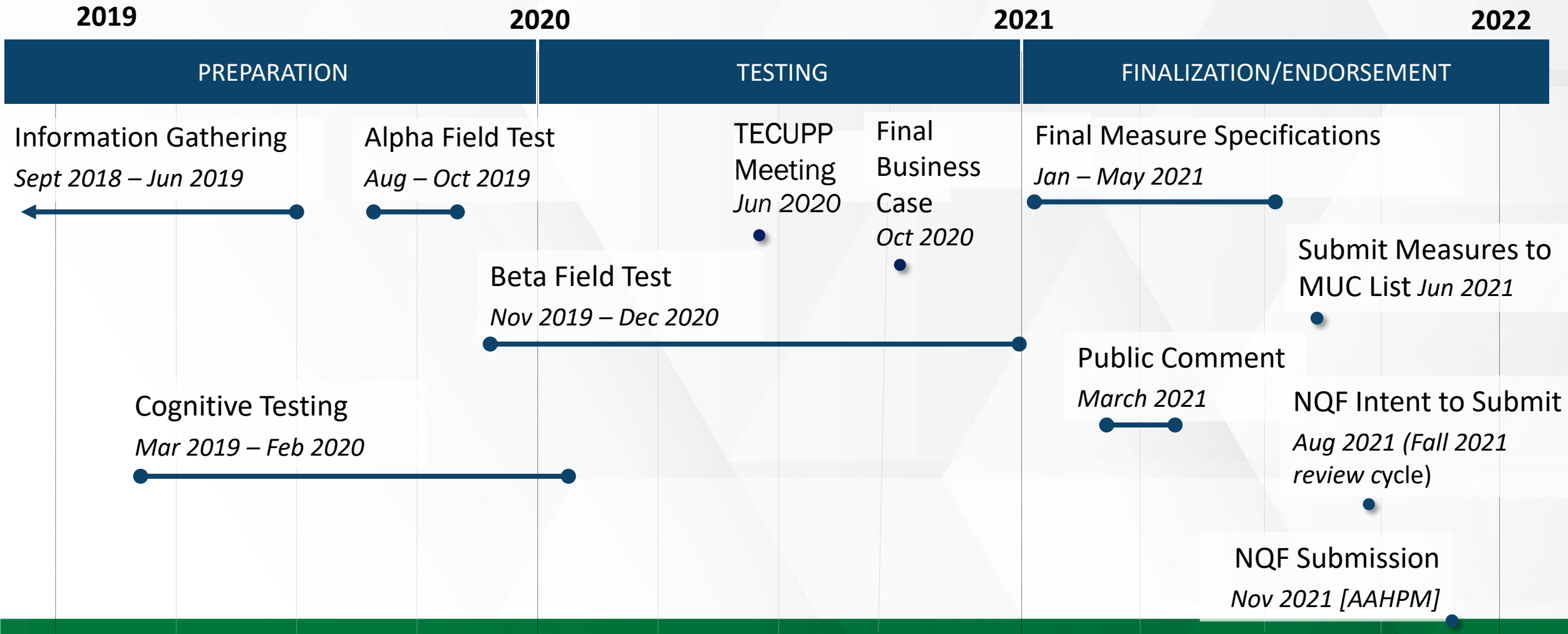
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Project Goal

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.

Project Timeline



Survey Instrument

- **Overall experience with provider and team in last 6 months**

- Heard and understood
- Trust/Comfort
- Whole person orientation
- CAHPS communication composite
- Pain/Help wanted for pain
- Emotional support
- Overall rating of provider and team

- **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

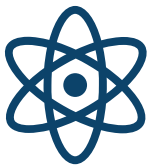


Goal: Establish data collection procedures and prepare for national field test (beta)

- What response rates could we expect?
- Would eligibility criteria yield an adequate sample?
- Could a web-based survey be feasible for beta?
- What could preliminary data tell us about the items and measures?



Participants: 300 patients across 5 outpatient palliative care programs



Methods: Mixed mode survey administration

Beta Field Test



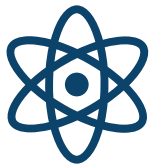
Goal: Examine reliability and validity of proposed quality measures and explore measure implementation for the QPP



Schedule: November 2019 to November 2020, paused 3/30/2020 due to COVID-19; resumed data collection mid-September 2020, last round of fielding anticipated December 2020.



Sample size goal: 6,000-7,500 sampled patients for 2,400-3,000 completed surveys (assuming 40% response rate)



Methods: “Enhanced” mixed mode administration (web to mail to phone)

Beta Field Test: Program Recruitment

		Midwest	Northeast	South	West	TOTAL
Hospice	Targeted Number of Programs	2	1	3	1	7
	Programs Recruited (with executed DUAs)	2	2	5	1	10
	Percent of Target	100%	200%	167%	100%	143%
Hospital	Targeted Number of Programs	5	9	7	7	28
	Programs Recruited (with executed DUAs)	5	6	7	7	25
	Percent of Target	100%	67%	100%	100%	89%
Other	Targeted Number of Programs	3	2	5	5	15
	Programs Recruited (with executed DUAs)	2	3	2	1	8
	Percent of Target	67%	150%	40%	20%	53%
TOTAL		9	11	14	9	43

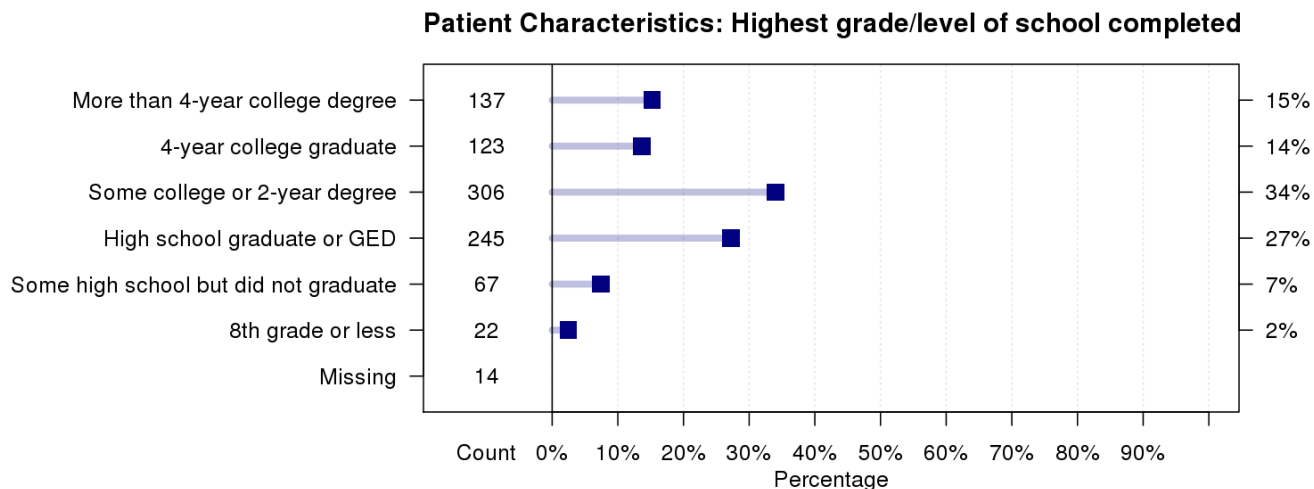
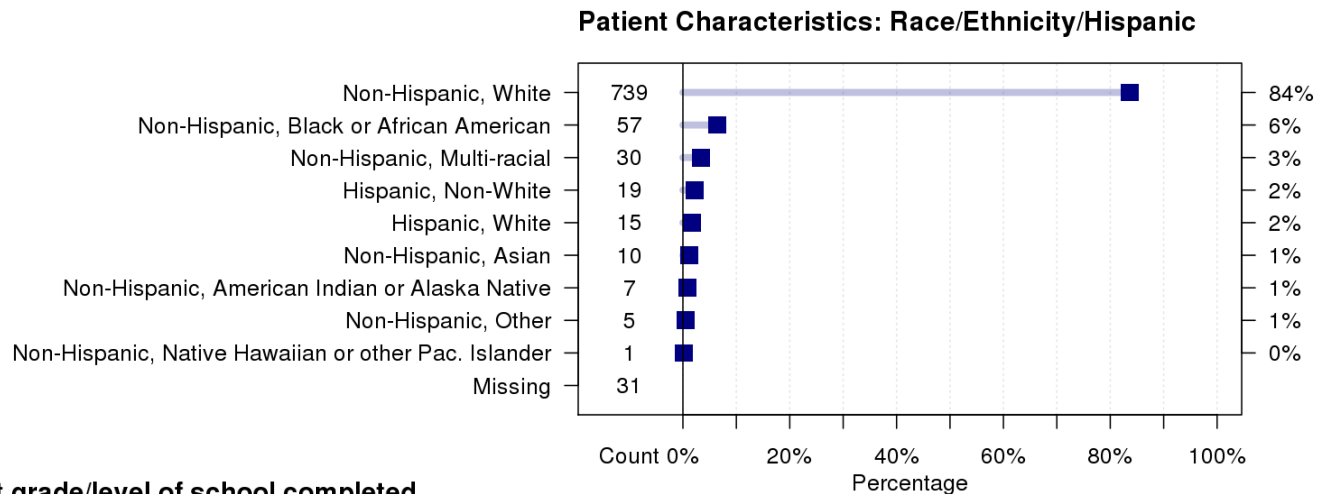
Beta Field Test: Interim Findings (April 2020)

Survey administration	Number		
Number of surveys fielded	2030	}	Patients removed from denominator
Number of patients eligible for inclusion	1811		
Number of completed surveys	914		
Mail surveys	424 (46%)		
Phone surveys	384 (42%)		
Web surveys	106 (12%)		
Response rate (914/1811)	51%		

Deceased	165
Other	54

Beta Field Test: Patient/Respondent Characteristics

Characteristics (n=914)	% (n) or M (SD)
Age	64.2 (sd = 13.8, N = 913)
Male	44.6% (n = 407, N = 913)
Proxy Assistance	20.5% (n = 187, N = 914)

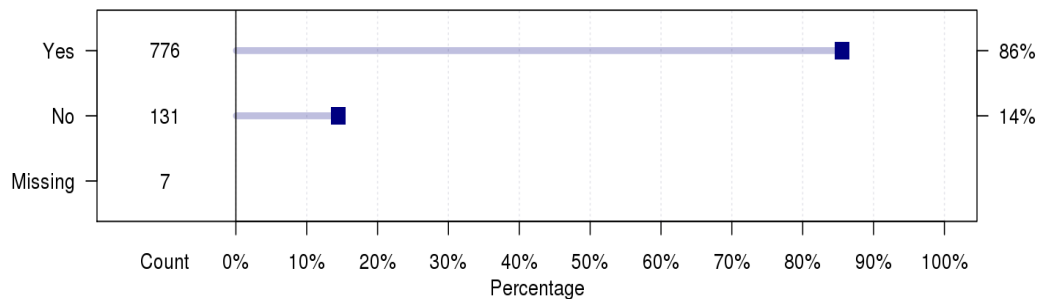


Most patients reported feeling heard and understood by their outpatient palliative care provider and team

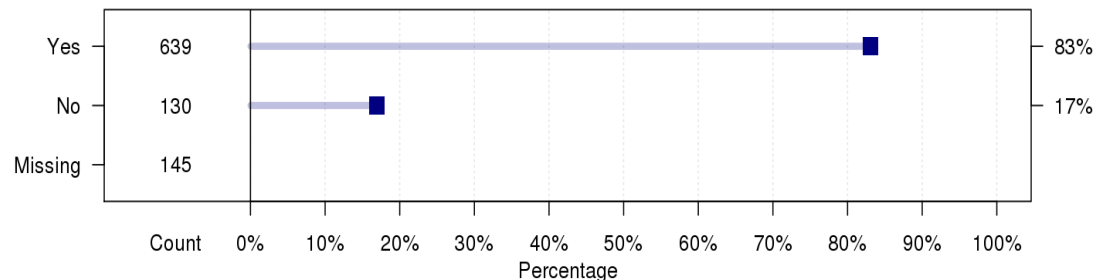
DE#	Question	Completely True	Very True	Somewhat True	A Little Bit True	Not at All True	N
Q12	I felt heard and understood by this provider and team.	71.3%	21.3%	4.2%	2.1%	1.2%	908
Q13	I trusted this provider and team.	75.5%	18.4%	3.9%	1.7%	0.7%	909
Q14	I felt comfortable asking this provider and team questions.	79.4%	15.1%	3.3%	1.3%	0.9%	908
Q15	I could tell this provider and team anything, even things I might not tell anyone else. I felt this provider and team ...	60.5%	23.5%	10.8%	2.6%	2.7%	899
Q16	Put my best interests first when making recommendations about my care.	73.6%	18.8%	4.7%	1.8%	1.1%	909
Q17	Always told me the truth about my health, even if there was bad news.	76.9%	17.0%	4.2%	1.2%	0.7%	904
Q18	Saw me as a person, not just someone with a medical problem.	78.4%	15.3%	4.0%	1.4%	0.9%	908
Q19	Knew what worried me most about my health.	64.0%	24.5%	8.9%	0.9%	1.8%	903
Q20	Understood what is important to me in my life.	64.7%	22.4%	9.9%	1.3%	1.8%	903
Q21	Would know what I would want done if I was unconscious or in a coma.	55.7%	22.3%	14.1%	2.6%	5.4%	875

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

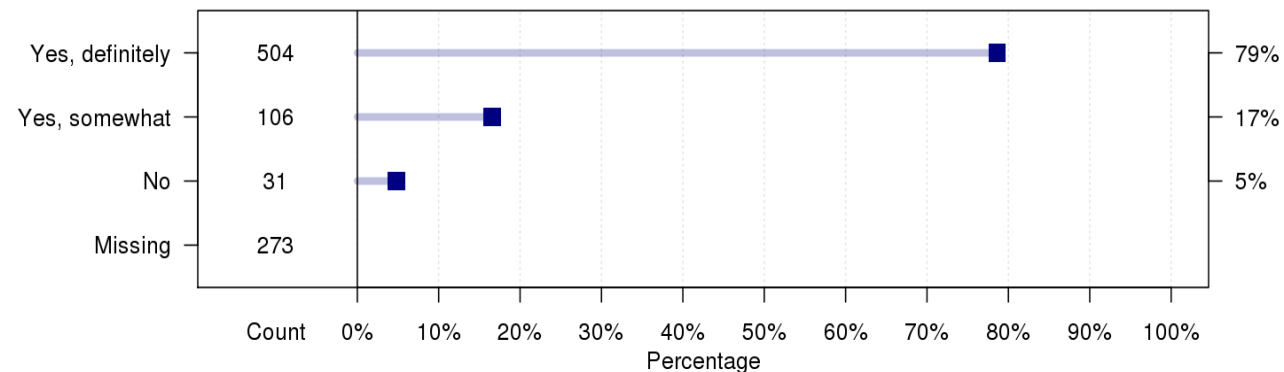
Q7: In the last 6 months, have you ever had pain?



Q8: In the last 6 months, did you want help from this provider and team for this pain?



Q9: In the last 6 months, did you get as much help as you wanted for your pain from this provider and team?



Feedback from participating programs

Heard and Understood:

- I love that measure. I think it measures something that is essential to the service we provide.
- That's [feeling heard and understood] the first step to understanding their goals and desires, which is the next step to understanding what they want, which is the next step to completing their documents for final care.

Getting Help for Pain:

- The goal is to get patient pain under control. If we aren't doing that, we aren't doing our job at all. It is a solid thing to be assessing.
- I think it's critical we measure that [getting help for pain]. It's part of what palliative medicine is.

Overall:

- It's been fantastic to be a part of this, it's a nice learning experience. Just being a part of this and the national movement is a real thing and we're honored.

Next Steps for Testing

- **We have resumed data collection with almost all participating test programs**
- **Further development of the measures:**
 - Construct Heard and Understood multi-item measure; evaluate reliability
 - Using test-retest methods, estimate reliability of the pain item.
 - Explore covariate adjustment, including survey mode
 - Risk adjustment and measure reliability/validity analyses will require more data to inform
- **COVID-19 may affect response patterns, and analyses may need to be adjusted**



Measure Implementation

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Why

Measuring what matters

- **Providers**
- **Patients**
- **Field of HPM**



How

Tap into Resources

1. Make new relationships

- 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



Polling Question #2

How likely are you to use these measures even if not required?

- Very likely
- Somewhat likely
- Not at all likely
- I don't know

Why or why not?



Stakeholder Engagement

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What's Unique: Patient-Centered Approach



“FOR US, BY US”

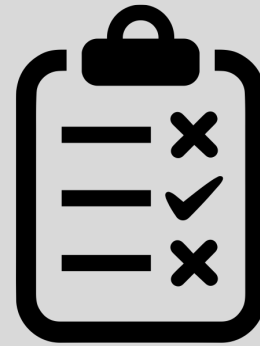
Stakeholder Engagement Deliverables



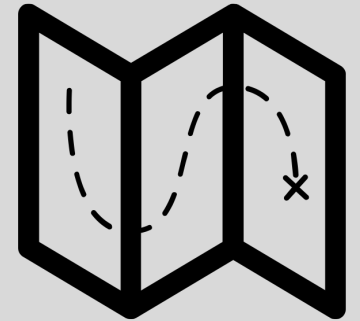
**Convene a
Technical Expert
Clinical End User
Panel (TECUPP)**



**Solicit diverse
care settings**



**Provide
opportunities for
public comment**

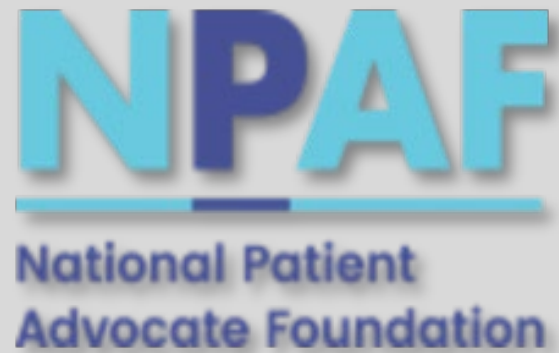


**Deploy strategic
communications**

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”



National Patient Advocate Foundation: “Patients care more about financial distress than physical 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”

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.



Public Comment Opportunities (2021)

- **Webinar**
 - **Co-Sponsored by the National Patient Advocate Foundation**
- **Online Feedback**
 - **Diverse stakeholders are invited to provide input through online portal**
- **www.nationalcoalitionhpc.org/MACRA**



How You Can Get Involved



➤ To Do Today:

- Write your questions in chat; for questions after this session: kast@aaahpm.org
- Identify Executive Leadership for your program to partner with
- Go to the Coalition website for public webinar and public comment information
- Follow @Coalitionhpc on Twitter
- Find QI resources at aaahpm.org/education/quality, IHI.org, qualityforum.org, ahrq.gov/tools

➤ Provide input:

- Join our public comment period. We need YOUR INPUT!
- *Stay tuned for more information.*

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