American Academy of Hospice and Palliative Medicine

CMS MACRA COOPERATIVE AGREEMENT “PALLIATIVE CARE QUALITY MEASURES PROJECT”

Summary of:

Technical Expert Clinical User Patient Panel (TECUPP) Virtual Meeting

June 15, 2020

This project is supported by the Centers for Medicare and Medicaid services (CMS) and the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $5.5 million dollars over three years with 100 percent funded by CMS/HHS. This funding was through a cooperative agreement between CMS and AAHPM from 2018 to 2021. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, CMS/HHS, or the U.S. Government.

Project, TECUPP, and MSP overview:

Through a Cooperative Agreement from the Centers for Medicaid and Medicare Services (CMS), the American Academy of Hospice and Palliative Medicine (AAHPM) is working with partners at the National Coalition for Hospice and Palliative Care (Coalition) and RAND Health (RAND) to create new palliative care patient reported outcome performance measures. The Palliative Care Quality Measures Project Team ("Project Team") is composed of staff members from AAHPM, the Coalition, RAND, the Center to Advance Palliative Care, and consultants Rebecca Swain-Eng, MS, CAE (SEA Healthcare), and Ellen Schultz (American Institutes for Research). Katherine Ast, MSW, LCSW, Director of Quality & Research for AAHPM, leads the team.

The AAHPM team convened a Technical Expert Clinical User Patient Panel (TECUPP) and Measure Specification Panel (MSP), which are chaired by Sydney Dy, MD, MS, FAAHPM, and Mary Ersek, PhD, RN, FPCN. The TECUPP and MSP contribute direction and thoughtful input on the development of the measures for patients with serious illness using their background as real-world clinical 'end-users,' experience with patients, caregivers, and family members, and expertise in measure development and testing methodologies. The TECUPP and MSP members represent a broad array of stakeholders including measure development experts, palliative care clinicians from the interdisciplinary care team, specialty society representatives, patient advocates, patients who experienced a serious illness or palliative cares services or their family members, and caregivers, healthcare industry representatives, diversity experts, and others.

Members of the TECUPP were selected from nominations received from the public and include representatives from national organizations such as AAHPM, AMDA – The Society for Post-Acute and Long-Term Care Medicine, American Association of Family Physicians (AAFP), American College of Physicians (ACP), American Geriatrics Society (AGS), American Society of Clinical Oncology (ASCO), Center to Advance Palliative Care (CAPC), Coalition to Transform Advanced Care (C-TAC), HealthCare Chaplaincy Network™ (HCCN), Hospice and Palliative Nurses Association (HPNA), National Hospice and Palliative Care Organization (NHPCO), National Patient Advocate Foundation (NPAF), Physician Assistants in Hospice and Palliative Medicine (PAHPM), Social Work Hospice and Palliative Network (SWHPN), Society of Pain and Palliative Care Pharmacists (SPPCP), and the Supportive Care Coalition (SCC).

As part of this Project, TECUPP members are expected to participate in the project over the course of three years and provide expertise and feedback on quality measures for patients with serious illness throughout the measure development lifecycle, as requested. A small subgroup of experts with highly technical measure development and specification expertise, the Measure Specification Panel (MSP) were selected from the TECUPP to evaluate proposed measure concepts, to provide input on initial feasibility and technical measure specifications, and review testing results to guide decision-making regarding each measure. The TECUPP and MSP had their first meetings, in-person, in Chicago on April 10 and April 11, 2019. On October 21, 2019, the TECUPP convened virtually for a second meeting. On June 15, 2020, the TECUPP convened virtually for a third meeting. The topics discussed at this third meeting included reviewing final Alpha field test results and preliminary Beta field test results (November 2019-April 2020), discussing the perceived impact of the COVID-19 pandemic on palliative care delivery and practices and ways to address the increased use of telehealth by palliative care practices in the Beta test, and how to address the lack of racial and ethnic diversity seen in preliminary Beta testing results.

TABLE 1 – TECUPP Composition:

Name	Organization	Member of the MSP	Present at Virtual TECUPP meeting (6/15/2020)	Additional COI disclosed during meeting
Steven M. Asch, MD, MPH	Stanford University and VA Palo Alto Healthcare System, Palo Alto, CA	Yes	Yes	Yes Led a small planning grant to Stanford from Facebook for clinical preventive services health outreach since October, now over.
Kathleen Bickel MD, MPhil, MS	University of Colorado School of Medicine, Aurora, CO	Yes	Yes	None
Lori Bishop, MHA, BSN, RN	National Hospice and Palliative Care Organization, Alexandria, VA	Yes	Yes	None
Brenda Blunt, DHA, MSN, RN	CVP Corp, Towson, MD	No	Yes	None
Amy Ciancarelli, BS, CPXP	Care Dimensions, Danvers, MA	No	Yes	None
Amy Davis, DO, MS, FACP, FAAHPM	Dr. Amy Davis Palliative Care and Symptom Support, Bala Cynwyd, PA	No	Yes	Yes Currently owns 78 shares of TEVA stock (currently worth approximately $940) Medical director for OptumRx, Prior Authorizations (medications); consultant to Maximus; eviCore, radiologic prior authorizations (prior) Independent palliative care physician; revenue from patients and payers Travel reimbursement from AAHPM related to attending PCPI meeting and Annual Mtg pre-conference session; Travel

				reimbursement from ACP related to patient advocacy activities in DC
Sa'Brina Davis, patient advocate, family caregiver	National Patient Advocate Foundation, Washington, DC	No	Yes	None
Sydney Dy, MD, MS, FAAHPM, *TECUPP Co - Chair	John Hopkins Bloomberg School of Public Health, Baltimore, MD	Yes	Yes	None
Mary Ersek, PhD, RN, FPCN, *TECUPP Co - Chair	Department of Veterans Affairs; U. of Pennsylvania Schools of Nursing and Medicine, Philadelphia, PA	Yes	Yes	None
Torrie Fields, MPH	Votive Health, San Francisco, CA	Yes	Yes	CEO of Votive Health, a serious illness management service; paid consultant to health plans on program evaluation; Votive Health, ownership & equity; Paid consultant to CAPC, CTAC; Board of Directors for SWHPN Advisor to Community Oncology Alliance
Elizabeth Fricklas, PA - C	Duke Health, Durham, NC	No	Yes	None
Joy Goebel, RN, PhD, FPCN	California State University Long Beach, Long Beach, CA	No	Yes	None
Matthew Gonzales, MD, FAAHPM	Institute for Human Caring and St. John's Health, Gardena, CA	No	No	N/A
Anna Gosline, SM	Blue Cross Blue Shield of Massachusetts, Boston, MA	No	No	None
Marian Grant, DNP, CRNP, ACHPN, FPCN, RN	Consultant, Baltimore, MD	No	Yes	N/A

George Handzo, MA, MDiv, BCC, CSSBB	HealthCare Chaplaincy Network©, New York, NY	No	Yes	None
Denise Hess, MDiv, BCC - PCHAC	Supportive Care Coalition; Providence St. Joseph Health, Hillsboro, OR	No	Yes	None
Sarah Hetue Hill, MA, PhD	CHRISTUS Santa Rosa Health System Group, St. San Antonio, TX	Yes	Yes	None
Faye Hollowell, BS, BM, patient advocate, family caregiver	National Patient Advocate Foundation, Washington, DC	No	Yes	None
Arif Kamal, MD, MBA, MHS, FAAHPM, FASCO	Duke University School of Medicine, Chapel Hill, NC	Yes	No	None
Rebecca Kirch, JD	National Patient Advocate Foundation, Washington, DC	No	Yes	None
Cari Levy, MD, PhD, CMD	AMDA –The Society for Post - Acute and Long -Term Care Medicine, Denver, CO	No	No	None
Hannah Luetke - Stahlman, MPA	Cerner Corporation, Kansas City, MO	No	Yes	None
Phillip Rodgers, MD, FAAHPM	University of Michigan Medical School, Ann Arbor, MI	Yes	Yes	None
Benjamin Schalet, PhD	Northwestern University, Chicago, IL	Yes	Yes	None
Tracy Schroepfer, PhD, MSW, MA	University of Wisconsin - Madison School of Social Work, Madison, WI	No	Yes	None
Cardinale B. Smith, MD, PhD	Icahn School of Medicine at Mount Sinai, New York, NY	Yes	Yes	None
Paul E. Tatum, III, MD, MSPH, CMD, FAAHPM, AGSF	Dell Seaton Medical Center at the University of Texas, Austin, TX	No	Yes	None
Martha Twaddle, MD, FACP, FAAHPM, HMDC	Northwestern Lake Forest Hospital Cancer Center, Lake Forest, IL	No	Yes	None

Kathryn Walker, PharmD, BCPS, CPE	University of Maryland; MedStar Health; Society of Palliative Care Pharmacists, Baltimore, MD	No	Yes	None

Project Team Staff Present:
Katherine Ast, MSW, LCSW (AAHPM); Joe Rotella, MD, MBA (AAHPM); Kelly McKenna, MA (AAHPM); Sangeeta Ahluwalia, PhD (RAND); Carrie Farmer, PhD (RAND); Maria Edelen, PhD, MA (RAND); Brian Vegetabile, PhD (RAND); Jessica Phillips, MS (RAND); Sarah Dalton, MA (RAND); Lori Frank, PhD, MA (RAND); Anne Walling, MD, PhD (RAND) Amy Melnick, MPA (The Coalition); Gwynn Sullivan, MSN (The Coalition); Cozzie King (The Coalition); Rebecca Swain-Eng, MS, CAE (SEA Healthcare)

Guests:
Wil Agbenyikey (CMS); Caroline Loeser; Aamna Kabani; Including: TECUPP members, Project Team staff, and guests there were a total of forty-four (44) attendees at this third TECUPP meeting.

Preview of Measures:
In alignment with CMS's Meaningful Measures framework, which identifies high priorities for quality measurement and improvement, CMS identified gaps in the Quality Payment Program (QPP) measure set. One gap identified was in palliative care measures. CMS selected AAHPM, with partners the Coalition and RAND, to address this gap through the creation of new quality measures. AAHPM had previously identified known gaps in quality measurement for palliative care, and thus was well suited to lead this work.

TABLE 2 – Proposed Measures for Discussion during the Virtual TECUPP Meeting:

Measure Name	**Description**
Palliative care outpatients' experience of feeling heard and understood	**Percentage of patients aged 18 years and older per year who are fielded a patient experience survey within 3 months of an outpatient palliative care visit, who report feeling heard and understood by their palliative care provider and team over the last six months**
Palliative care outpatients' experience of receiving desired help for pain	**Percentage of patients aged 18 years and older per year who are fielded a patient experience survey within 3 months of an 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**

PALLIATIVE CARE QUALITY MEASURES PROJECT

Technical Expert Clinical User Patient Panel (TECUPP) Virtual Meeting Summary
Monday June 15, 2020 12:00 am - 2:00 pm ET Meeting
Location: Virtual

TECUPP MEETING ON JUNE 15, 2020 SUMMARY

9:15am PT/ 12:15pm ET Welcome Remarks:

The meeting was scheduled to begin at 9:00am PT / 12:00pm ET. However, due to technical difficulties resulting in poor sound quality on Zoom, the meeting was delayed until the sound quality issues could be properly mitigated.

Presenters: TECUPP Co-Chairs Mary Ersek, PhD, RN, FPCN, and Sydney Dy, MD, MS, FAAHPM.

After welcoming everyone, the TECUPP observed a moment of silence to acknowledge the pandemic and issues of racial unrest throughout the United States.

9:20am PT/ 12:20pm ET Housekeeping, and Project Reorientation:

Presenter: Katherine Ast, MSW, LCSW, Director, Quality and Research, AAHPM

Katherine Ast welcomed the TECUPP members. She asked that comments and questions be typed into the chat box throughout the presentation and indicated that they would be answered throughout the meeting. Since the TECUPP is comprised of individuals with diverse expertise, Katherine reminded everyone that they have unique and valuable knowledge that will help provide strategic direction to this project.

A copy of the slide deck was shared prior to the meeting. A TECUPP meeting follow-up survey will be sent to all TECUPP members for them to complete to gain additional feedback after the meeting.

Conflict of interest responses were collected from TECUPP members prior to the meeting, displayed on a slide, and TECUPP members were asked to share any additional conflicts of interest verbally or in the chat box during the meeting. Beyond what was shared in advance of the Virtual Meeting (recorded above from Torrie Fields), one additional conflict of interest was disclosed in the chat box (recorded above from Steven Asch), and one additional conflict of interest was shared after the meeting in an email (recorded above from Amy Davis).

Project Reorientation:

TECUPP Roles and Responsibilities During This Meeting:

- Provide input on key decisions regarding data elements, testing design, testing results, and the proposed quality measures.
- Engage in group discussions with an open mind and critical eye.
- Share informed opinions freely.
- Remember the importance of a “by us, for us” quality measure development process for the palliative care field.

Project Goal:
To develop two patient-reported quality measures of outpatient palliative care experience for CMS's Merit-based Incentive Payment System (MIPS) under the Quality Payment Program (QPP) created by the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA). The Project Plan is to submit these measures to the 2021 Measures Under Consideration (MUC) list for consideration of incorporation into MIPS.

The Project Team reviewed the two measures under development with the TECUPP.

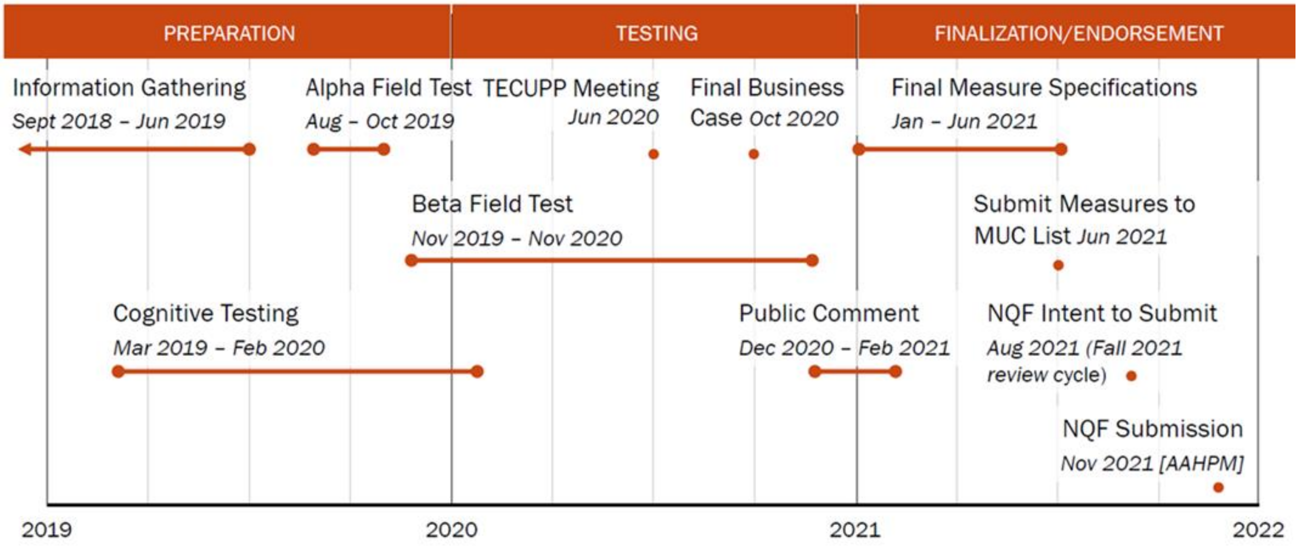
TABLE 3 – Measures for Discussion during the Virtual TECUPP Meeting:

Measure Name	**Description**
Palliative care outpatients' experience of feeling heard and understood	**Percentage of patients aged 18 years and older per year who are fielded a patient experience survey within 3 months of an outpatient palliative care visit, who report feeling heard and understood by their palliative care provider and team over the last six months**
Palliative care outpatients' experience of receiving desired help for pain	**Percentage of patients aged 18 years and older per year who are fielded a patient experience survey within 3 months of an 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**

Meeting Goal:
After an overview of Alpha field test results and preliminary Beta test results, the TECUPP was asked to provide feedback and discuss the effects of the COVID-19 pandemic on palliative care and practice, the applicability of including telehealth visits for palliative care services, the plan for restarting field testing data collection, and opportunities for stakeholder engagement. The goal of this meeting was to gather feedback from the extensive expertise of the TECUPP panel and use that feedback to improve the Project Plan.

Reviewed abridged project timeline:
The TECUPP was reoriented to the project timeline. The graphical timeline shared did not include an exhaustive list of project tasks. It showed the timeline for project measure development, testing, and finalization of measures at a high level. For example, the Project Team, led by the Coalition, will engage in stakeholder engagement throughout the duration of the project. It should be noted that although all stakeholder engagement activities were not all included on the timeline, sharing information and soliciting feedback from stakeholder groups around key findings and decision points will take place throughout the duration of the project.

FIGURE 1 – Abridged Project Timeline:



9:30am PT/ 12:30pm ET Update on Final Alpha Testing Results:

Presenter: Maria Edelen, PhD, MA, Senior Behavioral Scientist and Psychometrician, RAND Corporation

The purpose of the Alpha test was to begin testing the measure concepts, survey instrument, and feasibility of data collection. Five outpatient palliative care programs participated in the Alpha field test. Participating programs sent RAND sample files containing information on potentially eligible patients from the past six months. Three-hundred patients were included in the Alpha test sample. The Alpha Field Test sites included two programs in North Carolina, one program was in Colorado, one program in Ohio, and one program had patients in both Oregon and Washington.

RAND administered the Alpha test survey using a traditional mixed mode design, which included a mailed survey with telephone follow-up. Prior to receiving the survey, patients received a letter in the mail, which explained that they would be receiving a survey.

The Alpha test helped the Project Team determine the anticipated response rates. Of three hundred fielded surveys, one hundred and twenty were completed, which is an average of forty percent (40%) response rate.

Across the five programs, average response rates ranged from twenty-six percent (26%) to fifty- three percent (53%).

After applying eligibility criteria, a sufficient number of patients were identified using a three-month lookback period instead of a six-month lookback period (1,362 visits by 662 unique patients). This shows that there are enough patients within a three-month lookback period.

The Alpha test also helped the Project Team determine that it was feasible to include a web-based survey as an option during the Beta Field test, in addition to the mailed survey, since some of the practices had records of patient email addresses.

During the alpha test, there was concern around the response options for the “heard and understood” data elements (Very true, Mostly true, Somewhat true, A little bit true, Not at all true). The response distribution was highly skewed and respondents were having difficulty discerning the difference between “very true” and “mostly true” To mitigate this problem, RAND revised the response options to create more distinction between the top two response options as follows: (Completely true, Very true, Somewhat true, A little bit true, Not at all true). This change was guided by suggestions from previous TECUPP meetings, project advisor meetings, and input from the original item developer (who is also a project advisor).

The Alpha test used a convenience sample and thus offered limited program and patient representation. The Beta test is using a nationally representative sample of programs that are distributed by geographic region and program type.

9:30am PT/ 12:30pm ET Update on Preliminary Beta Test Results:

Presenter: Maria Edelen, PhD, MA, Senior Behavioral Scientist and Psychometrician, RAND Corporation

The Goal of the Beta Field test is to examine the reliability and validity of proposed quality measures and explore measure implementation for the QPP. The Beta test fielding period was originally scheduled from November 2019 through November 2020. Due to the COVID-19 pandemic, field testing data collection was paused, with the last round of fielding from March 30, 2020 to May 25, 2020. The overall sample size goal is six thousand (6,000) to seven thousand five hundred (7,500) sampled patients to get two thousand four hundred (2,400) to three thousand (3,000) completed surveys (assuming a forty percent 40% response rate).

The methods for data collection are enhanced mixed mode administration with web, mail and phone in both English and Spanish (planned pending completed translation).

Program recruitment was planned to represent diverse settings and geographic locations. At the time of this TECUPP Virtual Meeting there are forty-three programs participating in the Beta Field test.

TABLE 4 – Beta Program Recruitment:

		Midwest	**Northeast**	**South**	**West**	**TOTAL**
Hospice	Targeted Number of Programs	2	1	3	1	**7**
Hospice	Programs Recruited (with executed DUAs)	2	2	5	1	**10**
Hospice	Percent of Target	100%	200%	167%	100%	**143%**
		Midwest	**Northeast**	**South**	**West**	**TOTAL**
Hospital	Targeted Number of Programs	5	9	7	7	**28**
Hospital	Programs Recruited (with executed DUAs)	5	6	7	7	**25**
Hospital	Percent of Target	100%	67%	100%	100%	**89%**
		Midwest	**Northeast**	**South**	**West**	**TOTAL**
Other	Targeted Number of Programs	3	2	5	5	**15**
Other	Programs Recruited (with executed DUAs)	2	3	2	1	**8**
Other	Percent of Target	67%	150%	40%	20%	**53%**
TOTAL PROGRAMS		**9**	**11**	**14**	**9**	**43**

The preliminary data results represent data completed as of April 2020, which includes nine hundred and fourteen (914) completed surveys. By June 2020, the Beta field test has resulted in one thousand seven hundred and sixty-two (1,762) completed surveys; however, during the TECUPP meeting, participants reviewed only the results through April 2020. As originally designated in the measures, this summary of the Beta Field tests is inclusive of in-person visits and reflective of the prior three months.

TABLE 5 – Beta Surveys as of April 2020:

Survey Administration	Number
Number of surveys fielded	2030
Number of patients eligible for inclusion	1811
Number of completed surveys	914
Mail surveys	424 (46%)
Phone surveys	384 (42%)
Web surveys	106 (12%)
Response rate (914/1811)	51%

Patients who were deemed ineligible had either died (165) or were ineligible for other reasons (54). The primary other reason for ineligibility is the patient said that they did not have visit with the practice during the designated time period.

TABLE 6 – Patient/Respondent Characteristics:

Characteristics (n=914)	% (n) or M (SD)
Age	64.2% (SD = 13.8, N = 913)
Male	44.6% (n = 407, N = 913)
Proxy Assistance	20.5% (n = 187, N = 914)

TABLE 7 – Reason for Proxy Assistance:

Reason for Proxy Assistance	Phone	Mail	Web
Count of Proxy Response by Mode	72	102	13
Patient Helped Answer Some Questions	8.3% (n = 6)		
Read the questions to me		48% (n = 49)	53.8% (n = 7)
Wrote down the answers I gave		47.1% (n = 48)	7.7% (n = 1)
Answered for me		38.2% (n = 39)	46.2% (n = 6)
Translated into my language		2.9% (n = 3)	0% (n = 0)
Helped in some other way		5.9% (n = 6)	0% (n = 0)

As we have seen from our beta field test initial results, there was higher proxy assistance with completing the survey than we expected. The Project Team plans to take a closer look at the surveys that were answered with proxy assistance to understand if the proxy assistance is related to patient cognition. Cognitive function was measured with four items taken from the PROMIS measure set, which are completed by the respondent or proxy (self-report).

FIGURE 2 – Patient Characteristics: Race/Ethnicity/Hispanic

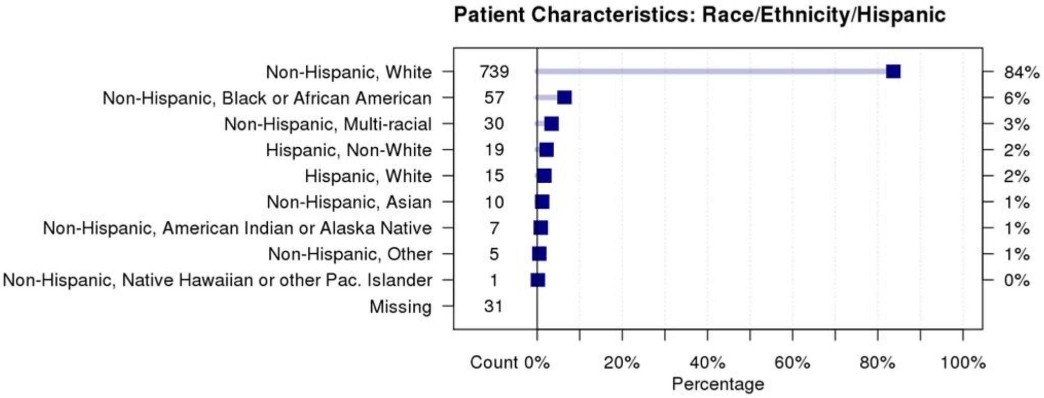
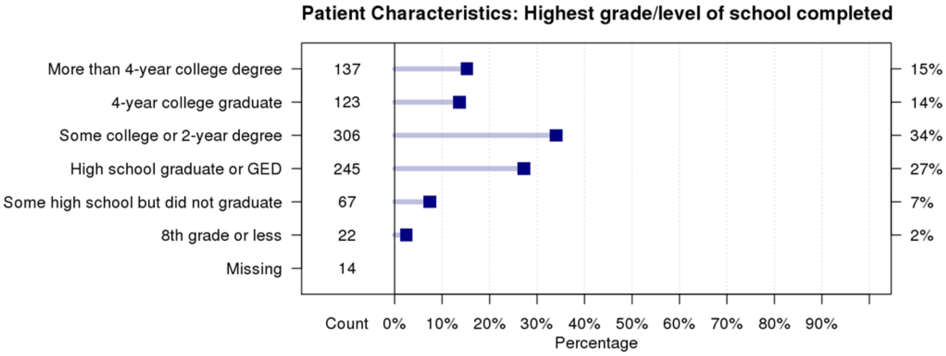


FIGURE 3 – Patient Characteristics: Highest Grade/Level of School Completed



Eighty-seven percent (87%) of Alpha test respondents were white, and seventy-three percent (73%) had some college or more, indicating that the Alpha sample was largely white and well educated. The Project Team had hoped to remedy this by having geographically diverse Beta Field test sites. However, eighty-four percent (84%) of preliminary Beta Field test respondents were white. Therefore, the non-white response rate is lower than we anticipated, which was discussed later in the TECUPP meeting. The education breakdown, in the Beta Field test results, seems reasonable.

FIGURE 4 – Patient Characteristics: Overall Health

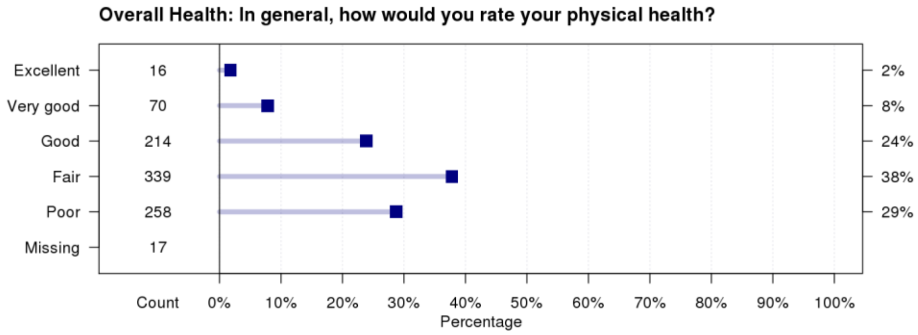


FIGURE 5 – Patient Characteristics: Overall Emotional and Mental Health

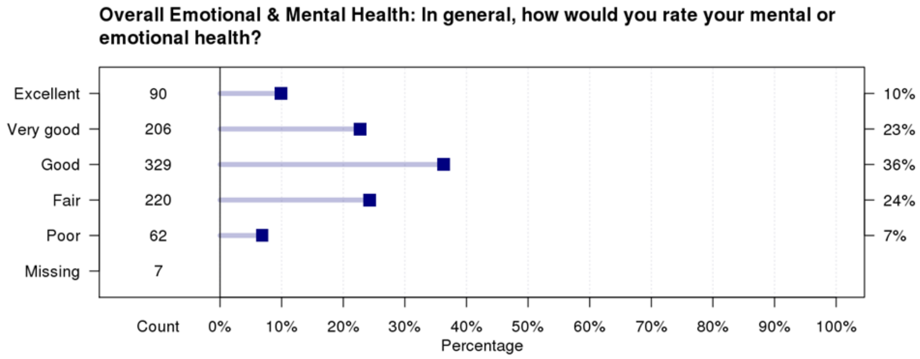
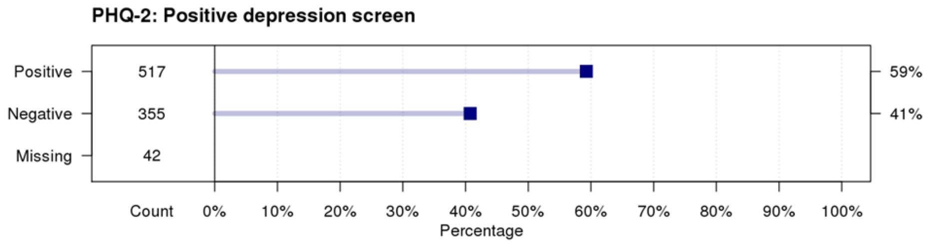


FIGURE 6 – Patient Characteristics: Depression



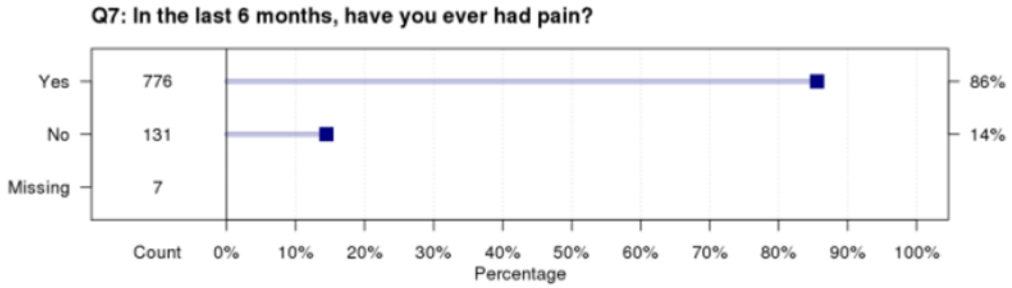
Maria explained that the distribution of physical health seems reasonable and the emotional health distribution is good. It is notable that almost sixty percent (60%) of patients screened positive for depression symptoms.

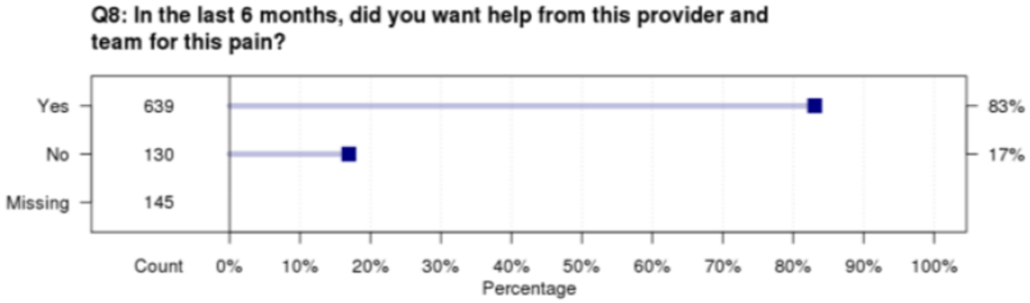
TABLE 9 – Respondents' Answers to Heard and Understood Questions:

Item Number	Question	Completely True	Very True	Somewhat True	A Little Bit True	Not at All True	N
Q12	I felt heard and understood by this provider and team.	71.3%	21.3%	4.2%	2.1%	1.2%	908
Q13	I trusted this provider and team.	75.5%	18.4%	3.9%	1.7%	0.7%	909
Q14	I felt comfortable asking this provider and team questions.	79.4%	15.1%	3.3%	1.3%	0.9%	908
Q15	I could tell this provider and team anything, even things I might not tell anyone else.	60.5%	23.5%	10.8%	2.6%	2.7%	899
	I felt this provider and team …						
Q16	Put my best interests first when making recommendations about my care.	73.6%	18.8%	4.7%	1.8%	1.1%	909
Q17	Always told me the truth about my health, even if there was bad news.	76.9%	17.0%	4.2%	1.2%	0.7%	904
Q18	Saw me as a person, not just someone with a medical problem.	78.4%	15.3%	4.0%	1.4%	0.9%	908
Q19	Knew what worried me most about my health.	64.0%	24.5%	8.9%	0.9%	1.8%	903
Q20	Understood what is important to me in my life.	64.7%	22.4%	9.9%	1.3%	1.8%	903
Q21	Would know what I would want done if I was unconscious or in a coma.	55.7%	22.3%	14.1%	2.6%	5.4%	875

Most patients indicated that they felt heard and understood. The revised response options did create additional distinction between the two options as anticipated.

FIGURE 7 – Respondents' Answers to Pain Questions:

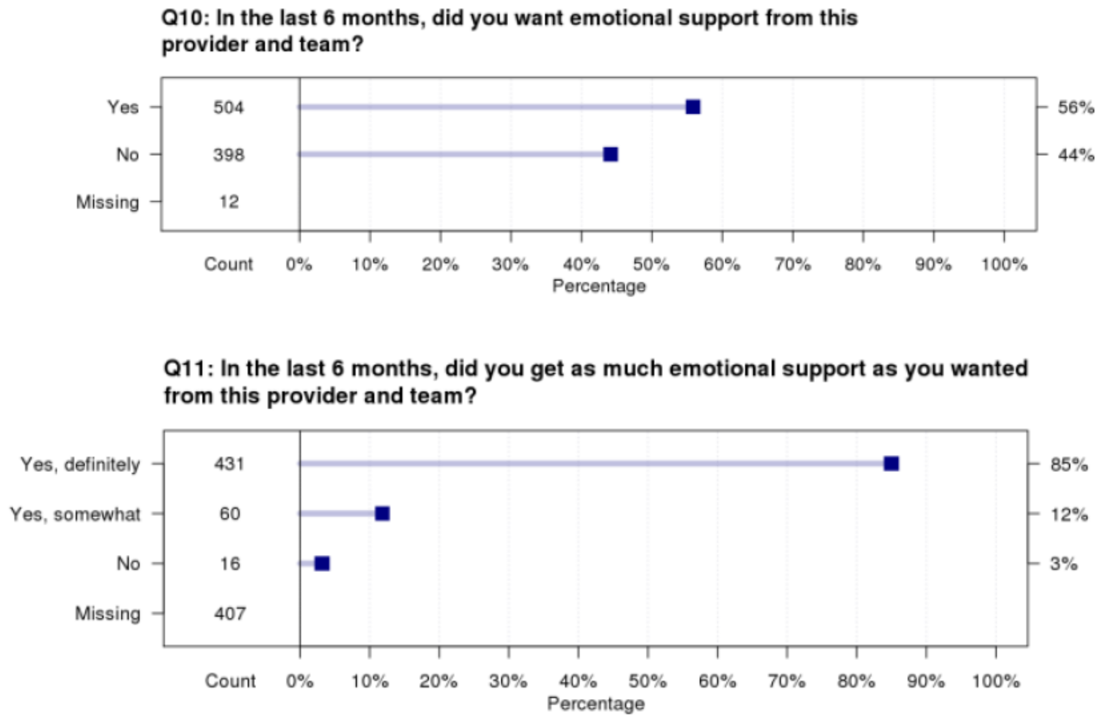

Q7: In the last 6 months, have you ever had pain?


Q8: In the last 6 months, did you want help from this provider and team for this pain?


Q9: In the last 6 months, did you get as much help as you wanted for your pain from this provider and team?

Over eighty percent (80%) of respondents said that they had pain and a majority said that they wanted help from their provider and team for their pain. Additionally, a majority of respondents said that they got the help that they wanted for their pain from their provider and team.

FIGURE 8 – Respondents' Answers to Emotional Support Questions:

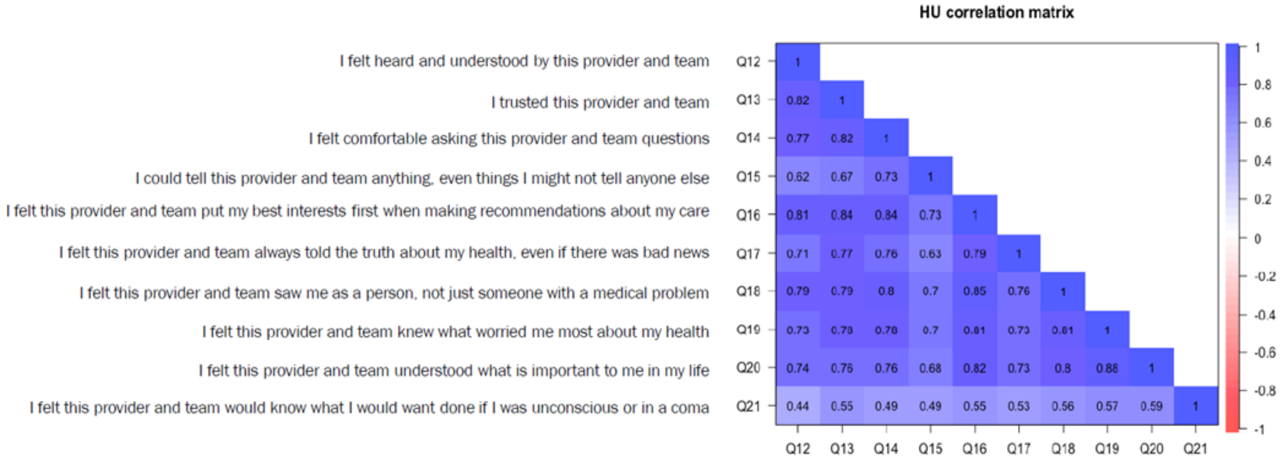


Q10: In the last 6 months, did you want emotional support from this provider and team?

Q11: In the last 6 months, did you get as much emotional support as you wanted from this provider and team?

Fewer respondents said that they wanted emotional support from their provider and team, relative to support for pain. Most respondents who wanted emotional support from their provider and team received the support that they wanted.

FIGURE 9 – Correlation Matrix for Heard and Understood Questions:



Most of the heard and understood items (i.e., survey questions) are correlated at 0.79 or higher. Given the high correlation between items, there are a lot of options for putting together a multi-item scale. Although no items seem empirically unworthy for consideration of inclusion in the final measure, it is important to limit the number of items included in the survey to minimize the data collection burden on patients. To reduce patient burden, the Project Team would like to identify the smallest set of items that would be acceptable and conceptually coherent, and still result in a reliable measure.

TABLE 10 – Heard and Understood Item Total Correlations:

Item Number	Item	Item-total correlation
Q16	I felt this provider and team put my best interests first when making recommendations about my care	0.84
Q20	I felt this provider and team understood what is important to me in my life	0.82
Q19	I felt this provider and team knew what worried me most about my health	0.81
Q13	I trusted this provider and team	0.81
Q18	I felt this provider and team saw me as a person, not just someone with a medical problem	0.80
Q14	I felt comfortable asking this provider and team questions	0.78
Q12	I felt heard and understood by this provider and team	0.76
Q17	I felt this provider and team always told the truth about my health, even if there was bad news	0.73
Q15	I could tell this provider and team anything, even things I might not tell anyone else	0.66
Q21	I felt this provider and team would know what I would want done if I was unconscious or in a coma	0.52

TABLE 11 – Confirmatory Factor Analysis of Heard and Understood Items:

Item Number	Item	CFA loadings
Q16	I felt this provider and team put my best interests first when making recommendations about my care	0.89
Q13	I trusted this provider and team	0.85
Q18	I felt this provider and team saw me as a person, not just someone with a medical problem	0.83
Q20	I felt this provider and team understood what is important to me in my life	0.83
Q19	I felt this provider and team knew what worried me most about my health	0.82
Q14	I felt comfortable asking this provider and team questions	0.82
Q12	I felt heard and understood by this provider and team	0.80
Q17	I felt this provider and team always told the truth about my health, even if there was bad news	0.76
Q15	I could tell this provider and team anything, even things I might not tell anyone else	0.68
Q21	I felt this provider and team would know what I would want done if I was unconscious or in a coma	0.53

As was previously mentioned, the Beta Field test data is being reviewed to determine if we can reduce the number of survey items in each measure in order to minimize the burden of data collection for patients. A confirmatory factor analysis will look at how well the items are working together. The Project Team may consider removing questions fifteen and twenty-one. Overall, we believe that there are strong options for items to include in a measure, but we require further analysis to reduce the number of items. Once options are finalized, we can proceed with convergent validity analysis and known groups validity analysis.

The data presented at the TECUPP Meeting is preliminary data and should be interpreted with caution. Factor loadings were exploratory and additional analyses will be performed in the future. Risk adjustment and reliability analyses will require more data to inform.

Next the RAND testing team will analyze the remaining results from the final round of fielding prior to the pause in data collection with the last round of field testing from March 30, 2020 to May 25, 2020. RAND will conduct additional analyses on this last round of field testing data including risk adjustment to help determine if the data can be combined with the previous data. Although the patients were being asked about visits that happened prior to the pandemic, they were answering this survey during the pandemic. As the Project Team looks to restart field testing data collection in the near future, analysis of the results will have to be mindful of data collected prior to the pandemic, during the pandemic, and after the pandemic to determine if the data are comparable and if they can be combined.

TECUPP members asked several questions about the preliminary Beta field test results:

- How was cognitive function measured? This was measured using four self-reported items from the cognitive function bank in PROMISE t-score metric, which is normed on a mean of 50 for the general population.
- Concern was expressed over the lack of diversity in the Beta field test respondents. This concern was discussed in more detail later in the meeting.
- A TECUPP member noted the decline in trust in our society and wondered if any of these questions are more or less sensitive to that? Although beyond the scope of the measure development project, it is one of many exogenous factors that could be impacting patient experience in general.
- Both TECUPP members and the Project Team identified the uncertainty about the impact of telehealth on patients' ability to feel heard and understood. It remains unclear the extent to which this project can shed light on the differences between patients' feelings of being heard and understood in- person verses during telehealth visits. This concern was discussed in more detail later in the meeting.

10:00am PT/ 1:00pm ET Discussion Measure Implementation:

Presenter: TECUPP Co-Chairs Mary Ersek, PhD, RN, FPCN, and Sydney Dy, MD, MS, FAAHPM

TECUPP members were instructed to reference the information presented today. TECUPP members were also asked to draw upon their expertise to help the Project Team understand the impact of the COVID-19 pandemic on palliative care practices. The TECUPP was prompted with the following questions:

- What is the impact on palliative care practices, particularly changes to care delivery?
- What is the impact on patient experience?
- What is the impact on palliative care quality measurement?

Discussion around the impact of telehealth on measure development and implementation was robust, and perceptions of and experience with telehealth varied greatly. Telehealth was initially excluded from the project measures as an applicable care setting. TECUPP members disagreed about the future inclusion of telehealth visits for the project measures. Prior to the pandemic, there was inconsistency in documentation of telehealth visits and telehealth visits were much less commonly utilized. Currently at the time of this meeting, CMS is reimbursing for most telehealth visits with more reliable, consistent and standard documentation of telehealth visits than previously seen prior to the pandemic. The continued reimbursement by CMS or other insurers for telehealth visits is unknown, but it appears that the use of telehealth visits and payment will continue. TECUPP members noted that although telehealth visits for patients receiving palliative care services are more frequent now, this was not the common way to see patients prior to the pandemic. Telehealth has been operating on a national scale for several months, which results in it being very new for some providers and some patients. The TECUPP members hypothesized that in the future there will be diverse modalities or care settings for patient interactions and providers will have to work with patients to determine the best modality for each patient.

Some TECUPP members recognized that telehealth can increase access to care for some patients or patient populations. However, other patients may face technological and resource challenges to accessing telehealth, specifically tele-video services. Regardless of the location of care, TECUPP members felt it was important for providers to establish a strong relationship with patients. TECUPP members had experiences with patients that like telehealth visits and patients that prefer in-person visits. TECUPP members again emphasized the importance of the relationship between providers and patients and how experiences for patients may differ if their first visit is by telehealth. One TECUPP member shared that their organization has been offering telehealth for years, and when they survey patients on their satisfaction, the score seems to relate to the provider’s level of comfort with telehealth.

There was concern from some TECUPP members that technological issues (access, reliability) may disproportionately effect minority populations or those with physical or mental challenges. One example presented was when patients have challenges connecting to video calls, they must switch to audio only, which is problematic for patients who are hard of hearing.

In response to the pandemic, the Project Team added questions about the COVID-19 pandemic impact and the use of telehealth for palliative care services or visits to the last round of survey collection prior to the pause in field testing data collection. As the Project Team looks to restart data collection this Fall, the hope is to explore potential differences in patient experience between patients receiving care at in-person visits and those receiving care via telehealth visits. This information could be useful in indicating the comparability of experience between in-person and telehealth visits, and the extent to which both types of visits could be used in patient experience measures. Ultimately when the measures are submitted to the consensus-based endorsement entity, the National Quality Forum (NQF), the Project Team will need to state what score(s) indicates successfully completing the measures. The TECUPP challenged the Project Team to determine if the scoring would be the same for in-person visits and for telehealth visits. As the use of telehealth for palliative care services is expected to persist into the future, it is important to define and measure the quality of care patients receiving using this modality of care delivery.

Also, in response to the pandemic, the Project Team paused field testing data collection, with the latest round concluding on May 25, 2020. The Project Team asked the TECUPP for feedback on when they thought it would make sense to restart data collection. RAND shared that they are conducting interviews with the Beta field test sites right now to understand their ability to restart. The TECUPP said that there might be some variance between different regions of the country as they respond to first and second waves of increased incidence of COVID-19 in the coming year. Therefore, they noted that the ability to restart field test data collection might depend on the disease incidence and prevalence in different regions of the country.

As was identified earlier, the TECUPP noted the current Beta field test sample contains predominantly white patients and/or family or caregivers who completed the survey. The TECUPP members emphasized that more diverse representation is critical to help the Project Team understand the overall or generalizable patient experience of care. To date, the Beta field test data has shown that most patients are rating their palliative care experience positively, but if the Beta test is not representative of the larger population then we might not be comprehensively capturing patient experience. A lack of a diverse sample may inaccurately represent patient experiences as mostly positive or "utopian." The Project Team is committed to focusing on increasing the diversity of our sample moving forward. After the Alpha test results came back, the Project Team focused on understanding how to include more geographic diversity and racial diversity for programs and patients participating in the Project for the Beta field test. The efforts, unfortunately, did not result in increasing racial diversity in the Beta field test to date. However, the Project Team will continue to focus on increasing racial diversity through attempting to recruit more diverse Beta field test sites, and by consulting experts.

10:50 am PT/ 1:50pm ET Closing Remarks:

Presenter: Katherine Ast, MSW, LCSW, Director, Quality and Research, AAHPM

The Project Team thanked the TECUPP members for their time and valuable feedback. The Project Team sent a short survey after the call. The TECUPP was informed of the survey and was asked to complete it.

Summary and Next Steps:

Participants were provided with a greater understanding of the project, preliminary Beta field test results, and project progress to date. Participants had a robust discussion around the impact of the COVID-19 pandemic on practice, the emerging importance of telehealth, and the importance of collecting a racially diverse sample.

The Project Team shared that they are hoping to restart data collection in September 2020, with a lookback period including June, July, and August. The Project Team is hoping to collect as much data as possible and that the data analysis will provide insights into the impact of the COVID-19 pandemic and telehealth on palliative care. Even though we are in unprecedented times, the expectation remains that patients receive high quality care.

After the TECUPP meeting, the Project Team will incorporate TECUPP recommendations, to the extent possible, into the project deliverables. Additionally, the TECUPP and MSP will continue to be reconvened at strategic points throughout the project to inform critical decisions.

TABLE 15 – Key TECUPP Recommendations for Project Team Consideration:

Discussion Topics	Key TECUPP Feedback and Recommendations
Effects of the COVID-19 pandemic on	-Main effects of the pandemic: huge increase in telehealth visits, increased referrals to palliative care for patients with COVID-19 -Palliative care has been highlighted as a valuable resource in the age of COVID-19, and opportunities for education have emerged

palliative care and practice	-Palliative care practices have been much busier during the pandemic crisis, but many of them have stabilized and are ready to resume data collection
The applicability of including telehealth visits for palliative care services in this current field test	-Prior to the pandemic, inconsistency in documentation characterized telehealth visits -CMS is now reimbursing for most telehealth visits with more reliable, consistent and standard documentation than previously seen -Continued reimbursement by CMS or other insurers for telehealth visits is unknown, but it seems clear that the use of telehealth visits and payment will continue -Recommendation: include telehealth visits in data collection where feasible, even if just for comparison to the in-person visits (not necessarily to combine the data, unless it's shown to be compatible)
The plan for restarting field testing data collection	-Recommendation: restart data collection in September 2020 -Caution: be mindful of data variance between different regions of the country as they respond to first and second waves of increased incidence of COVID-19 -Ability to restart field test data collection might depend on the disease incidence and prevalence in different regions of the country -Recommendation: explore potential differences in patient experience between patients receiving care at in-person visits and those receiving care via telehealth; would scoring be the same for in-person visits and for telehealth visits? Can we define and measure quality of care using this modality of care delivery?
Opportunities for stakeholder engagement	-Long-term goal: these patient-reported measures used for more than just palliative care; test in other populations for comparison -National Patient Advocate Foundation suggested co-hosting a webinar to inspire patients, family members and caregivers, and patient advocate volunteers to help champion the measures in their communities -Recommendation: outreach by the Project Team and TECUPP members to medical specialty societies to gain support for the measures and to hear questions or concerns -Plan public comment period
Lack of racial and ethnic diversity seen in preliminary Beta test results	-Widespread agreement that diverse representation is critical to understanding the overall or generalizable patient experience of care -If Beta test sample is not representative of the larger population then we might not be comprehensively capturing patient experience -Questions persist about why so many palliative care programs lack patient diversity -Recommendation: consult experts and make efforts to include more racial and ethnic diversity in programs and patients participating in the project