AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

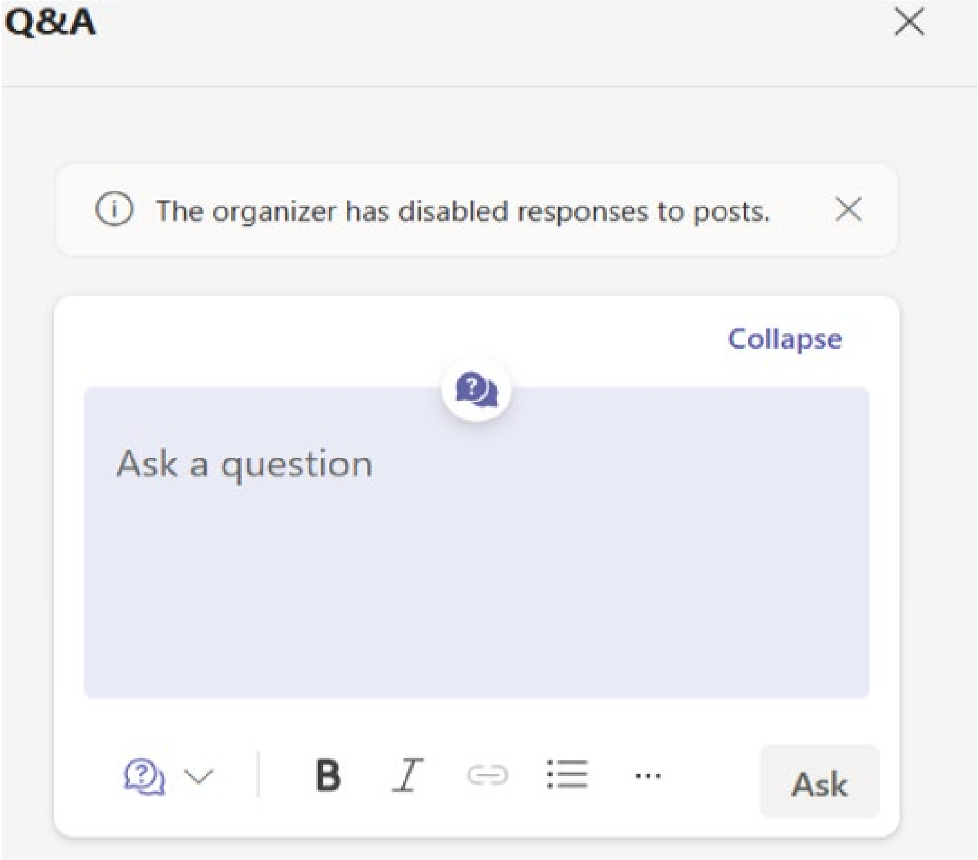
Introducing the CAHPS End-of-Life Care Survey

A Webcast Presented by the AHRQ CAHPS User Network
Thursday, January 15, 2026
1:00 – 2:00 pm ET

Technical Info

- Event Website: https://events.westat.com/cahps/webcast/
  - Download presentation slides from our event site
- Audio issues
- Poor connection
- Use Q&A to submit questions

Q&A



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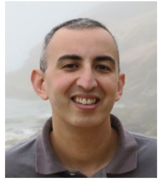
Ask a question

Agenda

- Welcome from AHRQ
- CAHPS Overview
- New End-of-Life Care Survey
- User Insights
- Questions and Answers

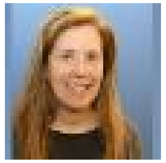
Speakers

Stephanie Fry, CPXP
Associate Vice President,
Westat
Moderator



Jonathan Bakdash, PhD
Social Science Analyst, CAHPS and SOPS Program
Agency for Healthcare Research and Quality

Rebecca Anhang Price, PhD
Senior Policy Researcher
RAND



Melissa Bradley
Associate Director, Survey Research Group
RAND

Susan Wang, MD
National Medical Director for Palliative Care
Kaiser Permanente

AHRQ'S CAHPS PROGRAM

Consumer Assessment of Healthcare Providers and Systems

Jonathan Bakdash, PhD
Center for Quality Improvement & Patient Safety, AHRQ
jonathan.bakdash@ahrq.hhs.gov

Agency for Healthcare Research and Quality

AHRQ is a research and development agency in the US Department of Health and Human Services

- **Health Systems Research:** Invest in research and evidence to make health care safer and improve quality.
- **Practice Improvement:** Create tools for health care professionals to improve care for their patients.
- **Data & Analytics:** Generate measures and data to track and improve performance and evaluate progress of the US health care system.
- AHRQ is not a regulatory agency and does not implement regulatory policy for payment, reimbursement, etc.
- AHRQ does not mandate the use of CAHPS surveys; requirements for using CAHPS surveys are established by other organizations

CAHPS Program Overview

- AHRQ's CAHPS program has advanced the science of measuring and improving **patient experience**:
  - Validated surveys for high-stakes purposes
  - Supplemental questions, including narrative items
  - Quality improvement resources
  - Voluntary databases for selected CAHPS surveys
  - Research to advance the science of patient experience measurement and improvement
- Free tools, materials, technical support, and other resources

Patient Experience

ASPECTS OF PATIENT EXPERIENCE

- Culturally Appropriate Care
- Care Coordination
- Courtesy and Respect
- Access to Care
- Communication with Clinicians
- Getting Information
- Shared Decision Making
- Self Management Support

CAHPS Principles

- Surveys focus on what patients want to know
- Stakeholder and user input are fundamental and ongoing
- Surveys are extensively tested
- Standardization supports comparability
- All surveys, tools, and resources are public domain

CAHPS Surveys

Measuring patient experience of care in different settings

Experience with Providers

- Clinicians and Medical Groups
- Hospices
- Home Health Care
- Surgical Care

Experience with Facility-Based Care

- Hospitals (adult and pediatric)
- Dialysis Centers
- Nursing Homes
- Outpatient Ambulatory Surgical Centers

Experience with Condition-Specific Care

- Cancer Care
- Mental Health Care

Experience with Health Plans

- Health Plans
- Dental Plans
- Home and Community-Based Services

Introducing the CAHPS® End-of-Life Care Survey

Rebecca Anhang Price, PhD
Senior Policy Researcher

Melissa Bradley
Associate Director, Survey Research Group

RAND

The CAHPS® End-of-Life Care Survey assesses experiences of health care in the last month of life

- Assesses care across all settings, including:
  - Home
  - Outpatient office/clinic
  - Assisted living facility
  - Nursing home / skilled nursing facility
  - Hospital or emergency room
  - Hospice

- Captures experiences with care transitions, which can be particularly challenging.

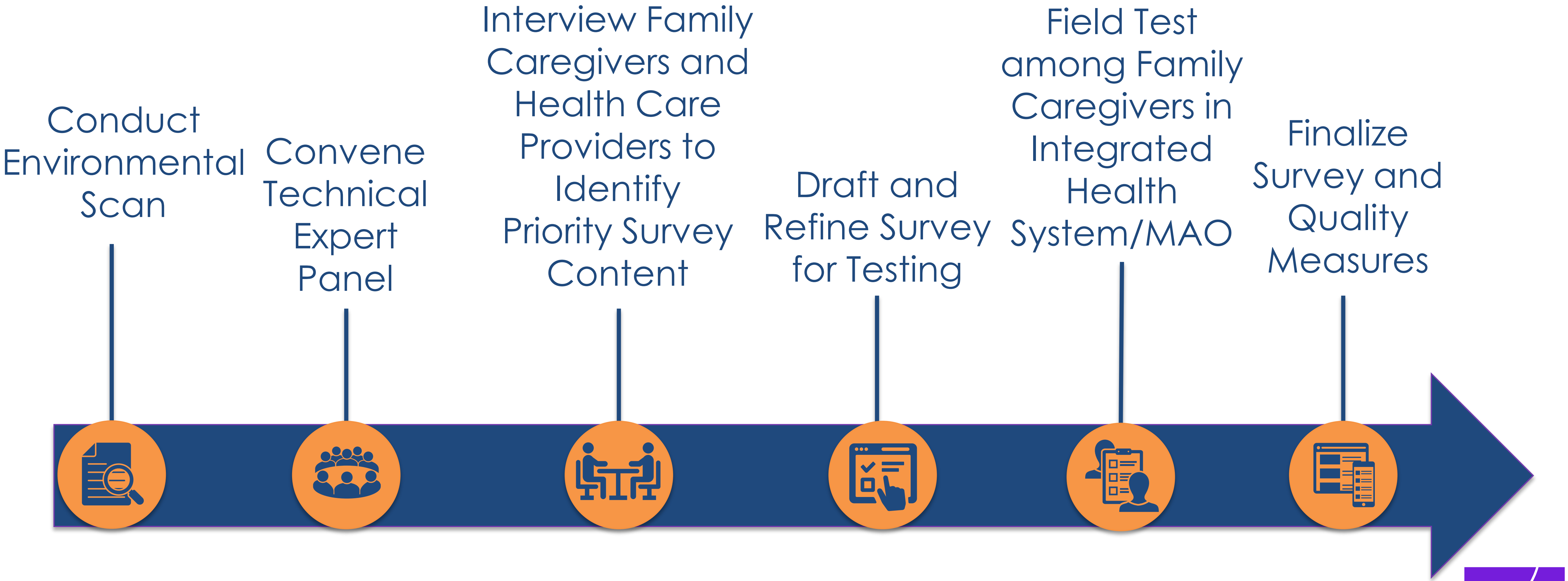
- Respondents are informal caregivers following the death of their family member or friend.

Assessment of the episode of end-of-life care is critical for promoting and evaluating value-based care

- Existing surveys allow for comparisons of health care providers (e.g., hospices or hospitals) or for population-level assessments of end-of-life care.

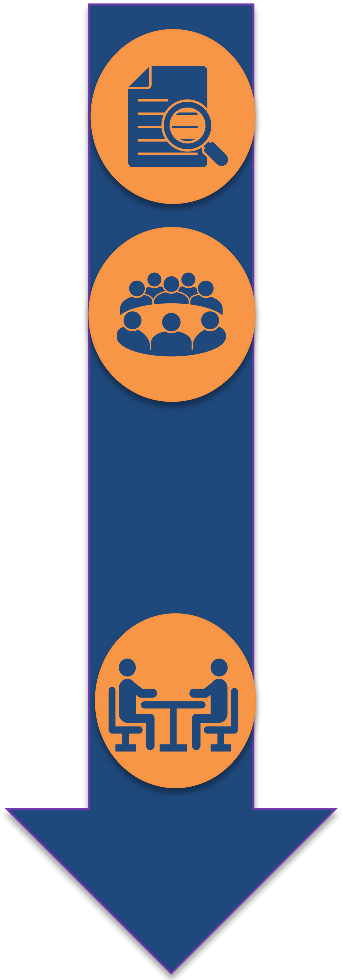
- The CAHPS End-of-Life Care Survey is designed for use by organizations that pay for or oversee care across settings:
  - Integrated health systems
  - Accountable care organizations
  - Medicare Advantage organizations

Survey development incorporated a range of stakeholder perspectives



- Conduct Environmental Scan
- Convene Technical Expert Panel
- Interview Family Caregivers and Health Care Providers to Identify Priority Survey Content
- Draft and Refine Survey for Testing
- Field Test among Family Caregivers in Integrated Health System/MAO
- Finalize Survey and Quality Measures

Survey design and content were derived from literature, experts, family caregivers, and health care providers



- Environmental scan yielded validated survey items regarding serious illness and end-of-life care from 175 surveys
- Technical expert panelists recommended that:
  - The reference period be the last month of life
  - Questions assess the care team's attentiveness to individual goals of care, coordination across care settings
- Family caregivers identified symptom management, respect for patient and family, responsiveness, and communication as priorities for survey content across care settings.
  - Health care providers and quality improvement leaders also highlighted the importance of soliciting and addressing patients' preferences.

Testing with family caregivers informed refinements to the draft survey

- Draft survey addressed priority content areas using previously-validated CAHPS questions and new questions, as needed.
- Cognitive interviews with family caregivers helped to refine:
  - Wording for questions about shared decision making and respect for wishes
  - Approach for orienting respondents re: which health care providers to assess
- Field test among caregivers of decedents receiving care from a large Medicare Advantage organization:
  - Established feasibility
  - Allowed for derivation and testing of quality measures

Final, 37-item survey can be used to derive 7 reliable, valid quality measures

Getting Timely Care	• Got needed help during regular office hours; during evenings, weekends, or holidays
Communication	• Explained things in a way that was easy to understand • Seemed to know the important information about medical history • Kept patient and family informed • Listened carefully
Treating Patient with Respect	• Treated patient with dignity and respect • Really cared about the patient
Getting Help for Symptoms	• Got needed help for pain; trouble breathing; anxiety or sadness
Emotional Support	• Right amount of emotional support to patient and family
Care Preferences	• Involved patient and family in decisions as much as desired • Did the best they could to respect family member's wishes; honor patient's desired location to pass away
Overall Rating	• 0-10

Field testing helps to test survey and administrative protocol

- Survey instrument
  - Are screener questions working?
  - Do any questions have high rates of missingness?
  - Are questions providing variance in response?

- Administration protocol
  - Are surveys reaching respondents?
  - Are response rates reasonable?
  - Can data collection be completed in the time allotted?

Field test employed mixed-mode data collection to maximize response rates

- Mixed-mode approach allows caregivers to choose their preferred response mode

- Survey fielding July – August 2022
  - Sample size: 1,700 cases

- All cases followed the same mail-phone protocol
  - One survey packet mailing
  - Follow-up by telephone 21 days after survey packet mailing
  - Field period ended 42 days after survey mailing

- Survey was available in English and Spanish

Survey sampling criteria considers characteristics of both decedents and caregivers

1. Adult decedents (i.e., age 18 or older)
    - Deaths within a predetermined month range (e.g., July to November 2021)
    - At least 2 health care visits in last year of life
    - Exclude deaths from traumatic causes

2. Identify decedents who have caregivers for which a mailing address or telephone number is available
    - Exclude caregivers with addresses outside U.S.

Challenges include limited information for caregivers

- High percentage of caregivers may have no address in sample file.
  - *Field test solution:* Use decedent address for mailing surveys to these caregivers.
- For some cases, caregiver last name may be missing.
  - *Field test solution:* Only contact these caregivers via phone mode.
- Caregiver language preference is likely to be unknown.
  - *Field test solution:* If decedent had a documented Spanish language preference, mail packet included both English and Spanish cover letter and survey.

Both general best practices and survey-specific considerations apply

- Sampling
  - Look for caregivers across multiple contact categories (e.g. caregivers defined as decedent's primary healthcare decision maker, primary caregiver, or emergency contact)
  - Clean sample file: format addresses, remove duplicate cases
  - Append and/or correct contact information, if possible

- Survey Instrument
  - Format survey to be easy to read (e.g., white space, font size, headings, clear skip patterns)
  - Include properly-formatted letter, survey, and postage-paid envelope in mail packets
  - Adapt survey for phone administration (e.g., introductions to response categories)
  - Translate into other languages using best practices

- Fielding protocol
  - Allow adequate time for response from each mode
  - Place phone calls at different days/times
  - Train interviewers for sensitivity

Further information

- More information about the CAHPS End-of-Life Care Survey, including survey materials in English and Spanish, and guidance for sampling, administration, and measure scoring, is available at: https://www.ahrq.gov/cahps/index.html

- Detailed results of the survey field test are described in a May 2025 *Journal of Palliative Medicine* article:
  - Anhang Price R, Tolpadi A, Elliott MN, Wang SE, Gozansky WS, Nguyen HQ, Teno JM, Ye F, Timmer MA, Bradley MA. Surveying Family Caregivers to Assess Quality of End-of-Life Care in Medicare Advantage. *J Palliat Med*. 2025. doi: 10.1089/jpm.2025.0062.

- Feel free to contact the RAND survey development team with further questions:
  - Rebecca Anhang Price (ranhangp@rand.org)
  - Melissa Bradley (mbradley@rand.org)

POLL QUESTION

What do you believe is the most valuable potential benefit of the CAHPS End-of-Life Care Survey? (select one)

- ☐ Provides actionable feedback for quality improvement
- ☐ Helps engage and motivate state and organizational leaders to implement best practices
- ☐ Provides valuable research data
- ☐ Increases transparency allowing patients and their families to make informed choices when selecting a provider

- ► Please submit your answer in the pop-up to participate in the poll.
- ► NOTE: If you are a MAC user you may not have this option

User Insights: Kaiser Permanente

Susan Elizabeth Wang MD, FAAHPM, HMDC
National Medical Director, Palliative Care, The Permanente Federation
Regional Chief, Geriatrics & Palliative Medicine, Southern CA Permanente Medical Group

susan.e.wang@kp.org

KAISER PERMANENTE®

Benefits for Kaiser Permanente (KP) Engagement in Field Testing

- Opportunity to address the entire episode of care for people at the end of life – including care transitions
    - ~1/2 of decedents choose hospice

- KP has conducted an Advanced Illness Care Experience Survey
    - Barriers to internal administration

- Access to patient-level data to better understand areas of improvement
    - Typically, CAHPS progress is reviewed through internal survey data and/or focus groups

Considerations for Survey Administration

- Locating accurate contacts
  - 90% of KP decedents had a documented health decision maker or emergency contact
  - Next of kin laws do not exist in many states

- Opportunity to standardize assessment of Health Care Decision Maker and Caregiver

- Timing of the survey – not too far out from the death event
  - Decedents July-Nov 2021, Survey Jul-Aug 2022
  - Consider a companion process for bereavement support ie condolence card

Feedback

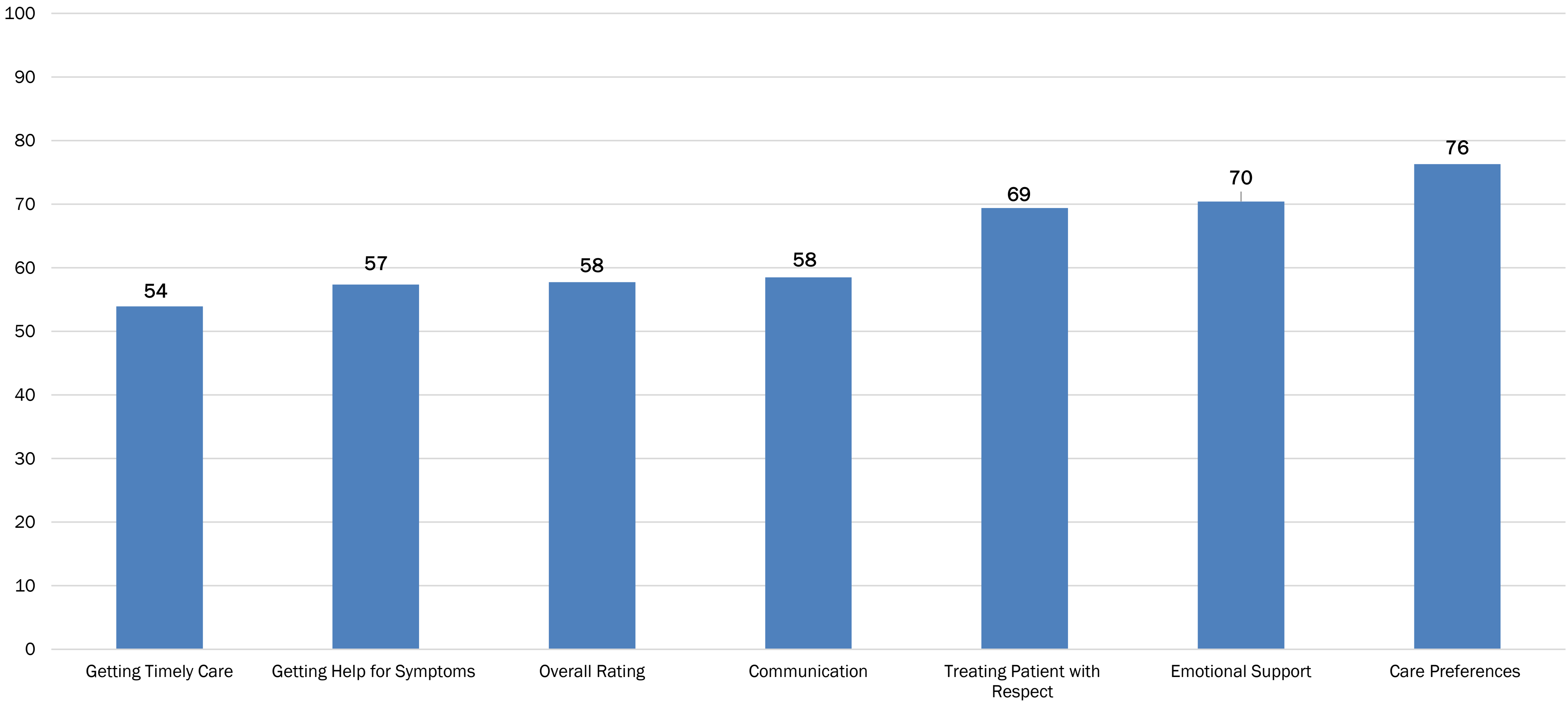
- 1700 CO/SCAL informal caregivers of decedents surveyed
- Average age 80, 49% female, 36% cancer diagnosis, 44% had an AD
- 75% of those who had Specialty Palliative Care also had Hospice

I feel like she got great care. I especially think the hospice care was excellent. The day she died the nurse stayed with us all day and arranged everything that needed to be done. The care was so good that I am considering changing my health care to Kaiser.

"…I didn't know the severity of her complications. Her doctors did not have communication amongst them. I felt lost and unprepared... My mother had an addiction and there was a bias toward her treatment. I don't think she was always given good care because of that. I feel like the doctors failed to guide me with her care and what to watch for. If so, then I would have been better facilitated to care for her."

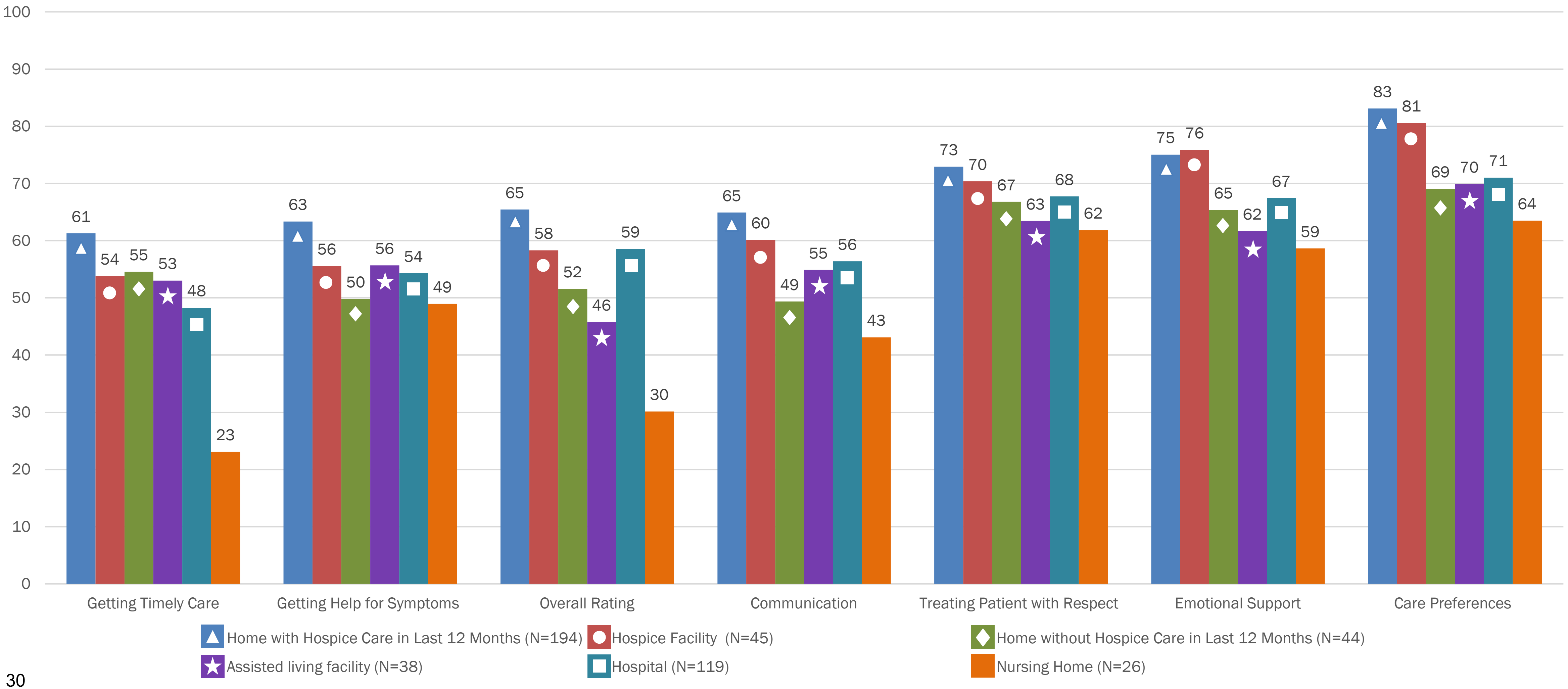
…from cancer patient to the beginning care plan, to palliative care to hospice, all the health care workers, social workers, etc. kept changing. I had to keep going over it all over and over. I had a literal phone book of numbers to call and I lived on the phone. A patient should be assigned to one caseworker who oversees the process from beginning to end. I have never been so exhausted in my life keeping track of it all. I had nothing left.

Caregivers reported most positive experiences with care preferences, most room for improvement in timeliness of care



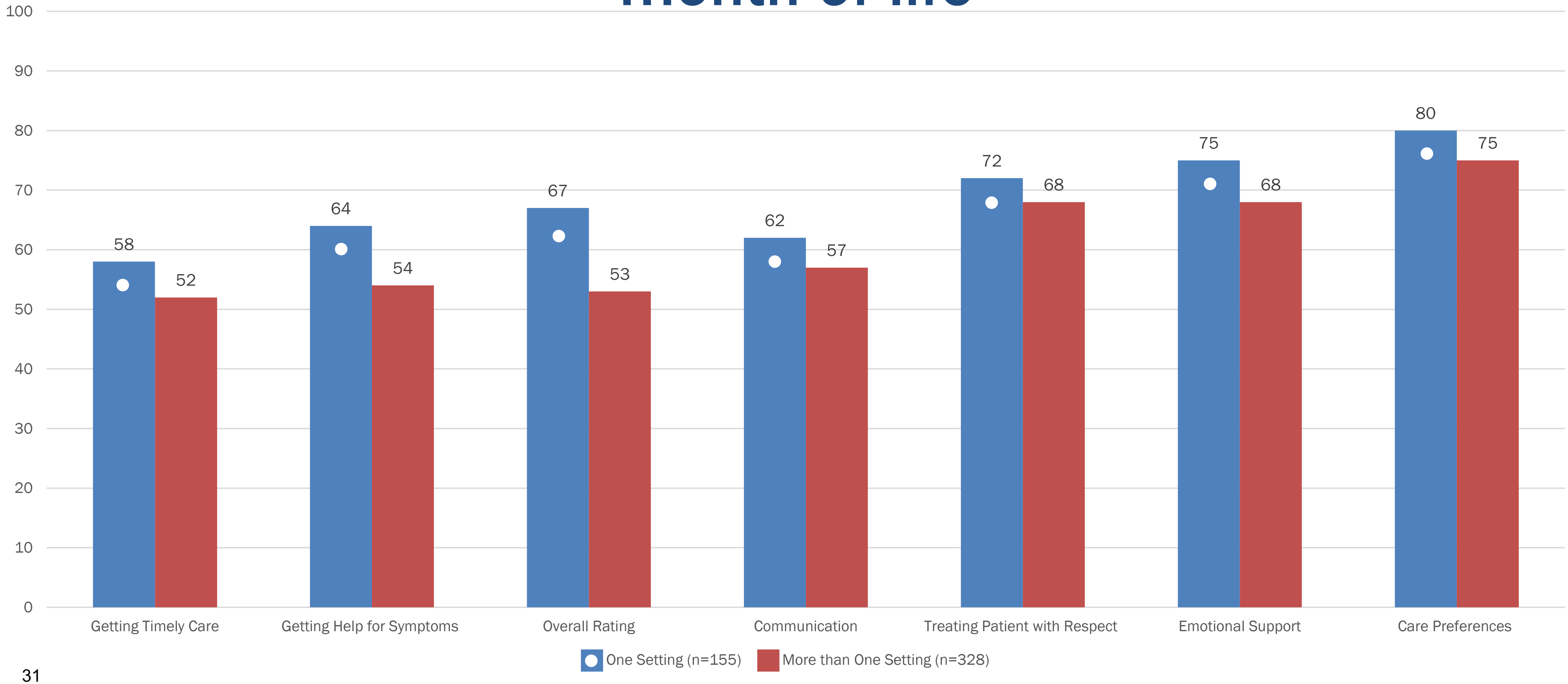
NOTE: Chart displays top-box scores.

There was substantial variation in reported care experiences across sites of death, with nursing home experiences consistently far worse



NOTE: Chart displays top-box scores by caregiver-reported sites of death; hospice care in last 12 months is from administrative records. Scores are adjusted for region and case mix.

Care experiences were substantially worse for those who experienced transitions across settings in the last month of life



NOTE: Chart displays top-box scores by caregiver-reported settings of care in the last month. Scores are adjusted for region and case mix.

Additional Insights

- Outreach to residential communities for older adults (ALFs, B&C)
- Many SNFs have opportunity for improvement in end-of-life care
- In any future health crisis, visitation policies should be established early and updated often
- Enhance KP Hospice branding to indicate that services are integrated
- Multimorbid, frail older adults do not have universal access to Hospice
- Opportunity for additional communication training

"I understand why she wanted hospice care. When you are 90 years old you should have that right…I called several times pleading to get her on hospice and they still said no…she died the next week alone in a hospital bed because they would not write the order.

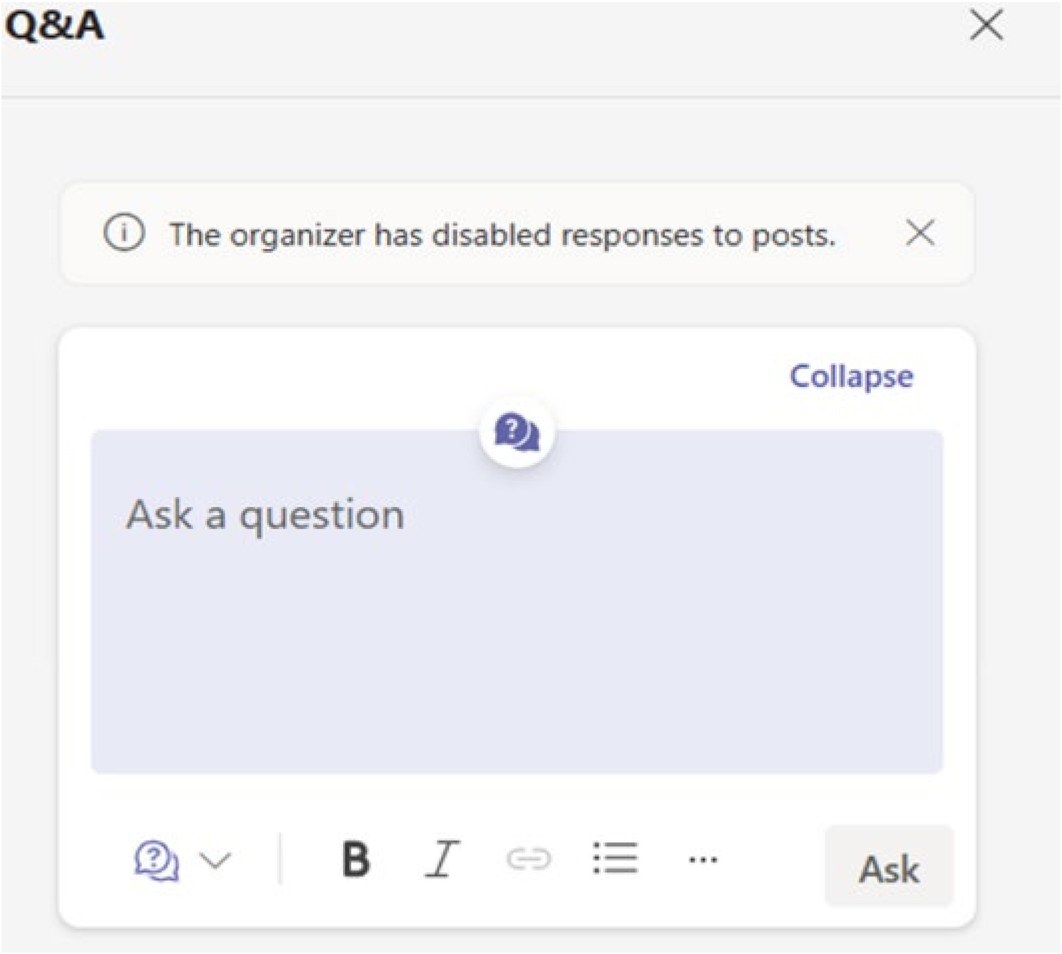
One clinician "would always use the word *unfortunately*, not giving us any hope for the situation"

Potential future applications

- Member retention data critical for health plans
- Goal concordance – conducted a chart review to understand drivers of too little or too much care
  - 79% reported the right amount of care, 18% had too little, and 3% had too much
    - Communication gaps across team members, with non-KP entities
    - Misconceptions about palliative care
  - Scale and expand measurement strategy
  - Should discordant interventions be reimbursed?

Plans for Further Implementation within KP

Q&A



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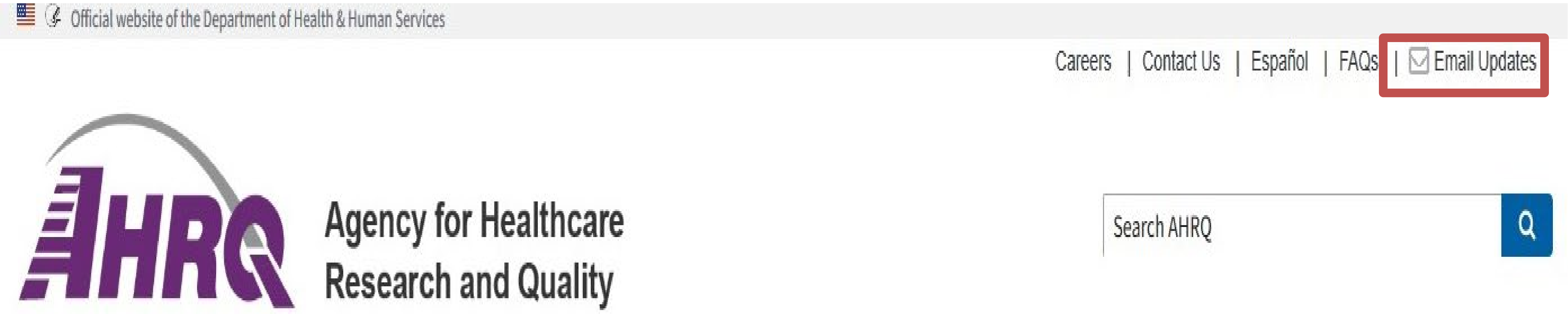


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CAHPS Contact Information

✉ E-mail: cahps1@westat.com

☎ Phone: 1-800-492-9261

💻 Website: www.ahrq.gov/cahps/

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