RESEARCH REPORT

Hospice Experience of Care Survey

Development and Field Test

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Preface

In September 2012, the Centers for Medicare & Medicaid Services (CMS) entered into a contract with the RAND Corporation to design and field-test a future Consumer Assessment of Healthcare Providers and Systems (CAHPS®) survey to measure the experiences that patients and their caregivers have had with hospice care. The survey was developed to provide a source of information from which selected measures could be publicly reported to beneficiaries and their family members as a decision aid for selection of a hospice program, aid hospices with their internal quality improvement efforts and external benchmarking with other facilities, and provide CMS with information for monitoring the care provided. CMS intends to implement the survey nationally in 2015. Eligible hospices will be required to administer the survey for a dry run for at least one month in the first quarter of 2015. Beginning in the second quarter of 2015, hospices will be required to participate on a monthly basis in order to receive the full Annual Payment Update.

In this report, we briefly summarize the work that we conducted to develop and field-test the new survey, referred to as the Hospice Experience of Care Survey during the field test and being implemented nationally as the CAHPS Hospice Survey beginning in 2015. We provide an overview of the survey development process, describe the field test design and procedures, present analytic methods and findings from the field test, and discuss the implications of those findings for the final survey instrument for national implementation.

This work was sponsored by CMS under contract number HHSM-500-2012-00126G, for which Lori Teichman serves as project officer. The research was conducted in RAND Health, a division of the RAND Corporation. A profile of RAND Health, abstracts of its publications, and ordering information can be found at http://www.rand.org/health.

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Abstract

The Centers for Medicare & Medicaid Services (CMS) has implemented care experience surveys for a variety of settings but none for hospice care. In September 2012, CMS contracted the RAND Corporation to design and field-test a future Consumer Assessment of Healthcare Providers and Systems (CAHPS®) survey to measure the experiences that patients and their caregivers have with hospice care. The survey was developed to (1) provide a source of information from which selected measures could be publicly reported to beneficiaries and their family members as a decision aid for selection of a hospice program, (2) aid hospices with their internal quality improvement efforts and external benchmarking with other facilities, and (3) provide CMS with information for monitoring the care provided. This report briefly summarizes the work conducted to develop and field-test the new survey, referred to as the Hospice Experience of Care Survey during the field test and being implemented nationally as the CAHPS Hospice Survey beginning in 2015. It provides an overview of the survey development process, describes the field test design and procedures, presents analytic methods and findings from the field test, and discusses the implications of those findings for the final survey instrument for national implementation.

Acknowledgments

This work was sponsored by the Centers for Medicare and Medicaid Services under contract HHSM-500-2012-00126G, for which Lori Teichman served as the contracting officer's representative. We gratefully acknowledge the expert input of Paul D. Cleary of the Yale School of Public Health, Ron D. Hays of the University of California at Los Angeles Department of Medicine, and Alan M. Zaslavsky of Harvard Medical School, as well as insight from the members of our technical expert panel and the family caregivers who participated in the our qualitative and cognitive interviews. We are thankful to Laura Giordano, Pat Spencer, and Marina Whitmore of the Health Services Advisory Group for their expert hospice recruitment activities; to Rosa-Elena Garcia of RAND for her contributions to data collection; and to Jamie Greenberg of RAND for excellent administrative assistance throughout the project.

This report was peer-reviewed according to the RAND Corporation standards for high-quality research and analysis.[1] We appreciate insightful reviews from Julie Brown and Carla Zema.

[1] RAND Corporation, "Standards for High-Quality Research and Analysis: Perpetuating RAND's Tradition of High-Quality Research," undated. As of June 27, 2014:
http://www.rand.org/standards.html

Abbreviations

ACO	Accountable Care Organization
AHRQ	Agency for Healthcare Research and Quality
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CI	confidence interval
CMA	case-mix adjustment
CMS	Centers for Medicare & Medicaid Services
FEHC	Family Evaluation of Hospice Care
HCAHPS	Consumer Assessment of Healthcare Providers and Systems Hospital Survey
HECS	Hospice Experience of Care Survey
ICC	intraclass correlation coefficient
IPU	inpatient unit
MCAHPS	Medicare Consumer Assessment of Healthcare Providers and Systems
MedPAC	Medicare Payment Advisory Commission
SD	standard deviation
TEP	technical expert panel

Chapter One. Introduction

The Centers for Medicare & Medicaid Services (CMS) has implemented experience-of-care surveys for a variety of settings, including traditional Medicare, Medicare Advantage and Part D Prescription Drug Plans, hospitals, and home health agencies. Although CMS and the Agency for Healthcare Research and Quality (AHRQ) have developed additional Consumer Assessment of Healthcare Providers and Systems (CAHPS®) surveys for in-center hemodialysis facilities, nursing homes, and clinician and group practices, none of these surveys addresses experiences with hospice care.

In September 2012, CMS entered into a contract with RAND to design and field-test a future CAHPS survey to measure the experiences that patients and their caregivers have had with hospice care. The survey was developed to (1) provide a source of information from which selected measures could be publicly reported to beneficiaries and their family members as a decision aid for selection of a hospice program, (2) aid hospices with their internal quality improvement efforts and external benchmarking with other facilities, and (3) provide CMS with information for monitoring the care provided. National implementation of the survey will begin in 2015. Eligible hospices will be required to administer the survey for a dry run for at least one month in the first quarter of 2015. Beginning in the second quarter of 2015, hospices will be required to participate on a monthly basis in order to receive the full Annual Payment Update.

In this report, we briefly summarize the work that we conducted to develop and field-test the new survey, referred to as the Hospice Experience of Care Survey (HECS) during the field test and being implemented nationally as the CAHPS Hospice Survey beginning in 2015. We provide an overview of the survey development process, describe the field test design and procedures, present analytic methods and findings from the field test, and discuss the implications of those findings for the final survey instrument for national implementation.

Chapter Two. Survey Instrument Development

Content and design of the HECS were informed by the following inputs:

- a call for topic areas in the Federal Register
- a review of the literature and environmental scan of existing tools for measuring experiences with end-of-life care
- qualitative inquiry (interviews and focus group) with primary caregivers of hospice patients
- input and feedback from survey and hospice care quality experts at a technical expert panel (TEP)
- cognitive testing with primary caregivers of hospice patients.

Call for Topic Areas

In response to a call for topic areas published in the Federal Register in January 2013, stakeholder groups provided suggestions for survey content, including the following:

- perceptions of the adequacy and frequency of provider visits
- measures of physical, psychosocial, and economic distress of patients receiving hospice care in the nursing home
- level of support from the nursing home in obtaining a hospice referral
- adequacy and redundancy of services from the hospice care team and the residential facility
- information about experiences with medication changes
- regular use of comprehensive symptom management instruments in the hospice setting
- speed and degree of symptom management, as well as flexibility in meeting patient needs
- availability of information to support informed decisionmaking by patients and their caregivers
- degree to which hospice providers discussed, understood, respected, and met patient and caregiver preferences regarding the extent and intensity of life-prolonging care
- specific items to address patient–provider communication; care coordination; shared decisionmaking; symptom management, including pain and anxiety; access to care; understanding hospice; respect and dignity; the care planning process; the caregiver's confidence to perform care tasks; emotional and spiritual support; caregiver circumstances; and recommendation of the hospice to others.

Literature Review and Environmental Scan

A systematic review of the peer-reviewed literature on experiences with end-of-life care identified 87 articles containing 50 unique survey tools. The most common categories of survey content were as follows:

- information, care planning, or communication (number of survey questions = 632)
- symptoms (303)

- provider care (223)
- spiritual, religious, or existential (187)
- overall assessment (134)
- psychosocial care (131)
- personal care (80)
- veteran care (72)
- responsiveness or timing (71)
- caregiver support (59)
- quality of death or last days (51)
- bereavement care (33)
- environment (28)
- patient-centered care (20)
- financial (14).

Qualitative Inquiry with Hospice Caregivers

To further inform the development of new survey content to assess experiences with hospice care, we conducted semistructured one-on-one interviews and a focus group with people who had recent experiences acting as caregivers for friends or family members in hospice care. Informed by a review of themes from the focus group and interview transcripts, the team recommended the following for the field test survey instrument:

- Provide an explanation of the types of personnel included in the term *hospice team*.
- Include a question about whether the hospice explained what kinds of services it could offer the family and patient.
- Include a question about care on the evenings, weekends, and holidays.
- Include questions to obtain information on communication and care responsibilities for patients receiving hospice care in nursing homes.
- Include a question about the amount of time spent with the patient.
- Include a question about dignity and respect provided to the patient.
- Include a question that captures the degree to which the hospice staff seemed to "really care" about the patient and family.
- Include a question about listening to the caregiver.
- Include a question about how much privacy the hospice staff afforded to the patient and his or her family.
- Include a question about caregiver trust of hospice team members.
- Include questions about the hospice team keeping the family informed about the patient's condition.
- Include a question about how well pain was managed.
- Include a question about side effects of the pain medication.
- Include a question about information provided about what to expect while a family member is actively dying.
- Include a question about follow-up care after the patient's death.

- Exclude questions about paperwork or intake procedures.
- Exclude questions about specific roles of hospice team members.

Technical Expert Panel

In December 2012, we convened a TEP, including experts on hospice care quality, survey research, and performance measurement and improvement, as well as people representing organizations that could have a major influence on the adoption of a standardized hospice care survey and promotion of its use in public reporting and quality improvement. TEP members agreed with the main survey content domains proposed: access to care and responsiveness, communication, shared decisionmaking, care coordination, symptom management and palliation, information and skills for caregivers, emotional and spiritual support, environment, and overall rating of care.

TEP members agreed that the field test should exclude from sampling those cases in which the hospice patient died within 48 hours of admission, there was no caregiver listed in hospice records, or the primary caregiver in hospice records was a nonfamilial or friend (i.e., legal) guardian. TEP members recommended that the survey be administered no sooner than one month after death and no later than six months after death but noted that the logistics of sampling (i.e., receipt of data from hospices, data processing and mailing) would likely preclude sampling before six weeks after death.

Cognitive Interviews

Given input from the call for topic areas, literature review, qualitative interviews and focus group, and TEP, we drafted and refined three setting-specific survey instruments for cognitive testing, one for the home setting, one for the nursing home setting, and one for the inpatient setting, including both freestanding hospice inpatient units (IPUs) and acute care hospitals.

The team conducted three rounds of cognitive interviews to test interpretation and comprehension of survey content, revising survey instruments and protocols between each round of interviews. Interviews resulted in refinements to the carrier phrase ("while your family member was in hospice care"); reorganization of the survey to separate items inquiring about the *respondent's* experience with hospice from items inquiring about the *patient's* experience; and replacement of an item about pain treatment decisions with an item about side effects of pain medicine.

Chapter Three. Field Test Design and Procedures

From November 12 through December 23, 2013, we conducted a field test of the three setting-specific versions of the HECS. The survey was administered between two and five months after the death of the hospice patient.

The field test was designed to assess survey administration procedures and to develop composite measures of hospice performance while enabling comparisons of response rates and response patterns for larger and smaller hospices and for the four settings of hospice care:

- home, which includes both home and assisted living facilities
- nursing home, which includes both skilled and regular nursing facilities
- two subsettings of inpatient care
  - acute care hospitals
  - freestanding hospice IPUs.

Eligibility Criteria

The following groups of hospice patients and the primary caregivers noted in their hospices' administrative records were eligible for inclusion in the sampling universe:

- patients over the age of 18
- patients with death at least 48 hours following admission to their final settings of hospice care
- patients for whom caregivers are listed or available and for whom caregiver contact information is known
- patients whose primary caregivers are people other than nonfamilial legal guardians
- patients for whom primary caregivers have U.S. or U.S. territory home addresses.

Patients or caregivers of patients who requested that they not be contacted (those who sign no-publicity requests while under the care of hospice or otherwise directly request not to be contacted) were excluded. Identification of patients and caregivers for exclusion was based on hospice administrative data.

Sampling Hospices

We used 2012 CMS Provider of Services and hospice claim files to characterize a sample frame of all hospices in the United States. We excluded hospices that were not eligible for or had terminated their participation in Medicare, those that had closed or had no claims for care services, and those that cared for fewer than ten decedents per month because these smaller hospices did not have enough volume to produce a large enough sample during the field test. We aimed to sample 30 hospice programs: 20 midsize to large ("larger") hospice organizations (with a target of

completed surveys for 30 decedents per larger organization) and ten smaller hospice organizations (with a target of completed surveys for ten patients per smaller organization). To increase the number of Spanish-speaking respondents, we sought to include at least one Puerto Rican hospice and one high-Hispanic mainland hospice.

In addition, to establish feasibility of survey implementation and identify potential challenges (e.g., variation in response rates or rates of missingness) related to hospice characteristics, we aimed to include a targeted number of hospices with the following characteristics in the final participating field test sample: a natural mix of hospices across four geographic regions in the United States, at least one hospice belonging to a national chain, ten to 15 for-profit hospices, one government hospice, and at least three rural hospices.

To satisfy these targets, we randomly selected hospices proportionately with respect to region and disproportionately with respect to hospice size, chain status, profit status, government ownership, and rural location. Because the design was not fully factorial, a simulation-based sampling approach was employed to derive a sample draw that was within a small prespecified tolerance. Our sample target was 2,430 across hospice care settings and hospice size. We assumed that 25 percent of deaths would be deemed ineligible and a 40-percent response rate from caregivers.

Sampling Deaths Within Hospices

Representatives from each hospice that agreed to participate in the field test submitted data files to support survey administration and analyses, including data on characteristics and care patterns of decedents, and contact information for primary caregivers. For each hospice, we identified and removed cases that were ineligible to participate.

To ensure a sufficient number of responses to compare experiences across settings of hospice care, we selected all eligible cases in the less common settings of care: nursing home, acute care hospital, and hospice IPU. We subsampled cases in the largest setting, home care, with a higher sampling rate of 50 percent in hospices with higher proportions of black or Hispanic decedents (defined as 10 percent or more in either category). Across all hospices, we sampled 729 cases in the home setting, 639 in nursing homes, 198 in acute care hospitals, and 701 in hospice IPUs, for a total of 2,267 cases.

Survey Administration Procedures

We used a mixed mode survey administration protocol, including one survey mailing, one prompt letter, and telephone as the secondary or nonresponse mode. In keeping with CAHPS Hospital Survey (HCAHPS) guidelines, the entirety of the field period, from initial survey mailing to cessation of calling, was no longer than 42 days (six weeks).

Survey Instruments

There were three setting-specific versions of the survey instrument, corresponding to the final setting in which the decedent received hospice care: home (including assisted living facility), nursing home, and inpatient (including acute care hospital and hospice IPU).

Several survey sections were identical across the three versions: "The Hospice Patient" (three items), "Your Role" (two items), "Starting Hospice Care" (two items), "Your Own Experience with Hospice" (seven items), "Overall Rating of Care" (three items), "About Your Family Member" (four items), and "About You" (seven items). The section "Your Family Member's Hospice Care" had 41 items on the home version, 37 items on the nursing home version, and 36 items on the inpatient version, and 33 of these items were the same across all three versions. The home version had an additional section, "Special Medical Equipment" (three items), and the inpatient version had an additional section, "The Hospice Environment" (three items). The home version had a total of 72 items, the nursing home version had 65 items, and the inpatient version had 67 items; 61 items were the same across all versions.

Field Test Results

Characteristics of Field Test Hospices, Decedents, and Caregiver Respondents

Thirty-three hospice programs from 29 hospice organizations agreed to participate in the field test. In keeping with our aim to include hospices with a range of size, ownership, geographic region, urbanicity, and chain status, 75.6 percent of hospices participating in the field test were small (ten to 29 deaths per month in the nonflu months of April through October), 39.4 percent were nonprofit, 12.1 percent were located in rural areas, and 15.2 percent were members of national chains. Compared with hospices nationwide, hospices participating in the field test were significantly more likely to be nonprofit ($p = 0.03$) and had lower rates of live discharge ($p = 0.07$). Hospices with fewer than ten deaths per month in nonflu months were not eligible to participate in the field test and therefore are not represented in the field test sample; such small hospices represent more than half (56.5 percent) of all hospices nationwide.

In all, 1,136 respondents completed the field test survey, reporting care experiences for 1,136 hospice decedents. The mean age of decedents was 79.8 years; 5.6 percent were black, and 4.3 percent were Hispanic. For more than one-third (34.7 percent) of decedents, the last setting of hospice care was a home or assisted living facility; the last location was a nursing home for 27.9 percent of decedents, a hospice freestanding IPU for 29.7 percent, and an acute care hospital for 7.8 percent. The age, sex, and race distributions of field test decedents were generally similar to the population of Medicare beneficiaries receiving hospice care. Hospice patients who died after less than 48 hours on hospice service were excluded from the field test; hence, the field test sample underrepresents those with short lengths of stay when compared with national data.

Nearly three-quarters (72.6 percent) of respondents were female, 44.8 percent were age 65 or older, and 5.8 percent were black. Nearly half (46.6 percent) were children of the hospice patient, while one-third were spouses or partners.

Response Rates

Unit nonresponse occurs when an eligible sampled individual does not respond to any of the items in a survey. We describe rates of unit nonresponse and response and assess hospice-, caregiver-, and decedent-level characteristics associated with unit nonresponse.

The overall response rate among eligible members of the sample was 53.6 percent (Table 3.1). The response rate in the home setting was slightly higher (56.5 percent) than in the other three care settings (51.3 to 52.9 percent). Multivariate regression analyses showed that the relationship between the survey caregiver and the decedent, previous receipt of the Family Evaluation of Hospice Care (FEHC) survey,[2] decedent age at death, decedent race or ethnicity, and length of final episode of hospice care are all significantly associated with the probability of response. In particular, spouses and parents were more likely to respond than children, those who were mailed the FEHC survey were less likely to respond, caregivers of older decedents were more likely to respond than those of younger decedents, and caregivers of Hispanic decedents were less likely to respond than those of decedents in other race or ethnicity categories. In addition, caregivers of decedents who had longer final episodes of hospice care were more likely to respond than those with shorter episodes. Given the anticipated suspension of the FEHC during national implementation of the HECS, we may expect improved response rates in national implementation. Specifically, FEHC mailing was associated with an 8.8-percent lower response rate than from those who were not mailed the FEHC in this field test, and about 90 percent of eligible caregivers were mailed the FEHC; given our observed overall response rate of 53.6 percent and the same administration procedures and field period, in the absence of the FEHC, we would expect a response rate of about 61.4 percent.

[2] Some hospices administered the FEHC survey to the same caregivers who later received the field test survey.

Table 3.1. Response Rates, by Setting and Survey Version

Respondent	Overall	Home Setting and Survey	Nursing Home Setting and Survey	Inpatient Settings and Survey		
				Acute Care Hospital Setting	Freestanding Hospice IPU Setting	Inpatient Survey
Surveyed	2,267	729	639	198	701	899
Administrative ineligible N (percentage of surveyed)	80 (3.5%)	23 (3.2%)	15 (2.3%)	22 (11.1%)	20 (2.9%)	42 (4.7%)
Nonparticipating ineligible N (percentage of surveyed)	66 (2.9%)	9 (1.2%)	25 (3.9%)	8 (4.0%)	24 (3.4%)	32 (3.6%)
Eligible N (percentage of surveyed)	2,121 (93.6%)	697 (95.6%)	599 (93.7%)	168 (83.7%)	657 (93.7%)	825 (91.8%)
Completes	1,136	394	317	88	337	425
Response rate among eligibles (%)	53.6	56.5	52.9	52.4	51.3	51.5

NOTE: The "Overall" column reflects the combined total of the home, nursing home, and inpatient surveys. The home and nursing home settings were each surveyed with their own instruments. Both the acute care hospital and freestanding hospice IPU settings were surveyed with the inpatient survey.

Caregivers with a longer time between decedent death and the beginning of mailing of the HECS; caregivers of younger decedents; and caregivers of black, Asian, and Pacific Islander decedents were less likely to respond by mail than by phone. Given that a longer time between the decedent's date of death and the date of first mailing tended to result in a lower probability of response by mail and thus a higher probability of response by phone and that mail mode is generally less costly than phone mode, this might suggest a recommendation that mailings go out more quickly than what we implemented in this field test. For example, these results suggest that delays between death and mailing that were in the highest quartile, a delay of 98 days or more, should be avoided in national implementation.

In addition, one-fifth of eligible nonresponding cases were unlocatable during the field test. Because caregivers may move or change contact information after patient death, this further underscores the need for fielding the survey in a timely manner after patient death. The number of unlocatable cases also highlights the need for hospices to give attention to verification of caregiver contact information and to consider collecting and maintaining multiple sources of contact information for caregivers.

These response analyses also show that, although caregivers of black and Hispanic decedents are less likely to respond to the survey in general than caregivers of white decedents are, caregivers of black and Asian decedents who do respond are more likely to respond by phone than by mail. With such small minority representation in the field test and likely across hospices in general, this highlights the importance of telephone follow-up to ensure that such groups are represented. Use of the telephone mode in addition to the mail mode yielded a group of respondents that was more similar to the eligible sample in terms of race and ethnicity of the decedent and in terms of other

characteristics, including relationship to decedent, age of decedent, and payer for hospice care, although differences still persist between all respondents and the eligible sampled group.

Item Nonresponse and Ceiling Effects

Item nonresponse occurs when a unit respondent inappropriately skips an item. We describe rates of item nonresponse and assess hospice-, caregiver-, and decedent-level characteristics associated with item nonresponse. In addition, we investigate floor and ceiling effects by examining both the number of respondents validating extreme response categories expressed as a proportion of valid responses obtained and the intraclass correlation coefficients (ICCs). ICCs measure the amount of variability in response among hospices. Low ICCs indicate highly similar mean scores across hospices relative to variability within hospices and may indicate that an item was poorly understood and requires modifications. However, a low ICC in combination with a very high or very low mean score may indicate a ceiling or floor effect (i.e., in which most hospices score near the maximum or minimum, limiting that question's ability to distinguish performance between hospices).

Item nonresponse analyses showed that overall item missingness among eligible items was 5.5 percent, with a lower item missingness rate observed in the home care setting, even though the survey instrument for this setting is longer (62.9 eligible items compared with 56.0 to 58.4 for the other care settings; see Table 3.2). Higher nonresponse in the non–home care settings was not restricted to setting-specific items asked only in the nursing home and inpatient survey instruments. This pattern may be due to caregivers of decedents in the home care setting being more familiar with their family members' care than caregivers of patients in other settings. Item missingness tended to be higher with an increased number of applicable items and for those items that appeared later in the survey instrument. Although there was a slightly higher item nonresponse rate among respondents by phone than by mail, it is common in CAHPS settings to see much higher item nonresponse by phone due to break-off (i.e., respondent hanging up before call is completed) than what was observed in this field test. This may indicate that break-off is less likely in the hospice survey because of the emotional content of the survey. Among unit respondents, several characteristics were associated with *higher* item missingness, including caregivers who were spouses or partners and non–family members (i.e., friends) of the decedent; caregivers of decedents covered by Medicaid or Medicaid and private insurance; caregivers of decedents in nursing home and inpatient care settings; and caregivers of decedents with primary diagnoses of dementia, neurological disease, or cardiovascular disease. Among unit respondents, several characteristics were associated with *lower* item missingness, including caregivers of younger decedents, caregivers of Asian and Pacific Islander decedents, caregivers of decedents with longer final episodes of hospice care, and caregivers who reported they usually or always took part in care of the decedent. This observed pattern in item nonresponse by caregiver relationship and decedent age may be driven largely by the fact that these caregivers may be older themselves and older age is often associated with higher item nonresponse in CAHPS. In addition, the fact that lower rates of inappropriate missingness were observed among caregivers who reported usually or always taking part in care for family members

than among those who sometimes took part in care is not surprising because these respondents likely know more about the care that was received.

Table 3.2. Item Nonresponse Rates, by Mode and by Final Setting of Care

		Mode		Final Setting of Care			
Item	All Respondents	All Mail Respondents	All Telephone Respondents	Home	Nursing Home	Acute Care Hospital	Freestanding Hospice IPU
N	1,136	784	352	394	317	88	337
Number of eligible items, of 80 total: mean (SD)	59.3 (4.8)	59.2 (4.8)	59.3 (4.8)	62.9 (4.5)	56.0 (3.7)	58.1 (3.7)	58.4 (3.2)
Number of nonlegitimate missing: mean (SD)	3.4 (8.9)	3.2 (8.3)	3.6 (10.3)	2.4 (6.8)	3.6 (9.7)	5.1 (11.6)	3.7 (9.5)
Percentage of eligible items missing: mean (SD)	5.5 (13.9)	5.3 (13.1)	5.8 (15.7)	3.7 (10.2)	6.1 (15.4)	8.3 (17.9)	6.1 (14.9)

NOTE: SD = standard deviation.

Table A.1 in Appendix A reports the number of applicable completed surveys, the number and proportion of legitimate skips, the number of legitimate responses, the number of nonlegitimate skips, and the proportion of nonlegitimate skips overall and by final setting of care. For many items, the inappropriate item skip rate is much lower for respondents in the home care setting than in the other three settings. Some health conditions were rare, and many respondents appropriately skipped the dependent items evaluating the hospice (for instance, 56.7 percent of respondents appropriately skipped an evaluative item on treatment of constipation, and 54.0 percent appropriately skipped an evaluative item on getting help for sadness). This decreases the power to test hospice's help for those conditions.

Floor and Ceiling Effects

We calculated the percentage of responses in the lowest and highest categories for each evaluative item. There were no items with 90 percent or more responses in the lowest category. The following items had more than 90 percent of responses in the highest category:

- While your family member was in hospice care, did the hospice team give you and your family member enough privacy?
- While your family member was in hospice care, how often did you have a hard time speaking with or understanding members of the hospice team because you spoke different languages?
- While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

- Did the hospice team get in the way of you spending time with your family member while he or she was dying?
- While your family member was in hospice care, were his or her room and bathroom kept clean?
- While your family member was in hospice care, was his or her room a comfortable place for you to be together?
- While your family member was in hospice care, was your family member's room a calm and soothing place for him or her?
- Did your family member get special medical equipment as soon as he or she needed it?
- Was the equipment picked up in a timely manner when your family member no longer needed it?
- How often did the hospice team treat your religious or spiritual beliefs with respect?
- While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?
- While your family member was in hospice care, how much emotional support did you get from the hospice team?

Estimated ICCs were generally very small for most items, indicating that there is very little variability between hospices. However, with the small number of respondents and small number of hospices with enough respondents to the item, our ability to precisely estimate ICCs in the field test may be limited. All items listed above with more than 90 percent of respondents in the highest category also had estimated ICCs with 95-percent confidence intervals (CIs) that overlapped 0, indicating very little or no variability between hospices, with the exception of "While your family member was in hospice care, were his or her room and bathroom kept clean?" which had an estimated ICC of 0.2785 (95-percent CI of 0.0731–0.484). In addition to this item, overall, only one additional item with a moderate ICC estimate was significantly different from 0: the item asking whether the caregiver spoke with a doctor as often as he or she needed to, with an ICC of 0.0779 (95-percent CI of 0.0002–0.1556).

In sum, the analysis of floor and ceiling effects showed that 12 items had high proportions of responses in the highest category, and 11 of these 12 also had very small ICC estimates, indicating a ceiling effect for these 11 items. For these 11 items, the ability to distinguish performance between hospices based on responses to these items is very limited. Given the anticipated larger number of respondents per hospice and larger number of hospices in national implementation, ICC estimates may be better calculated in national implementation.

Psychometric Analyses and Development of Composites

Composites are collections of items on the survey that assess similar content domains. When a set of items measures a given content domain, combining those items into a composite allows for a more precise estimate of a respondent's experience of care than would be possible from any single item and allows fewer measures to be presented to consumers, reducing cognitive burden. We constructed factor analytic models to establish domains of interest (i.e., composites) and calculated item- and scale-level correlations to ensure that the domains measure distinct content.

The analytic process resulted in the development of multi-item composites and single-item measures of key HECS domains, as follows. (Alpha is shown for multi-item composites, and refers to Cronbach's alpha, a 0-to-1 index that increases with the number of items in a domain and their average correlation with one another. Higher values indicate better measurement of the underlying construct that the composite is intended to measure.) Survey items in each of the multi-item composites and single-item measures are as follows:

- Hospice Team Communication (alpha = 0.89)
  - How often did the hospice team members listen carefully to you when you talked with them about problems with your family member's hospice care?
  - While your family member was in hospice care, how often did the hospice team listen carefully to you?
  - While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?
  - While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?
  - While your family member was in hospice care, how often did the hospice team members keep you informed about when they would arrive to care for your family member?
- Getting Timely Care (alpha = 0.72)
  - While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?
  - How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?
- Treating Your Family Member with Respect (alpha = 0.69)
  - While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?
  - While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?
- Providing Emotional Support (alpha = 0.68)
  - In the weeks after your family member died, how much emotional support did you get from the hospice team?
  - While your family member was in hospice care, how much emotional support did you get from the hospice team?
- Providing Support for Religious and Spiritual Beliefs
  - Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for *your* religious and spiritual beliefs did you get from the hospice team?

- Getting Help for Symptoms (alpha = 0.80)
  - How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?
  - Did your family member get as much help with pain as he or she needed?
  - How often did your family member get the help he or she needed for trouble with constipation?
  - How often did your family member get the help he or she needed for trouble breathing?
- Information Continuity
  - While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?
- Understanding the Side Effects of Pain Medication
  - Side effects of pain medicine include such things as sleepiness. Did any member of the hospice team discuss side effects of pain medicine with you or your family member?
- Hospice Care Training (home setting only) (alpha = 0.87)
  - Did the hospice team give you enough training about what to do if your family member became restless or agitated?
  - Did the hospice team give you enough training about if and when to give more pain medicine to your family member?
  - Did the hospice team give you enough training about how to help your family member if he or she had trouble breathing?
  - Did the hospice team give you enough training about what side effects to watch for from pain medicine?

The scales are generally moderately intercorrelated. There is a slight tendency for the intercorrelations between composites and measures to be highest for the Hospice Team Communication composite (r = 0.32 to 0.66). This is due in part to the survey generally assessing the communication between the hospice team and the family but is also reflective of the high internal consistencies of this composite. The intercorrelations are somewhat lower for the composites for Information Continuity (r = 0.23 to 0.38) and Providing Emotional Support (r = 0.16 to 0.53), indicating that these domains measure content that is somewhat distinct on the survey.

Case-Mix Adjustment

Previous research, both within and outside of CAHPS, has identified respondent characteristics that are not under the control of the entities being assessed but tend to be related to survey responses. For example, people who are older, those with less education, and those in better overall and mental health generally tend to give more positive ratings and reports of care in Medicare CAHPS (MCAHPS). Hence, entities with disproportionate numbers of patients with such characteristics (favorable case mix) are advantaged relative to those with a less favorable case mix. To ensure that

comparisons between hospices reflect differences in performance rather than differences in case mixes, responses must be adjusted for such characteristics.

We make recommendations for case-mix adjustment (CMA) of hospices participating in the field test, examine adjusted scores, and describe the impact of adjustment. Note that these are preliminary recommendations based solely on the field test and may be further shaped by information obtained from national implementation. In general, only respondent characteristics that are determined not to be endogenous (i.e., not to be related to satisfaction or quality of care) should be considered as potential case-mix adjusters. Given that the HECS is administered to caregiver proxy respondents and that there was information available about both respondents and decedents, we considered both respondent and decedent characteristics as potential case-mix adjusters. Outcomes examined were overall rating of hospice care, willingness to recommend the hospice, and the multi-item composites for Hospice Team Communication, Treating Your Family Member with Respect, Providing Emotional Support, and Getting Help for Symptoms.

Overall, little to moderate variation in the following respondent and decedent characteristics was observed among hospices in the field test: language of completed survey, payer type, language spoken at home, prior receipt of the FEHC, decedent age, decedent education, primary diagnosis of dementia or neurological disease versus other, and respondent education. A number of characteristics were significantly associated with at least one of six outcomes examined in either a univariate or multivariate model: respondent sex, primary diagnosis of dementia or neurological disease versus other, primary diagnosis of cardiovascular disease versus other, payer type, language spoken at home, and language of completed survey. Only prior receipt of the FEHC demonstrated substantial marginal impact on adjustment of hospice-level scores.

Though decedent age, decedent sex, decedent education, respondent age, and respondent education neither were significantly associated with any examined outcomes nor had moderate or large (standardized regression coefficient greater than 0.20 SD) nonsignificant effects, one might consider retaining them in the survey for CMA or other purposes. First, other CAHPS surveys, including MCAHPS and CAHPS for Accountable Care Organizations (ACOs), observe substantial variation in respondent age and respondent education among entities being evaluated and significant associations with ratings and reports of care and thus adjust for such respondent characteristics. Our potentially limited power in the field test to observe such effects leads us to recommend retaining these items in the survey for further evaluation in national implementation. Second, although improved power in national implementation will also allow further evaluation of decedent age, sex, and education as case-mix adjusters, we would also be interested in retaining these items in the survey regardless of adjustment potential to allow for description and reporting of observed true differences in quality of care by these characteristics at a national level. Similarly, this reasoning also supports the retention of survey items related to decedent race and ethnicity. Although this decedent characteristic was ruled out for CMA consideration, it should be retained in the survey so that potential disparities in quality of care can be examined moving forward. Respondent race and ethnicity, on the other hand, were not considered for adjustment and would likely not be needed for

future analyses. Furthermore, among respondents who answered survey items relating to the respondent's race and ethnicity and the decedent's race and ethnicity, race and ethnicity matched in 94.8 percent of cases.

Payer type demonstrated substantial variation among hospices and was significantly associated with multiple outcomes. Therefore, we recommend including this variable in the final CMA model. Note that this is similar to the inclusion of Medicaid dual eligibility in the CMA models for MCAHPS and CAHPS for ACOs.

Although the characteristic indicating whether a respondent was located in the same state as the hospice was included in our initial list of candidate adjusters and examined in these analyses, further discussion of this variable, along with potential inclusion of a variable indicating whether the respondent was located in the same city as the hospice, has led us to recommend that both variables be excluded from CMA consideration because they seem to be proxies for census region. In general, stakeholders do not tend to support adjustment for region in CAHPS, and, to maintain consistency with other CAHPS survey initiatives, we recommend not including variables that directly or indirectly measure region. Finally, although respondent's relationship to the decedent was not significantly associated with any examined outcomes and varied very little among hospices, we recommend including this characteristic provisionally in the CMA model for the field test and recommend further examination in national implementation.

For the purposes of providing hospice-level scores for hospices participating in the field test, we recommend a CMA model that includes the following:

- language of completed survey
- decedent age
- decedent education
- decedent sex
- payer type (all categories)
- primary diagnosis (all categories)
- respondent age
- respondent education
- respondent sex
- language spoken at home (all categories)
- relationship to decedent (all categories)
- prior receipt of FEHC survey.

This recommended CMA model should be further examined and evaluated in national implementation. Prior receipt of the FEHC is unlikely to be relevant in the context of national implementation. Future considerations could include discussion about whether one should categorize primary diagnosis as dementia or neurological disease versus cardiovascular disease versus other, categorize payer type as Medicare only versus Medicare and Medicaid versus Medicaid only versus Medicaid and private, categorize language spoken at home as English only versus other, and categorize relationship to decedent as spouse or partner versus other.

Association Between Hospice, Decedent, and Caregiver Characteristics and Hospice Experience of Care Survey Outcomes

We explore a range of hospice, patient, and caregiver characteristics that may be associated with differences in care experiences, particularly geographic region, hospice size, chain status and profit status at the hospice level, and setting of care at the decedent level.

Overall, across hospice, decedent, and caregiver characteristics, the mean overall rating of hospice care was 93.0 out of 100 (Table 3.3). Mean scores for each composite were generally high, ranging from 81.0 for Understanding the Side Effects of Pain Medication and 85.2 for Hospice Care Training to 94.9 for Information Continuity and 95.7 for Treating Your Family Member with Respect.

Table 3.3. Overall Unadjusted Mean Scores for Overall Rating, Willingness to Recommend, and Composites

Outcome	N	Unadjusted Person-Level Mean (SD)
Overall rating	1,102	93.0 (19.9)
Recommend hospice	1,102	93.1 (25.4)
Hospice Team Communication	1,117	91.2 (23.0)
Getting Timely Care	1,077	90.2 (26.5)
Treating Your Family Member with Respect	1,097	95.7 (17.1)
Providing Emotional Support	1,096	91.0 (34.1)
Providing Support for Religious and Spiritual Beliefs	547	96.2 (26.0)
Getting Help for Symptoms	948	90.2 (25.5)
Information Continuity	1,094	94.9 (21.7)
Understanding the Side Effects of Pain Medication	981	81.0 (45.2)
Hospice Care Training (home setting only)	362	85.2 (35.1)

Adjusted means varied greatly by hospice region, with lower adjusted means for overall rating and willingness to recommend for hospices in the Northeast and Puerto Rico. Regional results should be interpreted with caution given that field test hospices may not be representative of hospices within their regions and that Puerto Rico results reflect only one hospice. Chain hospices also tended to have lower adjusted mean scores than nonchain hospices. Differences in adjusted mean scores by hospice size were not observed for any outcomes examined.

In keeping with prior analyses reported by the Medicare Payment Advisory Commission (MedPAC) regarding important concerns with provision of hospice care in nursing homes, we find that reported experiences of care are typically worse in the nursing home setting (Table 3.4), particularly with regard to Understanding the Side Effects of Pain Medication, Getting Help for Symptoms, Getting Timely Care, and Hospice Team Communication. Such differences may be associated with different visit patterns in the nursing home setting (i.e., fewer visits from skilled

nursing staff). The field test findings support that experiences of care in freestanding hospice IPUs are rated best by caregivers. There were few significant associations between patient and respondent characteristics and outcomes.

Table 3.4. Adjusted Mean Response for Each Developed Composite, Overall Rating, and Willingness to Recommend, by Final Setting of Care

Outcome	Home (N = 394)	Nursing Home (N = 317)	Acute Care Hospital (N = 88)	Hospice IPU (N = 337)
Overall rating**	92.2 (90.2, 94.2)	90.2 (87.7, 92.6)	93.0 (89.8, 96.1)	96.6 (95.4, 97.8)
Recommend hospice**	92.0 (89.1, 94.8)	90.7 (88.2, 93.3)	91.2 (88.1, 94.3)	96.9 (95.8, 98.0)
Hospice Team Communication*	91.0 (89.1, 92.8)	88.5 (86.1, 90.9)	89.4 (86.4, 92.4)	94.4 (92.7, 96.2)
Getting Timely Care**	89.2 (87.2, 91.3)	87.3 (85.0, 89.6)	86.7 (82.5, 91.0)	94.7 (93.0, 96.5)
Treating Your Family Member with Respect	95.2 (93.7, 96.7)	95.3 (93.4, 97.2)	94.8 (92.8, 96.8)	98.9 (95.3, 98.4)
Providing Emotional Support*	90.2 (87.5, 92.8)	88.6 (84.7, 92.6)	92.5 (88.7, 96.3)	94.5 (92.1, 96.9)
Providing Support for Religious and Spiritual Beliefs	95.0 (92.4, 97.7)	95.2 (91.6, 98.8)	101.5 (98.5, 104.6)	98.1 (95.9, 100.3)
Getting Help for Symptoms**	89.8 (86.8, 92.9)	86.2 (84.0, 88.5)	86.3 (81.3, 91.3)	95.3 (92.0, 98.6)
Information Continuity	94.4 (92.6, 96.3)	94.9 (92.9, 96.9)	94.0 (91.4, 96.7)	95.5 (93.8, 97.2)
Understanding the Side Effects of Pain Medication**	89.5 (87.1, 92.0)	71.1 (66.6, 76.7)	73.7 (62.2, 85.2)	81.0 (77.2, 84.8)

NOTE: Each cell shows the adjusted mean and, in parentheses, the 95% CI. ** = $p \leq 0.001$. * = $p \leq 0.05$.

Open-Ended Responses

All versions of the field test instrument included an open-ended survey item meant to elicit detailed comments from respondents on both exemplars and problems related to the care the patient received from the hospice. One purpose of including the open-ended question was to determine whether any domains not represented by the field test questions should be considered for inclusion in the final survey.

The open-ended text responses were analyzed to identify general themes. Text responses were first coded as positive or negative. Positive and negative comments were furthered coded into 14 themes; themes were identified based on the survey content, and some emerged from the text itself. The most prevalent themes identified in the text included concern and respect, communication, emotional support, access, staff and team care, medication, knowledge imparted to caregiver, and religious support. The open-ended questions elicited rich and detailed responses regarding these themes but, for the most part, addressed issues for which survey questions already existed. Although the field test instrument included multiple questions regarding spiritual support, most of them were omitted from the final survey after analyses showed ceiling effects for these items. Respondents frequently spontaneously mentioned chaplain care in the open-ended questions; because of the

presumed significance of this type of care to caregivers, an item regarding religious and spiritual support was recommended for inclusion on the final survey instrument.

Chapter Four. Final Survey Instrument

We identified items to maintain for the final survey instrument using several general guidelines. First, we removed items that were included on the field test instrument solely to facilitate tests of construct validity (e.g., "Did your family member begin getting hospice care too early, at the right time, or too late?") and those that exhibited little variation or ceiling effects. Some items with limited variation were maintained because of the importance of the measured constructs to hospice stakeholders or consumers (e.g., an item regarding spiritual or religious support). For parallel items regarding caregivers' and decedents' experiences (e.g., "How often did the hospice team listen carefully to *you*?" and "to *your family member*?"), we generally included the item directed to the caregiver respondent rather than the decedent on the grounds that respondents' answers regarding their own experiences have greater face validity than proxy answers on behalf of family members. Finally, we retained items, such as respondent and decedent race and education, that may be used for CMA or other analytic purposes. Appendix B shows changes to the field test instrument resulting from the analyses described here.

Because few setting-specific items were maintained for the final version of the survey instrument and because it is simpler and less expensive to administer one survey instrument in national implementation than to administer multiple setting-specific versions, the three setting-specific survey instruments administered during the field test were consolidated into one instrument designed to measure experiences with care in all settings in which the patient received care. Items specific to the nursing home setting are presented under the heading "Hospice Care Received in a Nursing Home," and tailored nonapplicable responses are offered for items specific to the home setting. No inpatient-specific items were maintained for the final survey. The final recommended English-language survey instrument for 2015 national implementation is 47 items long and may be found online.[3]

[3] CMS, "CAHPS® HOSPICE Survey," last modified July 18, 2014. As of August 4, 2014: http://www.hospicecahpssurvey.org/Content/HomePage.aspx

Appendix A: Item Response Rates Among Unit Respondents

Table A.1. Item Response Rates Among Unit Respondents

Item	Applicable Completed Surveys	Appropriate Skip (N)	Appropriate Skip (%)	N Legitimate Responses	Nonlegitimate Skips (N)	Nonlegitimate Skips (%)				
						Overall	Home	Nursing Home	Acute Care Hospital	Hospice IPU
The hospice patient										
How related to decedent	1,136	0	0.0	1,117	19	1.7	0.8	1.3	2.3	3.0
Receive care from the hospice listed	1,136	0	0.0	1,112	24	2.1	1.3	1.6	4.5	3.0
Last location of care	1,136	0	0.0	1,112	24	2.1	0.5	1.9	3.4	3.9
Your role										
How often you oversaw care	1,136	0	0.0	1,104	32	2.8	0.8	3.5	5.7	3.9
Your first experience with hospice	1,136	0	0.0	1,106	30	2.6	1.0	1.9	4.5	4.7
Starting hospice care										
Hospice explained the kinds of care	1,136	0	0.0	1,111	25	2.2	0.8	1.9	2.3	4.2
Began getting hospice care too early, at the right time, or too late	1,136	0	0.0	1,101	35	3.1	2.0	3.5	3.4	3.9
Your family member's hospice care										
Needed to contact the hospice during evenings, weekends, or holidays	1,136	0	0.0	1,089	47	4.1	3.3	4.4	4.5	4.7
Got help from the hospice during evenings, weekends, or holidays	1,136	531	46.7	560	45	7.4	4.3	9.3	14.3	11.2
Informed about when hospice team would arrive	376	0	0.0	369	7	1.9	1.9			
Nursing home staff and hospice team worked well together	272	0	0.0	257	15	5.5		5.5		
Got as much help with personal care as needed	696	0	0.0	654	42	6.0		5.3	7.3	6.4
Personal care not done because nursing home staff expected the hospice team to take care of those needs	272	0	0.0	251	21	7.7		7.7		

Item	Applicable Completed Surveys	Appropriate Skip (N)	Appropriate Skip (%)	N Legitimate Responses	Nonlegitimate Skips (N)	Nonlegitimate Skips (%)				
						Overall	Home	Nursing Home	Acute Care Hospital	Hospice IPU
Got help as soon as you needed it	1,136	0	0.0	1,074	62	5.5	2.5	7.3	8.0	6.5
Got enough privacy	1,136	0	0.0	1,093	43	3.8	3.6	3.5	4.5	4.2
Different languages	1,136	0	0.0	1,095	41	3.6	2.8	3.2	3.4	5.0
Hospice seemed informed about condition and care	1,136	0	0.0	1,095	41	3.6	2.8	3.5	3.4	4.7
Spoke to a doctor as often as you needed	402	0	0.0	373	29	7.2			5.3	7.7
Hospice explained things in a way that was easy to understand	1,136	0	0.0	1,096	40	3.5	2.3	3.5	3.4	5.0
Hospice kept you informed about condition	1,136	0	0.0	1,092	44	3.9	3.0	2.8	4.5	5.6
Confusing or contradictory information about condition	1,136	0	0.0	1,094	42	3.7	3.0	3.2	4.5	4.7
Information from nursing home staff and hospice team differed	272	0	0.0	260	12	4.4		4.4		
Respected your needs and preferences	1,136	0	0.0	1,086	50	4.4	2.8	5.0	3.4	5.9
Hospice spent enough time with your family member	1,136	0	0.0	1,070	66	5.8	3.0	6.6	10.2	7.1
Hospice treated your family member with dignity and respect	1,136	0	0.0	1,093	43	3.8	2.8	3.5	4.5	5.0
Hospice cared about your family member	1,136	0	0.0	1,093	43	3.8	2.5	3.8	4.5	5.0
Talked with the hospice about any problems with hospice care	1,136	0	0.0	1,070	66	5.8	4.1	6.6	8.0	6.5
Hospice listened carefully to you about problems with care	1,136	674	59.3	402	60	13.0	8.1	12.8	25.0	17.6
Problems resolved as soon as you needed	1,136	674	59.3	398	64	13.9	8.1	15.2	25.0	18.5
Family member had any pain	1,136	0	0.0	1,073	63	5.5	4.3	7.9	5.7	4.7
Got help for pain	1,136	342	30.1	730	64	8.1	7.0	10.2	6.8	7.8

Item	Applicable Completed Surveys	Appropriate Skip (N)	Appropriate Skip (%)	N Legitimate Responses	Nonlegitimate Skips (N)	Nonlegitimate Skips (%)				
						Overall	Home	Nursing Home	Acute Care Hospital	Hospice IPU
Family member received any pain medicine	1,136	0	0.0	1,074	62	5.5	3.3	7.6	6.8	5.6
Got needed info about pain medicine	1,136	89	7.8	993	54	5.2	2.0	8.0	7.1	5.6
Hospice discussed side effects of pain medicine	1,136	89	7.8	981	66	6.3	2.8	9.4	7.1	7.2
Hospice trained about side effects of pain medicine	376	36	9.6	328	12	3.5	3.5			
Hospice trained when to give more pain medicine	376	36	9.6	329	11	3.2	3.2			
Family member had trouble breathing	1,136	0	0.0	1,089	47	4.1	2.8	5.4	4.5	4.5
Got help for trouble breathing	1,136	481	42.3	597	58	8.9	6.4	11.8	8.9	9.2
Got needed info from the hospice team about trouble breathing	1,136	481	42.3	596	59	9.0	6.8	11.2	8.9	9.7
Hospice trained about trouble breathing	376	151	40.2	210	15	6.7	6.7			
Family member had trouble with constipation	1,136	0	0.0	1,026	110	9.7	4.3	12.0	12.5	13.1
Got needed help for constipation	1,136	644	56.7	374	118	24.0	8.6	33.6	35.5	39.7
Family member was sad	1,136	0	0.0	1,059	77	6.8	4.3	6.9	9.1	8.9
Family member needed help with sadness	1,136	0	0.0	1,052	84	7.4	4.6	8.8	11.4	8.3
Got needed help for sadness	1,136	613	54.0	432	91	17.4	10.2	18.1	24.3	26.3
Family member was restless or agitated	376	0	0.0	369	7	1.9	1.9			
Hospice trained about what to do if restless or agitated	376	132	35.1	232	12	4.9	4.9			
Hospice trained how to move	376	82	21.8	283	11	3.7	3.7			
Hospice discussed your family member’s religious beliefs	1,136	0	0.0	1,067	69	6.1	4.3	7.3	10.2	5.9

Item	Applicable Completed Surveys	Appropriate Skip (N)	Appropriate Skip (%)	N Legitimate Responses	Nonlegitimate Skips (N)	Nonlegitimate Skips (%)				
						Overall	Home	Nursing Home	Acute Care Hospital	Hospice IPU
Treated your family member's religious beliefs with respect	1,136	284	25.0	770	82	9.6	7.0	11.0	16.9	9.6
Information about expectations while your family member was dying	1,136	0	0.0	1,092	44	3.9	2.8	4.7	4.5	4.2
Information provided in a way that was easy to understand	1,136	74	6.5	1,011	51	4.8	4.0	5.9	4.8	4.7
Hospice with you as soon as you needed after death	376	24	6.4	346	6	1.7	1.7			
Hospice got in way while he or she was dying	402	0	0.0	385	17	4.2			6.6	3.7
The hospice environment										
Room and bathroom kept clean	402	0	0.0	385	17	4.2			9.2	3.1
Room comfortable	402	0	0.0	387	15	3.7			7.9	2.8
Room calm	402	0	0.0	387	15	3.7			6.6	3.1
Special medical equipment										
Needed special medical equipment	376	0	0.0	369	7	1.9	1.9			
Got the equipment as soon as needed	376	24	6.4	346	6	1.7	1.7			
Equipment picked up in a timely manner	376	24	6.4	339	13	3.7	3.7			
Your own experience with hospice										
Hospice listened carefully to you	1,136	0	0.0	1,098	38	3.3	1.3	3.8	9.1	3.9
Hospice spent enough time with you	1,136	0	0.0	1,088	48	4.2	2.0	5.4	8.0	4.7
Hospice discussed your religious or spiritual beliefs	1,136	0	0.0	1,067	69	6.1	3.6	7.6	17.0	4.7
Hospice treated your religious beliefs with respect	1,136	515	45.3	549	72	11.6	6.9	14.6	32.1	8.9
Support for your religious beliefs	1,136	515	45.3	547	74	11.9	6.9	15.3	30.2	10.1

Item	Applicable Completed Surveys	Appropriate Skip (N)	Appropriate Skip (%)	N Legitimate Responses	Nonlegitimate Skips (N)	Nonlegitimate Skips (%)				
						Overall	Home	Nursing Home	Acute Care Hospital	Hospice IPU
from hospice										
Emotional support from hospice for caretaker before death	1,136	0	0.0	1,088	48	4.2	2.0	6.0	9.1	3.9
Emotional support from hospice for caretaker after death	1,136	0	0.0	1,063	73	6.4	3.6	6.9	11.4	8.0
Overall rating of care										
Rate hospice, 0 = worst and 10 = best	1,136	0	0.0	1,102	34	3.0	1.0	3.8	9.1	3.0
Recommend this hospice	1,136	0	0.0	1,102	34	3.0	1.0	4.7	9.1	2.1
About your family member										
Family member's education	1,136	0	0.0	1,072	64	5.6	3.6	6.3	11.4	5.9
Family member Hispanic	1,136	0	0.0	1,054	82	7.2	6.6	7.9	10.2	6.5
Family member's Hispanic group	1,136	1008	88.7	46	82	64.1	51.9	82.8	69.2	64.7
Family member's race	1,136	0	0.0	1,067	69	6.1	6.1	4.7	9.1	6.5
About you										
Caregiver's age	1,136	0	0.0	1,067	69	6.1	6.1	5.4	9.1	5.9
Caregiver's gender	1,136	0	0.0	1,068	68	6.0	6.3	5.0	9.1	5.6
Caregiver's education	1,136	0	0.0	1,060	76	6.7	7.1	5.4	9.1	6.8
Caregiver Hispanic	1,136	0	0.0	1,036	100	8.8	7.9	9.1	12.5	8.6
Caregiver's Hispanic group	1,136	983	86.5	54	99	64.7	56.4	85.3	62.5	60.4
Caregiver's race	1,136	0	0.0	1,059	77	6.8	5.6	5.7	12.5	7.7
Caregiver's home language	1,136	0	0.0	1,069	67	5.9	5.3	5.4	9.1	6.2

Appendix B: Summary of Changes to Field Test Survey

Table B.1. Summary of Changes to Field Test Survey

HECS Field Test Survey Item	Home	Inpatient	Nursing Home	Keep/Drop in Final Survey?	Notes
The hospice patient					
How are you related to the person listed on the survey cover letter?	X	X	X	Keep	
Did your family member receive care from the hospice listed on the survey cover letter?	X	X	X	Drop	In keeping with other CMS efforts, survey responses would have been kept regardless of whether the respondent answered yes or no to this item.
What was the last location in which your family member received care from this hospice?	X	X	X	Keep	
Your role					
While your family member was in hospice care, how often did you take part in or oversee care for him or her?	X	X	X	Keep	Needed to identify knowledgeable respondent; on field test, those responding "never" were instructed to stop survey. For national implementation, these respondents will complete demographic questions only.
Was your family member's hospice care your first experience with hospice services for a close friend or family member?	X	X	X	Drop	Included in field test survey for construct validity only; not evaluative
Starting hospice care					
Did the hospice team members explain the kinds of care and services they could give you and your family member?	X	X	X	Drop	Little variation or ceiling effect

HECS Field Test Survey Item	Home	Inpatient	Nursing Home	Keep/Drop in Final Survey?	Notes
Did your family member begin getting hospice care too early, at the right time, or too late?	X	X	X	Drop	Included in field test survey for construct validity only; not evaluative
Your family member's hospice care					
While your family member was in hospice care, did you need to contact the hospice team during evenings, weekends, or holidays for questions or help with your family member's care?	X	X	X	Keep	Gatekeeper to next question
How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?	X	X	X	Keep	Although this item has a ceiling effect, responsiveness on evenings and weekends has been previously shown to help identify low-performing hospices.
While your family member was in hospice care, how often did the hospice team members keep you informed about when they would arrive to care for your family member?	X			Keep	Home-only item; will be tested in cognitive interviews to determine whether tailored inapplicable response is needed
While your family member was in hospice care, how often did the nursing home staff and hospice team work well together to care for your family member?			X	Keep	Nursing home only; will be tested in cognitive interviews to determine best tailored inapplicable response or skip pattern
Personal care needs include bathing, dressing, eating meals and changing bedding. While your family member was in hospice care, how often did your family member get as much help with personal care as he or she needed?		X	X	Supplemental set	Hospices may not feel they are reasonably accountable for personal care.

HECS Field Test Survey Item	Home	Inpatient	Nursing Home	Keep/Drop in Final Survey?	Notes
While your family member was in hospice care, were your family member's personal care needs ever not taken care of because the nursing home staff expected the hospice team to take care of those needs?			X	Drop	Confusing question; may be difficult for respondents to accurately attribute failed care to nursing home versus hospice staff
While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?	X	X	X	Keep	
While your family member was in hospice care, did the hospice team give you and your family member enough privacy?	X	X	X	Drop	Little variation or ceiling effect
While your family member was in hospice care, how often did you have a hard time speaking with or understanding members of the hospice team because you spoke different languages?	X	X	X	Supplemental set	Little variation or ceiling effect; consider for supplemental item set; could be relevant for hospices with need to assess cultural competence
While your family member was in hospice care, did the hospice team seem informed and up to date about your family member's condition and care?	X	X	X	Drop	Very highly correlated with items in Hospice Team Communication composite
While your family member was in hospice care, did you speak to a doctor as often as you needed?		X		Supplemental set	Only remaining inpatient-specific item, so dropped to streamline survey
While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?	X	X	X	Keep	
While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?	X	X	X	Keep	
While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?	X	X	X	Keep	

HECS Field Test Survey Item	Home	Inpatient	Nursing Home	Keep/Drop in Final Survey?	Notes
While your family member was in hospice care, how often was the information you were given about your family member by the nursing home staff different from the information you were given by the hospice team?			X	Keep	Nursing home only; will be tested in cognitive interviews to determine best tailored inapplicable response or skip pattern
While your family member was in hospice care, how often did the hospice team respect your needs and preferences?	X	X	X	Drop	Very highly correlated with items in Hospice Team Communication composite
While your family member was in hospice care, how often did the hospice team spend enough time with your family member?	X	X	X	Drop	Very highly correlated with items in Hospice Team Communication composite
While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?	X	X	X	Keep	Important construct in qualitative work
While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?	X	X	X	Keep	Important construct in qualitative work
While your family member was in hospice care, did you talk with the hospice team about any problems with your family member's hospice care?	X	X	X	Keep	Gatekeeper to next question
How often did the hospice team members listen carefully to you when you talked with them about problems with your family member's hospice care?	X	X	X	Keep	
How often were problems with your family member's hospice care resolved as soon as you needed?	X	X	X	Drop	Very highly correlated with other items in Hospice Team Communication composite
While your family member was in hospice care, did he or she have any pain?	X	X	X	Keep	Gatekeeper to next question
Did your family member get as much help with pain as he or she needed?	X	X	X	Keep	
While your family member was in hospice care, did he or she receive any pain medicine?	X	X	X	Keep	Gatekeeper to question about side effects of pain medicine
Did you get the information you needed from the hospice team about your family member's pain medicine?	X	X	X	Drop	

HECS Field Test Survey Item	Home	Inpatient	Nursing Home	Keep/Drop in Final Survey?	Notes
Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with you or your family member?	X	X	X	Keep	One-item assessment of pain medication and shared decisionmaking
Did the hospice team give you enough training about what side effects to watch for from pain medicine?	X			Keep	Home-only item
Did the hospice team give you enough training about whether and when to give more pain medicine to your family member?	X			Keep	Home-only item
While your family member was in hospice care, did your family member ever have trouble breathing or receive treatment for trouble breathing?	X	X	X	Keep	Gatekeeper to next question
How often did your family member get the help he or she needed for trouble breathing?	X	X	X	Keep	
How often did you get the information you needed from the hospice team about your family member's trouble breathing?	X	X	X	Drop	
Did the hospice team give you enough training about how to help your family member if he or she had trouble breathing?	X			Keep	Home-only item
While your family member was in hospice care, did your family member ever have trouble with constipation?	X	X	X	Keep	Gatekeeper to next question
How often did your family member get the help he or she needed for trouble with constipation?	X	X	X	Keep	
While your family member was in hospice care, did he or she show any feelings of anxiety or sadness?	X	X	X	Drop	Two gatekeepers for question about anxiety and sadness symptom assessment; more yes responses to need-help gatekeeper than to this one
Did your family member need help with feelings of anxiety or sadness?	X	X	X	Keep	Gatekeeper to next question
How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?	X	X	X	Keep	
While your family member was in hospice care, did he or she ever become restless or agitated?	X			Keep	
Did the hospice team give you enough training about what to do if your family member became restless or agitated?	X			Keep	Home-only item

HECS Field Test Survey Item	Home	Inpatient	Nursing Home	Keep/Drop in Final Survey?	Notes
Moving your family member includes things like helping him or her turn over in bed or get in and out of bed or a wheelchair. Did the hospice team give you enough training about how to safely move your family member?	X			Keep	
While your family member was in hospice care, did any member of the hospice team discuss your family member's religious or spiritual beliefs?	X	X	X	Drop	Gatekeeper to next question
How often did the hospice team treat your family member's religious or spiritual beliefs with respect?	X	X	X	Drop	Keep question about respondent's religious and spiritual beliefs: greater face validity
Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?	X	X	X	Keep	
Was the information provided in a way that was easy to understand?	X	X	X	Drop	Highly correlated with prior question
When your family member died, was the hospice team with you or available as soon as you needed?	X			Drop	Little variation or ceiling effect
Did the hospice team get in the way of you spending time with your family member while he or she was dying?		X		Drop	Little variation or ceiling effect
The hospice environment					
While your family member was in hospice care, were his or her room and bathroom kept clean?		X		Supplemental set	Little variation; although ICC is significant, 97.5% of field test respondents selected highest response category
While your family member was in hospice care, was his or her room a comfortable place for you to be together?		X		Drop	Little variation or ceiling effect
While your family member was in hospice care, was your family member's room a calm and soothing place for him or her?		X		Drop	Little variation or ceiling effect
Special medical equipment					
Special medical equipment includes things like hospital beds, wheelchairs, and oxygen. While your family member was in hospice care, did your family member need special medical equipment?	X			Supplemental set	

HECS Field Test Survey Item	Home	Inpatient	Nursing Home	Keep/Drop in Final Survey?	Notes
Did your family member get the equipment as soon as he or she needed it?	X			Supplemental set	Little variation or ceiling effect; however, this rarely occurring problem is of great concern to families
Was the equipment picked up in a timely manner when your family member no longer needed it?	X			Supplemental set	Little variation or ceiling effect; however, this rarely occurring problem is of great concern to families
Your own experience with hospice					
While your family member was in hospice care, how often did the hospice team listen carefully to you?	X	X	X	Keep	
While your family member was in hospice care, how often did the hospice team spend enough time with you?	X	X	X	Drop	Very highly correlated with other items in Hospice Team Communication composite
While your family member was in hospice care, were your religious or spiritual beliefs discussed with any member of the hospice team?	X	X	X	Drop	Alternative religious and spiritual item preferred because requires fewer items on the survey to evaluate religious and spiritual care
How often did the hospice team treat your religious or spiritual beliefs with respect?	X	X	X	Drop	Alternative religious and spiritual item preferred because requires fewer items on the survey to evaluate religious and spiritual care

HECS Field Test Survey Item	Home	Inpatient	Nursing Home	Keep/Drop in Final Survey?	Notes
Support for religious or spiritual beliefs includes talking, praying, quiet time, and other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?	X	X	X	Keep	Although this item has limited variation, religious and spiritual support is a vital part of the hospice benefit, and assessment of it is valued by hospice staff, particularly chaplains.
While your family member was in hospice care, how much emotional support did you get from the hospice team?	X	X	X	Keep	Important construct in qualitative work
In the weeks after your family member died, how much emotional support did you get from the hospice team?	X	X	X	Keep	Important construct in qualitative work
Overall rating of care					
Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?	X	X	X	Keep	
Would you recommend this hospice to your friends and family?	X	X	X	Keep	Parallel to other CAHPS surveys; appreciated by providers
In thinking about your experiences with hospice, was there anything that went especially well or that you wish had gone differently for you and your family member? Please tell us about those experiences.	X	X	X	Supplemental set	CMS will not require an open-ended item.
About your family member					
What is the highest grade or level of school that your family member completed?	X	X	X	Keep	May be needed for CMA
Was *your family member* of Hispanic, Latino/a, or Spanish origin or descent?	X	X	X	Keep	May be needed for CMA; combine with next question
Which group best describes your family member?	X	X	X	Keep	
What was your family member's race? Please mark one or more.	X	X	X	Keep	May be needed for CMA
About you					
What is your age?	X	X	X	Keep	May be needed for CMA
Are you male or female?	X	X	X	Keep	May be needed for CMA
What is the highest grade or level of school that you have completed?	X	X	X	Keep	May be needed for CMA

HECS Field Test Survey Item	Home	Inpatient	Nursing Home	Keep/Drop in Final Survey?	Notes
Are you of Hispanic, Latino/a, or Spanish origin or descent?	X	X	X	Drop	Highly correlated with family-member ethnicity
Which group best describes you?	X	X	X	Drop	Highly correlated with family-member ethnicity
What is your race? Please mark one or more.	X	X	X	Drop	Highly correlated with family-member race
What language do you *mainly* speak at home?	X	X	X	Keep	May be needed for CMA