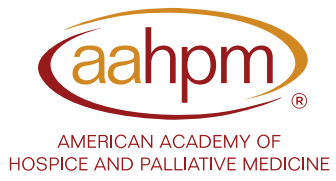




# Implementation Guide

*ELEVATING PATIENT AND CAREGIVER VOICES*



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## About the American Academy of Hospice and Palliative Medicine

The [American Academy of Hospice and Palliative Medicine](#) (AAHPM) is the professional organization for physicians specializing in hospice and palliative medicine (HPM), and the membership also includes nurses, social workers, and other health and spiritual care providers committed to improving quality of life for seriously ill patients and their families. For more than 30 years, AAHPM has been dedicated to expanding access to high-quality palliative care and advancing the discipline of HPM through professional education and training, development of a specialist workforce, support for clinical practice standards, research, and public policy advocacy. AAHPM is governed by a 17-member board of directors and managed by 16 full-time staff along with additional, scalable support provided by Association Management Center based in Chicago, IL.

# I. Purpose of the Implementation Guide

The American Academy of Hospice and Palliative Medicine (AAHPM) developed this implementation guide (Guide) to help palliative care teams implement and collect data for two patient-reported outcome performance measures (PRO-PMs) for quality improvement (QI) and regulatory reporting efforts.

The Palliative Care Measures Project was led by AAHPM, with subrecipients the [RAND Corporation](#) and the [National Coalition for Hospice and Palliative Care](#), and was funded under the [Medicare Access and CHIP Reauthorization Act of 2015](#) (MACRA) to develop two quality measures. The project was a cooperative agreement between the Centers for Medicare and Medicaid Services (CMS) and AAHPM from September 2018 to September 2021. The cooperative agreement number is 1V1CMS331639-03-00.

## How to Use the Guide

This Guide is not a list of requirements but rather describes options for clinicians depending on how they intend to use the measures, resources available, level of technical experience and expertise, and individual site/program needs. The Guide is organized into modular sections that enable the reader to select and use the most relevant content. Hyperlinks to best-practice tools and additional resources are included throughout the Guide.

Use the Implementation Guide to

- generate ideas for how to overcome lack of internal resources (eg, time, budget) and make the case for senior leadership to buy into quality improvement project(s)
- navigate infrastructure and processes—specifically, how to begin a new PRO-PM program or how to successfully adjust an existing one
- set expectations regarding the types of capabilities that will be required (eg, staff, processes)
- ensure consistent implementation with step-by-step instructions, checklists, and timelines
- apply the measures for quality improvement and quality reporting efforts.

## Who Should Use the Guide?

This Guide was designed to help clinicians and their palliative care teams implement two new PRO-PMs for palliative care in QI and/or quality reporting program efforts. The Guide is designed to support varying levels of experience and expertise.

The measures described in this Guide were designed and tested in outpatient palliative care settings with patients aged 18 years and older who have serious illness. The measures have not been tested or validated with other patient populations or in other clinical settings. However, this does not prevent clinicians and programs from implementing these measures in other patient populations or care settings for QI efforts. Additional details about the measures and related links are provided in the next section.

## What You Will Gain from Using the Guide

- Ability to describe the measure concepts of the PRO-PMs and understand why they are important to patients
- Tools to demonstrate the value of the measures and help gain support from senior leadership
- Tools and resources necessary to implement the PRO-PMs
- Resources to help you choose a survey vendor
- Strategies for implementing the measures
- Knowledge of what is needed to report the measures to quality reporting programs
- Resources to implement QI projects

## II. Overview of the Measures and Why They Are Important

Quality measures are defined by CMS as “[tools that help us measure or quantify healthcare processes, outcomes, patient perceptions, and organizational structure and/or systems that are associated with the ability to provide high-quality health care and/or that relate to one or more quality goals for health care.](#)” The two measures fall under the category of patient-reported outcome performance measures and are intended for palliative care providers to evaluate the quality of care they deliver based upon patient-reported experience.

### Description of the Measures

**Measure 1: Patients’ experience of feeling heard and understood**

**Measure 2: Patients’ experience of receiving desired help for pain**

#### Measure 1: Ambulatory Palliative Care Patients’ Experience of Feeling Heard and Understood (See the [Measure Information Form \[MIF\].](#))

##### MEASURE DESCRIPTION

This is a multidata 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.”

##### DENOMINATOR

All patients aged 18 years and older who had an ambulatory palliative care visit

##### NUMERATOR

Calculated using top-box scoring, which reflects the percentage of patient respondents that gives the most positive response across the four data elements

##### DENOMINATOR EXCLUSIONS

- Patients who do not respond to at least one of the four data elements in the multidata element measure
- Patients who do not complete the patient experience survey within 6 months of the eligible ambulatory palliative care visit
- Patients who respond on the patient experience survey that they did not receive care by the listed ambulatory palliative care provider in the last 6 months (disavowal)
- Patients who were deceased when the survey reached them
- Patients for whom a proxy completed the entire survey on their behalf for any reason (no patient involvement)

##### DATA SOURCES

Patient medical records (paper-based or electronic) and patient-reported data and surveys

Patient eligibility is determined based on coded visit information in the electronic health record. Patient-reported data is collected via survey instrument. The instrument was developed for this measure and can be completed via Web survey, on paper, or over the telephone in English. A Spanish-language translation for the survey instrument is available, but the quality measures were not formally tested in Spanish.

#### Measure 2: Ambulatory Palliative Care Patients’ Experience of Receiving Desired Help for Pain (See the [Measure Information Form \[MIF\].](#))

##### MEASURE DESCRIPTION

The percentage of patients aged 18 years and older who had an ambulatory palliative care visit and report receiving the help they wanted for their pain from their palliative care provider and team within 6 months of the ambulatory palliative care visit

## DENOMINATOR

All patients aged 18 years and older who had an ambulatory palliative care visit

## NUMERATOR

The number of patients aged 18 years and older who report getting the help they wanted for their pain by their palliative care provider and team within 6 months of the ambulatory palliative care visit

## DENOMINATOR EXCLUSIONS

- Patients who do not complete and return the patient experience survey within 6 months of the eligible ambulatory palliative care visit
- Patients who respond on the patient experience survey that they did not receive care by the listed ambulatory palliative care provider in the last 6 months (disavowal)
- Patients who were deceased when the survey reached them
- Patients for whom a proxy completed the entire survey on their behalf for any reason (no patient involvement)
- Patients who respond “No” to the questions, “In the last 6 months, have you ever had pain?” or “In the last 6 months, did you want help from this provider and team for this pain?”

## DATA SOURCES

Patient medical records (paper-based or electronic) and patient-reported data and surveys

Patient eligibility is determined based on coded visit information in the electronic health record. Patient-reported data is collected via survey instrument. The instrument was developed for this measure and can be completed via Web survey, on paper, or over the telephone in English.

## Why Use These Measures

There are many reasons why you should use these measures.

- ✓ These measures put people at the heart of care. The measures apply a person-centered approach that recognizes the person *beyond the disease* and prioritizes peoples’ health concerns *as they see them*.
- ✓ These measures are in alignment with the top needs people are seeking from their palliative care providers and teams. People living with serious illness and their caregivers and family members were intentionally and consistently included throughout the measure development process.
- ✓ These measures address significant gaps in care. The palliative care field has prioritized these measure concepts—meaningful, skilled communication and nuanced symptom management (pain)—as essential aspects of quality care delivery. (See [Clinical Practice Guidelines for Quality Palliative Care, 4th edition](#).)
- ✓ These measures can help clinicians and palliative care teams identify resources such as training or protocols you might need to provide high-value, excellent patient care.
- ✓ These measures can be used at the practice or institution level to improve and monitor the quality of the healthcare services delivered. The measures may potentially be used in the CMS Quality Payment Program (QPP) in future years upon approval from CMS.
- ✓ The business case for each measure provides many more reasons to use the measures (note: business cases were developed before final specifications were completed; do not use the specifications contained in these documents for measure implementation):
  - [Business case for the “Feeling Heard and Understood” measure](#)
  - [Business case for the “Receiving Desired Help for Pain” measure](#)

## Feedback Received During Public Comment and from Testing Sites

These measure concepts are extremely important, as demonstrated by the feedback received during the measure development public comment period (February 1, 2021–March 2, 2021) with the receipt of over 200 comments from clinicians, patients, families, and caregivers.

## Feedback from Providers

Providers were likely to use both measures and felt that they get to the heart of what palliative care is about.

- Feeling heard and understood: 83% very or somewhat likely to use
- Receiving desired help for pain: 72% very or somewhat likely to use

## Feedback from Patients

Patients were enthusiastic about the two measures, with 87% very or somewhat likely to complete the patient experience surveys.

- Patients were primarily excited about the opportunity to drive change and improve the experience for future palliative care patients.
- Patients were pleased with these measures because they align with what they are seeking from providers.
- “When you feel heard and understood you feel important and safe.”
- “Who is the best gauge of the patient’s pain if not the patient. Patient autonomy is very important and maintaining as much of it as possible.”

## Feedback from Programs That Participated in Testing the Measures

### FEELING 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.”

### RECEIVING DESIRED 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 [receiving desired 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.”

### III. Getting Started with Quality Improvement

Strong and committed leadership is key for success in any QI implementation. A crucial first step in beginning any QI effort is getting buy-in from senior leadership, staff, and patients to support and engage in your QI project and use the measures in practice. This buy-in is the launching pad to planning and implementing these PRO-PMs at your program. In addition, stakeholder engagement and partnership are paramount to continued success, participation, and advancement of any new initiatives. Successful new advancements in QI and measure utilization require strong relationships, trust, and collaboration. Moreover, partnership with stakeholders on specific projects/measure use will allow your organization to reduce the overall administrative burden by focusing on a project that can add the most value. Lastly, the data garnered from any QI project can be used for multiple purposes with appropriate support and resources. Thoughtful consideration for resources, staffing, and analytics needs to be planned out in advance of launching any QI initiatives or using measures in practice.

In this section we outline resources for programs to assist with helping your stakeholders understand the importance of measuring quality and capturing the patient voice to improve care and services provided.

#### Table of Resources to Assist with Making the Case

| SOURCE  | NAME OF RESOURCE   | DESCRIPTION  | NOTES   |
|---|--|--|---|
| The Agency for Healthcare Research and Quality (AHRQ) | <a href="#">Toolkit for Using the AHRQ Quality Indicators</a> : PowerPoint presentations to be used when making the case to boards and senior leadership | This toolkit contains PowerPoint presentations that can assist boards and senior leadership in understanding the importance and implications of QI programs. The presentations are specific to the AHRQ Quality Indicators for hospitals but contain key points to justify any QI programs and measures. | Tip: condense key points to present to committees, boards, organizational leaders, or performance improvement teams. Delete, add, or modify slides to best suit your organization's needs.  |
| AHRQ  | <a href="#">Toolkit for Using the AHRQ Quality Indicators</a> : staff engagement presentation  | This resource includes a PowerPoint presentation template that can be used to engage frontline and other staff.  | Key points: <ul style="list-style-type: none"> <li>• Make a plan for improvement together with a variety of staff who work in different roles (eg, physicians, nurses, social workers).</li> <li>• Identify potential barriers and how to overcome them.</li> </ul> |

| SOURCE | NAME OF RESOURCE  | DESCRIPTION   | NOTES  |
|--------|---|---|--|
| AHRQ   | <a href="#">Toolkit for Using the AHRQ Quality Indicators</a>   | This toolkit includes examples, descriptions, instructions, and templates of the following resources: <ul style="list-style-type: none"> <li>• Getting Ready for Change Self-Assessment</li> <li>• Case Studies of Improvement Implementation</li> <li>• Improvement Methods Overview</li> <li>• Project Charter template</li> <li>• Return on Investment Estimation</li> </ul> |  |
| AHRQ   | <a href="#">Consumer Assessment of Healthcare Providers and Systems (CAHPS) Ambulatory Care Improvement Guide</a> | This toolkit contains a section describing the clinical and business cases for improving patient experience.  | Though this is specific to the CAHPS surveys, you can use similar justification for implementing these shorter PRO-PMs.  |
| AHRQ   | <a href="#">CAHPS Ambulatory Care Improvement Guide</a>   | This resource includes a section on “Determining Where to Focus Efforts to Improve Patient Experience.”   | Because the two new PRO-PMs are scored similarly to CAHPS, you can use this section to help understand how to analyze survey results and other sources of related information. |
| AHRQ   | <a href="#">CAHPS Ambulatory Care Improvement Guide</a>   | This toolkit also contains practical strategies for improving patient experience.   | Includes access to care and information, communication between patients and providers, coordination of care, customer service, and health promotion/ education                 |

Translating your quality measure scores or performance rates from using these measures or other quality measures into actionable data that can be used to drive QI is a worthwhile pursuit. In this section, we outline resources for programs to begin or advance their QI programs.

Will these interventions result in improvement?

- Not all changes are improvements...
- ...But all improvements are the result of changes!

## How to Use the Measures in a Quality Improvement Project

There are common steps that clinicians and their teams may follow to continually improve the quality of health care provided. These steps or elements are common to [Lean](#), [Six Sigma](#), [Plan-Do-Study-Act \(PDSA\)](#), and other workflow or processes for implementing QI projects.

### Elements of Any Quality Improvement Process or Workflow





## New to QI and Need Help Getting Started?

The first steps in a QI project using quality measures are

1. Define the nature and scope of the problem or issue.
2. Describe what to do to address the issue or the problem.
3. Identify the results of addressing the issue or problem.
4. Identify lessons learned, key findings, and strengths of the project.

## MODEL FOR IMPROVEMENT

What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?

## Table of Resources for Planning a Quality Improvement Project

| SOURCE                                     | NAME OF RESOURCE                            | DESCRIPTION  | NOTES   |
|--|---|--|---|
| Institute for Healthcare Improvement (IHI) | <a href="#">Plan-Do-Study-Act Worksheet</a> | Direct link to IHI's PDSA Worksheet  | You will need to create a free IHI account to access this resource. |
| IHI  | <a href="#">QI Project Management</a>       | This toolkit describes strategies to effectively plan and manage QI projects and includes ideas for each strategy.   | You will need to create a free IHI account to access this resource. |
| IHI  | <a href="#">QI Essentials Toolkit</a>       | This toolkit includes examples, descriptions, instructions, and templates of the following resources: <ul style="list-style-type: none"> <li>• Cause and Effect Diagram (“fishbone”)</li> <li>• Driver Diagram</li> <li>• Failure Modes and Effects Analysis</li> <li>• Flowchart</li> <li>• Histogram</li> <li>• Pareto Chart</li> <li>• PDSA Worksheet</li> <li>• Project Planning Form</li> <li>• Run Chart and Control Chart</li> <li>• Scatter Diagram</li> </ul> | You will need to create a free IHI account to access this resource. |

## Already Have an Existing Quality Improvement Program?

If you already have an established QI program, you may need to review and update some of your strategies if you have not previously collected patient-reported data.

This measure development project intentionally incorporated patients and caregivers throughout the development process to ensure that the project was patient centered. As you look to implement these PRO-PM measures, we encourage you to think about ways to incorporate the patient voice into your work.

Patient centricity can also be illustrated by office practices such as online appointment scheduling or weekend hours. Establishing a patient and family advisory committee or involvement is also a key factor when launching initiatives.

## PRINCIPLES OF PATIENT-CENTERED MEASUREMENT

- Patient driven
- Holistic
- Transparent
- Comprehensible and Timely
- Co-Created

American Institutes for Research (AIR). *Principles for Making Health Care Measurement Patient-Centered*. <https://www.air.org/sites/default/files/Patient-Centered-Measurement-Principles-April-2017.pdf>. Published April 2017. Accessed May 6, 2022.

***“Clinicians practicing patient-centered care have to embrace a different set of guiding principles than those who practice more the paternalistic medicine of the past, James Rickert, MD, an orthopedic surgery specialist wrote in a seminal 2012 Health Affairs [blog post](#).”***

*Heath S. What does patient-centered care truly mean? Patient Engagement HIT. August 27, 2021. <https://patientengagementhit.com/news/what-does-patient-centered-care-truly-mean>*

***“Physicians practicing patient-centered care improve their patients’ clinical outcomes and satisfaction rates by improving the quality of the doctor-patient relationship, while at the same time decreasing the utilization of diagnostic testing, prescriptions, hospitalizations, and referrals.”***

*Rickert J. Patient-centered care: what it means and how to get there. Health Affairs Blog. January 24, 2012. doi: 10.1377/hblog20120124.016506*

## Resource for Making Measurement More Patient Centered

| SOURCE | NAME OF RESOURCE   | DESCRIPTION   |
|--------|--|---|
| AIR    | <a href="#">Principles for Making Healthcare Performance Measurement More Patient-Centered</a> | This resource offers five principles that drive patient-centered measurement. |

According to the [American Academy of Family Physicians](#), key phrases and best practices for patient-centered communication include

- “Which of these is the most concerning to you?”
- “Because we have limited time, which of these problems would you like to discuss today?”
- “That makes sense.”
- “Could you summarize what we have discussed so far?”
- “Tell me more about what was worrying you.”
- “What difficulties are you facing because of your illness?”
- “I can understand how that might upset you.”
- “It must be a lot of stress to deal with...”

In addition, as we have outlined, these measures were tested using a survey vendor outside of the point of care. This was done to alleviate any pressure a patient might feel completing a survey within their provider’s office or being administered directly by their provider.

QI projects can be independent or part of larger systemic improvement efforts. One larger effort is a Learning Health System. Learning Health Systems are organizations that are continuously self-studying and adapting using data and analytics to help gain knowledge, engage stakeholders, and implement behavior change. Continuous efforts to review and iterate are extremely important. If you are interested in learning more about Learning Health Systems, visit the [AHRQ website](#).

## IV. Implementation Strategies and Survey Vendors

- [The Core Quality Measures Collaborative's \(CQMC\) 2021 Implementation Guide](#) has some great examples of implementation strategies and step checklists.
- Ensure consistent implementation with step-by-step instructions, simplified checklists, and timelines.
- Build the team and create the workflow.
- Consider budget implications.
- Seek out and select best practices and suggestions for improvement.

As part of our work and our attention to the process CMS follows for measure development in the CMS Measures Management System (MMS) Blueprint (latest version available: [MMS Blueprint process](#)), we examined feasibility of implementation of these measures into practice. The environmental scan identified several existing approaches to assessing patient experience of care that informed our thoughts regarding the use of these measures in practice.

CAHPS surveys are the most prevalent approach to collecting and reporting data on patient experience of care and are commonly used in CMS quality measurement programs. They are the gold standard for collecting patient experience of care information. As of late 2021, there are two existing patient experience measures in the Merit-Based Incentive Payment System (MIPS), and they both use CAHPS survey data (including CAHPS for MIPS). One of the conditions of using a CAHPS survey is that you use it as is and ask every question on every topic. Choice exists regarding the new PRO-PM surveys described in this document; clinicians can choose to implement only the “Feeling Heard and Understood” measure, only the “Receiving Desired Help for Pain” measure, or both. Other approaches for collecting data and implementing patient experience of care measures, particularly those including Web-based tools (eg, through patient portals, email surveys, text messaging, and other electronic platforms), are increasingly being considered as they are less burdensome and more agile approaches to data collection, though these are still limited in their use.

During the development and testing of these measures, there were several implementation options considered and evaluated. The AAHPM team sought CMS guidance regarding pursuing alternative, novel approaches to patient experience data collection. CMS was open to suggestions on novel ways of implementation. During testing, the AAHPM team explored various options for measure implementation in practice, including employing mixed modes in survey measure testing, and other ideas obtained from feedback from test programs, project advisors, the Technical Expert Clinical User Patient Panel, and other stakeholders. During the measure testing process, the RAND team acted as a survey vendor by mailing out patient experience surveys with telephone follow-up. An email version of the survey was also tested for programs that collected patient email addresses.

For practices or sites that plan to implement these measures in MIPS, measure implementation comprises a post-visit assessment and consists of sending out the patient survey for the measure(s) chosen to the eligible patients. Data collection would be done through a survey vendor. (There is more flexibility in mode of administration if a program implements the measures for QI only.)

### Selecting a Survey Vendor

It is recommended that palliative care providers and programs contract with a survey vendor to field surveys and process data on their behalf. Programs are highly encouraged to choose a vendor that has the capability to fully follow the protocol for survey administration outlined later in this document. Considerations and recommendations when selecting a survey vendor include

- Ensure the survey vendor has experience administering surveys to similar patient populations.
- Ensure the survey vendor has experience in survey administration in all of the recommended survey modes.
- If the program has a significant Spanish-speaking population, ensure the survey vendor has experience administering surveys in Spanish.
- Ensure the survey vendor has established procedures in place to safeguard identifiable information.
- Ensure the survey vendor has the ability to tailor survey materials for your program (eg, program name and branding) and for each sampled patient.
- Ensure the survey vendor has the capabilities and capacity to administer the survey during the desired time frame, including having a sufficient number of interviewers.
- Ensure the survey vendor has an established survey management system to track the status of each sampled patient.
- Ensure the costs associated with fielding the survey and cleaning, processing, and analyzing the data are clear and transparent.

# Proposed Mechanism for Measure Data Collection and Reporting



Palliative care programs contract with survey vendor to collect patient-reported outcome data.



Survey vendor prepares analytic data set and applies scoring methodology.



Survey vendor or palliative care program uploads measure information to CMS.

## Measure Data Collection

1. Palliative care programs contract with survey vendor to field the survey.
2. Programs identify all eligible patients (eg, all adult patients with at least one ambulatory palliative care visit within a 3-month period) on a rolling basis over the course of a reporting year.
3. Programs transmit eligible patient information (eg, name, provider name, visit date(s), contact information) to the survey vendor.
4. Survey vendor administers mixed-mode survey to eligible patients (via Web, mail, then telephone).
5. Survey vendor prepares analytic data set that includes patient data and survey data.
6. Survey vendor applies measure scoring methodology (eg, exclusion criteria, risk adjustment, multi-item scoring, top-box scoring).

## Measure Data Reporting

1. Survey vendor provides measure information to palliative care program.
2. Palliative care program uploads measure information to CMS using the “Log-In and Upload” option.

OR

1. Survey vendor submits measure information to CMS as a third-party intermediary on behalf of the palliative care program.

## Table of Resources for Implementation Strategies

| SOURCE                            | NAME OF RESOURCE   | DESCRIPTION   | NOTES   |
|-----------------------------------|--|---|---|
| US Department of Veterans Affairs | <a href="#">Quality Enhancement Research Initiative Implementation Roadmap</a> | This free downloadable toolkit is a comprehensive, practical guide for healthcare practitioners and researchers to plan and deploy methods to support uptake of effective practices in routine care settings. | <p>Pearls of the Roadmap include</p> <ul style="list-style-type: none"> <li>• tools and methods to support implementation efforts based on strong science</li> <li>• user-friendly, practical approach to overcome barriers and resource constraints, with case studies</li> <li>• strategies to align health system goals and provider and patient needs.</li> </ul> |
| CQMC                              | <a href="#">CQMC Implementation Guide</a>                                      | This comprehensive resource contains implementation strategies for all phases of measure implementation, including technical considerations such as benchmarking and performance targets.                     | <p>Key elements for successful measure implementation:</p> <ol style="list-style-type: none"> <li>1. Leadership and planning</li> <li>2. Stakeholder engagement and partnership</li> <li>3. Measure alignment</li> <li>4. Data and QI support</li> </ol>  |

| SOURCE  | NAME OF RESOURCE                                  | DESCRIPTION  | NOTES  |
|---|---|--|--|
| PCPI and The Wright Center for Graduate Medical Education | <a href="#">Closing the Referral Loop toolkit</a> | The toolkit includes resources and guidance based on the experience and lessons learned during a pilot project supported by PCPI and The Wright Center for Graduate Medical Education. | Key reference points: <ul style="list-style-type: none"> <li>• Introduction—Why Change?</li> <li>• Resources for Process Flow Mapping</li> <li>• Implementation Time Line and Project Plan</li> <li>• Lessons Learned</li> <li>• Key Change Package Ideas</li> <li>• Patient Engagement</li> </ul> |

Please see Appendix A for the “Feeling Heard and Understood” measure and Appendix B for the “Receiving Desired Help for Pain” measure. These documents include

1. Overview of the Survey
2. Considerations Before Implementing the Survey, including Selecting a Survey Vendor
3. Fielding the Survey, including Proxy Assistance
4. Constructing Measure Scores, including risk adjustment
5. supplemental materials, including complete surveys in English and Spanish.

There are many ways to leverage the power of data to improve care. Some of the ways that healthcare providers and clinicians can use these measures include the following:

- ✓ Provide education about pain management to patients to properly set expectations.
- ✓ Develop education for providers to ensure that they have the skill set to manage all types of pain and conduct meaningful conversations with patients.
- ✓ Conduct research with patients to examine external factors that affect process flow.
- ✓ Set boundaries and establish testing processes for patients with opioid use disorder.
- ✓ Advocate for resources to support quality patient care.

## V. Quality Reporting Programs and Maintenance of Certification

Clinicians and healthcare organizations collect and report measures for quality reporting programs (for regulatory purposes) and accreditation/certification programs. The largest organization or agency with a quality payment program, public reporting, and quality payment models is CMS.

### Quality Payment Program

| SOURCE | NAME OF RESOURCE  | DESCRIPTION  | NOTES   |
|--------|---|--|---|
| CMS    | <a href="#">The Quality Payment Program Resource Library</a>                              | Houses fact sheets, specialty guides, technical guides, user guides, helpful videos, and more  |   |
| CMS    | <a href="#">Traditional MIPS</a>  | Under Medicare, the QPP is currently composed of two reporting option tracks—the first is MIPS.  |   |
| CMS    | <a href="#">Alternative Payment Model (APM) Performance Pathway</a>                       | Under Medicare, the QPP is currently composed of two reporting option tracks—the second is APMs.   |   |
| CMS    | <a href="#">MIPS Value Pathways (proposed)</a>  | Under Medicare, the QPP includes a new proposed third track for 2023—the MIPS Value Pathways.  |   |
| CMS    | <a href="#">QPP Participation Status</a>  | Clinicians interested in participating in MIPS can check their QPP participation eligibility.  | Getting started with MIPS and APMs  |
| CMS    | <a href="#">MIPS Participation Options Overview</a>                                       | Determine how you will participate in MIPS.  | Getting started with MIPS and APMs  |
| CMS    | <a href="#">Reporting Traditional MIPS</a><br><br><a href="#">APM Performance Pathway</a> | Determine how you will report data for traditional MIPS.<br><br>APM Performance Pathway overview<br><br>If you are eligible, select performance measures and activities. | Getting started with MIPS and APMs  |
| CMS    | <a href="#">Four facets of Traditional MIPS</a>   | The four facets of MIPS are quality (reporting on measures), improvement activities, promoting interoperability, and cost.   |   |
| CMS    | <a href="#">Three facets of APM Performance Pathway</a>                                   | The three facets of APM Performance Pathway are quality, improvement activities, and promoting interoperability.   | Verify your eligibility; submit your data; review your feedback; preview your data for public reporting; note the application of payment adjustments. |

## Other Quality Reporting Programs

| SOURCE  | NAME OF RESOURCE   | DESCRIPTION  | NOTES   |
|---|--|--|---|
| CMS   | <a href="#">List of different Quality Reporting Programs and Compare Sites</a> | As the largest payer of healthcare services in the United States, CMS operates many programs to enhance the quality of care for patients and improve the way providers are paid. This is a list of the different quality reporting programs and compare sites CMS maintains. |   |
| <a href="#">The National Committee for Quality Assurance (NCQA)</a> | <a href="#">Healthcare Effectiveness Data and Information Set (HEDIS) FAQs</a> | NCQA maintains HEDIS for health plans that serve 191 million people.   | Healthcare payers also operate quality reporting programs. HEDIS is one of health care's most widely used performance improvement tools, and NCQA provides virtual seminars, webinars, and on-demand training on quality innovations. |

## Maintenance of Certification

For practicing clinicians, there are requirements to meet continuing medical education and practice improvement standards to maintain board certification and other approvals by local and state bodies.

### Types of Physician Certification

| SOURCE   | NAME OF RESOURCE   | DESCRIPTION   | NOTES |
|--|--|---|-------|
| AAHPM  | <a href="#">Maintenance of Certification for Allopathic Clinicians</a> | Fact sheet about Maintenance of Certification for allopathic clinicians |       |
| <a href="#">American Osteopathic Association</a> | <a href="#">Osteopathic Continuous Certification</a>                   | Overview of osteopathic Maintenance of Certification                    |       |

## VI. Summary and Resources

In summary, use the Guide to

- generate ideas for how to overcome lack of internal resources (eg, time, budget) and make the case to senior leadership
- navigate infrastructure and processes—specifically, how to begin a new PRO-PM program and how to successfully adjust an existing one
- set expectations regarding the types of capabilities that will be required (eg, staff, processes)
- ensure consistent implementation with step-by-step instructions, simplified checklists, and timelines
- apply the measures for QI efforts
- analyze data from the measures to help patients, health systems, and insurers see the value of palliative care.

### Links to Additional Resources

- [Electronic Clinical Quality Improvement Resource Center Glossary](#) (standardized definitions)
  - Suggested items to look up: clinical decision support implementation activities, clinical quality measure, denominator, eligible clinician, end user, environmental scan, Meaningful Measures Framework, measure score, measure steward, measure testing, measure validity, numerator, patient-reported outcome, patient-reported outcome measure, patient-reported outcome-based performance measure, quality measure, scoring, SMART objectives, specification, stakeholder, target/initial population, user experience, workflow diagram
- [National Consensus Project Clinical Practice Guidelines for Quality Palliative Care](#)
- National Coalition for Hospice and Palliative Care [Quality Measures Project website](#)
- Public Health Foundation: [Public Health Improvement Resource Center](#)
- AAHPM also has many quality resources on its [website](#). The headings are
  - Measuring What Matters—read the top 10 measures that matter
  - Palliative Care Measures Project—learn about the two new patient reported experience measures for outpatient palliative care and MACRA
  - The Palliative Care Quality Collaborative—read about the field's new quality registry
  - Quality Improvement Education—see why QI projects are important
  - Study Materials—visit [AAHPM Learn](#) for QI products
  - AAHPM Quality News
  - Hospice and Palliative Care Quality Resources

For questions and additional information, please contact [info@aaahpm.org](mailto:info@aaahpm.org).

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## Appendix A

# Recommended Survey Administration Procedures and Measure Scoring Methodology

Measure Name: *Feeling Heard and Understood*

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# 1. Introduction

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The Centers for Medicare & Medicaid Services (CMS) entered a 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 ambulatory palliative care experience: *Feeling Heard and Understood* and *Receiving Desired Help for Pain* from one's palliative care provider and team. The measures are intended to assess the extent to which patients who used ambulatory palliative care felt heard and understood by their palliative care provider and team and received the help they wanted for their pain.

The content, design and recommended administration procedures of survey items used to construct these two patient-reported measures were informed by (1) a literature scan of existing surveys and measures of patient experience, (2) focus groups with palliative care providers, patients and caregivers (3) broad stakeholder input through a Technical Expert Clinical User Patient Panel, project advisors and public comment (4) cognitive interviews to refine item wording and response options, and (5) national field testing to confirm the validity and reliability of these measures and feasibility of implementation. Using information acquired during development and testing, this document contains recommended guidelines for implementing the *Feeling Heard and Understood* patient experience survey and calculating performance measure scores.

By providing this guidance, ambulatory palliative care providers and programs are encouraged to implement the survey and calculate measure scores. Measure scores can help providers and programs to better understand their patients' experience of care, assist in targeting quality improvement efforts, and ultimately improve patient experience.

## 2. Overview of the Survey

---

The survey instrument is composed of 11 items (see Appendix A.1) and covers the following topics:

1. confirming the patient's provider and team
2. the care received from their provider and team within the last six months related to feeling heard and understood
3. demographic information
4. involvement of a proxy

The *Feeling Heard and Understood* measure is based on responses to four survey items using a response scale of: “Completely true”, “Very true”, “Somewhat true”, “A little bit true”, and “Not at all true”.

### 3. Considerations Before Implementing the Survey

---

#### Sample Size

We found that measure reliability is sensitive to smaller (i.e., lower patient volume) programs. For a reliable *Feeling Heard and Understood* measure, we recommend an average sample size, at the program level, of 37 participants responding to the four *Feeling Heard and Understood* items. Based on an estimated response rate range of 37% to 46% as was found in the measure testing process, ambulatory palliative care programs with annual visit volume of between approximately 80 and 100 adult patients could achieve the minimum average sample size required for a reliable measure.

#### Survey Mode

The recommended protocol for this survey is an enhanced mixed-mode: web to mail to telephone. The sequence and combination of these recommended modes was tested nationally and resulted in a high response rate. During analysis, an adjustment for survey mode is applied to measure scores to account for differences due to mode used to collect completed surveys.

In order to successfully administer the full data collection protocol, programs must collect complete and accurate patient contact information (e.g., email addresses, mailing addresses and telephone numbers) and be able to provide this data in a usable form to their survey vendor. A more detailed description of tested and recommended fielding procedures is provided later in this guide.

#### Required Program Data Variables

The following variables are required for sampling activities and survey administration. Programs should provide complete data for each of the variables in a readable form to their survey vendor. Missing information, if any, should be clearly noted.

- Program name recognizable by patients
- Visit date
- Visit type
- Provider name
- Provider type
- Patient name
- Patient date of birth
- Patient gender
- Patient deceased
- Patient contact information
  - Email address (optional)

- Mailing address
- Telephone number(s)

## Administering the Survey in Spanish

Survey materials were tested in and are available in English. Statistical properties of the two performance measures are based on English survey responses only. A Spanish translation of the mailed survey is also available, although it has not been field tested. A translation process using two independent translators was utilized to translate the survey to Spanish. See Appendix A.2 for a copy of the Spanish survey instrument.

## Selecting a Survey Vendor

Ambulatory palliative care providers and programs will need to contract with a survey vendor to field surveys and process data on their behalf. Programs are highly encouraged to choose a vendor that has the capability to fully follow the protocol for survey administration outlined in this document. Considerations and recommendations when selecting a survey vendor include:

- The survey vendor should have experience administering surveys to similar patient populations.
- The survey vendor should have experience in survey administration in all of the recommended survey modes.
- If the program has a significant Spanish-speaking population, they should select a survey vendor with experience administering surveys in Spanish
- Ensure the survey vendor has established procedures in place to safeguard identifiable information.
- Ensure the survey vendor has the ability to tailor survey materials for your program (i.e., program name and branding) and for each sampled patient.
- Ensure that the survey vendor has the capabilities and capacity to administer the survey during the desired time frame including having a sufficient number of interviewers.
- Ensure that the survey vendor has an established survey management system to track the status of each sampled patient.
- Costs associated with fielding the survey and cleaning, processing, and analysis.

## 4. Fielding the Survey

---

### Sample Frame

A sample frame is a list of all eligible patients in the unit being analyzed (e.g., the ambulatory palliative care program). Below are recommended criteria when determining which patients to include in the survey sample frame file:

- Include patients with at least one ambulatory palliative care visit with a MIPS-eligible provider during the three-month lookback period in the measurement year
  - Ambulatory palliative care visits are defined as:
    - ICD-10 Z51.5 (Encounter for Palliative Care), **OR**
    - Provider Hospice and Palliative Care Specialty Code 17; **AND**
    - CPT 99201-99205 (New Office Visit); OR CPT 99211-99215 (Established Office Visit); or Place of service (POS) Code 11 – Office.
  - MIPS-eligible provider types are defined as:
    - For performance year 2019, MIPS-eligible providers include physicians, osteopathic practitioners, chiropractors, physicians assistants, nurse practitioners, clinical nurse specialists, certified nurse anesthetists, physical therapists, occupational therapists, clinical psychologists, qualified speech-language pathologists, qualified audiologists, and registered dietitians or nutrition professionals who exceed the Performance Year 2019 low-volume threshold at the individual-level or at the group-level when reporting as a group<sup>1</sup>.
- Exclude patients aged  $\leq 18$  years on date of encounter (i.e., eligible visit)
- Exclude patients identified as deceased (if any)
- Exclude patients who have already been sent a survey in the measurement year

Next, survey vendors should identify a reference provider to be named on the survey instrument for each patient, by selecting the MIPS-eligible provider who the patient saw most often within the three-month lookback period in the measurement year. Ties should be broken by provider type, giving preference to providers holding primary responsibility for patient care outcomes (e.g., physician or physician-designee over nurse or therapist).

---

<sup>1</sup> Centers for Medicare and Medicaid Services, “Medicare Program; Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2019,” Federal Register, Vol. 83, No. 226, November 23, 2018, pp. 59452ff. As of April 18, 2021: <https://www.govinfo.gov/content/pkg/FR-2018-11-23/pdf/2018-24170.pdf>





### *Email Invitation*

Patients with email addresses in their contact information are emailed an invitation to complete the survey by web in lieu of the prenotification letter. Content in the email invitation mirrors content found in the prenotification letter (i.e., patient's program and provider, the entity conducting the survey, assurance of confidentiality, toll-free number) and includes a link to the web survey that is unique to the patient. A copy of the email invitation to the web survey used in the national field test can be found in Appendix A.4.

### *Email Reminders*

Patients with email addresses receive up to two reminder emails, with similar content as the invitation and a unique link to the web survey. A copy of the email reminder can be found in Appendix A.5.

### *Web Survey*

The content of the web survey should mirror that in the mailed survey. The platform used to administer the web survey is the decision of the program and/or survey vendor. In keeping with best practices, it is recommended that the web survey be formatted to present one survey item on each screen.

### *Mail Survey Packet*

The mailed survey packet includes a cover letter, pre-paid postcard, hardcopy (i.e., paper copy) of the survey and pre-paid business reply envelope. The survey cover letter includes a reprise of the information in the prenotification along with language indicating the voluntary nature of the survey, privacy and confidentiality safeguards, how the data would be used, and indicating that the patient can get help from a proxy to complete the survey. The survey packet also included a pre-paid postcard that should be returned with updated address information for the patient or to indicate that the patient is deceased.

### *Computer-assisted Telephone Interview (CATI) Survey*

Patients who do not complete the survey by web or mail move to telephone follow-up. Telephone follow-up is completed by a trained interviewer using a CATI survey. The CATI survey includes a script introducing the interviewer, purpose of the survey, time estimate to complete the interview, assurance of confidentiality, collects proxy information (if proxy-assistance is needed), and asks all survey items found in the web and mailed survey instruments. The CATI survey used in the national field test is available in Appendix A.6.

## Recommended Survey Fielding Procedures

An enhanced mixed-mode survey administration design, web to mail with telephone follow-up, is recommended. A step-by-step description of fielding procedures used in testing and recommended for fielding is provided below.

1. Email invitations (for cases with email addresses) are sent on the same day as mailed prenotification letters (for cases without email addresses).
2. Up to two reminder emails are sent if the web survey is not completed. The first email reminder is sent a day after the email invitation, and the second reminder is sent two days after the first reminder email (three days after the email invitation, excluding weekends).  
**Note:** Maintain an inbox for patients or proxies to address any technical queries, or to inform the survey vendor that the named patient is deceased. Cases that complete the web survey, refuse, or are otherwise finalized are not sent the survey packet mailing.
3. Survey packets are mailed one week following the initial email invitation or mailed prenotification letter.  
**Note:** Survey vendors should scan and enter responses upon receipt of completed mail surveys. Cases coded as a complete or a refusal do not move to the CATI component of data collection.
4. Four weeks after initial email invitations or mailed prenotification letters are sent, active cases move to the CATI component of data collection. Up to eight attempts are made to contact the patient and complete the interview over the telephone, with a ninth attempt possible if the eighth resulted in a firm callback. After eight attempts over four weeks are made to contact the patient, the case is considered a “non-response.”

Figure 2. Recommended Survey Fielding Procedures



## Proxy Assistance

Proxy assistance is allowed when completing the survey. The survey instrument collects information on the use of a proxy and type of assistance. Proxy-only responses (i.e., surveys completed without any input from the patient) are excluded. An adjustment for proxy assistance is applied to measure scores to account for differences in measure components due to the proxy involvement.

## 5. Constructing Measure Scores

---

### Variables Needed for Scoring

- Unique patient ID
- Responses to measure survey items
  - The measure is composed of the following four items:
    - 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.
  - Individuals can respond to each survey item using discrete values ranging from 0 – “Not at all True,” to 4 – “Completely True.” A response of “4 – Completely True” is considered a top-box response.
- Mode used to complete the survey
- Use of proxy assistance

### Scoring Methodology

The *Feeling Heard and Understood* measure score is defined as the proportion of top-box responses (i.e., where the most favorable response option “Completely true” was selected) to the four survey items. Scores on this measure range from 0 to 1 and can be converted to a percentage, by multiplying by 100.

#### *Steps for Constructing the Unadjusted Measure Score*

1. For each item, convert each individual’s response to a binary score (i.e., 1 or 0) using top-box scoring (i.e., if the response option “Completely true” was selected then the item score=1, otherwise item score=0).
2. For each individual, calculate the average top-box response based on the 4 items (i.e., the average of the 4 0/1 item scores).
3. For each program/provider, calculate the average of the individual average top-box responses obtained in step 2 (i.e., the average across patients within each program).

### Unadjusted Scoring Example

To demonstrate this, consider five hypothetical patients answering the four questions with response values ranging from 0 – “Not at all True,” to 4 – “Completely True” (the top-box response). In this example we assume no missing data and do not include case-mix adjustment variables. The raw responses for these five hypothetical patients are below in the Table 1. Blue shading highlights the top-box response.

**Table 1: Example Raw Patient Responses**

| Program ID | Patient   | Ques 1 | Ques 2 | Ques 3 | Ques 4 |
|------------|-----------|--------|--------|--------|--------|
| ZZ         | Ann       | 2      | 4      | 4      | 4      |
| ZZ         | Barry     | 4      | 1      | 3      | 3      |
| ZZ         | Catherine | 4      | 4      | 4      | 4      |
| ZZ         | Donald    | 1      | 4      | 2      | 4      |
| ZZ         | Evelyn    | 3      | 4      | 3      | 4      |

These responses are converted into top-box responses below in Table 2:

**Table 2: Example Patient Responses Converted to Top-Box**

| Program ID | Patient   | Ques 1 | Ques 2 | Ques 3 | Ques 4 |
|------------|-----------|--------|--------|--------|--------|
| ZZ         | Ann       | 0      | 1      | 1      | 1      |
| ZZ         | Barry     | 1      | 0      | 0      | 0      |
| ZZ         | Catherine | 1      | 1      | 1      | 1      |
| ZZ         | Donald    | 0      | 1      | 0      | 1      |
| ZZ         | Evelyn    | 0      | 1      | 0      | 1      |

We then calculate the individual average top-box response in Table 3:

**Table 3: Example Average Top-Box Responses at the Individual Level**

| Program ID | Patient   | Ques 1 | Ques 2 | Ques 3 | Ques 4 | Ind. Avg. |
|------------|-----------|--------|--------|--------|--------|-----------|
| ZZ         | Ann       | 0      | 1      | 1      | 1      | 0.75      |
| ZZ         | Barry     | 1      | 0      | 0      | 0      | 0.25      |
| ZZ         | Catherine | 1      | 1      | 1      | 1      | 1.00      |
| ZZ         | Donald    | 0      | 1      | 0      | 1      | 0.50      |
| ZZ         | Evelyn    | 0      | 1      | 0      | 1      | 0.50      |

**Table 4: Example Unadjusted Score the Program Level**

| Program ID                             | Patient   | Ques 1 | Ques 2 | Ques 3 | Ques 4 | Ind. Avg.        |
|--|-----------|--------|--------|--------|--------|------------------|
| ZZ                                     | Ann       | 0      | 1      | 1      | 1      | 0.75             |
| ZZ                                     | Barry     | 1      | 0      | 0      | 0      | 0.25             |
| ZZ                                     | Catherine | 1      | 1      | 1      | 1      | 1.00             |
| ZZ                                     | Donald    | 0      | 1      | 0      | 1      | 0.50             |
| ZZ                                     | Evelyn    | 0      | 1      | 0      | 1      | 0.50             |
| <b>Unadjusted Score for Program ZZ</b> |           |        |        |        |        | <b>3/5 = 0.6</b> |

The score of 0.60 represents the expected proportion of top-box responses among the *Feeling Heard and Understood* measure items within a program assuming, as we did for this example, that all responses returned from the program were the same mode (mail) and same proxy assist type (none). Note that the calculation of the individual average score in the far right column can easily accommodate missing data. For example, if the response to question 3 for patient “Ann” was missing instead of 1, the individual average would be  $0+1+1/3$  or 0.667. In fact, an individual average score can be calculated for each patient as long as that patient has at least one non-missing response to the 4 items.

*Scoring with Adjustment*

In some cases, such as when comparing programs to each other, there are additional analytic considerations, such as the need for case mix adjustment. Data within a program is likely to resemble the following, in Table 5, where patients responded via different survey modes and some used proxy assistance.

**Table 5: Example Program Data, with Considerations for Adjustment**

| Program ID | Patient ID | Survey Mode | Proxy Assistance | Q1 | Q2 | Q3 | Q4 | # Top-Box | Items answered | Ind. Avg. |
|------------|------------|-------------|------------------|----|----|----|----|-----------|----------------|-----------|
| J          | A          | Mail        | No               | 2  | 4  | 4  | -  | 2         | 3              | 0.67      |
| J          | B          | Mail        | No               | 4  | 1  | 3  | 3  | 1         | 4              | 0.25      |
| J          | C          | Phone       | No               | 4  | 4  | 4  | 4  | 4         | 4              | 1.00      |
| J          | D          | Web         | No               | 1  | 4  | 2  | 4  | 2         | 4              | 0.50      |
| J          | E          | Phone       | Yes              | 3  | 4  | 3  | 4  | 2         | 4              | 0.50      |

To account for the effect of survey mode and proxy assistance, it is necessary to construct an adjusted measure score. The steps to do this are as follows:

1. For each item, convert each individual’s response to a binary score (i.e., 1 or 0) using top-box scoring, as described above.
2. Estimate a binomial hierarchical regression model that:

- a. estimates the average top-box response for the measure (i.e., across all individuals) within the sample (i.e., all individuals within all eligible programs); and
- b. includes regression terms (e.g., for risk adjustment variables like survey mode or proxy assistance) to estimate the program scores. The hierarchy assumes that patients nest within programs.

The model for analysis of individual  $j$  within program  $i$  is:

$$Y_{ij} \sim \text{Binomial}(p_j, n_j), \quad \text{where } n_j \equiv \text{as the number of items ind. } j \text{ responds to}$$

$$p_j \equiv \text{logit}^{-1}[(\beta_0 + b_i P_i) + X_{ij}^T \alpha]$$

Where there is an assumption that  $b_i \sim N(0, \sigma_b^2)$  and where  $\beta_0$  represents overall average program performance, each term  $P_i$  is an indicator that patient  $j$  experienced care from provider  $i$  and therefore  $b_i$  represents the provider specific offset from the overall performance and  $X_{ij}^T \alpha$  captures risk adjustment (specifically for survey mode and proxy measures). Because a logit transformation is used in the estimation and in order to obtain a program score in terms of proportion of top-boxes, and retransformation is conducted where the risk adjusted score is estimated as:

$$\text{Score}_{i \text{ adj}} = \frac{\exp(b_i + \beta_0)}{1 + \exp(b_i + \beta_0)}$$

Therefore, the formula above states that the model will be assessed at all baseline covariate values. The model accommodates data from surveys with at least one (of the four) *Feeling Heard and Understood* survey items completed.

In practice, programs would not be expected to conduct the risk adjustment analyses on their own. The risk adjustment model is not estimable within a single program, since it needs to be combined with other programs' data. Instead, programs would be required to submit the individual level data needed to construct this model to a centralized entity who would calculate the adjusted scores.

Specifically, programs would need to submit each patient's:

1. individual average heard and understood measure score (the values in the far right columns of tables 3 - 5),
2. an indicator of the presence of proxy assistance (1=yes, 0=no), and
3. the mode of survey administration (web, mail, phone).

## PATIENT EXPERIENCE SURVEY

### SURVEY INSTRUCTIONS

- This survey should be completed by the patient indicated on the survey cover letter.
- You can ask a family member or friend for help with this survey.
- If you are a family member or friend helping with this survey or completing this survey for the patient indicated on the survey cover letter, please remember that all survey questions ask about the patient's experiences. Please do not consider your own experiences or information in the answers you provide.
- Use a dark colored pen to fill out the survey.
- Place an X directly inside the square indicating a response, like in the sample below.

Yes

No

- This survey uses the word “provider” throughout. When we say “provider”, we mean a medical provider like a doctor or a nurse.

Please return the completed survey in the provided pre-paid envelope to:

**[MAILING ADDRESS HERE]**



## YOUR PROVIDER AND TEAM

1. Our records show that you got care from the provider and team named below in the last 6 months.

[Provider] and team

Is that right?

- Yes
- No → If No, please return the completed survey in the pre-paid envelope.

The questions in this survey will refer to the provider named in Question 1 as “this provider and team.” Please think of this provider and team as you answer the survey.

## YOUR OVERALL EXPERIENCE WITH THIS PROVIDER AND TEAM

2. 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.

- Completely true
- Very true
- Somewhat true
- A little bit true
- Not at all true

3. I felt this provider and team put my best interests first when

making recommendations about my care.

- Completely true
- Very true
- Somewhat true
- A little bit true
- Not at all true

4. I felt this provider and team saw me as a person, not just someone with a medical problem.

- Completely true
- Very true
- Somewhat true
- A little bit true
- Not at all true

5. I felt this provider and team understood what is important to me in my life.

- Completely true
- Very true
- Somewhat true
- A little bit true
- Not at all true

## ABOUT YOU (THE PATIENT)

**6. What is the highest grade or level of school that you have completed?**

- 8th grade or less
- Some high school but did not graduate
- High school graduate or GED
- Some college or 2-year degree
- 4-year college graduate
- More than 4-year college degree

**7. Are you of Hispanic or Latino origin or descent?**

- Yes, Hispanic or Latino
- No, not Hispanic or Latino

**8. What is your race? Please choose one or more**

- White
- Black or African American
- Asian
- Native Hawaiian or other Pacific Islander
- American Indian or Alaska Native
- Other

Some other language (please print):

**10. Did someone help you with this survey?**

- Yes
- No → **If No, please return the completed survey in the pre-paid envelope.**

**11. How did that person help you complete the survey? Check all that apply.**

- Read the questions to me
- Wrote down the answers I gave
- Answered the questions for me
- Translated the questions into my language

**Thank you for completing this survey.**

**Please return the completed survey in the provided pre-paid envelope.**

**[MAILING ADDRESS HERE]**

**9. What language do you mainly speak at home?**

- English
- Spanish

## Encuesta sobre la experiencia del paciente

### INSTRUCCIONES PARA LA ENCUESTA

- Esta encuesta se debe completar por la persona indicada en la carta de presentación de esta encuesta.
- Usted puede pedirle a un familiar o a un amigo que le ayude con esta encuesta.
- Si usted es un familiar o amigo que está ayudando con la encuesta o contestando la encuesta para la persona indicada en la carta de presentación de esta encuesta, por favor recuerde que todas las preguntas de la encuesta se refieren a las experiencias del paciente. Por favor, no considere sus propias experiencias ni información relacionada con usted en las respuestas que usted proporcione.
- Use un bolígrafo de tinta oscura para completar la encuesta.
- Marque con una 'X' dentro del cuadro para indicar su respuesta, como en el siguiente ejemplo de abajo.
  - Si
  - No
- A lo largo de toda esta encuesta se utiliza la frase "profesional médico". Cuando decimos "profesional médico" nos referimos a un profesional médico como un doctor o una enfermera.

**Por favor devuelva la encuesta con sus respuestas en el sobre adjunto con el porte o franqueo prepago a:**

**[MAILING ADDRESS HERE]**

## SU PROFESIONAL MÉDICO Y EL EQUIPO DE ÉL/ELLA

**1. Según nuestros registros, usted recibió atención médica en los últimos 6 meses del profesional médico y su equipo médico cuyo nombre aparece a continuación.**

*[Label for provider and team]*

¿Es correcta esta información?

- Sí
- No--> Si contestó "No", pase a la pregunta 23

**Las preguntas de esta encuesta se van a referir al profesional médico y a su equipo médico cuyo nombre aparece en la pregunta 1 como “este profesional médico y su equipo médico.” Por favor piense en este profesional médico y su equipo médico al contestar las preguntas de la encuesta.**

## SU EXPERIENCIA GENERAL CON ESTE PROFESIONAL MÉDICO Y SU EQUIPO

**Pensando en su experiencia general con este profesional médico y su equipo médico en los últimos 6 meses, ¿qué tan ciertas son las siguientes afirmaciones?**

**2. Me sentí escuchado y comprendido por este profesional médico y su equipo médico.**

- Muy cierta
- Mayormente cierta
- Bastante cierta
- Un poco cierta
- Nada cierta

**3. Sentí que este profesional médico y su equipo médico consideraban ante todo lo que era mejor para mí al hacer recomendaciones sobre mi atención.**

- Muy cierta
- Mayormente cierta
- Bastante cierta
- Un poco cierta
- Nada cierta

**4. Sentí que este profesional médico y su equipo médico me vieron como una persona,**

**no sólo como alguien con un problema médico.**

- Muy cierta
- Mayormente cierta
- Bastante cierta
- Un poco cierta
- Nada cierta

**5. Sentí que este profesional médico y su equipo médico entendían qué es lo importante para mí en la vida.**

- Muy cierta
- Mayormente cierta
- Bastante cierta
- Un poco cierta
- Nada cierta

### SOBRE USTED (EL PACIENTE)

**6. ¿Cuál es el grado o nivel escolar más alto que ha completado?**

- 8 años de escuela o menos
- 9 a 12 años de escuela, pero sin graduarse
- Graduado de la escuela secundaria (*high school*), Diploma de escuela secundaria, preparatoria, o su equivalente (o GED)
- Algunos cursos universitarios o un título universitario de un programa de 2 años
- Título universitario de 4 años
- Título universitario de más de 4 años

**7. ¿Es usted de ascendencia u origen hispano o latino?**

- Sí, hispano o latino
- No, ni hispano ni latino

**8. ¿A qué raza pertenece? Marque una o más.**

- Blanca
- Negra o Afroamericana
- Asiática
- Nativa de Hawái o de otras islas del Pacífico
- Indígena norteamericana o nativa de Alaska
- Otra

**9. ¿En qué idioma habla usted principalmente en casa?**

- Inglés
- Español
- Otro idioma (Por favor escriba en letra de molde):

**10. ¿Alguien le ayudó con esta encuesta?**

- Yes
- No-->Si contestó "No", devuelva la encuesta completada en el sobre con porte o franqueo pagado

**11. ¿Cómo le ayudó esta persona a completar la encuesta? Marque todas las que correspondan.**

- Me leyó las preguntas
- Anotó las respuestas que le di
- Contestó las preguntas por mí
- Tradujo las preguntas a mi idioma
- Me ayudó de otra forma

**Gracias por contestar esta encuesta.**

**Por favor devuelva la encuesta con sus respuestas en el sobre adjunto con el porte o franqueo prepago a:**

**[MAILING ADDRESS HERE]**

## Appendix A.3

---

«Patient Full Name»  
«Street1» «Street2»  
«City», «State» «Zip»

Dear «Patient»,

«Program Name» is working with the American Academy of Hospice and Palliative Medicine and the RAND Corporation on research to learn about the care patients receive from their healthcare providers.

In a few days, you will receive a **Patient Experience Survey** in the mail. «Program Name» has provided your contact information to the RAND Corporation, a non-profit organization that does research on health care quality, so they can send you the survey.

The survey will ask about the care you get from «Provider» and Team at «ProgName». The information you provide will be kept private and confidential. Your answers will never be matched with your name. No one involved in your care will see your individual answers.

***We hope that you will take the time to fill out the survey.*** If you have any questions about this survey, please call us toll-free at [PHONE NUMBER HERE]. You may also call this number if you want to complete the survey by phone.

Sincerely,

Sangeeta C. Ahluwalia, PhD  
RAND Project Director  
Senior Policy Researcher  
RAND Corporation

Katherine Ast, MSW, LCSW  
AAHPM Project Director  
Director, Quality and Research  
American Academy of Hospice and Palliative Medicine

## Appendix A.4

---

### **Initial email invitation:**

FROM: Patient Experience Survey Staff <patientsurvey@rand.org>  
SUBJECT: Survey about Your Care from [PROGRAM NAME]

Dear [Patient\_First\_Name] [Patient\_Middle\_Initial] [Patient\_Last\_Name],

[Program Name] is working with the American Academy of Hospice and Palliative Medicine and the RAND Corporation on research to learn about the care patients receive from their healthcare providers. **We are interested in learning about the care you received from [Provider\_Name] and Team at [Program\_Name].**

[Program Name] has provided your contact information to the RAND Corporation, a non-profit organization that does research on health care quality, so we can send you this survey. To begin the survey, please **[CLICK HERE]**.

The survey will only take about 15 minutes to complete. You can ask a family member or friend for help with this survey or ask them to complete the survey for you.

It is your choice to answer the survey, and your choice will not affect any of the services you get from [Program\_Name]. Your answers will be received by our survey team, and we will take every precaution to protect your privacy and confidentiality. [Program\_Name] will not know whether you answered the survey and no one involved in your care will see your individual answers. Your name will not be linked to your survey responses in any of our reports.

***We hope that you will take the time to fill out the survey.*** If you have any questions, or if you would like to complete this survey over the phone, please call our toll-free number at [PHONE NUMBER HERE].

Thank you very much for your help with this important survey.

Sincerely,

Sangeeta C. Ahluwalia, PhD  
RAND Project Director  
Senior Policy Researcher  
RAND Corporation

Katherine Ast, MSW, LCSW  
AAHPM Project Director  
Director, Quality and Research  
American Academy of Hospice and Palliative Medicine



## Appendix A.5

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### **Reminder email:**

FROM: Patient Experience Survey Staff <patientsurvey@rand.org>  
SUBJECT: REMINDER: Survey about Your Care from [PROGRAM NAME]

Dear [Patient\_First\_Name] [Patient\_Middle\_Initial] [Patient\_Last\_Name],

[Program Name] is working with the American Academy of Hospice and Palliative Medicine and the RAND Corporation on research to learn about the care patients receive from their healthcare providers. **We are interested in learning about the care you received from [Provider\_Name] and Team at [Program\_Name].**

We recently sent you a link to complete the survey and have not yet heard back from you. To begin the survey, please [**CLICK HERE**].

The survey will only take about 15 minutes to complete. ***We hope that you will take the time to fill out the survey.***

It is your choice to answer the survey, and your choice will not affect any of the services you get from [Program\_Name]. Your answers will be received by our survey team, and we will take every precaution to protect your privacy and confidentiality. [Program\_Name] will not know whether you answered the survey and no one involved in your care will see your individual answers. Your name will not be linked to your survey responses in any of our reports.

If you have any questions, or if you would like to complete this survey over the phone, please call our toll-free number at [PHONE NUMBER HERE].

Thank you very much for your help with this important survey.

Sincerely,

Sangeeta C. Ahluwalia, PhD  
RAND Project Director  
Senior Policy Researcher  
RAND Corporation

Katherine Ast, MSW, LCSW  
AAHPM Project Director  
Director, Quality and Research  
American Academy of Hospice and Palliative Medicine

## SURVEY INTRODUCTION

I1. Hi, my name is [INTERVIEWER NAME] and I'm calling from the RAND Corporation. May I speak with [PATIENT]?

<1> YES [GOTO I2]

<2> CALL BACK NEEDED [GO TO CALLBACK]

<3> PATIENT NOT ABLE TO DO PHONE CALL, PROXY NEEDED [GOTO I3]

<4> PATIENT DECEASED [GO TO INTC, CODE INELIGIBLE]

<5> UNAVAILABLE DURING FIELD PERIOD [GO TO INTC, CODE UNAVAILABLE]

<6> REFUSE [GO TO REFUSAL]

<7> NO ONE BY THAT NAME IN HH

I2. PATIENT COMES TO PHONE:

(Hi, my name is [INTERVIEWER NAME] and I'm calling from the RAND Corporation.) We are calling you because you recently visited [PROVIDER NAME] and Team at [PROGRAM NAME] and we are interested in learning about the care you received.

We are conducting a survey to learn about the care people receive from [PROVIDER NAME] and Team at [PROGRAM NAME] You may remember getting a letter or a survey from us in the mail.

I'm calling today to do the survey with you over the phone. The survey will take about 15 minutes. It is your choice to answer the survey, and your choice will not affect any of the services you get from [PROVIDER NAME] and Team.

Your answers will be received by our survey team, and we will take every precaution to protect your privacy and confidentiality. Your name will not be linked to your survey responses in any of our reports. [PROVIDER NAME] and Team at [PROGRAM NAME] will not know whether you answered the survey.

We hope that you will help us learn about the care you get from [PROGRAM NAME]. Can we start the survey?

**IF PATIENT WANTS HELP TO ANSWER SURVEY:**

Thank you for letting me know. If you like, someone can help you to answer the questions. Or, if you prefer, someone can answer the questions for you.

This person needs to be someone who knows about the care you receive from [PROVIDER] and Team at [PROGRAM NAME]. Is there someone who can help?

- <1> YES (INCLUDING WITH HELPER) [START INTERVIEW]
- <2> YES, PATIENT WANTS ANOTHER PERSON TO BE PROXY [GO TO I4]
- <3> CALL BACK NEEDED [GO TO CALLBACK]
- <4> PATIENT NEEDS HELP TO PARTICIPATE, PROXY NEEDED [GOTO I3]
- <5> NEEDS PROXY/HELPER: BUT NONE AVAILABLE [GO TO NOHELP]
- <6> PATIENT DECEASED [GO TO INTC, CODE INELIGIBLE]
- <7> PROGRAM DISAVOWAL [GO TO INTC, CODE PROGRAM DISAVOWAL]
- <8> UNAVAILABLE DURING FIELD PERIOD [GO TO INTC, CODE UNAVAILABLE]
- <9> REFUSE [GO TO REFUSAL]
- <10> ALREADY RETURNED SURVEY BY MAIL [GO TO MAILED]
- <11> WILL RETURN SURVEY BY MAIL [GO TO WILLMAIL]

### 13. IF PATIENT NOT ABLE TO SPEAK ON THE PHONE, FIND PROXY:

Thank you for letting me know.

We are calling because [PATIENT NAME], received care from [PROVIDER NAME] and Team at [PROGRAM NAME] and we are interested in learning about the care he or she received.

We would like to interview someone else to answer on [PATIENT NAME]'s behalf. This person needs to be someone who knows about the care [PATIENT NAME] receives from [PROVIDER NAME] and Team at [PROGRAM NAME]]. Is there someone who could answer these questions for (him/her)?

- <1> YES, PERSON ON PHONE WILL BE PROXY [GO TO I4]
- <2> YES, ANOTHER PERSON MAY BE PROXY [GO TO I4]
- <3> NO PROXY AVAILABLE [GO TO NOHELP]
- <4> PATIENT DECEASED [GO TO INTC, CODE DECEASED]
- <5> REFUSE [GO TO REFUSAL]
- <6> ALREADY RETURNED SURVEY BY MAIL [GO TO MAILED]
- <7> WILL RETURN SURVEY BY MAIL [GO TO WILL MAIL]

I4. COLLECT PROXY INFORMATION:

What is (your/that person's) name? Could I also get (your/his/her) address and phone number?

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

PHONE NUMBER: \_\_\_\_\_

I5. PROCEED WITH PROXY:

IF PROXY COMES TO PHONE, PROCEED TO INTERVIEW. ELSE SCHEDULE CALLBACK.

<1> YES, PROXY COMES TO PHONE [GO TO I6]

<2> CALL BACK NEEDED [GO TO CALLBACK]

I6. PROXY INTRO:

(Hi, my name is [INTERVIEWER NAME] and I'm calling from the RAND Corporation.)

(As I mentioned,) we are calling because [PATIENT NAME] received care from [PROVIDER NAME] and Team at [PROGRAM NAME] and we are interested in learning about the care he or she received.

Since [PATIENT NAME] cannot complete the survey, I'm calling today to conduct the survey with you. The survey will take about 15 minutes.

It is your choice to answer the survey, and your choice will not affect any of the services [PATIENT NAME] gets from [PROVIDER NAME] and Team at [PROGRAM NAME].

Your answers will be received by our survey team, and we will take every precaution to protect your privacy and confidentiality. Your name will not be linked to your survey responses in any of our reports. [PROVIDER NAME] and Team at [PROGRAM NAME] will not know whether you answered the survey.

We hope that you will help us learn about the care [PATIENT NAME] gets from [PROVIDER NAME] and Team. Can we start the survey?

<1> YES [START INTERVIEW]

<2> CALL BACK NEEDED [GO TO CALLBACK]

<3> DIFFERENT PROXY NEEDED [GOTO I4]

- <4> PATIENT DECEASED [GO TO INTC, CODE DECEASED]
- <5> PROGRAM DISAVOWAL [GO TO INTC, CODE PROGRAM DISAVOWAL]
- <6> REFUSE [GO TO REFUSAL]
- <7> ALREADY RETURNED SURVEY BY MAIL [GO TO MAILED]
- <8> WILL RETURN SURVEY BY MAIL [GO TO WILL MAIL]

## MONITOR

This call may be monitored for quality improvement purposes. May we begin?

- <1> YES
- <2> NO, CALLBACK
- <3> NO

## INTERVIEW

IF PROXY, ASK 1intro

IF NO PROXY, GO TO QUESTION 1intro2

1intro. Please remember that all survey questions ask about the patient’s experiences. Unless a question says otherwise, please do not consider your own experiences or information in the answers you provide.

1intro2. Before we begin, I just want to let you know that this survey uses the word “provider” throughout. When we say “provider”, we mean a medical provider like a doctor or a nurse.

1. Our records show that [IF PATIENT: you/IF PROXY:<PATIENT NAME>] got care from [PROVIDER NAME] and team in the last 6 months. Is that right?

- <1> YES
- <2> NO à IF NO, GO TO QUESTION 23
- <d> DON’T KNOW à If DON’T KNOW, GO TO QUESTION 23
- <r> REFUSED à IF REFUSED, GO TO QUESTION 23

2intro. The questions in this survey will refer to [PROVIDER NAME] and team as “this provider and team.” Please think of this provider and team as you answer the survey.

3intro. Thinking about [IF PATIENT: your /IF PROXY:<PATIENT NAME>'s] overall experience with this provider and team in the last 6 months, how true are the following statements?

2. [IF PATIENT: I /IF PROXY: (He/She)] felt heard and understood by this provider and team.

Would you say this is...

- <1> Completely true,
- <2> Very true,
- <3> Somewhat true,
- <4> A little bit true, or
- <5> Not at all true?
- <d> DON'T KNOW
- <r> REFUSED

3. [IF PATIENT: I /IF PROXY: (He/She)] felt this provider and team put [IF PATIENT: my/IF PROXY: (his/her)] best interests first when making recommendations about [IF PATIENT: my/IF PROXY: (his/her)] care.

Would you say this is...

- <1> Completely true,
- <2> Very true,
- <3> Somewhat true,
- <4> A little bit true, or
- <5> Not at all true?
- <d> DON'T KNOW
- <r> REFUSED

4. [IF PATIENT: I /IF PROXY: (He/She)] felt this provider and team saw IF PATIENT: me /IF PROXY: (him/her)] as a person, not just someone with a medical problem.

Would you say this is...

- <1> Completely true,
- <2> Very true,
- <3> Somewhat true,
- <4> A little bit true, or
- <5> Not at all true?
- <d> DON'T KNOW

<r> REFUSED

5. [IF PATIENT: I /IF PROXY: (He/She)] felt this provider and team understood what is important to [IF PATIENT: me /IF PROXY: (him/her)] in [IF PATIENT: my /IF PROXY: (his/her)] life.

Would you say this is...

<1> Completely true,

<2> Very true,

<3> Somewhat true,

<4> A little bit true, or

<5> Not at all true?

<d> DON'T KNOW

<r> REFUSED

6. What is the highest grade or level of school that [IF PATIENT: you have /IF PROXY:<PATIENT NAME> has] completed? Is it...

<1> 8th grade or less,

<2> Some high school but did not graduate,

<3> High school graduate or GED,

<4> Some college or 2-year degree,

<5> 4-year college graduate, or

<6> More than 4-year college degree?

<d> DON'T KNOW

<r> REFUSED

7. [IF PATIENT: Are you /IF PROXY: Is <PATIENT NAME>] of Hispanic or Latino origin or descent?

<1> YES, HISPANIC OR LATINO

<2> NO, NOT HISPANIC OR LATINO

<d> DON'T KNOW

<r> REFUSED

8. What is [IF PATIENT: your /IF PROXY:<PATIENT NAME>'s] race? Please choose one or more.

- @ White?
- @2 Black or African American?
- @3 Asian?
- @4 Native Hawaiian or other Pacific Islander?
- @5 American Indian or Alaska Native?
- @6 Something else?

- <1> YES
- <0> NO
- <d> DON'T KNOW
- <r> REFUSED

9. What language [IF PATIENT: do you /IF PROXY: does <PATIENT NAME>] mainly speak at home? Please listen to all response choices before you answer. Would you say that [IF PATIENT: you /IF PROXY: <PATIENT NAME>] mainly [IF PATIENT: speak/IF PROXY: speaks] ...

- <1> English, à IF ENGLISH, GO TO QUESTION 37skip
- <2> Spanish, or à IF SPANISH, GO TO QUESTION 37skip
- <3> Some other language?
- <d> DON'T KNOWà IF DON'T KNOW, GO TO QUESTION 37skip
- <r> REFUSEDà IF REFUSED, GO TO QUESTION 37skip

9os. What other language do [IF PATIENT: do you /IF PROXY: does <PATIENT NAME>] mainly speak at home?

SPECIFY:\_\_\_\_\_

10skip. IF RESPONDENT=PROXY GO TO QUESTION 11

10. Did someone help you with this survey?

- <1> YES
- <2> NO à IF NO, GO TO END
- <d> DON'T KNOW à IF DON'T KNOW, GO TO END
- <r> REFUSED à IF REFUSED, GO TO END



11proxy. Did [PATIENT NAME] help answer any questions on this survey?

<1> YES à IF YES, GO TO QUESTION 40

<2> NO à IF NO, GO TO QUESTION 40

<d> DON'T KNOW à IF DON'T KNOW, GO TO QUESTION 40

<r> REFUSED à IF REFUSED, GO TO QUESTION 40

11. How did that person help you complete the survey? Did they

CODE ALL THE APPLY

@1 Read the questions to you

@3 Answered the questions for you

@4 Translated the questions into your language

@5 Help in some other way

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

END. Those are all the questions I have, thank you for your time.

## Appendix B

# Recommended Survey Administration Procedures and Measure Scoring Methodology

Measure Name: *Receiving Desired Help for Pain*

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# 1. Introduction

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The Centers for Medicare & Medicaid Services (CMS) entered a 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 ambulatory palliative care experience: *Feeling Heard and Understood* and *Receiving Desired Help for Pain* from one's palliative care provider and team. The measures are intended to assess the extent to which patients who used ambulatory palliative care felt heard and understood by their palliative care provider and team and received the help they wanted for their pain.

The content, design and recommended administration procedures of survey items used to construct these two patient-reported measures were informed by (1) a literature scan of existing surveys and measures of patient experience, (2) focus groups with palliative care providers, patients and caregivers (3) broad stakeholder input through a Technical Expert Clinical User Patient Panel, project advisors and public comment (4) cognitive interviews to refine item wording and response options, and (5) national field testing to confirm the validity and reliability of these measures and feasibility of implementation. Using information acquired during development and testing, this document contains recommended guidelines for implementing the *Receiving Desired Help for Pain* patient experience survey and calculating performance measure scores.

By providing this guidance, ambulatory palliative care providers and programs are encouraged to implement the survey and calculate measure scores. Measure scores can help providers and programs to better understand their patients' experience of care, assist in targeting quality improvement efforts, and ultimately improve patient experience.

## 2. Overview of the Survey

---

The survey instrument is composed of 10 items (see Appendix B.1) and covers the following topics:

1. confirming the patient's provider and team
2. the care received from their provider and team within the last six months related to receiving the help they wanted for pain
3. demographic information
4. involvement of a proxy

The *Receiving Desired Help for Pain* measure is based on responses to one survey item plus two screening, or gate, items assessing (1) if the patient had pain and (2) wanted help for their pain. The final, core pain item uses a responses scale of: “Yes, definitely”, “Yes, somewhat”, and “No”.

### 3. Considerations Before Implementing the Survey

---

#### Sample Size

We found that measure reliability is sensitive to smaller (i.e., lower patient volume) programs. For a reliable *Receiving Desired Help for Care* measure, we recommend an average sample size, at the program-level, of 33 participants responding to the *Receiving Desired Help for Care* survey item. Based on an estimated response rate range of 37% to 46% as was found in the measure testing process, ambulatory palliative care programs with annual visit volume of between approximately 80 and 100 adult patients could achieve the minimum average sample size required for a reliable measure.

#### Survey Mode

The recommended protocol for this survey is an enhanced mixed-mode: web to mail to telephone. The sequence and combination of these recommended modes was tested nationally and resulted in a high response rate from a diverse group of patients. During analysis, an adjustment for survey mode is applied to measure scores to account for differences due to mode used to collect completed surveys.

In order to successfully administer the full data collection protocol, programs must collect complete and accurate patient contact information (e.g., email addresses, mailing addresses and telephone numbers) and be able to provide this data in a usable form to their survey vendor. A more detailed description of tested and recommended fielding procedures is provided later in this guide.

#### Required Program Data Variables

The following variables are required for sampling activities and survey administration. Programs should provide complete data for each of the variables in a readable form to their survey vendor. Missing information, if any, should be clearly noted.

- Program name recognizable by patients
- Visit date
- Visit type
- Provider name
- Provider type
- Patient name
- Patient date of birth
- Patient gender
- Patient deceased

- Patient contact information
  - Email address (optional)
  - Mailing address
  - Telephone number

## Administering the Survey in Spanish

Survey materials were tested in and are available in English. Statistical properties of the two performance measures are based on English survey responses only. A Spanish translation of the mailed survey is also available, although it has not been field tested. A translation process using two independent translators was utilized to translate the survey to Spanish. See Appendix B.2 for a copy of the Spanish survey instrument.

## Selecting a Survey Vendor

Ambulatory palliative care providers and programs will need to contract with a survey vendor to field surveys and process data on their behalf. Programs are highly encouraged to choose a vendor that has the capability to fully follow the protocol for survey administration outlined in this document. Considerations and recommendations when selecting a survey vendor:

- The survey vendor should have experience administering surveys to similar patient populations.
- The survey vendor should have experience in survey administration in all of the recommended survey modes.
- If the program has a significant Spanish-speaking population, they should select a survey vendor with experience administering surveys in Spanish
- Ensure the survey vendor has established procedures in place to safeguard identifiable information.
- Ensure the survey vendor has the ability to tailor survey materials for your program (i.e., program name and branding) and for each sampled patient.
- Ensure that the survey vendor has the capabilities and capacity to administer the survey during the desired time frame, including having a sufficient number of interviewers.
- Ensure that the survey vendor has an established survey management system to track the status of each sampled patient.
- Costs associated with fielding the survey and cleaning, processing, and analysis.

## 4. Fielding the Survey

---

### Sample Frame

A sample frame is a list of all eligible patients in the unit being analyzed (e.g., the ambulatory palliative care program). Below are recommended criteria when determining which patients to include in the survey sample frame file:

- Include patients with at least one ambulatory palliative care visit with a MIPS-eligible provider during the three-month lookback period in the measurement year
  - Ambulatory palliative care visits are defined as:
    - ICD-10 Z51.5 (Encounter for Palliative Care), **OR**
    - Provider Hospice and Palliative Care Specialty Code 17; **AND**
    - CPT 99201-99205 (New Office Visit); OR CPT 99211-99215 (Established Office Visit); or Place of service (POS) Code 11 – Office.
  - MIPS-eligible provider types are defined as:
    - For performance year 2019, MIPS-eligible providers include physicians, osteopathic practitioners, chiropractors, physicians assistants, nurse practitioners, clinical nurse specialists, certified nurse anesthetists, physical therapists, occupational therapists, clinical psychologists, qualified speech-language pathologists, qualified audiologists, and registered dietitians or nutrition professionals who exceed the Performance Year 2019 low-volume threshold at the individual-level or at the group-level when reporting as a group<sup>1</sup>.
- Exclude patients aged  $\leq 18$  years on date of encounter (i.e., eligible visit)
- Exclude patients identified as deceased (if any)
- Exclude patients who have already been sent a survey in the measurement year

Next, survey vendors should identify a reference provider to be named on the survey instrument for each patient, by selecting the MIPS-eligible provider who the patient saw most often within the three-month lookback period in the measurement year. Ties should be broken by provider type, giving preference to providers holding primary responsibility for patient care outcomes (e.g., physician or physician-designee over nurse or therapist).

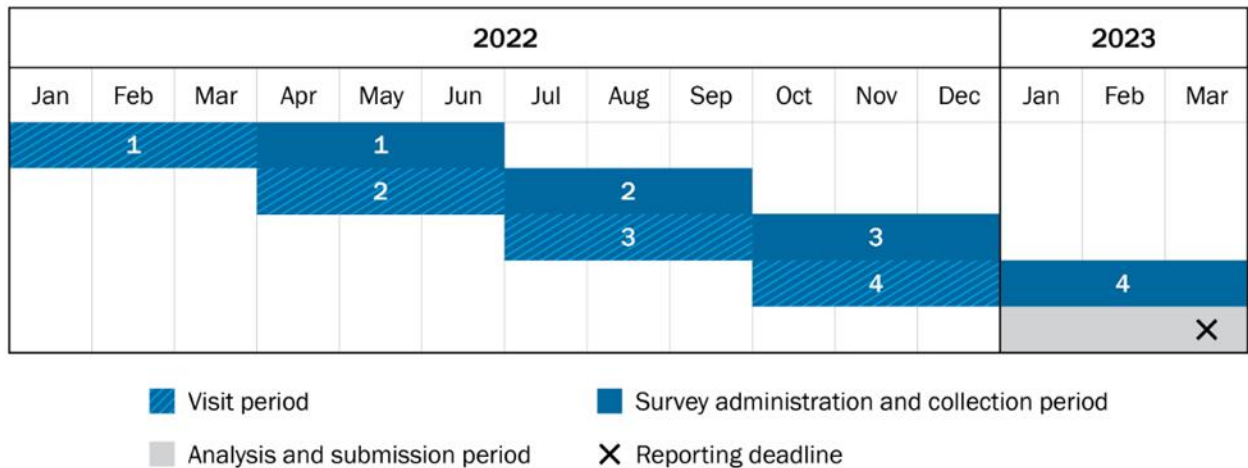
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<sup>1</sup> Centers for Medicare and Medicaid Services, “Medicare Program; Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2019,” Federal Register, Vol. 83, No. 226, November 23, 2018, pp. 59452ff. As of April 18, 2021: <https://www.govinfo.gov/content/pkg/FR-2018-11-23/pdf/2018-24170.pdf>



This process is repeated on a quarterly basis. Eligible visits that take place during the three-month lookback period are fielded surveys during the subsequent three-months. Data is aggregated over a 12-month, or measurement year, reporting period (Figure 1).

**Figure 1. Example Data Collection and Reporting Schedule for Measure Performance Year 2022**



Programs should work with their survey vendor to determine the preferred and most feasible format of sample files in advance. Programs should ensure that sample files are transferred to the survey vendor using methods that are compliant with the Health Insurance Portability and Accountability Act.

## Survey Materials

### *Prenotification Letter*

The prenotification letter informs patients when to expect to receive the survey. It references the patient’s program and provider, identifies the entity conducting the survey, provides assurance of confidentiality, and provides a toll-free number that could be called if the patient has questions about the survey. Research<sup>2</sup> indicates that a prenotification letter can be helpful in adding legitimacy to survey efforts. In addition, since some patients may be too ill to complete the survey themselves, the prenotification letter allows time for patients to arrange help to complete the survey and alert caregivers to the upcoming survey mailing. A copy of the prenotification letter used in the national field test can be found in Appendix B.3.

<sup>2</sup> Dillman, Don A., Jolene D. Smyth, and Leah Melani Christian, *Internet, Phone, Mail, and Mixed-mode Surveys: The Tailored Design Method*. 4th ed., Hoboken, N.J.: John Wiley & Sons, Inc., 2014.

### *Email Invitation*

Patients with email addresses in their contact information are emailed an invitation to complete the survey by web in lieu of the prenotification letter. Content in the email invitation mirrors content found in the prenotification letter (i.e., patient's program and provider, the entity conducting the survey, assurance of confidentiality, toll-free number) and includes a link to the web survey that is unique to the patient. A copy of the email invitation to the web survey can be found in Appendix B.4.

### *Email Reminders*

Patients with email addresses receive up to two reminder emails, with similar content as the invitation and a unique link to the web survey. A copy of the email reminder can be found in Appendix B.5.

### *Web Survey*

The content of the web survey should mirror that in the mailed survey. The platform used to administer the web survey is the decision of the program and/or survey vendor. In keeping with best practices, it is recommended that the web survey be formatted to present one survey item on each screen.

### *Mail Survey Packet*

The mailed survey packet includes a cover letter, pre-paid postcard, hardcopy (i.e., paper copy) of the survey and pre-paid business reply envelope. The survey cover letter includes a reprise of the information in the prenotification along with language indicating the voluntary nature of the survey, privacy and confidentiality safeguards, how the data would be used, and indicating that the patient can get help from a proxy to complete the survey. The survey packet also included a pre-paid postcard that should be returned with updated address information for the patient or to indicate that the patient is deceased.

### *Computer-assisted Telephone Interview (CATI) Survey*

Patients who do not complete the survey by web or mail move to telephone follow-up. Telephone follow-up is completed by a trained interviewer using a CATI survey. The CATI survey includes a script introducing the interviewer, purpose of the survey, time estimate to complete the interview, assurance of confidentiality, collects proxy information (if proxy-assistance is needed), and asks all survey items found in the web and mailed survey instruments. The CATI survey used in the national field test is available in Appendix B.6.

## Recommended Survey Fielding Procedures

An enhanced mixed-mode survey administration design, web to mail with telephone follow-up, is recommended. A step-by-step description of fielding procedures used in testing and recommended for fielding is provided below.

1. Email invitations (for cases with email addresses) are sent on the same day as mailed prenotification letters (for cases without email addresses).
2. Up to two reminder emails are sent if the web survey is not completed. The first email reminder is sent a day after the email invitation, and the second reminder is sent two days after the first reminder email (three days after the email invitation, excluding weekends).

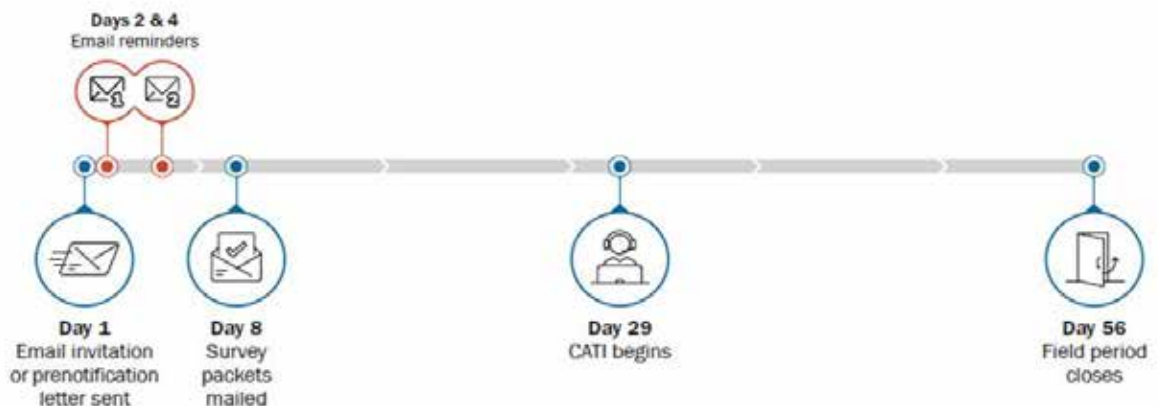
**Note:** Maintain an inbox for patients or proxies to address any technical queries, or to inform the survey vendor that the named patient is deceased. Cases that complete the web survey, refuse, or are otherwise finalized are not sent the survey packet mailing.

3. Survey packets are mailed one week following the initial email invitation or mailed prenotification letter.

**Note:** Survey vendors should scan and enter responses upon receipt of completed mail surveys. Cases coded as a complete or a refusal do not move to the CATI component of data collection.

4. Four weeks after initial email invitations or mailed prenotification letters are sent, active cases move to the CATI component of data collection. Up to eight attempts are made to contact the patient and complete the interview over the telephone, with a ninth attempt possible if the eighth resulted in a firm callback. After eight attempts over four weeks are made to contact the patient, the case is considered a “non-response.”

Figure 2. Recommended Survey Fielding Procedures



## Proxy Assistance

Proxy assistance is allowed when completing the survey. The survey instrument collects information on the use of a proxy and type of assistance provided. Proxy-only responses (i.e., surveys completed without any input from the patient) are excluded. An adjustment for proxy assistance is applied to measure scores to account for differences in measure components due to the proxy involvement.

## 5. Constructing Measure Scores

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### Variables Needed for Scoring

- Unique patient ID
- Responses to measure survey item and gateway items
- Mode used to complete the survey
- Use of proxy assistance

### Scoring Methodology

The *Receiving Desired Help for Pain* measure score is defined as the proportion of top-box responses (i.e., “Yes, definitely”) to the single, core, measure survey item: “In the last 6 months, did you get as much help as you wanted for your pain from this provider and team?”. Individual patient scores range from 0 to 1 and can be converted to a percentage, by multiplying by 100.

The steps for constructing the adjusted measure score are as follows:

1. Convert each individual’s response to a binary score (i.e., 1 or 0) using top-box scoring, as described above.
2. Estimate a binomial hierarchical regression model that:
  - a. estimates the average top-box response for the measure (i.e., across all individuals) within the sample (i.e., all individuals within all eligible programs); and
  - b. includes regression terms (e.g., for risk adjustment variables like survey mode or proxy assistance) to estimate the program scores. The hierarchy assumes that patients nest within programs.

The model for analysis of individual  $j$  within program  $i$  is

$$Y_{ij} \sim \text{Bernoulli}(p_j)$$
$$p_j \equiv \text{logit}^{-1}[(\beta_0 + b_i P_i) + X_{ij}^T \alpha]$$

where there is an assumption that  $b_i \sim N(0, \sigma_b^2)$  and where  $\beta_0$  represents overall average program performance, each term  $P_i$  is an indicator that patient  $j$  experienced care from provider  $i$ , and therefore  $b_i$  represents the provider specific offset from the overall performance and  $X_{ij}^T \alpha$  captures risk adjustment (specifically for survey mode and proxy measures). Because a logit transformation is used in the estimation and in order to obtain a program score in terms of proportion of “Yes, definitely”, and retransformation is conducted where the risk adjusted score is estimated as

$$Score_{i\ adj} = \frac{\exp(b_i + \beta_0)}{1 + \exp(b_i + \beta_0)}$$

Therefore, the formula above states that the model will be assessed at all baseline covariate values.

In practice, programs would not be expected to conduct the risk adjustment analyses on their own. The risk adjustment model is not estimable within a single program since it needs to be combined with other programs' data. Instead, programs would be required to submit the individual level data needed to construct this model to a centralized entity who would calculate the adjusted scores.

Specifically, programs would need to submit each patient's:

1. individual average heard and understood measure score (the values in the far right columns of tables 3 - 5),
2. an indicator of the presence of proxy assistance (1=yes, 0=no), and
3. the mode of survey administration (web, mail, phone).

## PATIENT EXPERIENCE SURVEY

### SURVEY INSTRUCTIONS

- This survey should be completed by the patient indicated on the survey cover letter.
- You can ask a family member or friend for help with this survey.
- If you are a family member or friend helping with this survey or completing this survey for the patient indicated on the survey cover letter, please remember that all survey questions ask about the patient's experiences. Please do not consider your own experiences or information in the answers you provide.
- Use a dark colored pen to fill out the survey.
- Place an X directly inside the square indicating a response, like in the sample below.

Yes

No

- This survey uses the word “provider” throughout. When we say “provider”, we mean a medical provider like a doctor or a nurse.

Please return the completed survey in the provided pre-paid envelope to:

**[MAILING ADDRESS HERE]**

### YOUR PROVIDER AND TEAM

1. Our records show that you got care from the provider and team named below in the last 6 months.

[Provider] and team

Is that right?

- Yes
- No → If No, please return the completed survey in the pre-paid envelope.

The questions in this survey will refer to the provider named in Question 1 as “this provider and team.” Please think of this provider and team as you answer the survey.

### YOUR OVERALL EXPERIENCE WITH THIS PROVIDER AND TEAM

2. In the last 6 months, have you ever had pain?
- Yes
- No → If No, please return the completed survey in the pre-paid envelope.
3. In the last 6 months, did you want help from this provider and team for this pain?
- Yes
- No → If No, go to Question 5
4. In the last 6 months, did you get as much help as you wanted for

your pain from this provider and team?

- Yes, definitely
- Yes, somewhat
- No

### ABOUT YOU (THE PATIENT)

5. What is the highest grade or level of school that you have completed?
- 8th grade or less
- Some high school but did not graduate
- High school graduate or GED
- Some college or 2-year degree
- 4-year college graduate
- More than 4-year college degree
6. Are you of Hispanic or Latino origin or descent?
- Yes, Hispanic or Latino
- No, not Hispanic or Latino
7. What is your race? Please choose one or more
- White
- Black or African American
- Asian
- Native Hawaiian or other Pacific Islander
- American Indian or Alaska Native
- Other
8. What language do you mainly speak at home?
- English



Spanish

Some other language (please  
print):

**9. Did someone help you with this survey?**

Yes

No → **If No, please return the completed survey in the pre-paid envelope.**

**10. How did that person help you complete the survey? Check all that apply.**

Read the questions to me

Wrote down the answers I gave

Answered the questions for me

Translated the questions into my language

**Thank you for completing this survey.**

**Please return the completed survey in the provided pre-paid envelope.**

**[MAILING ADDRESS HERE]**

## Encuesta sobre la experiencia del paciente

### INSTRUCCIONES PARA LA ENCUESTA

- Esta encuesta se debe completar por la persona indicada en la carta de presentación de esta encuesta.
- Usted puede pedirle a un familiar o a un amigo que le ayude con esta encuesta.
- Si usted es un familiar o amigo que está ayudando con la encuesta o contestando la encuesta para la persona indicada en la carta de presentación de esta encuesta, por favor recuerde que todas las preguntas de la encuesta se refieren a las experiencias del paciente. Por favor, no considere sus propias experiencias ni información relacionada con usted en las respuestas que usted proporcione.
- Use un bolígrafo de tinta oscura para completar la encuesta.
- Marque con una 'X' dentro del cuadro para indicar su respuesta, como en el siguiente ejemplo de abajo.
  - Si
  - No
- A lo largo de toda esta encuesta se utiliza la frase "profesional médico". Cuando decimos "profesional médico" nos referimos a un profesional médico como un doctor o una enfermera.

**Por favor devuelva la encuesta con sus respuestas en el sobre adjunto con el porte o franqueo prepago a:**

**[MAILING ADDRESS HERE]**

## SU PROFESIONAL MÉDICO Y EL EQUIPO DE ÉL/ELLA

**1. Según nuestros registros, usted recibió atención médica en los últimos 6 meses del profesional médico y su equipo médico cuyo nombre aparece a continuación.**

*[Label for provider and team]*

¿Es correcta esta información?

- Sí
- No--> Si contestó "No", pase a la pregunta 23

**Las preguntas de esta encuesta se van a referir al profesional médico y a su equipo médico cuyo nombre aparece en la pregunta 1 como “este profesional médico y su equipo médico.” Por favor piense en este profesional médico y su equipo médico al contestar las preguntas de la encuesta.**

## SU EXPERIENCIA GENERAL CON ESTE PROFESIONAL MÉDICO Y SU EQUIPO

**Pensando en su experiencia general con este profesional médico y su equipo médico en los últimos 6 meses, ¿qué tan ciertas son las siguientes afirmaciones?**

**2. En los últimos 6 meses, ¿alguna vez tuvo usted algún dolor?**

- Sí
- No-->Si contestó “No”, pase a la pregunta 10

**3. En los últimos 6 meses, ¿quiso usted ayuda de este profesional médico y su equipo médico para este dolor?**

- Sí
- No--> Si contestó "No", pase a la pregunta 10

**4. En los últimos 6 meses, ¿recibió usted toda la ayuda que quería para su dolor de parte de este profesional médico y su equipo médico?**

- Sí, definitivamente
- Sí, hasta cierto punto sí
- No

## SOBRE USTED (EL PACIENTE)

**5. ¿Cuál es el grado o nivel escolar más alto que ha completado?**

- 8 años de escuela o menos
- 9 a 12 años de escuela, pero sin graduarse
- Graduado de la escuela secundaria (*high school*), Diploma de escuela secundaria, preparatoria, o su equivalente (o GED)
- Algunos cursos universitarios o un título universitario de un programa de 2 años
- Título universitario de 4 años
- Título universitario de más de 4 años

**6. ¿Es usted de ascendencia u origen hispano o latino?**

- Sí, hispano o latino
- No, ni hispano ni latino

**7. ¿A qué raza pertenece? Marque una o más.**

- Blanca
- Negra o Afroamericana
- Asiática
- Nativa de Hawái o de otras islas del Pacífico
- Indígena norteamericana o nativa de Alaska
- Otra

**8. ¿En qué idioma habla usted principalmente en casa?**

- Inglés
- Español
- Otro idioma (Por favor escriba en letra de molde):

**9. ¿Alguien le ayudó con esta encuesta?**

- Yes
- No-->Si contestó "No", devuelva la encuesta completada en el sobre con porte o franqueo pagado

**10. ¿Cómo le ayudó esta persona a completar la encuesta? Marque todas las que correspondan.**

- Me leyó las preguntas
- Anotó las respuestas que le di
- Contestó las preguntas por mí
- Tradujo las preguntas a mi idioma
- Me ayudó de otra forma

**Gracias por contestar esta encuesta.**

**Por favor devuelva la encuesta con sus respuestas en el sobre adjunto con el porte o franqueo prepago a:**

**[MAILING ADDRESS HERE]**

## Appendix B.3

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«Patient Full Name»  
«Street1» «Street2»  
«City», «State» «Zip»

Dear «Patient»,

«Program Name» is working with the American Academy of Hospice and Palliative Medicine and the RAND Corporation on research to learn about the care patients receive from their healthcare providers.

In a few days, you will receive a **Patient Experience Survey** in the mail. «Program Name» has provided your contact information to the RAND Corporation, a non-profit organization that does research on health care quality, so they can send you the survey.

The survey will ask about the care you get from «Provider» and Team at «ProgName». The information you provide will be kept private and confidential. Your answers will never be matched with your name. No one involved in your care will see your individual answers.

***We hope that you will take the time to fill out the survey.*** If you have any questions about this survey, please call us toll-free at [PHONE NUMBER HERE]. You may also call this number if you want to complete the survey by phone.

Sincerely,

Sangeeta C. Ahluwalia, PhD  
RAND Project Director  
Senior Policy Researcher  
RAND Corporation

Katherine Ast, MSW, LCSW  
AAHPM Project Director  
Director, Quality and Research  
American Academy of Hospice and Palliative Medicine

## Appendix B.4

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### **Initial email invitation:**

FROM: Patient Experience Survey Staff <patientsurvey@rand.org>  
SUBJECT: Survey about Your Care from [PROGRAM NAME]

Dear [Patient\_First\_Name] [Patient\_Middle\_Initial] [Patient\_Last\_Name],

[Program Name] is working with the American Academy of Hospice and Palliative Medicine and the RAND Corporation on research to learn about the care patients receive from their healthcare providers. **We are interested in learning about the care you received from [Provider\_Name] and Team at [Program\_Name].**

[Program Name] has provided your contact information to the RAND Corporation, a non-profit organization that does research on health care quality, so we can send you this survey. To begin the survey, please **[CLICK HERE]**.

The survey will only take about 15 minutes to complete. You can ask a family member or friend for help with this survey or ask them to complete the survey for you.

It is your choice to answer the survey, and your choice will not affect any of the services you get from [Program\_Name]. Your answers will be received by our survey team, and we will take every precaution to protect your privacy and confidentiality. [Program\_Name] will not know whether you answered the survey and no one involved in your care will see your individual answers. Your name will not be linked to your survey responses in any of our reports.

***We hope that you will take the time to fill out the survey.*** If you have any questions, or if you would like to complete this survey over the phone, please call our toll-free number at [PHONE NUMBER HERE].

Thank you very much for your help with this important survey.

Sincerely,

Sangeeta C. Ahluwalia, PhD  
RAND Project Director  
Senior Policy Researcher  
RAND Corporation

Katherine Ast, MSW, LCSW  
AAHPM Project Director  
Director, Quality and Research  
American Academy of Hospice and Palliative Medicine

## Appendix B.5

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### **Reminder email:**

FROM: Patient Experience Survey Staff <patientsurvey@rand.org>  
SUBJECT: REMINDER: Survey about Your Care from [PROGRAM NAME]

Dear [Patient\_First\_Name] [Patient\_Middle\_Initial] [Patient\_Last\_Name],

[Program Name] is working with the American Academy of Hospice and Palliative Medicine and the RAND Corporation on research to learn about the care patients receive from their healthcare providers. **We are interested in learning about the care you received from [Provider\_Name] and Team at [Program\_Name].**

We recently sent you a link to complete the survey and have not yet heard back from you. To begin the survey, please **[CLICK HERE]**.

The survey will only take about 15 minutes to complete. ***We hope that you will take the time to fill out the survey.***

It is your choice to answer the survey, and your choice will not affect any of the services you get from [Program\_Name]. Your answers will be received by our survey team, and we will take every precaution to protect your privacy and confidentiality. [Program\_Name] will not know whether you answered the survey and no one involved in your care will see your individual answers. Your name will not be linked to your survey responses in any of our reports.

If you have any questions, or if you would like to complete this survey over the phone, please call our toll-free number at [PHONE NUMBER HERE].

Thank you very much for your help with this important survey.

Sincerely,

Sangeeta C. Ahluwalia, PhD  
RAND Project Director  
Senior Policy Researcher  
RAND Corporation

Katherine Ast, MSW, LCSW  
AAHPM Project Director  
Director, Quality and Research  
American Academy of Hospice and Palliative Medicine



**SURVEY INTRODUCTION**

I1. Hi, my name is [INTERVIEWER NAME] and I'm calling from the RAND Corporation. May I speak with [PATIENT]?

<1> YES [GOTO I2]

<2> CALL BACK NEEDED [GO TO CALLBACK]

<3> PATIENT NOT ABLE TO DO PHONE CALL, PROXY NEEDED [GOTO I3]

<4> PATIENT DECEASED [GO TO INTC, CODE INELIGIBLE]

<5> UNAVAILABLE DURING FIELD PERIOD [GO TO INTC, CODE UNAVAILABLE]

<6> REFUSE [GO TO REFUSAL]

<7> NO ONE BY THAT NAME IN HH

## 12. PATIENT COMES TO PHONE:

(Hi, my name is [INTERVIEWER NAME] and I'm calling from the RAND Corporation.) We are calling you because you recently visited [PROVIDER NAME] and Team at [PROGRAM NAME] and we are interested in learning about the care you received.

We are conducting a survey to learn about the care people receive from [PROVIDER NAME] and Team at [PROGRAM NAME] You may remember getting a letter or a survey from us in the mail.

I'm calling today to do the survey with you over the phone. The survey will take about 15 minutes. It is your choice to answer the survey, and your choice will not affect any of the services you get from [PROVIDER NAME] and Team.

Your answers will be received by our survey team, and we will take every precaution to protect your privacy and confidentiality. Your name will not be linked to your survey responses in any of our reports. [PROVIDER NAME] and Team at [PROGRAM NAME] will not know whether you answered the survey.

We hope that you will help us learn about the care you get from [PROGRAM NAME]. Can we start the survey?

### **IF PATIENT WANTS HELP TO ANSWER SURVEY:**

Thank you for letting me know. If you like, someone can help you to answer the questions. Or, if you prefer, someone can answer the questions for you.

This person needs to be someone who knows about the care you receive from [PROVIDER] and Team at [PROGRAM NAME]. Is there someone who can help?

- <1> YES (INCLUDING WITH HELPER) [START INTERVIEW]
- <2> YES, PATIENT WANTS ANOTHER PERSON TO BE PROXY [GO TO I4]
- <3> CALL BACK NEEDED [GO TO CALLBACK]
- <4> PATIENT NEEDS HELP TO PARTICIPATE, PROXY NEEDED [GOTO I3]
- <5> NEEDS PROXY/HELPER: BUT NONE AVAILABLE [GO TO NOHELP]
- <6> PATIENT DECEASED [GO TO INTC, CODE INELIGIBLE]
- <7> PROGRAM DISAVOWAL [GO TO INTC, CODE PROGRAM DISAVOWAL]
- <8> UNAVAILABLE DURING FIELD PERIOD [GO TO INTC, CODE UNAVAILABLE]
- <9> REFUSE [GO TO REFUSAL]
- <10> ALREADY RETURNED SURVEY BY MAIL [GO TO MAILED]
- <11> WILL RETURN SURVEY BY MAIL [GO TO WILLMAIL]

13. IF PATIENT NOT ABLE TO SPEAK ON THE PHONE, FIND PROXY:

Thank you for letting me know.

We are calling because [PATIENT NAME], received care from [PROVIDER NAME] and Team at [PROGRAM NAME] and we are interested in learning about the care he or she received.

We would like to interview someone else to answer on [PATIENT NAME]'s behalf. This person needs to be someone who knows about the care [PATIENT NAME] receives from [PROVIDER NAME] and Team at [PROGRAM NAME]]. Is there someone who could answer these questions for (him/her)?

- <1> YES, PERSON ON PHONE WILL BE PROXY [GO TO I4]
- <2> YES, ANOTHER PERSON MAY BE PROXY [GO TO I4]
- <3> NO PROXY AVAILABLE [GO TO NOHELP]
- <4> PATIENT DECEASED [GO TO INTC, CODE DECEASED]
- <5> REFUSE [GO TO REFUSAL]
- <6> ALREADY RETURNED SURVEY BY MAIL [GO TO MAILED]
- <7> WILL RETURN SURVEY BY MAIL [GO TO WILL MAIL]

14. COLLECT PROXY INFORMATION:

What is (your/that person's) name? Could I also get (your/his/her) address and phone number?

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

PHONE NUMBER: \_\_\_\_\_

15. PROCEED WITH PROXY:

IF PROXY COMES TO PHONE, PROCEED TO INTERVIEW. ELSE SCHEDULE CALLBACK.

- <1> YES, PROXY COMES TO PHONE [GO TO I6]
- <2> CALL BACK NEEDED [GO TO CALLBACK]

## 16. PROXY INTRO:

(Hi, my name is [INTERVIEWER NAME] and I'm calling from the RAND Corporation.)

(As I mentioned,) we are calling because [PATIENT NAME] received care from [PROVIDER NAME] and Team at [PROGRAM NAME] and we are interested in learning about the care he or she received.

Since [PATIENT NAME] cannot complete the survey, I'm calling today to conduct the survey with you. The survey will take about 15 minutes.

It is your choice to answer the survey, and your choice will not affect any of the services [PATIENT NAME] gets from [PROVIDER NAME] and Team at [PROGRAM NAME].

Your answers will be received by our survey team, and we will take every precaution to protect your privacy and confidentiality. Your name will not be linked to your survey responses in any of our reports. [PROVIDER NAME] and Team at [PROGRAM NAME] will not know whether you answered the survey.

We hope that you will help us learn about the care [PATIENT NAME] gets from [PROVIDER NAME] and Team. Can we start the survey?

- <1> YES [START INTERVIEW]
- <2> CALL BACK NEEDED [GO TO CALLBACK]
- <3> DIFFERENT PROXY NEEDED [GOTO I4]
- <4> PATIENT DECEASED [GO TO INTC, CODE DECEASED]
- <5> PROGRAM DISAVOWAL [GO TO INTC, CODE PROGRAM DISAVOWAL]
- <6> REFUSE [GO TO REFUSAL]
- <7> ALREADY RETURNED SURVEY BY MAIL [GO TO MAILED]
- <8> WILL RETURN SURVEY BY MAIL [GO TO WILL MAIL]

## MONITOR

This call may be monitored for quality improvement purposes. May we begin?

- <1> YES
- <2> NO, CALLBACK
- <3> NO

## INTERVIEW

IF PROXY, ASK 1intro

IF NO PROXY, GO TO QUESTION 1intro2

1intro. Please remember that all survey questions ask about the patient's experiences. Unless a question says otherwise, please do not consider your own experiences or information in the answers you provide.

1intro2. Before we begin, I just want to let you know that this survey uses the word "provider" throughout. When we say "provider", we mean a medical provider like a doctor or a nurse.

1. Our records show that [IF PATIENT: you/IF PROXY:<PATIENT NAME>] got care from [PROVIDER NAME] and team in the last 6 months. Is that right?

<1> YES

<2> NO à IF NO, GO TO QUESTION 23

<d> DON'T KNOW à If DON'T KNOW, GO TO QUESTION 23

<r> REFUSED à IF REFUSED, GO TO QUESTION 23

2intro. The questions in this survey will refer to [PROVIDER NAME] and team as "this provider and team." Please think of this provider and team as you answer the survey.

3intro. Thinking about [IF PATIENT: your /IF PROXY:<PATIENT NAME>'s] overall experience with this provider and team in the last 6 months, how true are the following statements?

2. In the last 6 months, [IF PATIENT: have you /IF PROXY: has <PATIENT NAME>] ever had pain?

<1> YES

<2> NO à IF NO, GO TO QUESTION 10

<d> DON'T KNOW à IF DON'T KNOW, GO TO QUESTION 10

<r> REFUSED à IF REFUSED, GO TO QUESTION 10

3. In the last 6 months, did [IF PATIENT: you /IF PROXY:<PATIENT NAME>] want help from this provider and team for this pain?

<1> YES

<2> NO à IF NO, GO TO QUESTION 10

<d> DON'T KNOW à IF DON'T KNOW, GO TO QUESTION 10

<r> REFUSED à IF REFUSED, GO TO QUESTION 10

4. In the last 6 months, did [IF PATIENT: you /IF PROXY:<PATIENT NAME>] get as much help as [IF PATIENT: you /IF PROXY: (he/she)] wanted for [IF PATIENT: your /IF PROXY: (his/her)] pain from this provider and team? Would you say...
- <1> Yes, definitely,
  - <2> Yes, somewhat, or
  - <3> No?
  - <d> DON'T KNOW
  - <r> REFUSED
5. What is the highest grade or level of school that [IF PATIENT: you have /IF PROXY:<PATIENT NAME> has] completed? Is it...
- <1> 8th grade or less,
  - <2> Some high school but did not graduate,
  - <3> High school graduate or GED,
  - <4> Some college or 2-year degree,
  - <5> 4-year college graduate, or
  - <6> More than 4-year college degree?
  - <d> DON'T KNOW
  - <r> REFUSED
6. [IF PATIENT: Are you /IF PROXY: Is <PATIENT NAME>] of Hispanic or Latino origin or descent?
- <1> YES, HISPANIC OR LATINO
  - <2> NO, NOT HISPANIC OR LATINO
  - <d> DON'T KNOW
  - <r> REFUSED
7. What is [IF PATIENT: your /IF PROXY:<PATIENT NAME>'s] race? Please choose one or more.
- @ White?
  - @2 Black or African American?
  - @3 Asian?
  - @4 Native Hawaiian or other Pacific Islander?
  - @5 American Indian or Alaska Native?
  - @6 Something else?

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

8. What language [IF PATIENT: do you /IF PROXY: does <PATIENT NAME>] mainly speak at home? Please listen to all response choices before you answer. Would you say that [IF PATIENT: you /IF PROXY: <PATIENT NAME>] mainly [IF PATIENT: speak/IF PROXY: speaks] ...

<1> English, à IF ENGLISH, GO TO QUESTION 37skip

<2> Spanish, or à IF SPANISH, GO TO QUESTION 37skip

<3> Some other language?

<d> DON'T KNOWà IF DON'T KNOW, GO TO QUESTION 37skip

<r> REFUSEDà IF REFUSED, GO TO QUESTION 37skip

- 8os. What other language do [IF PATIENT: do you /IF PROXY: does <PATIENT NAME>] mainly speak at home?

SPECIFY: \_\_\_\_\_

9skip. IF RESPONDENT=PROXY GO TO QUESTION 11

9. Did someone help you with this survey?

<1> YES

<2> NO à IF NO, GO TO END

<d> DON'T KNOW à IF DON'T KNOW, GO TO END

<r> REFUSED à IF REFUSED, GO TO END

- 10proxy. Did [PATIENT NAME] help answer any questions on this survey?

<1> YES à IF YES, GO TO QUESTION 40

<2> NO à IF NO, GO TO QUESTION 40

<d> DON'T KNOW à IF DON'T KNOW, GO TO QUESTION 40

<r> REFUSED à IF REFUSED, GO TO QUESTION 40

10. How did that person help you complete the survey? Did they

CODE ALL THE APPLY

@1 Read the questions to you

@3 Answered the questions for you

@4 Translated the questions into your language

@5 Help in some other way

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

END. Those are all the questions I have, thank you for your time.