

## FINAL SUMMARY REPORT

September 2021

### OVERVIEW

Under the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA), the Centers for Medicare and Medicaid Services (CMS) was directed to develop performance measures for clinicians. To meet these requirements, CMS contracted with the American Academy of Hospice and Palliative Medicine (AAHPM) to develop two patient reported outcome performance measures (PRO-PMs) in the areas of pain/symptom management and communication for patients with serious illness, including those receiving palliative care (Cooperative Agreement #1V1CMS331639-01-00). The project was funded for three years, September 13, 2018 – September 13, 2021.

To fulfill their requirements, AAHPM partnered with the National Coalition of Hospice and Palliative Care (Coalition) and RAND Health (RAND) to establish the [Palliative Care Quality Measures Project](#) and develop two patient-centered palliative care measures for CMS's Quality Payment Program (QPP) including the Merit-Based Incentive Payment System (MIPS) and alternative payment models (APMs).

By the end of the project, two new patient reported experience measures were tested at over 43 outpatient palliative care programs across the U.S. and are *now available* for palliative care and other clinicians to evaluate the quality of care they deliver based upon patient reported experience.

Specifically, the measures assess the quality of care provided by asking:

#### 1. *How much patients felt heard and understood*

- 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."

#### 2. *If patients got the help they wanted for their pain*

- 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.

For specific details about the measures and testing results, see article published in the *Journal of Pain and Symptom Management*, Incorporating the patient and caregiver voice in palliative care quality measure development, DOI: <https://doi.org/10.1016/j.jpainsymman.2021.08.001>.

## COALITION ROLE: STAKEHOLDER ENGAGEMENT

The Coalition was contracted as a subrecipient and partner of the [Palliative Care Quality Measures Project](#) to be responsible for stakeholder engagement deliverables because of its central position, leadership expertise and longstanding relationships with key stakeholders in the palliative care field, including working collaboratively and consistently with leaders from national organizations representing physicians, physician assistants, social workers, palliative care programs, hospices, researchers, pharmacists, and chaplains (i.e., the core interdisciplinary team [IDT]).

### STAKEHOLDER ENGAGEMENT DELIVERABLES

The Coalition's primary responsibility with the project was to engage stakeholders throughout the measure development process, in collaboration with the AAHPM project team, as follows:

1. **Convene a Technical Expert Clinical User Patient Panel (TECUPP) and Measure Specification Panel (MSP)** to support the development and refinement of the proposed measure concepts;
2. **Solicit participation from diverse care settings** to ensure broad representation during informational interviews and the measure testing process;
3. **Provide opportunities for input and public comment** at appropriate intervals throughout the project; and
4. **Develop and deploy a strategic communication and dissemination plan** for sharing information on this project and the specific measures broadly among key audiences.

## COALITION TASKS AND ACCOMPLISHMENTS

### Technical Expert Clinical User Patient Panel (TECUPP)

To be inclusive of a broader range of stakeholders, the Coalition assisted with establishing a TECUPP instead of the traditional Technical Expert Panel (TEP) to provide expert and stakeholder input on the development of the measures for patients with serious illness.

The TECUPP was composed of eight individuals who brought lived experience with serious illness as a patient, family member, caregiver, or patient advocate, alongside 22 others with experience as measure developers, physicians, nurses, physicians assistants, chaplains, pharmacists, social workers, specialty society representatives, healthcare industry representatives, and diversity experts, all of whom represented 17 national organizations.

A measure specification panel (MSP), a subset of the TECUPP, was also created to provide expertise in measure development and testing methodologies.

See the TECUPP [Announcement](#), [Roster](#), and [Charter](#).

By the end of the project, the TECUPP and MSP were convened four times, in-person and virtually following the CMS Measures Blueprint process, to help refine and finalize the proposed

measure concepts, review alpha and beta testing results, provide continued input on measure specification and value, and help to inform testing parameters as needed.

Specifically, the Coalition was responsible for:

- Overseeing the TECUPP recruitment, nomination, and selection process, as well as collaborating with the [National Patient Advocate Foundation](#) (NPAF) to ensure that patients with serious illness and caregivers were included.
- Coordinating the TECUPP in-person and virtual meetings, including an initial orientation meeting held March 2019. See the TECUPP Meeting Summary Reports: [April 2019](#), [October 2019](#), and [June 2020](#).
- Drafting bi-monthly project updates for the TECUPP members that were emailed from the project director.

### **Broad Public Participation**

To support stakeholder engagement, the Coalition assisted the AAHPM team with outreach and facilitation of educational webinars. A total of two educational webinars were held between years one-three of the project.

The purpose of the webinars was to provide information about the project to stakeholders and gain feedback specifically from patients, caregivers, and clinical end users, after key milestones during various stages of the project. The webinars were open to potential end-users of these measures to gain their input and buy-in along the project lifecycle and were free of charge.

By the end of the project, the Coalition coordinated the logistics, developed an outreach/marketing plan, created and promoted announcements via various communication venues, hosted, and collated participant evaluations for the following two webinars:

1. [Measuring Up! New Palliative Care Quality Measures Project](#), held June 26, 2019, with 269 attendees.
  - Objectives for the webinar were: 1) Discuss national palliative care measure initiatives, 2) Describe the MACRA Palliative Care Measures Project, 3) Explain how the MACRA project evolved, and 4) Identify how organizations can get involved with the MACRA project.
  - Webinar [recording](#) and [handout](#) are available.
2. [Launching the Future of Palliative Care: Patient-Reported Experience Measures](#), held February 1, 2021, with 202 attendees.
  - Objectives for the webinar were: 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, and 4) Detail how participants can take action to provide input supporting these measures and their broad use.
  - Webinar [recording](#), [handout](#), and [chat Q&A](#) are available.

## Public Comment

In addition to obtaining stakeholder feedback about the measures during the two webinars, the Coalition worked with the AAHPM project team to coordinate, promote, and facilitate a public comment period held February 1 – March 2, 2021.

The purpose of the public comment period was to obtain specific feedback through an online survey from wide array of stakeholders, including patients, caregivers, clinicians, and other professionals, on the importance of *implementing* the two proposed patient-reported experience measures. The survey contained ten multiple-choice questions (excluding demographics), with an opportunity for free text comment in each question, and two additional open-ended questions.

The Coalition solicited public comments using the following methods:

- Posted a call for public comment on the CMS public comment website and the project website.
- Emailed multiple notifications to over 500 individual stakeholders and national stakeholder organizations
- Announced the public comment period during the educational webinar held February 1, 2021, as well as during a [session](#) at AAHPM's Annual Assembly held February 19, 2021
- Posted announcements on the Coalition's e-newsletter and twitter, and through the Coalition's member organizations
- Published a [blog](#), *Palliative Care Quality Measures Project Update: In the Home Stretch and Going into Public Comment*

The Coalition also worked closely with National Patient Advocacy Foundation to ensure that patients with serious illness, families, caregivers, and patient advocates could comfortably submit comments as well as to promote the public comment period through their outreach and communications mechanisms. [Hear NPAF Volunteer, Faye Hollowell](#), discuss the importance of the two measures.

**The total number of individual public comment respondents was 207, that included:**

- Patient/Caregiver/Family Members/Advocates (combined): 71
  - *Note: this was 36% of the total respondents.*
- Providers/Clinicians (serious illness care): 87
- Other Healthcare Professionals: 28
- Representatives from National Organizations: 21

Based on the public comments, there was strong support for the measures with a strong majority of clinicians indicating they would be very or somewhat likely to use the heard and understood (83%) and desired help for pain (72%) measures.

Patients, families, caregivers, and advocates also indicated strong support, with 79% and 73% reporting they felt the measures capture important information, respectively. *The Public Comment Summary Report will be posted on the project's website once approved by CMS.*

## Strategic Communications

To engage a broad array of stakeholders over the entire span of the project, the Coalition developed a strategic communications plan and communication materials that the AAHPM project team, TECUPP members, Coalition members and other stakeholders used to disseminate information and resources about the project to the larger palliative care community, that included:

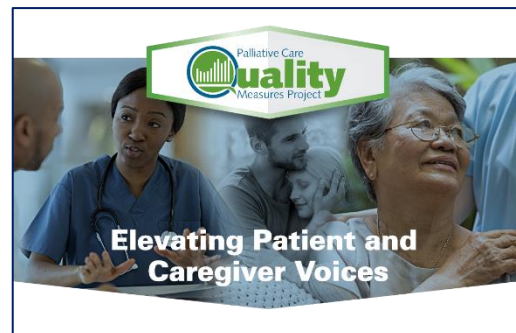
- Project logo
- Key messages for the AAHPM project team and TECUPP members
- [Test site recruitment](#)
- News blurbs in the Coalition's bimonthly e-newsletter, [Coalition Edition](#)
- [Project FAQ](#)
- Project accomplishments in the Coalition's *Impact Reports*: [2019](#) and [2020](#)
- Blog posts: [November 1, 2019](#) and [January 4, 2021](#)
- PowerPoints for the two educational webinars: [June 26, 2019](#) and [February 1, 2021](#)

Other resources that the Coalition recently coordinated and will be made available once approved by CMS are:

- Stakeholder engagement blog article that will be submitted for publication
- PowerPoint for future conferences and meetings
- Two-page handout to supplement the new PowerPoint

To support the dissemination of the project's communications, the Coalition developed, maintained, and updated the [project website](#) during the entire three years.

The Coalition also managed the project's email communication ([macra@nationalcoalitionhpc.org](mailto:macra@nationalcoalitionhpc.org)) and provided other communication support as requested by the AAHPM project team.



In addition, the Coalition also used its monthly meetings to periodically update our 13 organizational members on the project as well as the Coalition's Quality Workgroup and Communications Workgroup meetings.

## LESSONS LEARNED

### Patient and Caregiver Inclusion

We learned firsthand the value of creating opportunities for patients, family members, caregivers, and patient advocates with lived experience of palliative care to drive key decisions throughout the measure development process.

A key strategy was convening a Technical Expert Clinical User Patient Panel (TECUPP) that was an expansion of the more traditional Technical Expert Panel (TEP) that typically includes clinician-researchers, psychometricians, and other measurement experts. The TECUPP was

composed of eight individuals who brought lived experience with serious illness as a patient, family member, caregiver, or patient advocate, alongside 22 others with experience as measure developers, physicians, nurses, physicians assistants, chaplains, pharmacists, social workers, specialty society representatives, healthcare industry representatives, and diversity experts.

Throughout the entire project, the TECUPP itself provided a holistic view of palliative care that recognized patients – as well as the palliative care teams treating them – as whole people with differing circumstances, life histories, and experiences within and outside of the health care system.

### **Stakeholder Engagement**

We learned that having a dedicated team/entity that was solely focused on investing in relationships and open communication with a broad array of stakeholders yielded a high level of engagement.

First, by designating the Coalition to lead stakeholder engagement efforts – including supporting patients, family members, caregivers, and advocates throughout their role as members of the TECUPP – helped us continually assess how well we were staying true to the goal of being patient-centered and adapt when needed.

Also, building support for the measures among palliative care stakeholders required devoted time to provide transparent and comprehensible communication to ensure that all stakeholders had access to easy-to-understand information and opportunities to provide feedback at key points in the measure development process.

Overall, this effort paid off when we sought formal public comments towards the end of the measure development process. We received over 200 public comments, with similar numbers of patients, family members, caregivers, and advocates commenting as clinicians and other health care professionals.

### **Strategic Communications**

We learned the importance of communicating with stakeholders *early and often*.

In addition to providing regular updates to all groups directly contributing to the measures' development (e.g., TECUPP members, field testing sites, project advisors, and Coalition members), the Coalition was responsible for providing newsletter updates, webinars, and presentations to a broader group of stakeholders who would be impacted using the measures once fully developed and potentially integrated into the CMS Quality Payment Program. This included health system leaders, palliative care professionals, medical specialty societies, patients, and advocacy groups.

Inviting a broad array of stakeholders through a variety of communication channels to ask questions, raise concerns or suggest improvements to the measures while they were still under development forced our team to be proactive in sharing information in ways that would ultimately improve our measure development process.

It also spurred our team to be thoughtful about *how* to share information in ways that were accessible and meaningful to the many stakeholders whose perspectives were important to inform the new measures. We spent time developing plain language descriptions of the

measures and measure development process and a strategic communications plan focused on two-way exchange of ideas at key points throughout development process.

Again, this additional attention and time that was focused on communications paid off when we sought public comment specifically to inform measure implementation which showed strong support for the measures from a majority of clinicians as well as patients, families, caregivers, and patient advocates.

## CONTINUED ACTIVITIES (Post Project)

The Coalition will continue to maintain and support ongoing communications about the measures, that includes:

- Hosting the [project webpage](#) in perpetuity
- Providing pertinent updates about the measures re: NQF endorsement, publications, etc., via:
  - Monthly member meetings
  - Quality and Communication Workgroup meetings
  - *Coalition Edition*, bimonthly e-newsletter
  - Twitter
- Featuring project accomplishments in the Coalition's *2021 Impact Report*

## CONTACT

For more information about the project and measures, please contact Katherine Ast, MSW LCSW, Director of Quality and Research, American Academy of Hospice and Palliative Medicine, at [kast@aahpm.org](mailto:kast@aahpm.org).

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