WORKING PAPER

MACRA Palliative Care Quality Measure Development

Summary Report of Alpha Testing

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Overview of Project and Objectives

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 palliative care experience, broadly in the domains of symptoms and communication. The measures are intended to assess the extent to which patients receiving outpatient clinic-based palliative care received the help they wanted for their symptom(s), and the extent to which they felt heard and understood by their palliative care provider and team. Under this agreement, AAHPM is working to advance quality measurement in palliative care through the engagement of stakeholders such as measure development technical experts, clinicians, clinical specialty societies, patient advocacy groups, patients/families/caregivers, healthcare systems, and other stakeholder groups. AAHPM has partnered with the National Coalition for Hospice and Palliative Care and RAND Health Care to develop the proposed measures.

Existing evidence and expert consensus have highlighted significant unmet need among seriously ill persons and gaps in symptom management and meaningful communication measures, despite the noted importance of these domains to patients and their families. These gaps may be particularly pronounced in outpatient settings, where patients and families have limited access to palliative care services and may struggle to manage their illness and accept their trajectory. AAHPM seeks to address these gaps through the following project objectives:

- Develop, test, and implement two patient-reported performance measures for patients receiving outpatient, clinic-based, palliative care.
- Ensure that the proposed measures incorporate the patient voice and preferences and are broadly applicable to patients with serious illness and their families receiving palliative care services in a range of outpatient primary and specialty care settings.
- Convene a technical expert panel that incorporates patient, caregiver, and family input directly into the measure development, specification, testing, and implementation processes.
- Submit the proposed palliative care measures to CMS' 2021 Measures Under Consideration (MUC) list for the Quality Payment Program (QPP) and to the National Quality Forum (NQF) for review and endorsement by the consensus-based entity so that clinicians can measure and improve the quality of care received by patients in outpatient, clinic-based, palliative care.

Proposed Measure(s)

The proposed measures to be developed are:

- Palliative care outpatients' experience of feeling heard and understood: The percentage of patients aged 18 years and older with at least 1 outpatient palliative care visit in 3 months who complete a patient experience survey within 6 months of the outpatient palliative

care visit and report feeling heard and understood by their palliative care provider and team.

- Palliative care outpatients' experience of receiving desired help for pain: The percentage of patients aged 18 years and older with at least 1 outpatient palliative care visit in 3 months who complete a patient experience survey within 6 months of the outpatient palliative care visit, who report having pain and wanting help for their pain, and who report getting the help they wanted for their pain by their palliative care provider and team over the last six months.

These quality measures will be derived from patient-reported data elements (i.e., items) administered via mixed-mode survey that will be refined and tested for data element reliability and validity among patients receiving outpatient clinic-based palliative care. Measure testing is being conducted in three phases: an English-language cognitive testing phase was completed in Summer 2019, a small feasibility pilot study ("alpha test") phase was conducted from August to October 2019 and is the subject of this summary memo, and a large national field test ("beta test") phase began in October 2019 and will continue through October 2020. The alpha test focused on providing evidence for feasibility, while the beta test will build on the alpha test evidence and provide additional evidence in the form of psychometric properties of the items, detailed specification of the measures, and evaluation of their performance.

The purpose of this memo is to provide an overview of the aims of alpha testing; describe the study design; and discuss quantitative findings, qualitative feedback from programs, and lessons learned from alpha, which inform the beta test.

Alpha Testing

The formative alpha test phase sought to establish the data collection processes that will be used in the beta test and identify challenges and necessary refinements to the testing plan prior to the beta test. The alpha test was expected to help the testing team

- determine response rates and explore approaches to optimizing the number of complete responses
- assess the rates of, and reasons for, caregiver ("proxy respondent") response versus patient response
- identify data elements with low reliability potentially due to high rates of missingness or "topping out"
- establish optimal site recruitment processes
- understand data capabilities across sites and tailor sample file requests accordingly
- establish average times from site recruitment to survey fielding, to adjust the beta test timeline
- explore the feasibility of email/web-based survey fielding for the beta test.

In the following sections, we describe the data sample and recruitment protocol, data collection procedures, the final alpha sample, and findings from testing.

Data Sample

Population Description

The target population includes adult patients age 18 years or older who had received palliative care services in the study outpatient clinics. The focus of the proposed measures will be on care provided by the palliative care provider and team within a six-month period.

Sample Size Determination

The sample was a multi-stage cluster sample, with the primary sampling unit being the Clinician. Clinicians were clustered within groups or programs. All inferential statistics and sample size calculations took into account the sampling design when estimating variances.

Program Sampling and Recruitment

Recruitment for the alpha test drew from the same data source as is being used in the beta field test. We identified approximately 360 palliative care groups or programs in the United States that reported providing outpatient, clinic-based palliative care to the Mapping Community Palliative Care Project and The National Palliative Care Registry, both of which are managed by the Center to Advance Palliative Care (CAPC) and capture self-reported program information. Information regarding the alpha test was broadly disseminated to palliative care programs via an informational webinar hosted by the National Coalition for Hospice and Palliative Care (NCHPC) in June 2019, as well as a study website hosted by NCHPC (https://www.nationalcoalitionhpc.org/macra/).

From this list of 360 palliative care programs, as of January 2020 RAND's Survey Research Group (SRG) had contacted 214 to discuss participation in the alpha and/or beta tests. Out of the 214 palliative care programs contacted about the study, 65 programs were deemed ineligible because they provided no outpatient care (despite their submitted program information to the CAPC registries), were less than six months old, saw fewer than 20 patients over the prior six months, were a PACE or VA program, or had no MIPS-eligible practitioners who provided care to patients. We sought to oversample patients from larger groups or programs (i.e., those with more individual patients), and to stratify our sampling and recruitment efforts by administrative home type (i.e., hospice, hospital, outpatient, and other administration) and by geographic location to ensure representation across U.S. Census Regions (Table 1). Programs were assigned to recruitment queues according to these criteria and, working down the list for each queue, SRG contacted programs until a sufficient number were recruited.

Program recruitment contact began with an introductory email followed by a telephone call from SRG staff members. Contact continued until quotas for each group (i.e., setting type and geographic region) were reached and Data Use Agreements (DUAs) were in place. Because the timeline for each site to complete any internal legal and/or institutional review board (IRB)

review varied greatly, SRG discussed participation in both the alpha and beta study during recruitment efforts.

The first five programs with sufficient provider and patient volume were included in the alpha study (two from North Carolina, one from Ohio, one from Oregon, and one from Colorado). This small number of programs was planned to provide sufficient variability to confirm our design assumptions (i.e., average of three providers per group or program, average of ten patients per provider in a three-month period, survey response rate of 40 percent). SRG, working with RAND statistics and research programming staff, then requested and obtained sample files (i.e., a data file of all patients ["cases"] who had an outpatient palliative care visit in the prior six months) from participating groups, cleaned and merged data, and identified patient cases meeting eligibility criteria (i.e., aged 18 years and older with at least one outpatient palliative care visit with a MIPS-eligible provider in three months). The alpha field period ran from August 8, 2019, through October 3, 2019.

Table 1. Overall Program Recruitment Targets, as of January 2020*

		Midwest	Northeast	South	West	TOTAL
Hospice	Target sites to recruit	3	1	3	1	7
	Sites recruited	2	2	5	1	10
Hospital	Target sites to recruit	5	9	7	7	28
	Sites recruited	4	5	8	7	24
Outpatient/Other	Target sites to recruit	3	2	5	5	15
	Sites recruited	3	2	3	1	9
All Settings	Target sites to recruit	11	11	15	13	49
	Sites recruited	9	9	16	9	43

*Recruitment is ongoing

Patient Sampling

Across the five recruited programs included in the alpha field test, 645 patients cared for by 20 providers were identified as eligible (i.e., had at least 1 outpatient palliative care visit in the prior 3 months) to receive the survey.

Surveys were fielded with 300 randomly selected patients, yielding completed surveys for 40 percent, or 120 patients (77 by mail, 43 by phone). Table 2 shows the breakdown across the five programs.

Table 2. Patient sample breakdown by program

	Program 1	Program 2	Program 3	Program 4	Program 5	TOTAL
Location	NC	OH	OR	NC	CO	N/A
# of eligible patients	74	182	122	35	232	645
# of fielded surveys	50	83	49	35	83	300

# of completed surveys	24	31	26	9	30	120
Response rate	48%	37%	53%	26%	36%	40%
# of providers in sample	1	5	6	2	6	20

Of the 180 patients who did not complete a survey, 120 could not be reached by phone after eight attempts, 23 did not have viable phone numbers, 20 were deceased, 14 refused to participate (12 patient refusals, 1 proxy refusal, and 1 patient was too ill), 2 were incomplete, and 1 patient indicated never having received care from the named provider.

Data Collection

Procedure

During the alpha test, we used a mixed-mode survey administration procedure; i.e., mail with telephone follow-up. Prior work estimating the effect of the mode of survey administration on response rates and response tendencies for the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey (a survey of patient experience of hospice and end-of-life care) found that response rates were 42.6 percent for mail-only survey administration, 37.9 percent for telephone-only, and 52.6 percent for mail with telephone follow-up.[1] Although it may be reasonable to expect up to a 52 percent response rate based on this prior work, we assumed a lower response rate to conservatively account for potential differences due to the population being sampled (bereaved caregivers vs. palliative care patients).

First, a pre-notification letter was mailed to inform patients of their eligibility and the upcoming survey. The prenotification letter informed the patient that they would receive the survey within a few days. It referenced their program and provider, the organization conducting the research, and provided a toll-free number that could be called if the patient had any questions about the survey. Dillman indicates that a prenotification letter can be helpful in adding legitimacy to survey efforts.[2] In addition, since some patients would likely be too ill to complete the survey or perhaps even open an envelope themselves, the prenotification letter would both allow time for the patient to arrange help to complete the survey and alert caregivers to the upcoming survey mailing. Returned undeliverable letters or calls from caregivers who opened patient mailings would provide notification that the patient was deceased or moved.

The use of the prenotification letter was followed within a week by a mailed cover letter and survey. The survey included questions related to individuals' care experiences with their identified palliative care provider and team, as well as questions about their general health and

[1] Parast, L., Elliott, M. N., Hambarsoomian, K., Teno, J., & Anhang Price, R. (2018). Effects of survey mode on consumer assessment of Healthcare Providers and Systems (CAHPS) hospice survey scores. *Journal of the American Geriatrics Society*, *66*(3), 546-552.

[2] Dillman, D.A, Smyth, J.D., & Christian, L.M. (2014). *Internet, Phone, Mail, and Mixed-mode Surveys. The Tailored Design Method. 4th Edition*. John Wiley & Sons, Inc., Hoboken, New Jersey.

demographic characteristics. The survey cover letter included both 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 could get help or use a proxy to complete the survey. The survey packet also included a postage-paid postcard that could be returned with updated address information for the patient or to indicate that the patient was deceased.

If the survey was not returned within three weeks of survey mailing, an attempt was made to contact the patient by telephone and complete the survey via computer-assisted telephone interview (CATI). The CATI survey was attempted approximately eight times before the individual was considered a "non-response."

As part of the alpha test, we collected the percentage of patients per program with e-mail addresses on file and accessible to us to estimate the potential for utilizing a web-based survey mode during the beta test. For alpha, email addresses were available for 77 out of 645 eligible patients (12%) and 32 out of the 300 patients who were fielded surveys (11%). Moreover, email contact information for the 32 out of 300 patients who were fielded surveys all came from a single site; the other four sites did not have email contact information for their patients.

Data Elements Collected

Data elements included in the survey were selected through a multi-step process. First, potential patient-reported data elements in the domains of communication, symptom management, and overall experience with palliative care were identified through extensive literature review and stakeholder input, including patient/caregiver interviews and provider focus groups. Results from these information gathering activities are described in detail in a separately published report (RAND RR4273; citation TBD). Second, the results of these information gathering activities were presented to the members of the project Technical Expert Clinical User Patient Panel (TECUPP), who provided additional input and selected those data elements most relevant to the project goal of establishing feasibility, reliability, and validity of the proposed measures (AAHPM TECUPP Summary Report; citation TBD). Third, data elements emerging from the TECUPP discussion and selection process were cognitively tested in survey format with patients and caregivers to evaluate comprehensibility and feasibility of administration (Summary Memo forthcoming). Throughout the data element review and selection process, project team members with expertise in item development and psychometrics, as well as the project advisory committee, were actively engaged in processing input, applying additional insight, and facilitating selection. Table 3 displays the data elements collected during alpha testing via survey instrument, which include: ten data elements about communication, trust, and personhood, including a specific data element about feeling heard and understood [Heard and Understood]; four data elements comprising the CAHPS communication composite [CAHPS communication], three data elements about receiving desired help for pain [Help for Pain], and two data elements about receiving desired emotional support [Desired Emotional Support].

Multiple Heard and Understood data elements – in addition to the specific data element about feeling heard and understood - were included and tested with the intention of evaluating the possibility of constructing a multi-item scale, as well as to assess construct validity. The CAHPS communication data elements were included for validation purposes, that is, to examine the association between the CAHPS communication total score with the proposed Heard and Understood data elements. All three Help for Pain data elements were included to inform the proposed pain measure. The Desired Emotional Support data elements were included to collect additional descriptive information on the care provided to patients. Additionally, patient demographics, overall health, and mental/emotional health were collected. Items were also included to collect data on whether a proxy helped with survey completion, the relationship of the proxy with the patient, type of assistance received to complete the survey, and other forms of involvement by the proxy in the patient's daily living. The full alpha test survey instrument is included in Appendix A.

Table 3. List of Data Elements Collected Ordered by Concept (in italics)

Communication: Heard and Understood/Personhood	Response Options
I felt heard and understood by this provider and team	[Very true, Mostly true, Somewhat true, A little bit true, Not at all true][3]
I trusted this provider and team	
I felt comfortable asking this provider and team questions	
I could tell this provider and team anything, even things I might not tell anyone else	
I felt this provider and team put my best interests first when making recommendations about my care	
I felt this provider and team always told the truth about my health, even if there was bad news	
I felt this provider and team saw me as a person, not just someone with a medical problem	
I felt this provider and team knew what worried me most about my health	
I felt this provider and team understood what is important to me in my life	
I felt this provider and team would know what I would want done if I was unconscious or in a coma	
CAHPS Communication	
In the last 6 months, how often did this provider and team explain things in a way that was easy to	[Never, Sometimes, Usually, Always]

[3] Statement structures and corresponding rating response categories were selected based on expert panel input and cognitive interview findings.

understand?	
In the last 6 months, how often did this provider and team listen carefully to you?	
In the last 6 months, how often did this provider and team show respect for what you had to say?	
In the last 6 months, how often did this provider and team spend enough time with you?	
Symptoms; Pain	
In the last 6 months, have you ever had pain?	[Yes/No]
In the last 6 months, did you want help from this provider and team for this pain?	[Yes/No]
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]
Symptoms; Emotional Support	
In the last 6 months, did you want any emotional support from this provider and team?	[Yes/No]
Did you get as much emotional support as you wanted from this provider and team?	[Yes, definitely/Yes, somewhat/No]
Overall experience of care	
Using any number from 0 to 10, where 0 is the worst provider possible and 10 is the best provider possible, what number would you use to rate this provider and team?	[0 – 10]
Demographics and General	
In general, how would you rate your overall health?	[Excellent, Very good, Good, Fair, Poor]
In general, how would you rate your overall mental or emotional health?	[Excellent, Very good, Good, Fair, Poor]
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]
Are you of Hispanic or Latino origin or descent?	[Yes, Hispanic or Latino/No, not Hispanic or Latino]
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]
What language do you <u>mainly</u> speak at home?	[English/Spanish/Some other language]
Proxy Response	
Did someone help you with this survey?	[Yes/No]
Who helped you complete the survey?	[Spouse or partner, Child, Sibling, Parent, Other family member or friend, Paid caregiver, Someone else]
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, Helped in some other way] Multiple responses allowed.

For what reason did someone help you complete this survey? (Check all that apply)	[Too sick, Trouble with memory, Trouble seeing or reading, Hard of hearing, Do not understand English, Wanted someone else to complete the survey, Patient is in a coma, Patient has passed away, Some other reason]
How familiar is the person who helped you complete the survey with your condition and care?	[Completely, Very, Somewhat, A little, Not at all]
How often does the person who helped you complete the survey also help you make decisions about your medical treatment?	[Never, Sometimes, Usually, Always]
Does the person who helped you complete this survey also provide or help with any of the following? (Check all that apply)	[Companionship or supervision, Transportation, Homemaking, Personal care assistance, Healthcare assistance, Financial assistance, Other activities] Check all that apply.

Analyses

We descriptively analyzed the overall patient sample including demographics, self-reported health, primary reason for palliative care as indicated by programs, and rates for proxy assistance and proxy related items (e.g., relationship of proxy to patient, type of assistance provided for survey completion). We calculated frequencies for the Heard and Understood, pain, and emotional support data elements, and we calculated basic psychometrics for a potential multi-item Heard and Understood scale (e.g., item-total correlations and coefficient, or Cronbach's alpha, to evaluate scale internal consistency).We evaluated validity by calculating frequencies for the CAHPS communication items and associations between Heard and Understood data elements and the CAHPS total score, as well as associations with data elements asking about receiving help wanted for pain and emotional support. In addition, we qualitatively analyzed feedback from the site interviews to characterize feasibility, perceived utility of the proposed measures, and lessons learned from alpha testing. In the following section we present additional detail on each of these procedures and discuss the findings from alpha testing.

Results

Patient Demographics and Characteristics

Patient characteristics (i.e., age and gender) were examined for associations with non-response. Patient non-response was not significantly associated with gender. However, it was significantly associated with age ($F_{(1,279)} = 9.36$, $p<.01$) such the average age of non-responders was 58 years compared to 62 years for responders. Table 4 presents demographic data for the 120 patients who participated in the alpha field test. Overall, the sample included more females (63 percent) than males and was primarily non-Hispanic white (79 percent). Slightly over one-third (36 percent) had at least a college degree, about one-third had some college education (35 percent), nearly one-fifth had a high school diploma or GED (19 percent), and 10 percent reported less than a high school education. In general, patients rated their overall mental and

emotional health higher than their overall health. Specifically, nearly two-thirds of all patients reported at least good overall mental and emotional health. However, for ratings of overall health, nearly 70 percent of patients reported having either fair (39 percent) or poor (30 percent) health.

Regarding patient primary diagnoses, data obtained from practices indicated that nearly half of all patients (46 percent) had a form of cancer (e.g., breast, colorectal, lung or other chest cavity). Several patients had pulmonary conditions (4 percent pneumonias and other infectious lung diseases; 4 percent non-infectious respiratory disease), heart conditions (2 percent congestive heart failure; 3 percent other heart disease); and chronic kidney (2 percent) or liver (2 percent) disease. Lastly, slightly over one-third (36 percent) of patients had "other" primary diagnoses (e.g., multiple sclerosis, spastic hemiplegia, general palliative care, and other symptoms and signs involving the genitourinary system).

Table 4. Frequencies (percent) for Patient Demographics, Self-reported Health, and Primary Diagnoses

Demographics	Frequency (%)
Age [M (SD)]	62.3 (13.9)
Female	75 (62.5)
Race/ethnicity	
Non-Hispanic White	93 (78.8)
Non-Hispanic Asian	1 (0.8)
Non-Hispanic Black	9 (7.6)
Non-Hispanic American Indian or Alaska Native	3 (2.5)
Non-Hispanic Multi-racial/ethnic	7 (5.9)
Non-Hispanic Other	2 (1.7)
Hispanic White	2 (1.7)
Hispanic American Indian or Alaska Native	1 (0.8)
Education	
< High school	12 (10.1)
High school or GED	22 (18.5)
Some college	42 (35.3)
College	17 (13.4)
Beyond college	28 (22.7)
Overall health	
Excellent	3 (2.6)
Very good	9 (7.7)
Good	24 (20.5)
Fair	46 (39.3)

Poor	35 (29.9)
Overall mental and emotional health	
Excellent	7 (6.0)
Very good	30 (25.6)
Good	38 (32.5)
Fair	28 (23.9)
Poor	14 (12.0)
Primary diagnosis*	
Cancer	48 (45.7)
Pneumonias and other infectious lung diseases	4 (3.8)
Non-infectious respiratory disease	4 (3.8)
Congestive heart failure	2 (1.9)
Other heart disease	3 (2.9)
Chronic kidney disease	2 (1.9)
Chronic liver disease	2 (1.9)
Parkinson's and other degenerative diseases	2 (1.9)
Other (e.g., multiple sclerosis, spastic hemiplegia, MDD)	38 (36.2)

* Data on patient primary diagnoses were available for 105 of the 120 patients in alpha testing.

Proxy Assistance

Table 5 shows the rates for proxy assistance, relationship to patient, types of proxy assistance, proxy familiarity with patient condition and care, and other forms of patient-proxy interactions. Overall, 17 patients (14 percent) indicated receiving proxy assistance. For these 17 patients, seven proxies were spouses, three were another family member or friend, three were a child, and one was a sibling. Three respondents did not indicate their relation to the patient. As for the type of assistance the proxy provided to complete the survey, nearly half (47 percent) of proxies completed the survey for the patient. Writing down answers for the patient (29 percent) and reading questions for the patient (24 percent) accounted for the other most frequent ways the proxy assisted in completing the survey. Only one proxy assisted the patient to complete the survey in some other manner. Regarding reasons for needing/wanting proxy assistance, the most frequent reasons were that the patient wanted someone else to complete the survey (35 percent) or because the patient had trouble with memory (29 percent). Additional reasons included the patient being too sick (18 percent), having trouble seeing or reading (18 percent), or being hard of hearing (12 percent). Lastly, for four patients, responses (one write-in and three over the phone) indicated that proxy assistance was due to other reasons not listed, which included the patient had a stroke and was unable to complete the survey, could not be reached by phone, could not speak, and was not available. In general, proxies were quite familiar with the patient's condition and care, with 12 (71 percent) indicating being either very or extremely familiar. Three

proxies indicated being not at all familiar with the patient's condition and care. Further, for 13 patients (76 percent), responses indicated that the proxy always assisted the patient in decisions about medical treatment; one indicated usually assisting and three never assisting in decisions. Finally, for the majority of patients, responses indicated that proxies were involved in other aspects of the patient's life. Specifically, companionship (88 percent), transportation (82 percent), health care assistance (77 percent), homemaking (71 percent), and financial assistance (65 percent) were most frequently noted. Additionally, personal care assistance (41 percent) and other activities (18 percent) were also noted.

Table 5. Proxy assistance rates and characteristics

Data element	Frequency (%)
Proxy assistance	17 (14.3)
Among those who reported proxy assistance (n=17)	
Proxy relation to patient	
Spouse or partner	7 (41.2)
Child	3 (17.6)
Sibling	1 (5.9)
Other family member or friend	3 (17.6)
Types of proxy assistance*	
Read questions	4 (23.5)
Wrote down answers for me	5 (29.4)
Answered questions for me	8 (47.1)
Helped in some other way	1 (5.9)
Reason for proxy assistance*	
Too sick	3 (17.6)
Trouble with memory	5 (29.4)
Trouble seeing or reading	3 (17.6)
Hard of hearing	2 (11.8)
Do not understand English	-
Wanted someone else to complete the survey	6 (35.3)
Patient was in coma	-
Other	4 (23.5)
Proxy familiarity with patient condition and care	
Extremely	12 (70.6)
Very	2 (11.8)
Somewhat	-
A little	-
Not at all	3 (17.6)

Proxy assistance in decisions about medical treatment	
Never	3 (17.6)
Sometimes	-
Usually	1 (5.9)
Always	13 (76.5)
Other help or services provided by proxy*	
Companionship (talking, reading, keeping company) or supervision	15 (88.2)
Transportation (driving to doctor appointments, driving for errands)	14 (82.4)
Homemaking (shopping, cleaning, preparing meals)	12 (70.6)
Personal care assistance (feeding, bathing, toileting, dressing, grooming)	7 (41.2)
Healthcare assistance (help with medications, wound care)	13 (76.5)
Financial assistance (paying bills, managing budget)	11 (64.7)
Other activities	3 (17.6)

(*) denotes data elements with a 'check all that apply' option. As such, percentages do not sum to 100 percent. Percentages reported reflect the percent of proxies/patients endorsing a given response option out the total number of proxies (n=17).

Heard and Understood

Table 6 shows the response frequencies for the Heard and Understood data elements. Missing data at the data element level was minimal, ranging from 0.8 to 2.5 percent, but was slightly higher (4.2 percent) for the data element asking about the provider and team knowing what the patient would want done if unconscious or in a coma. While some data elements displayed variability, patients generally rated all Heard and Understood data elements very high, such that most statements were rated *very true* or *mostly true* of their provider and team and seldomly rated as *somewhat true*, *a little bit true*, or not *at all true*. Across all data elements, patient *very true* ratings ranged from 69 to 91 percent, with the highest rates belonging to data elements about being seen as a person and not just someone with a medical problem (91 percent); being told the truth about health even if bad news (89 percent); and trusting the provider and team (88 percent). There was more variability in responses for the data elements asking about being able to tell the provider and team anything and whether the provider and team would know what the patient wanted if unconscious or in a coma. In both cases, at most 70 percent rated these statements as *very true* with *mostly true* being the next most frequent option. Across all data elements, *not at all true* ratings ranged from 1 to 6 percent, while ratings of *a little bit true* did not exceed 2 percent.

Table 6. Response Frequencies for Heard and Understood Data Elements [count (percent)]

Data Element	Very true	Mostly true	Somewhat true	A little bit true	Not at all true
I felt heard and understood by this provider and team	94 (79.0)	16 (13.4)	3 (2.5)	2 (1.7)	4 (3.4)

Data Element	Very true	Mostly true	Somewhat true	A little bit true	Not at all true
I trusted this provider and team	105 (88.2)	8 (6.7)	2 (1.7)	2 (1.7)	2 (1.7)
I felt comfortable asking this provider and team questions	104 (87.4)	9 (7.6)	2 (1.7)	2 (1.7)	2 (1.7)
I could tell this provider and team anything, even things I might not tell anyone else	83 (70.3)	23 (19.5)	5 (4.2)	—	7 (5.9)
I felt this provider and team…					
put my best interests first when making recommendations about my care	101 (85.6)	9 (7.6)	5 (4.2)	2 (1.7)	1 (0.8)
always told the truth about my health, even if there was bad news	104 (88.9)	9 (7.7)	1 (0.9)	1 (0.9)	2 (1.7)
saw me as a person, not just someone with a medical problem	107 (90.7)	4 (3.4)	5 (4.2)	—	2 (1.7)
knew what worried me most about my health	92 (78.0)	21 (17.8)	3 (2.5)	—	2 (1.7)
understood what is important to me in my life	97 (82.2)	16 (13.6)	1 (0.8)	2 (1.7)	2 (1.7)
would know what I would want done if I was unconscious or in a coma	79 (68.7)	20 (17.4)	10 (8.7)	2 (1.7)	4 (3.5)

Table 7 presents the item-total score correlations and coefficient alpha for the Heard and Understood data elements. Both item-total correlations and coefficient alpha provide psychometric information about the reliability of a multi-item scale. The item-total correlation is computed by correlating each item (i.e., data element) with the total test score (i.e., raw summary score) excluding that item. Higher item-total correlations (> 0.20)[4] suggest the item is a good indicator of what the entire item set intends to measure. For the Heard and Understood data elements, item-total correlations ranged from 0.59 to 0.88, indicating that all data elements are generally good indictors of the general construct being measured. The largest item-total correlations were for data elements asking about trusting the provider and team (0.88) and being seen as a person and not just someone with a medical condition (0.87). The lowest item-total correlation was with the data element asking whether the provider and team would know the patient's wishes if unconscious or in a coma. Coefficient alpha for the scale was also high (0.94), indicating excellent reliability according to conventional criteria (> 0.70).[5] Overall, these results provide support for using a multi-item scale for measuring the heard and understood construct.

[4] Kline, P. (1986). A handbook of test construction: Introduction to psychometric design. Methuen & Co. New York: NY.

[5] Nunnally, J. C. (1978). *Psychometric theory* (2nd ed.). McGraw-Hill. New York: NY.

Table 7. Item-total Correlations for Heard and Understood Data Elements

Data Element	n	Item-total correlation
I felt heard and understood by this provider and team	119	0.68
I trusted this provider and tram	119	0.88
I felt comfortable asking this provider and team questions	119	0.85
I could tell this provider and team anything, even things I might not tell anyone else	118	0.70
I felt this provider and team…		
put my best interests first when making recommendations about my care	118	0.80
always told the truth about my health, even if there was bad news	117	0.73
saw me as a person, not just someone with a medical problem	118	0.87
knew what worried me most about my health	118	0.80
understood what is important to me in my life	118	0.84
would know what I would want done if I was unconscious or in a coma	115	0.59
Coefficient alpha (α)	0.94	

Symptom Management – Pain

Table 8 shows the response frequencies for the three pain data elements. Missing data was minimal across the three items, with only one response missing to the data element asking about having pain in the past six months. The majority of patients (86 percent) reported experiencing pain in the past six months. Of the 102 patients who experienced pain in the past six months, 78 percent reported wanting help from the provider and team for their pain. Of those who reported wanting help for their pain, 77 percent indicated that they *definitely* received the help they wanted, and 15 percent reported *somewhat* receiving the help they wanted. In total, six patients (8 percent) indicated not receiving the help they wanted for their pain. Overall, there was variability in patient responses to whether they received the help they wanted.

Table 8. Response Frequencies for Pain Data Elements

Data Element	Frequency (%)
Pain	
In the past 6 months, have you had pain?	
Yes	102 (85.7)
Among those who experienced pain (n=102)	

In the past 6 months, did you want help for your pain?	
Yes	79 (77.5)
Among those who wanted help for pain (n=79)	
In the past 6 months, did you get as much help as you wanted?	
Yes, definitely	61 (77.2)
Yes, somewhat	12 (15.2)
No	6 (7.6)

Symptom Management – Emotional Support

Table 9 shows the response frequencies for the two emotional support data elements. Missing data was minimal, with only two patients not responding to these data elements and three proxies indicating they did not know whether the patient wanted emotional support from the provider and team. Nearly three-quarters (73 percent) of patients indicated wanting emotional support from their provider and team. Of the 84 patients who reported wanting emotional support, 82 percent indicated *definitely* receiving as much emotional support as wanted and 16 percent reported *somewhat* receiving the emotional support they wanted. In total, two patients (2.4 percent) indicated not receiving the emotional support they wanted from the provider and team.

Table 9. Response Frequencies for Emotional Support

Data Elements	Frequency (%)
Emotional Support	
In the past 6 months, did you want emotional support from this provider and team?	
Yes	84 (73.0)
Among those who wanted emotional support (n=84)	
In the past 6 months, did you get as much emotional support as you wanted from this provider and team?	
Yes, definitely	69 (82.1)
Yes, somewhat	13 (15.5)
No	2 (2.4)

Validity

CAHPS communication data elements were included in the survey to examine the validity of the Heard and Understood data elements. Table 10 shows the response frequencies for the CAHPS communication data elements. Missing data was minimal at the data element level, ranging from 0.8 to 1.7 percent. Similar to Heard and Understood data elements, the majority of responses were clustered at the high end, indicating that, in general, patients tended to report good communication with the provider and team. This observed trend in the well-established

CAHPS data elements is encouraging, as it enables us to assess whether there are unique problems with the distribution of our Heard and Understood items. Across all CAHPS data elements, between 84 and 88 percent of patients indicated that the provider and team *always* explained things in a way that was easy to understand, listened carefully to the patient, showed respect for what they had to say, and spent enough time with them. Only between 3 and 6 percent of patients responded *sometimes* or *never* to each of the data elements.

Convergent validity was examined by inspecting the correlations between the ten Heard and Understood data elements (scores ranging from 1 to 5 for each data element) with the CAHPS communication total score (scores ranging from 1 to 4 for each data element with an overall total score ranging from 4 to 16). The average CAHPS total score was 15.22 (*SD* = 1.97). Correlations between Heard and Understood data elements and the CAHPS total score were moderate to strong and ranged from 0.52 to 0.89. Specifically, the highest correlations with the CAHPS total score were for the data elements asking about the provider and team putting the patients' interest first when making a recommendation about care (0.89); telling the patient the truth about health even if bad news (0.88); feeling comfortable asking questions (0.87); and trusting the provider and team (0.85). Further, the data element directly asking whether the patient felt heard and understood was strongly correlated (0.78) with the CAHPS total score. The lowest correlation with the CAHPS total score was with the data element asking about the provider and team knowing the patient's wishes if unconscious or in a coma (0.52). The moderate to high correlations with the CAHPS total score provide evidence supporting the convergent validity of the Heard and Understood data elements.

Table 10. Response Frequencies for CAHPS Communication Items [count (percent)]

Data Elements	Never	Sometimes	Usually	Always
In the last 6 months, how often did this provider and team…				
explain things in a way that was easy to understand?	1 (0.8)	2 (1.7)	16 (13.6)	99 (83.9)
listen carefully to you?	2 (1.7)	4 (3.4)	10 (8.5)	102 (86.4)
show respect for what you had to say?	2 (1.7)	5 (4.2)	7 (5.9)	105 (88.2)
spend enough time with you?	3 (2.5)	1 (0.8)	12 (10.1)	103 (86.6)

It was hypothesized that feeling heard and understood would be associated with receiving the help wanted for pain (scored from 1 to 3), as well as receiving desired emotional support (scored from 1 to 3) from the provider and team. As such, convergent validity was tested by correlating the Heard and Understood data elements with each of these data elements. Receiving the help wanted for pain (scored from 1 to 3) was low-to-moderately correlated with Heard and Understood data elements and ranged from 0.28 to 0.53. Receiving wanted emotional support (scored from 1 to 3) was moderately correlated with Heard and Understood data elements and

ranged from 0.37 to 0.67. Specifically, the data element directly asking whether the patient felt heard and understood by the provider and team was moderately correlated with both receiving the help wanted for pain (0.43) and receiving desired emotional support (0.59). The correlations between feeling heard and understood and each of these data elements provide further evidence supporting the convergent validity of Heard and Understood data elements as well as for the receiving wanted help for pain data element.

Site Interviews

Interviews were conducted with programs participating in the alpha test following the data collection phase to gather information about their experiences in terms of the feasibility, feedback, and their perspectives on implementation. Overall, the programs were positive about their participation and found the results on their program's performance on the survey to be helpful feedback for their program.

Methods

The interview protocol was developed to focus on different aspects of the alpha data collection, including feasibility around the process of identifying eligible patients, any feedback programs may have received from patients during the alpha test, feedback on a summary report sent to programs following the alpha test, and implementation and what programs may currently do to gather patient experiences of care.

All five alpha test programs were contacted by email to participate in a 30-minute telephone interview to gather information about their site's participation in the alpha test. Programs were first contacted on November 19, 2019, a week after receiving a summary report of their program's survey results from the alpha test. We communicated to program contacts that they could invite any individuals on their team to join the phone call who assisted with the process of identifying eligible patients. Interviews were conducted by phone with four alpha test programs and included the program contact (i.e., palliative care health care provider or program director) and one or two individuals who managed the identification of eligible patients (i.e., data analyst, business analyst). One of the alpha test programs did not respond to the request for an interview despite multiple attempts. Interviews were conducted between November 25, 2019, and December 6, 2019. Interviews were audio-recorded, and the recordings were used to supplement the notes taken during the interviews.

Findings

Feasibility

Programs described the process of identifying eligible patients for the data file as "manageable" and a relatively "smooth" process. This was typically a two-step process involving pulling data from the patient's electronic medical record and then a manual process of going

through each record to find additional information needed for the data requested. All four programs had assistance from a data specialist, business analyst, or a contact in their billing department to assist with preparing the data file. One alpha test program noted that, if their site did not have a business analyst who could help with writing a query in their database to pull the information from the electronic medical record, the process would have been more challenging, and it may not have been feasible for their program to participate in the alpha test. Most programs described additional research in their databases or a manual process of going through the medical record to extract data that were requested (i.e., going through the chart to make sure the patient was still an active patient and not deceased as well as deleting duplicate patients).

Feedback

All four programs stated that the information presented in the summary report was both helpful and useful for their programs and highlighted potential educational opportunities for patients and providers. Two programs noted that they had to look carefully for the response rate but appreciated the disclaimer about the report reflecting only data from the alpha phase with no comparative data. One palliative care program coordinator commented that she would have liked to have seen some qualitative data such as open-responses and an opportunity for patients to provide more information beyond a "yes" or "no" response.

One physician, the chief medical officer for the site, commented that some of the negative feedback on pain management may have come from patients whose providers cut back on opioids to treat their pain. Because of recent transitions in palliative care to redirect pain management from opioids to alternative treatments, this physician stated that this refocus away from opioids may have made some patients unhappy about their pain management and thus may have prompted less favorable responses in the survey.

Two programs received feedback from patients who asked about the survey. One of these programs reported that some of their palliative care providers were unaware of the program's participation in MACRA when a few patients approached them about the survey. Subsequently, the program contact (chief medical officer) explained the program's participation in MACRA to the providers so that they could communicate this to their patients if any other questions arose.

Implementation

We asked contacts from the four programs to comment on their ability to communicate with patients and caregivers electronically as a way to consider an electronic option for implementation of the survey. Only one program described collecting email addresses from patients and reported that about 75% of their patients provide an email address. The other three programs do not directly collect email addresses from patients; indeed, one program noted that their compliance department restricts any kind of external communication with patients through email, including through a patient portal. Three of the four programs reported that they do use an app or online patient portal to communicate with patients, which was mentioned as a potential

mode for sending a survey to patients (but not always to caregivers). None of the programs had prior experience administering electronic surveys and had mixed perceptions about whether their patients would complete an electronic survey. Some programs commented that their palliative care patients are older and seriously/terminally ill and would likely not complete an electronic survey, whereas other programs noted that their patients and caregivers might prefer the ease of an electronic survey, provided adequate computer experience.

Lessons Learned for Beta

A key reason for conducting the alpha test was to inform procedures during the beta test. We anticipated that the alpha test would inform beta recruitment, patient identification and program data capabilities, fielding procedures, and survey content and administration. Below we highlight some of these key findings and how they might affect the beta test.

Program Recruitment Processes

A common challenge we encountered while recruiting outpatient palliative care programs for the alpha test was the need to support sites as they navigated their internal administrative approval processes. This included IRB review processes, legal or contractual processes for reviewing the project data use agreement (DUA), IT approval processes (e.g., for a site coordinator to gain access to and share the necessary patient-level data), and general site leadership approval and endorsement. The need to go through such processes often delayed a site's alpha test, extending the anticipated recruitment time built into our overall study timeline. In addition, many site coordinators did not have prior experience navigating these processes and sought assistance from our team. Though our ability to navigate other sites' specific processes was limited, we implemented the following tools/changes to support recruitment for the beta test:

- We created an IRB support package, including all relevant RAND approvals and official project documentation, for sites to submit with their IRB application (if applicable).
- We developed an IRB summary document (included in the package), describing in simple terms our study procedures and data safeguarding plans, that sites can share with administrators. Text from this document could be used in site-specific IRB applications, if applicable.
- We established the range of potential processes a site might have to undertake and the likely resources needed to navigate these successfully. This helped us clearly communicate what could be needed to participate in the study to potential sites, so they were better prepared to engage in the process.
- We adjusted our overall study timeline to allow additional time for recruitment if necessary and determined that recruitment would likely need to be ongoing even as the beta field test was underway, to allow "rolling" onboarding of potential sites.
- We increased our communication about the project and our outreach to sites at national forums to allow for earlier outreach and time for sites to consider the implications of

participating. These forums also allowed sites opportunities to ask questions of project team members and other sites to better understand the study overall.

Determining Patient-Level Study Eligibility

Based on input from our TECUPP and project advisory panel, our primary eligibility criteria for patients to receive a survey was that they have one outpatient palliative care visit in a three-month period. However, other options discussed included two outpatient palliative care visits and a longer (six-month) eligibility period. Considerations included ensuring that the visit experience was recent enough for a patient to be able to answer the survey questions, that the patient had enough experience with the palliative care provider and team to answer the survey, and that loss due to physical decline (e.g., if there was too much time between the visit and survey administration) or death was minimized. During the alpha test, we were able to establish that there was little difference in the total number of patients yielded based on one visit in three months versus one visit in six months. Specifically, of the 996 patients identified with one eligible outpatient palliative care visit in 6 months, most patients (n=662; 66%) had the eligible visit in the prior 3 months. This is important because the more recent the qualifying visit, the more recent the patient's experience with outpatient palliative care is likely to be, minimizing potential recall bias. In addition, we established that more patients were yielded using the criteria of one visit in three months versus two visits in three months. Specifically, among the 662 patients with at least one qualifying visit in 3 months, 318 patients had only one visit in that timeframe. Requiring two outpatient palliative care visits in 3 months would thus reduce the potential eligible sample by almost half, offsetting any benefit to be gained by the greater exposure to the palliative care program. As such, and in consultation with our project advisors and expert panel, we finalized eligibility for the beta test as one outpatient visit in a three-month period. This had the added implication of providing reassurance that our initial assumptions regarding sample size were conservative, and that we would likely reach the necessary number of providers/practice and patients/provider within (or even earlier) the planned beta field period.

Program Identification of Palliative Care Patients

During the alpha test, we sought to better understand how palliative care programs could identify eligible patients to be surveyed. This has important implications not only for the conduct of the beta test but also for implementation and measure specifications. For example, measure eligibility could be based on all visits coded as palliative care visits or based on all visits with providers with an NPI taxonomy code for hospice and palliative medicine (i.e., palliative care specialty providers only). Given increased support for integrating palliative care into standard care, and the broad definition of what palliative care encompasses, we anticipated challenges with identifying patients currently receiving outpatient palliative care services. Based on interviews with alpha test sites, as well as a review of the data files sent to us from the alpha test

sites, we found that programs inconsistently coded palliative care visits, and that few sites used the ICD-10-CM code for "Encounter for palliative care (Z51.5) at all. In addition, we learned that it would be challenging to use the provider's specialty code to identify palliative care-specific visits because health systems often did not update NPI codes to reflect new board certifications, or only listed a single primary NPI code (typically the highest-level taxonomy code; e.g., internal medicine). These challenges were further confirmed in discussions with project advisors and TECUPP members with expertise in this area. An implication of these challenges for implementation might be that only a narrow set of visits, e.g., those that are coded with ICD-10-CM Z51.5, would be eligible for the proposed measures. Over time, the use of these measures within performance and accountability programs could drive much-needed improvements in coding practice for the field.

Survey Administration Procedures

During alpha testing we sought to obtain feedback on some of our survey administration procedures, including whether email or web could be a viable survey mode, whether the inclusion of a postage-paid postcard to allow recipients to opt-out of receiving a survey under special circumstances would be beneficial, and the extent to which the pre-notification and survey cover letters provided relevant context to recipients. Only one of the five alpha test sites collected and provided email contact information for their included patients, with approximately 65 percent data availability, while the other four alpha sites did not collect/record email contact information at all. This suggests the possibility that a minority of programs collect email data, but when they do, the email information available from these programs would be high enough to warrant inclusion of an email- or web-based component to the fielding procedure (e.g., emailed survey link prior to mailed survey) in the beta test.

During the alpha test, five postcards were returned indicating that the patient recipient had died, thereby allowing the team to exclude these cases earlier in the process and avoid unnecessary phone follow-up for survey completion. During the telephone contact, fourteen additional patients were confirmed deceased. Given the potential cost for the data collection, and, more importantly, the impact of phoning families of a recently deceased loved one, it was determined that the postcard was an effective inclusion in the study and should be retained as part of the beta test survey administration procedure.

Lastly, we received some proactive feedback from points of contact at two alpha test sites, who had received a request from a single patient each to clarify the purpose of the survey. This feedback led us to revise the content of both the pre-notification and survey cover letters to clarify 1) the purpose of the study; 2) how the patient was identified for the survey and how their data were handled; and 3) how the palliative care program was involved in the study and survey administration procedures.

Changes to Survey Data Elements

While there was some variability in item responses to Heard and Understood data elements, there was evidence of some potential ceiling effects (i.e., topping off). For instance, when asked about being seen as a person and not just someone with a medical problem, 91% of patients indicated this was *very true* with only 9% spread across the other four response options (mostly true, somewhat true, a little bit true, not at all true). This finding raised the possible need to revise the rating categories for these data elements in order to create greater distinctions between categories. Specifically, we hypothesized the distinction between the *very true* and *mostly true* rating options may not have been clear enough to respondents. Prior work led by Dr. Robert Gramling, the developer of the original Heard and Understood data element and also a project advisor for the current project, suggested that using the word "completely" instead of "very" or "a lot" to quantify how much the patient felt heard and understood created greater distance between the top two response categories. Findings from cognitive interviews with hospitalized patients in his study indicated patients perceived "completely" to be equivalent to 100%, or an A+ grade, while the terms "very" and "a lot" covered a broader rating; e.g., 90% to 100%). We further consulted with other project advisors including members of the PROMIS initiative and experts in Item Response Theory, as well as our own project psychometricians, to explore appropriate changes to the survey. Finally, in discussion with the TECUPP, revisions were made to the response option labels to create a clearer distinction between categories; specifically, the top two rating response options for the Heard and Understood data elements were revised to *completely true* and *very true*. Remaining response options were retained (i.e., *somewhat true*, *a little bit true, not at all true*).

Other changes to the survey included the addition of several new data elements intended to be used in beta to better characterize the sample but also for known groups validity testing, possible risk adjustment, and performance measure stratification. The new data elements capture changes in self-reported overall health, pain interference with daily activities, depressive mood, and cognitive functioning (Table 11). The additional data elements after the alpha test increased the survey length from 35 items to 43 total items. Though this increase does not cause concern regarding response rates, we will monitor response rates in beta to understand the impact of these additional items. Looking to implementation, the overall survey is not expected to include all 43 items, since many are included solely for testing and analytic purposes.

Table 11. New Data Elements Included in Beta Testing

Changes in overall health
Compared to 3 months ago, how is your overall health now?
Pain interference
In general, how much does pain interfere with your day to day activities?

Depressive mood
Over the last 2 weeks, how often have you been bothered by having little interest or pleasure in doing things?
Over the last 2 weeks, how often have you been bothered by feeling down, depressed, or hopeless?
Cognitive Function
Over the last 2 weeks, how often has your thinking been slow?
Over the last 2 weeks, how often has it seemed like your brain was not working as well as usual?
Over the last 2 weeks, how often have you had to work harder than usual to keep track of what you were doing?
Over the last 2 weeks, how often have you had trouble shifting back and forth between different activities that require thinking?

Summary and Next Steps

Findings from the alpha test support the planned procedures for the national beta test, provide guidance for improvements to the survey administration to increase feasibility and response rates, and offer preliminary evidence of measure reliability and validity. The national beta test began in October 2019 and will continue for up to 12 months, or until adequate sample is achieved to establish measure performance. During the beta test, we will continue to engage sites to obtain information on measure usability and use, feasibility, and value. Upon completion of the test, we will prepare documentation on the use of the proposed measures in accountability programs, per the requirements of the cooperative agreement.

Appendix A: Alpha Test Survey Instrument

PATIENT EXPERIENCE SURVEY

SURVEY INSTRUCTIONS

- This survey should be completed by the person indicated on the survey cover letter.
- You can ask a family member or friend for help with this survey or ask them to complete the survey for you.
- If you are a family member or friend helping with this survey or completing this survey for the person indicated on the survey cover letter, 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.
- 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:

RAND Corporation
Attn: Ryan McKay – M2W
1776 Main Street
Santa Monica, CA 90401

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 Label] and team

Is that right?

☐ Yes

☐ No → **If No, go to Question 23**

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 CARE FROM THIS PROVIDER AND TEAM IN THE LAST 6 MONTHS

The following questions ask about the care you have received from this provider and team in the last 6 months.

2. In the last 6 months, how often have you seen this provider and team for your care?

☐ I have seen this provider and team many times for my care

☐ I have seen this provider and team a few times for my care

☐ I have seen this provider and team only one time for my care

3. In the last 6 months, how often did this provider and team explain things in a way that was easy to understand?

☐ Never

☐ Sometimes

☐ Usually

☐ Always

4. In the last 6 months, how often did this provider and team listen carefully to you?

☐ Never

☐ Sometimes

☐ Usually

☐ Always

5. In the last 6 months, how often did this provider and team show respect for what you had to say?

☐ Never

☐ Sometimes

☐ Usually

☐ Always

6. **In the last 6 months, how often did this provider and team spend enough time with you?**

   ☐ Never

   ☐ Sometimes

   ☐ Usually

   ☐ Always

7. **In the last 6 months, have you ever had pain?**

   ☐ Yes

   ☐ No → **If No, go to Question 10**

8. **In the last 6 months, did you want help from this provider and team for this pain?**

   ☐ Yes

   ☐ No → **If No, go to Question 10**

9. **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

10. **In the last 6 months, did you want emotional support from this provider and team?**

    ☐ Yes

    ☐ No → **If No, go to Question 12**

11. **In the last 6 months, did you get as much emotional support as you wanted from this provider and team?**

    ☐ Yes, definitely

    ☐ Yes, somewhat

    ☐ No

YOUR OVERALL EXPERIENCE WITH THIS PROVIDER AND TEAM

12. **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.

    ☐ Very true

    ☐ Mostly true

    ☐ Somewhat true

    ☐ A little bit true

    ☐ Not at all true

13. **I trusted this provider and team.**

    ☐ Very true

    ☐ Mostly true

    ☐ Somewhat true

    ☐ A little bit true

    ☐ Not at all true

14. I felt comfortable asking this provider and team questions.

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ A little bit true
- ☐ Not at all true

15. I could tell this provider and team anything, even things I might not tell anyone else.

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ A little bit true
- ☐ Not at all true

16. I felt this provider and team put my best interests first when making recommendations about my care.

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ A little bit true
- ☐ Not at all true

17. I felt this provider and team always told me the truth about my health, even if there was bad news.

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ A little bit true
- ☐ Not at all true

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

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ A little bit true
- ☐ Not at all true

19. I felt this provider and team knew what worried me most about my health.

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ A little bit true
- ☐ Not at all true

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

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ A little bit true
- ☐ Not at all true

21. I felt this provider and team would know what I would want done if I was unconscious or in a coma.

- ☐ Very true
- ☐ Mostly true
- ☐ Somewhat true
- ☐ A little bit true
- ☐ Not at all true

22. Using any number from 0 to 10, where 0 is the worst provider and team possible and 10 is the best provider and team possible, what number would you use to rate this provider and team? Mark one number.

- ☐ 0 Worst provider and team possible
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10 Best provider and team possible

ABOUT YOU (THE PATIENT)

23. In general, how would you rate your overall health?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

24. In general, how would you rate your overall mental or emotional health?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

25. 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

26. Are you of Hispanic or Latino origin or descent?

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

27. 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

28. What language do you <u>mainly</u> speak at home?

- ☐ English
- ☐ Spanish
- ☐ Some other language (please print):

29. Did someone help you with this survey?

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

30. Who helped you complete this survey?

- ☐ Spouse or partner
- ☐ Child
- ☐ Sibling
- ☐ Other family member or friend
- ☐ Paid caregiver
- ☐ Someone else (please print):

31. 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
- ☐ Helped in some other way

32. For what reason did someone help you complete this survey? Check all that apply.

- ☐ Too sick
- ☐ Trouble with memory
- ☐ Trouble seeing or reading
- ☐ Hard of hearing
- ☐ Do not understand [English/Spanish]
- ☐ Wanted someone else to complete the survey
- ☐ Patient is in a coma
- ☐ Patient has passed away
- ☐ Some other reason (please print):

33. How familiar is the person who helped you complete the survey with your condition and care?

- ☐ Extremely
- ☐ Very much
- ☐ Somewhat
- ☐ A little
- ☐ Not at all

34. How often does the person who helped you complete the survey also help you make decisions about your medical treatment?

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

35. Does the person who helped you complete this survey also provide or help you with any of the following? Check all that apply.

- ☐ Companionship (talking, reading, keeping company) or supervision
- ☐ Transportation (driving to doctor appointment, driving for errands)
- ☐ Homemaking (shopping, cleaning, preparing meals)
- ☐ Personal care assistance (feeding, bathing, toileting, dressing, grooming)
- ☐ Healthcare assistance (help with medications, wound care)
- ☐ Financial assistance (paying bills, managing budget)
- ☐ Other activities (please print):

Thank you for completing this survey.
Please return the completed survey in the provided pre-paid envelope.

RAND Corporation
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