Launching the Future of Palliative Care: 
Patient-Reported Experience Measures
February 1, 2021

Welcome!
- Katherine Ast, MSW, LCSW, Director, Quality and Research, American Academy of Hospice and Palliative Medicine
- Rebecca Kirch, JD, Executive Vice President, Policy and Programs, National Patient Advocate Foundation
- Sangeeta Ahluwalia, PhD, Senior Policy Researcher, RAND Corporation
- Jeanie Youngwerth, MD, FAAHPM, Director, Palliative Care Service, Department of Medicine, University of Colorado Anschutz Medical Campus
- Gwynn Sullivan, MSN, Project Director, National Coalition for Hospice and Palliative Care

Objectives
1. Introduce two new palliative care patient-reported experience measures.
2. Explain how the measures were developed and included patient and caregiver voices.
3. Describe the importance of the measures and how they can be used to improve care quality.
4. Detail how you can take action to provide input supporting these measures and their broad use.

Agenda
- What’s this project about? Katherine
- What’s different and unique? Rebecca
- How were the measures developed? Sangeeta
- How can the measures be used? Jeanie
- What’s next? Here’s where you come in! Gwynn
- Q & A: from the Chat All
- Closing comments Katherine

Questions?
- Please write all your questions in the Chat.
- Our Project Team will monitor the Chat and we’ll answer as many questions as possible during the Q & A section.
- Any questions we don’t get to will be answered and made available after the webinar.
Polling Question #1

Who is in our audience?
(check all that applies)

- Patient/Family/Caregiver/Advocate
- Palliative Care Clinician/Team Member/Provider
- Other Health Care Professional/Administrator
- Representative from a National Organization/Association
- Representative from the Measurement Community

Polling Question #2

Have you previously provided input informing new health policy or quality measures?

- Yes
- No
- Not Sure

What’s this project about?

Development of Palliative Care Measures

- AAHPM, in partnership with the National Coalition for Hospice and Palliative Care (Coalition) and the RAND Corporation, was awarded a three-year cooperative agreement from Centers for Medicare and Medicaid Services (CMS) to develop patient-reported quality measures for community-based palliative care. (See more details on the project webpage.)
- The measures are intended for use in CMS’s Quality Payment Program to help support meeting patient needs by promoting quality improvement activities among providers.
- Through partnership with the National Patient Advocate Foundation, the project team sought and incorporated the perspectives of patients and caregivers as an essential aspect of developing quality measures that would be meaningful.

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Project Goal

Develop two patient-reported quality measures of outpatient palliative care experience that matter to people receiving care.

- These new measures will be used by providers in CMS’s Merit-Based Incentive Payment System (MIPS) and Alternative Payment Models (APMs) under the Quality Payment Program (QPP) created by MACRA.

Proposed Measures: Person-Centered Emphasis

<table>
<thead>
<tr>
<th>Communication</th>
<th>Symptom Management</th>
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<tbody>
<tr>
<td>Palliative care outpatients’ experience of feeling heard and understood</td>
<td>Palliative care outpatients’ experience of receiving desired help for pain</td>
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### Why these particular measures?

- Palliative care field has prioritized these measure concepts as **essential aspects of quality care delivery.**
- Measures address significant gaps in care, namely in nuanced symptom management (pain) and skilled communication that is meaningful.
- Patient experience measures are largely lacking (except for the CAHPS survey, which some say is long and burdensome).
- Providers need quality measures for accountability that align with essential skills that patients, caregivers and family members agree are important.
- New alternative payment models (APMs) that prioritize “value” need a measurable way to distinguish good performance from poor performance.

### Innovative and Inclusive Project Plan

- Explicitly makes patients, caregivers and family **proactive parts of the team** – for care quality and accountability.
- Recognizes that peoples’ challenges and care needs change over time.
- Targets outpatient setting, but approach is **applicable in ALL care settings** for quality improvement initiatives that meet peoples’ needs.

### The Power of Skilled Communication: Making Trusted Care Happen

<table>
<thead>
<tr>
<th>Talk about the care that matters</th>
<th>Knowing what’s important to patients and caregivers is paramount. They want:</th>
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<tbody>
<tr>
<td>Tell the people that matter</td>
<td>1) Understandable, accurate information</td>
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<td>2) Personalized to meet their pressing needs and concerns</td>
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<td>3) Engagement as partners</td>
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<td>4) Care that matches their priorities</td>
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- knowing what's important to patients and caregivers is paramount. They want:
  - 1) Understandable, accurate information
  - 2) Personalized to meet their pressing needs and concerns
  - 3) Engagement as partners
  - 4) Care that matches their priorities

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

- Applies a person-centered approach that **recognizes the person beyond the disease**
- Prioritizes peoples’ health concerns as **they see them**

Knowing what’s important to patients and caregivers is paramount. They want:
1) Understandable, accurate information
2) Personalized to meet their pressing needs and concerns
3) Engagement as partners
4) Care that matches their priorities
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.

Sa’Brina Davis, NPAF Volunteer

How were the measures developed?

Two Proposed Patient Experience Measures

- **Communication**
  - Palliative care outpatients’ experience of feeling heard and understood

- **Symptom Management**
  - Palliative care outpatients’ experience of receiving desired help for pain

Development Timeline

- **Preparation**
  - Alpha Field Test: Aug - Oct 2019
  - Beta Field Test: Nov 2019 - Jan 2020

- **Testing**
  - We Are Here

- **Finalization/Endorsement**
  - Submit Measures to MUC List: Jun 2021
  - Submit Measures to NQF: Nov 2021 (AAHPM)
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

Heard and Understood Measure

The Heard and Understood measure is comprised of four survey questions:

- "Thinking about your overall experience with this provider and team in the last 6 months, how true are the following statements?"
  - I felt heard and understood by this provider and team.
  - I felt this provider and team put my best interests first when making recommendations about my care.
  - I felt this provider and team saw me as a person, not just someone with a medical problem.
  - I felt this provider and team understood what is important to me in my life.

Alpha Field Test

- Goal was to better understand capabilities of fielding a patient survey and to prepare for the national field test (beta)
- Tested across 300 patients and 5 outpatient palliative care programs
- Results informed decisions about eligibility criteria, survey procedures and response rates estimates

Heard and Understood Measure

Preliminary analyses show:

- Most patients rate their provider and team positively (69%) however measure performance varies between programs (variance in average program scores=0.018)
- Approximately 115 returned surveys would be needed per program, per year, to reliably distinguish measure performance between programs

Help Wanted for Pain Measure

The Help Wanted for Pain measure is constructed using responses from three survey questions:

- "In the last 6 months, have you ever had pain?"
- "In the last 6 months, did you want help from this provider and team for this pain?"
- "In the last 6 months, did you get as much help as you wanted for your pain from this provider and team?"

National Beta Field Test

- Used a web-to-mail-to-phone survey design
- Surveys sent to over 8,800 adult patients receiving care from 43 outpatient palliative care programs across the U.S.
- As of mid-December 2020, 3,600 surveys returned
- Data from these surveys are being used to establish the reliability and validity of the two proposed measures and to finalize measure specifications
Help Wanted for Pain Measure

• Preliminary analyses show a high prevalence of pain among patients and wanting help for pain from palliative care providers and teams.
• The majority of patients reported “definitely” (81%) or “somewhat” (16%) getting as much help as they wanted for their pain.
• Performance varied between programs (variance in average program scores=0.049).
• Approximately 55 returned surveys would be needed per program, per year, to reliably distinguish measure performance between programs.

Feedback from Test 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 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 very meaningful experience. Just being a part of this and the national movement is a real thing and we’re honored.

Why?

• Meet the needs of people living with serious illness
• Work together as a team
• Build public demand for palliative care

How?

Patients/Caregivers:
• Tell your story
• Advocate for your needs
• Voice what matters most

Clinicians/Providers:
• Build the relationships
• Align priorities
• Seek opportunities

You have a choice!

How can the measures be used?

The Ask

We can make a difference together.

Please give your support of the measures during the public comment.
What's next? Here's where you come in!

Opportunity #1
Support Patient-Centered Care
- Clinicians/Providers/Professionals: Give quality care based on patients’ unique needs!
- Patients/Families/Caregivers: Receive quality care based on your unique needs!

Opportunity #2
Give Feedback via Public Comment
Easy three-step process:
1. Click HERE to answer survey
2. Choose your category:
   - Clinician/Provider/Professional
   - Patient/Family/Caregiver
3. Answer seven questions (estimated time is only 2-5 minutes)

Opportunity #3
Stay Informed
- See project updates: www.nationalcoalitionhpc.org/macra
- Follow us on Twitter: @coalitionhpc
- Contact us: macra@nationalcoalitionhpc.org

Public Comment Questions

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<th>Clinician/Provider/Professional</th>
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<tr>
<td>1. How likely would you choose to report on these measures?</td>
<td>1. Do you think the Heard and Understood measure captures important information?</td>
</tr>
<tr>
<td>2. Which measure(s) would you elect to report?</td>
<td>2. What could a health care team do to help you and other patients feel more heard and understood?</td>
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<tr>
<td>3. How feasible would it be to implement these measures?</td>
<td>3. Do you think the Help Wanted for Pain measure captures important information?</td>
</tr>
<tr>
<td>4. How likely are you to use Heard and Understood measure to improve your practice and/or the care you provide?</td>
<td>4. What could a health care team do to help you and other patients get the help you want for pain?</td>
</tr>
<tr>
<td>5. How likely are you to use Help Wanted for Pain measure to improve your practice and/or the care you provide?</td>
<td>5. How likely would you be to complete a survey about your experience with your health care provider and team?</td>
</tr>
<tr>
<td>6. Please indicate your support (for each measure).</td>
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Questions?
Q & A from the Chat
Closing Message: Faye Hollowell, NPAF Volunteer

Thank you!

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Closing Message: Sa'Brina Davis, NPAF Volunteer

Act Now!

Take Two (minutes)!

Public Comment Period
February 1 – March 2, 2021

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