1. What is the AAHPM CMS MACRA Palliative Care Measures Project?

The Centers for Medicare & Medicaid Services (CMS) has cooperative agreement #1V1CMS331639-01-00 with the American Academy of Hospice and Palliative Medicine (AAHPM) as part of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) to develop two patient-reported measures of palliative care experience. The cooperative agreement name is the “Palliative Care Measures Project.” The measures will assess the extent to which patients receiving outpatient clinic-based palliative care received the help wanted for pain, and felt heard and understood by their palliative care provider and team. AAHPM's partners on the project are the National Coalition for Hospice and Palliative Care (Coalition) and RAND Health Care (RAND).

2. What is the timing for this project?

This cooperative agreement began September 14, 2018 and will conclude September 13, 2021.

During year one of the project, we:
- Conducted an environmental scan and hosted provider focus groups;
- Conducted patient, family member, and caregiver interviews;
- Selected a Technical Expert Clinical User Patient Panel (TECUPP) and Measure Specification Panel (MSP);
- Held our first TECUPP and MSP meetings;
- Conducted cognitive interviews with English- and Spanish-speaking patients and caregivers;
- Hosted quarterly calls with expert advisors;
  - Advisors are physician experts in palliative care measurement, whose responsibilities include reviewing all measure components and providing guidance on project tasks and implementation.
- Began alpha testing, which is a formative testing phase utilizing five palliative care outpatient sites;
- Alpha testing aims to establish the data collection processes that be used in the national field test (beta test) and identify challenges and refinements necessary to the testing plan.
- Hosted a public webinar.

During year two of the project, we will:
- Conclude alpha testing;
- Conduct beta testing, a nationally representative test that will utilize fifty palliative care outpatient sites;
  - Beta testing aims to establish the psychometric properties of the data elements; feasibility with regards to administration, mode, and calculation of the quality measures; final measure technical specifications; and the reliability of the measure.
- Refine the measures and survey instruments;
- Continue to engage TECUPP and MSP members;
- Host quarterly calls for our expert advisors.

During year three of the project, we will:
- Host a public comment period;
- Finalize the measures and survey instruments;
- Submit measures for consideration of inclusion in CMS’s Quality Payment Program (QPP);
- Prepare and submit measures for consideration of National Quality Forum (NQF) endorsement;
- Use the new measures to begin developing practice improvement projects;
- Write up measure testing results for publication in a peer-reviewed journal.

3. How is this project funded?

AAHPM, in partnership with the National Coalition for Hospice and Palliative Care and the RAND Corporation, was awarded a $5.5 million cooperative agreement from CMS to develop patient-reported quality measures.

4. How were the measure concepts chosen for the project?

During 2017, the Coalition’s Quality Workgroup examined measure development goals prioritized by various expert
panels convened in the previous two to three years. The conveners included: AAHPM and the Hospice and Palliative Nurses Association's Measuring What Matters project and subsequent work from the Gordon & Betty Moore Foundation, Icahn School of Medicine, University of Washington and Pew Charitable Trusts. Upon examining CMS's Measure Development Plan and Gap Analysis, the Workgroup recommended a focus on performance measures for use in CMS's Quality Payment Program (QPP) that:

- Are relevant and meaningful to palliative care clinicians and any clinician caring for seriously ill patients;
- Demonstrate the value of palliative care to program funders and external stakeholders;
- Reflect nuanced symptom-based measures to show how complex trade-offs occur, and not penalize clinicians when a decrease in pain intensity or other quantifiable outcome is not achieved;
- Address identified measurement gaps, including outcome and patient reported measures; and
- Involve expansion of existing measures or development of new measures.

5. What is the TECUPP and how were the members chosen?

To support the Palliative Care Measures Project, we created a Technical Expert Clinical User Patient Panel (TECUPP) and Measure Specification Panel (MSP). The TECUPP members represent a broad array of stakeholders including measure development experts, palliative care clinicians from the interdisciplinary team, specialty society representatives, patient advocates, patients with past experience of serious illness, family members, caregivers, healthcare industry representatives, diversity experts, and others. Members of the TECUPP were selected from nominations received from the public.

The purpose of the TECUPP is to provide strategic feedback and direction to the project, which will help ensure that the new measures will be patient-centered and meaningful to seriously ill patients and their caregivers. The MSP is made up of 11 members of the TECUPP, selected for their specialized clinical measure development expertise. MSP participants are expected to review and provide expertise on measure specifications, provide technical feedback following the public comment period, and review measure testing methodologies and results and provide feedback. Both panels are chaired by Sydney Dy, MD, MS, FAAHPM, and Mary Ersek, PhD, RN, FPCN. Access the TECUPP and MSP roster online.

6. What opportunities are there for the public to get involved?

- **Participate in the testing** - All programs that provide outpatient palliative care services to adult patients are invited to learn more about serving as a test site for this project. There will be minimal burden on programs who participate in this effort; all data collection and survey activities will be conducted by AAHPM and its contractors; and an honorarium will be provided. Information and an interest form can be found on the Palliative Care Measures Project website. Questions? Reach out to RAND toll-free by phone at 1-833-278-3915 or email at macrarecruitment@rand.org.

- **Provide input during the public comment period** - We will be hosting a public comment period in January of 2021. More information will be made available as we get closer to that time.

7. Why is this project focused on “outpatient palliative care” and how is it defined?

For this project, we are focused on patients receiving palliative care in outpatient clinics because of the rapid growth of outpatient clinics and growing need to provide palliative services further upstream (i.e., in ambulatory settings and in the primary care context). Telephone or telehealth visits may count (we would love to speak further with sites about this), but visits in home or skilled nursing facilities (SNFs) are not eligible.

Specifically, we are looking for sites with patients who have had at least one visit to outpatient, clinic-based palliative care in a defined timeframe. We acknowledge that the home-based care setting is important; however, there are other measure development efforts focused specifically on home-based care, so we are avoiding duplication of efforts and maximizing harmonization across projects.

8. How can I learn more and stay up-to-date on the project?

- **Listen to the public webinar** about the project held on June 26, 2019. The recording and handout of the webinar are posted on the National Coalition for Hospice and Palliative Care website.

- **Stay up to date** with these and other opportunities on the Palliative Care Measures Project website.