

Overview

The **American Academy of Hospice and Palliative Medicine** (AAHPM) is partnering with the **National Coalition for Hospice and Palliative Care** and **RAND** to create two patient reported experience measures. The measures will assess the extent to which adult patients receiving outpatient clinic-based palliative care *received the help they wanted for pain, and felt heard and understood by their palliative care provider and team*.

The project is a cooperative agreement (#1V1CMS331639-01-00) between the Centers of Medicare & Medicaid Services (CMS) and AAHPM as part of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) and is officially named “Palliative Care Measures Project.” This three-year cooperative agreement began September 14, 2018 and will conclude September 13, 2021.

Patient Experience Measures

The two specific measure concepts that are approved for testing are as follows:

1. **Palliative care outpatients’ experience of receiving desired help for pain:** *The percentage of patients aged 18 years and older with at least one outpatient palliative care visit in three months, reporting pain and wanting help for their pain, who report getting the help they wanted for their pain from their palliative care provider and team.*
2. **Palliative care outpatients’ experience of feeling heard and understood:** *The percentage of patients aged 18 years and older with at least one outpatient palliative care visit in three months, answering a survey question about feeling heard and understood, who report feeling heard and understood by their palliative care provider and team.*

“Outpatient Palliative Care” Focus

Patients receiving palliative care in outpatient clinics are the focus of this project because of the rapid growth of outpatient clinics and the growing need to provide palliative services further upstream (e.g., in ambulatory settings and primary care). Also, since there are other measure development efforts focused specifically on home-based care, this project seeks to avoid duplication of efforts and maximize harmonization with other projects.

Test sites selected will have patients who have had at least one visit to an outpatient clinic-based palliative care provider in a defined timeframe. Telephone or telehealth visits may count, but visits in home or skilled nursing facilities are not eligible for inclusion in this testing.

How to Get Involved

- **Learn more:** Listen to the public webinar about the project, held on June 26, 2019.
 - The recording and handout are posted at www.nationalcoalitionhpc.org/macra-webinar.
- **Stay up to date:** Visit the project website periodically and follow [@Coalitionhpc](https://twitter.com/Coalitionhpc) on Twitter.
- **Provide input:** A public comment period will be held in early 2021. *Stay tuned for more information.*

Purpose of Measures

Prior to this project, other national efforts examined CMS's *Measure Development Plan and Gap Analysis* and a collective recommendation was made to develop performance measures for use in CMS's Quality Payment Program (QPP) with the following goals:

- Are relevant and meaningful to palliative care clinicians, any clinician caring for seriously ill patients, and patients and caregivers;
- 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 measures; and
- Involve expansion of existing measures or development of new measures.

Stakeholder Engagement

Key stakeholders from national organizations representing the core interdisciplinary team in the palliative care field, people living with serious illness and family members and/or caregivers will be engaged throughout the measure development process, as follows:

1. A Technical Expert Clinical User Patient Panel (TECUPP) and Measure Specification Panel (MSP) are convened to support the development and refinement of the proposed measure concepts;
2. Participation from diverse care settings is solicited to ensure broad representation during informational interviews and the measure testing process;
3. Opportunities are provided for input and public comment at appropriate intervals throughout the project; and
4. A strategic communication and dissemination plan will be developed and deployed broadly among key audiences for sharing information about this project and the specific measures.

Timeline

Year One Deliverables (2018-2019):

- Conduct an environmental scan and host provider focus groups
- Conduct patient, family member, and caregiver interviews
- Select a Technical Expert Clinical User Patient Panel (TECUPP) and Measure Specification Panel (MSP)
- Hold the first TECUPP and MSP meetings
- Conduct cognitive interviews with English- and Spanish-speaking patients and caregivers
- Begin alpha testing, a formative testing phase utilizing five sites
- Host a public webinar

Year Two Deliverables (2019-2020):

- Conclude alpha testing
- Conduct beta testing; a nationally representative test utilizing up to 50 sites
- Refine the measures and survey instruments
- Continue to engage TECUPP and MSP members

Year Three Deliverables (2020-2021):

- Host a public comment period
- Finalize the measures and survey instruments
- Prepare and submit measures for consideration for National Quality Forum (NQF) endorsement
- Submit measures for consideration for inclusion in CMS's Quality Payment Program (QPP)
- Use the new measures to begin developing practice improvement projects
- Write up measure testing results for publication in a peer-reviewed journal