

CAHPS[®] Hospice Survey
Quality Assurance
Guidelines

Version 1.0
August 2014



THIS PAGE
INTENTIONALLY
LEFT BLANK

CAHPS[®] Hospice Survey

Quality Assurance Guidelines

ACKNOWLEDGMENTS

These Specifications were prepared under contract to the Centers for Medicare & Medicaid Services (CMS) by the RAND Corporation in collaboration with the Health Services Advisory Group and Brown University.

CMS is pleased to acknowledge the role of the Agency for Healthcare Research and Quality, its CAHPS grantees, and Joan M. Teno, MD, MS of Brown University in developing and testing the Consumer Assessment of Healthcare Providers and Systems (CAHPS^{®1}) Hospice Survey.

¹ CAHPS[®] is a registered trademark of the Agency for Healthcare Research and Quality, a U.S. Government agency.

CAHPS Hospice Survey Quality Assurance Guidelines Table of Contents

<i>I. Reader's Guide</i>	<i>1</i>
➤ Purpose of Quality Assurance Guidelines	
➤ <i>CAHPS Hospice Survey Quality Assurance Guidelines V1.0</i> Contents	
<i>II. Introduction and Overview</i>	<i>5</i>
➤ Background	
➤ CAHPS Hospice Survey Instrument	
➤ CAHPS Hospice Survey Data Collection and Submission Timeline	
<i>III. Program Requirements</i>	<i>9</i>
➤ Overview	
➤ Purpose of the CAHPS Hospice Survey	
➤ Roles and Responsibilities	
➤ CAHPS Hospice Survey Minimum Business Requirements	
➤ CAHPS Hospice Survey Rules of Participation	
<i>IV. Communications and Technical Support</i>	<i>21</i>
➤ Overview	
➤ CAHPS Hospice Survey Information and Technical Assistance	
➤ General Information, Announcements and Updates	
➤ To Communicate with CMS Regarding the CAHPS Hospice Survey	
<i>V. Sampling Protocol</i>	<i>23</i>
➤ Overview	
➤ Eligibility for the CAHPS Hospice Survey	
➤ Sample Frame Creation	
➤ Sampling Procedure	
➤ Method of Sampling	
<i>VI. Mail Only Survey Administration</i>	<i>29</i>
➤ Overview	
➤ Production of Questionnaire and Related Materials	
➤ Mailing of Materials	
➤ Data Receipt and Retention	
➤ Personnel Training	
➤ Quality Control Guidelines	
➤ Monitoring and Quality Oversight	
➤ Safeguarding Decedent/Caregiver Confidentiality	
➤ Data Security	
➤ Data Retention and Storage	

CAHPS Hospice Survey Quality Assurance Guidelines Table of Contents

VII. Telephone Only Survey Administration	43
➤ Overview	
➤ Telephone Interviewing Systems	
➤ Telephone Attempts	
➤ Obtaining and Updating Telephone Numbers	
➤ Data Receipt and Retention	
➤ Electronic Telephone Interviewing System	
➤ Quality Control Guidelines	
➤ Safeguarding Decedent/Caregiver Confidentiality	
VIII. Mixed Mode Survey Administration	53
➤ Overview	
➤ Mail Protocol	
➤ Data Receipt and Retention of Mailed Questionnaires	
➤ Quality Control Guidelines for Mail Data	
➤ Telephone Protocol	
➤ Telephone Interviewing Systems	
➤ Receipt and Retention of Telephone Data	
➤ Electronic Telephone Interviewing System	
➤ Quality Control Guidelines for Telephone Data Collection	
➤ Safeguarding Decedent/Caregiver Confidentiality	
IX. Data Coding and Data File Preparation	73
➤ Overview	
➤ Random, Unique, De-Identified Tracking Number	
➤ File Specifications	
➤ Decision Rules and Coding Guidelines	
➤ Survey Skip Patterns	
➤ Header Record	
➤ Decedent/Caregiver Administrative Record	
➤ Survey Results Record	
➤ Disposition of Survey Codes	
➤ Definition of a Completed Survey	
➤ Survey Response Rate	

CAHPS Hospice Survey Quality Assurance Guidelines Table of Contents

X. <i>Data Submission</i>	89
➤ Overview	
➤ Data Submission Process	
➤ Data File Submission Dates	
➤ Survey Vendor Authorization Process	
➤ Preparation for Data Submission	
➤ Survey File Submission Naming Convention	
➤ Password Authentication	
➤ Organization of the CAHPS Hospice Survey Data Warehouse	
➤ File Encryption	
➤ Instructions for Accessing the CAHPS Hospice Survey Data Warehouse	
➤ Data Auditing and Validation Checks	
➤ Data Submission Reports	
XI. <i>Oversight Activities</i>	95
➤ Overview	
➤ Oversight Activities	
➤ CAHPS Hospice Survey Model Quality Assurance Plan (QAP)	
➤ Analysis of Submitted Data	
➤ Site Visits/Conference Calls	
➤ Non-compliance and Sanctions	
XII. <i>Exception Request Process</i>	99
➤ Overview	
➤ Exception Request Process	
XIII. <i>Discrepancy Report Process</i>	101
➤ Overview	
➤ Discrepancy Report Process	
XIV <i>Data Quality Checks</i>	103
➤ Overview	
➤ Traceable Data File Trail	
➤ Review of Data Files	

CAHPS Hospice Survey Quality Assurance Guidelines Table of Contents

XV. Appendices

- A. Minimum Business Requirements
- B. CAHPS Hospice Survey Vendor Authorization Form
- C. CAHPS Hospice Survey Data Warehouse Access
- D. Sample File Layout
- E. XML File Layout Version 1
 - Sample XML File Layout
- F. Interviewing Guidelines for Telephone Surveys
- G. Frequently Asked Questions for Customer Support
- H. CAHPS Hospice Survey Model Quality Assurance Plan
- I. CAHPS Hospice Survey Exception Request Form
- J. CAHPS Hospice Survey Discrepancy Report Form
- K. CAHPS Hospice Survey Participation Exemption for Size Form
- L. Examples of Additional Supplemental Questions for Survey Vendor Use
- M. CAHPS Hospice Mail Survey (English)
- N. CAHPS Hospice Mail Survey (Spanish)
- O. Telephone Script (English)
- P. Telephone Script (Spanish)

Reader's Guide

Purpose of Quality Assurance Guidelines

The *CAHPS Hospice Survey Quality Assurance Guidelines V1.0* manual has been developed by the Centers for Medicare & Medicaid Services (CMS) to standardize the survey data collection process and to ensure comparability of data reported through the CAHPS Hospice Survey. This Reader's Guide provides survey vendors with a high-level overview and reference for essential information presented in the *CAHPS Hospice Survey Quality Assurance Guidelines V1.0*. Readers are directed to the related chapters of the *CAHPS Hospice Survey Quality Assurance Guidelines V1.0* for more detail.

CAHPS Hospice Survey Quality Assurance Guidelines V1.0 Contents

The *CAHPS Hospice Survey Quality Assurance Guidelines V1.0* contains chapters that address CAHPS Hospice Survey administration requirements. These include:

Introduction and Overview

This chapter includes a description of the CAHPS Hospice Survey initiative and the history of its development.

Program Requirements

This chapter presents the Program Requirements, including the purpose of the CAHPS Hospice Survey, the Roles and Responsibilities for participating organizations (i.e., CMS, hospices and survey vendors), Minimum Business Requirements to administer the CAHPS Hospice Survey, and Rules of Participation.

Communications and Technical Support

This chapter includes information about communications and technical support available to survey vendors administering the CAHPS Hospice Survey and other interested parties.

Sampling Protocol

This chapter describes the process and requirements for selecting a random sample of decedents whose primary informal caregiver (caregiver) will be selected to respond to the CAHPS Hospice Survey.

Modes of Survey Administration

CAHPS Hospice Survey Quality Assurance Guidelines V1.0 chapters VI to VIII describe each of the three allowed modes of survey administration: Mail Only, Telephone Only, and Mixed methodology of mail with telephone follow-up. These chapters address the administration of the CAHPS Hospice Survey, data receipt and retention, and quality control guidelines for each of the three modes. Each mode of survey administration requires adherence to a standardized protocol and timeline.

Data Coding and Data File Preparation

The CAHPS Hospice Survey utilizes standardized protocols for file specifications, coding and submission of data. Survey vendors will submit data files via the CAHPS Hospice Survey Data Warehouse. This chapter contains information about preparing the CAHPS Hospice Survey data files for submission, including information on the requirements for coding and interpreting ambiguous or missing data elements in returned surveys.

Data Submission

This chapter contains information about preparing and submitting survey data files to the CAHPS Hospice Survey Data Warehouse, including the survey vendor authorization process, the survey vendor data submission registration process, and the data submission process.

Oversight Activities

This chapter provides information on the oversight activities that the CMS-sponsored CAHPS Hospice Survey Project Team conducts to verify compliance with CAHPS Hospice Survey protocols. These oversight activities include, but are not limited to: review of survey vendor's CAHPS Hospice Survey Quality Assurance Plan (QAP), analyses of submitted data, site visits/teleconference calls, additional activities related to the administration of the CAHPS Hospice Survey, and possible outcomes of non-compliance.

Exception Request Process

This chapter describes the process for reviewing methodologies that vary from standard CAHPS Hospice Survey protocols. The exception request process is designed to allow for flexibility while maintaining the integrity of the data.

Discrepancy Report Process

This chapter describes the process for notifying CMS of any discrepancies from standard CAHPS Hospice Survey protocols during the survey administration process.

Data Quality Checks

This chapter provides an overview describing the importance of data quality checks and examples of data quality check activities as recommended by the CAHPS Hospice Survey Project Team.

Appendices

The Appendices include the CAHPS Hospice Surveys and mailing materials [English and Spanish (Chinese to be provided under separate cover)]; telephone (English and Spanish) scripts; suggested supplemental questions; supporting interviewing documents; data file layout specifications; survey authorization form; form for accessing the CAHPS Hospice Survey Data Warehouse; the survey vendor model QAP; and the forms for submitting requests for protocol exceptions, submitting discrepancy reports and the exemption for size.

For More Information

For program information and to view important updates and announcements, visit the CAHPS Hospice Survey Web site at: <http://www.hospicecahpsurvey.org>.

To Provide Comments or Ask Questions

For information and technical assistance, contact CAHPS Hospice Survey Information and Technical Support via email at: hospicecahpsurvey@HCQIS.org or call 1-844-472-4621.

Introduction and Overview

Background

Before the development of the CAHPS Hospice Survey, there was no official national standard survey to measure experience with hospice care. The CAHPS Hospice Survey will be implemented using detailed standard survey administration protocols to allow for fair comparisons across hospices.

Centers for Medicare & Medicaid Services (CMS) developed the CAHPS Hospice Survey with input from many stakeholders, including other government agencies, industry stakeholders, consumer groups, other key individuals, and organizations involved in hospice care. The survey was designed to measure and assess the experiences of decedents who died while receiving hospice care as well as the experiences of their caregivers. The survey aims to produce comparable data on decedents'/caregivers' perspectives of care that allow objective and meaningful comparisons between hospices on domains that are important to consumers, and create incentives for hospices to improve their quality of care.

Note: The term decedent/caregiver is used throughout this manual to identify the patient who died while receiving hospice care (decedent) and the informal primary caregiver (i.e., family member or friend) identified to receive and respond to the CAHPS Hospice Survey (caregiver).

CAHPS Hospice Survey Development, Data Collection and Reporting

The development process for the survey began in 2012 and included: a public request for information about publically available measures and important topics to measure (78 FR 5458); a review of the existing literature on tools that measure experiences with end-of-life care; exploratory interviews with caregivers of hospice decedents; a technical expert panel attended by survey development and hospice care quality experts; cognitive interviews to test draft survey content; incorporation of public responses to Federal Register notices (78 FR 48234); and a field test conducted by CMS in November and December 2013.

Thirty-three programs from 29 hospice organizations participated in the field test, which was designed to assess survey administration procedures among hospices of varying size, geographic region, chain status, ownership, and urbanicity. Respondents were caregivers of patients who died while receiving hospice care in the prior two to five months. In all, 1,136 respondents, representing the three main settings of hospice care (home, nursing home and inpatient; including freestanding hospice inpatient unit and acute care hospitals), completed the field test survey.

National Implementation of the CAHPS Hospice Survey will begin on January 1, 2015 and hospices will be required to contract with an approved CAHPS Hospice Survey vendor to conduct the survey in order for the hospice to meet the Hospice Quality Reporting Program requirements.

Office of Management and Budget (OMB) and Public Comment Process

The OMB's Paperwork Reduction Act clearance process for the CAHPS Hospice Survey requires two Federal Register Notices. The initial notice was published in May 2014 (CMS-1609-P). A 30-day Federal Register Notice was published in August 2014.

Preparation for CAHPS Hospice Survey Data Collection

Survey vendors interested in administering the CAHPS Hospice Survey must apply to participate and must attend Introduction to CAHPS Hospice Survey Training, as well as all subsequent CAHPS Hospice Survey Update Training sessions. Training is offered via Webinar. At a minimum, the survey vendor's Project Manager must attend the CAHPS Hospice Survey training sessions. In addition, subcontractors that are responsible for major functions of CAHPS Hospice Survey administration must attend CAHPS Hospice training.

During the first quarter of calendar year (CY) 2015, hospices will be required to conduct a dry run of the survey for at least one month of patient deaths (deaths which occurred in January 2015, February 2015, or March 2015). Beginning in April 2015, all hospices will be required to participate in the survey on an ongoing basis. The one "dry run month," plus the nine months of April 2015 to December 2015 participation, will be required to meet the pay for reporting requirement of the Hospice Quality Reporting Program for the fiscal year (FY) 2017 annual payment update (APU).

The CAHPS Hospice Survey treats the patient who died while in hospice care and his or her informal primary caregiver (i.e., family member or friend) as the unit of care. Each contracted hospice must provide specified decedent/caregiver data to its survey vendor on a monthly basis.

CAHPS Hospice Survey Instrument

Components of the CAHPS Hospice Survey Instrument

The standardized 47 question CAHPS Hospice Survey instrument is composed of the following measures:

- Nine Quality Measures
 - Hospice Team Communication (comprised of five CAHPS Hospice Survey items)
 - Getting Timely Care (comprised of two CAHPS Hospice Survey items)
 - Treating Family Member with Respect (comprised of two CAHPS Hospice Survey items)
 - Providing Emotional Support (comprised of two CAHPS Hospice Survey items)
 - Getting Help for Symptoms (comprised of four CAHPS Hospice Survey items)
 - Support for Religious and Spiritual Beliefs (comprised of one CAHPS Hospice Survey item)
 - Information Continuity (comprised of one CAHPS Hospice Survey item)
 - Understanding the Side Effects of Pain Medication (comprised of one CAHPS Hospice Survey item)
 - Getting Hospice Care Training (comprised of four CAHPS Hospice Survey items)

The CAHPS Hospice Survey will be available in English, Spanish and Chinese. The Chinese mail survey is in traditional and simplified characters and targets both Mandarin and Cantonese speakers.

The CAHPS Hospice Survey will be administered using the Mail Only Mode, Telephone Only Mode, or Mixed Mode (mail with telephone follow-up).

CAHPS Hospice Survey Data Collection and Submission Timeline

Data collection for sampled decedents/caregivers must be initiated two months following the month of patient death. The data collection process must be completed within 42 calendar days after initial contact. Submission of the data to the CAHPS Hospice Survey Data Warehouse will occur quarterly. Please see the schedule outlined in the table below.

Month of Death	Initial Contact with Sampled Decedents/Caregivers	Data Submission to the CAHPS Hospice Survey Data Warehouse
January 2015	April 1, 2015	August 12, 2015
February 2015	May 1, 2015	
March 2015	June 1, 2015	
April 2015	July 1, 2015	November 1, 2015
May 2015	August 1, 2015	
June 2015	September 1, 2015	
July 2015	October 1, 2015	February 10, 2016
August 2015	November 1, 2015	
September 2015	December 1, 2015	
October 2015	January 1, 2016	May 11, 2016
November 2015	February 1, 2016	
December 2015	March 1, 2016	

Program Requirements

Overview

This chapter describes the Program Requirements, which include the purpose of the CAHPS Hospice Survey, roles and responsibilities for participating organizations, the Rules of Participation, and Minimum Business Requirements to administer the CAHPS Hospice Survey. Survey vendors administering the CAHPS Hospice Survey must meet all of the Minimum Business Requirements.

Purpose of the CAHPS Hospice Survey

The CAHPS Hospice Survey and its administration protocols are designed to produce standardized information about decedents'/caregivers' perspectives of care that allows objective and meaningful comparisons of hospices on topics that are important to consumers. In the future, public reporting of CAHPS Hospice Survey results will create incentives for hospices to improve the quality of care while enhancing accountability in healthcare by increasing transparency.

In order to fulfill these goals, it is essential that, to the fullest extent possible:

- caregivers respond to the CAHPS Hospice Survey, and
- caregivers' responses are informed only by the care their family member's or friend's received from the hospice named on the survey cover

CMS carefully developed the CAHPS Hospice Survey and its administration protocols to achieve the following outcomes:

- to increase the likelihood that caregivers will respond to the survey, the CAHPS Hospice Survey should be the first survey a caregiver receives about their family member's or friend's experience of hospice care
- to ensure that the caregiver's responses are unbiased and reflect only his or her family member's or friend's experience of care, hospices and survey vendors (and anyone acting on their behalf) must not attempt to influence how the caregiver responds to CAHPS Hospice Survey items

Roles and Responsibilities

The following content clarifies the roles and responsibilities of participating organizations.

CMS Roles and Responsibilities

CMS supports the standardization of the survey administration and data collection methodologies for measuring and reporting caregivers' perspectives on their family members' or friends' hospice care as follows:

- Provide CAHPS Hospice Survey administration protocols through the *CAHPS Hospice Survey Quality Assurance Guidelines*
- Train survey vendors to administer the CAHPS Hospice Survey
- Provide technical assistance via CAHPS Hospice Survey Information and Technical Support and distribute information about survey administration procedures and policy updates on the CAHPS Hospice Survey Web site at www.hospicecahpsurvey.org

- Provide quality oversight to ensure that the CAHPS Hospice Survey is credible, useful and practical to allow for valid comparisons to be made across hospices

Hospice Roles and Responsibilities

It is the responsibility of the Medicare-certified hospice to participate every month in the CAHPS Hospice Survey.

Some hospices may be exempted for size from participation for a given annual payment update (APU) period. The only scenario under which a Medicare-certified hospice provider can be exempted from participation in the CAHPS Hospice Survey is described below:

- The Participation Exemption for Size process has been created to provide hospices meeting the size criteria a means to request consideration for this exemption. For the calendar year (CY) 2015 data collection period, Medicare-certified hospices that have served fewer than 50 survey-eligible decedents/caregivers in the period from January 1, 2014 through December 31, 2014 can apply for an exemption from CAHPS Hospice Survey CY 2015 data collection and reporting requirements. To qualify for the survey exemption for CY 2015, hospices must submit a Participation Exemption for Size Form online via the CAHPS Hospice Survey Web site (www.hospicecahpsurvey.org). For the CY 2015 data collection period, this form must be submitted no later than August 12, 2015. The form must be completed in its entirety. Please see Appendix K for specific information to be submitted on the Participation Exemption for Size Form.
 - The Participation Exemption for Size Form will be reviewed by the CAHPS Hospice Survey Project Team. Hospices will need to include the number of survey-eligible decedents/caregivers for CY 2014, the total number of patients discharged alive, and the number of decedents who fall into each ineligibility category [i.e., under the age of 18, died within 48 hours of admission to hospice care, decedent has no caregiver of record (a patient for whom no caregiver is listed in the medical record or administrative data), caregiver is a non-familial legal guardian, caregiver has a foreign home address, decedent/caregiver requested not to be contacted].

*Note: For multiple hospice programs sharing one CCN, the survey-eligible decedent/caregiver count is the total from **all** programs.*

If a hospice is eligible to participate, it must:

- Contract with an approved CAHPS Hospice Survey vendor to administer their survey

Note: No organization, firm, or business that owns, operates, or provides staffing for a hospice is permitted to administer its own CAHPS Hospice Survey or administer the survey on behalf of any other hospice in the capacity as a CAHPS Hospice Survey vendor. Such organizations will not be approved by CMS as CAHPS Hospice Survey vendors.

- Authorize the contracted survey vendor to collect and submit CAHPS Hospice Survey data to the CAHPS Hospice Survey Data Warehouse on the hospice's behalf (refer to Appendix B)

- Work with their approved survey vendor to determine a date each month by which to provide their survey vendor with the monthly decedents/caregivers list
- By the agreed-upon date each month, compile and deliver to the survey vendor a complete and accurate decedents/caregivers list with the caregiver information that will enable the survey vendor to administer the survey
- Use a secure method to transmit monthly decedents/caregivers lists to the survey vendor
- Review data submission reports to ensure that their survey vendor has submitted data on time and without data problems
- Avoid influencing caregivers in any way about whether or how to answer the CAHPS Hospice Survey. For example, a hospice may not suggest that caregivers decline to be contacted for the survey, or provide any information to caregivers about how to answer the survey
- Understand the hospices' responsibilities regarding participation in the Hospice Quality Reporting Program, including key date ranges and deadline dates

Survey Vendor Roles and Responsibilities

CAHPS Hospice Survey vendors are subject to the following requirements:

- Survey vendors must have physical plant resources available to handle the volume of surveys being administered, in addition to systematic processes that effectively track sampled decedents'/caregivers' progress through the data collection protocol and caregivers' responses to the survey. System resources are subject to oversight activities including site visits to physical locations (including the physical locations of subcontractors, if applicable).
- Complete the Participation Form for Survey Vendors and become approved to administer the CAHPS Hospice Survey. Participation Forms will be available on the CAHPS Hospice Survey Web site prior to the scheduled Introduction to CAHPS Hospice Survey Webinar training session.
- Participate in and successfully complete the Introduction to CAHPS Hospice Survey webinar training session and all update training sessions
 - The survey vendor's designated CAHPS Hospice Survey project manager must also complete a Training Quiz after participating in CAHPS Hospice Survey webinar training sessions
- Ensure that all survey vendor staff who work on the CAHPS Hospice Survey are trained and follow the standard CAHPS Hospice Survey protocols and guidelines
- Work with the client hospice's staff to create monthly decedent/caregiver lists, including data elements needed
- Designate a date each month by which the hospice must provide each monthly decedents/caregivers list
- Receive and perform checks of the monthly decedents/caregivers lists provided by each hospice to ensure that they include the entire eligible population and all required data elements
- Follow the Rules of Participation (see below) to administer the CAHPS Hospice Survey
- Comply with all requirements of the Health Insurance Portability and Accountability Act (HIPAA) Security and Privacy Rules during all survey administration and data collection processes

- <http://www.cms.gov/Regulations-and-Guidance/HIPAA-Administrative-Simplification/HIPAAGenInfo/index.html>
 - <http://www.cms.gov/Regulations-and-Guidance/HIPAA-Administrative-Simplification/HIPAAGenInfo/PrivacyandSecurityStandards.html>
 - <http://www.hhs.gov/ocr/privacy/>
- Meet all CAHPS Hospice Survey due dates (including submission of QAPs and survey materials for review) or risk revocation of approval to administer the CAHPS Hospice Survey
 - Receive and perform checks of the decedent/caregiver list to verify that it includes the entire eligible population and all required data elements
 - When updated decedent/caregiver lists are received, prior to data submission, the survey vendor should update all decedent/caregiver administrative information available. In addition, the survey vendor must perform quality checks to track and verify changes from the original decedent/caregiver lists.
 - Prepare sample frame
 - Draw sample of decedents/caregivers according to the sampling protocols contained in the *CAHPS Hospice Survey Quality Assurance Guidelines*
 - Administer the CAHPS Hospice Survey and oversee the quality of work of staff and subcontractors, if applicable, according to protocols contained in the *CAHPS Hospice Survey Quality Assurance Guidelines*
 - Verify that each contracted hospice has authorized the survey vendor to submit data on the hospice's behalf
 - Submit data files to the CAHPS Hospice Survey Data Warehouse in accordance with the survey file layouts by data submission deadlines
 - Review CAHPS Hospice Survey Data Submission Reports and confirm successful upload of contracted hospices' data files to the CAHPS Hospice Survey Data Warehouse
 - Perform quality checks of all survey administration processes and document the performance of the quality check activities
 - Assign and train organizational staff with appropriate back-up responsibilities for coverage of key staff
 - Maintain active contract(s) with hospice(s) in order to retain approval status (see Minimum Business Requirements)
 - Survey vendors administering Telephone Only and Mixed Modes of survey administration must use telephone interviewers who do not know decedents/caregivers either professionally or personally

Note: If a survey vendor is non-compliant with program requirements for any of their contracted hospices, the non-compliant action could affect the hospice's APU for a given fiscal year. In addition, approved survey vendors that are non-compliant with CAHPS Hospice Survey protocols may lose their CAHPS Hospice Survey approval status.

CAHPS Hospice Survey Minimum Business Requirements

An entity must be approved by CMS in order to administer the CAHPS Hospice Survey and submit CAHPS Hospice Survey data to the CAHPS Hospice Survey Data Warehouse. A survey vendor must meet ALL of the CAHPS Hospice Survey Minimum Business Requirements. In addition, subcontractors performing major CAHPS Hospice Survey administration functions (e.g., mail/telephone operations) must also meet ALL of the CAHPS Hospice Survey Minimum Business Requirements that pertain to that role.

- Approved CAHPS Hospice Survey vendors must fully comply with the CAHPS Hospice Survey oversight activities
 - Participate in CAHPS Hospice Survey oversight activities to ensure compliance with CAHPS Hospice Survey technical specifications and survey requirements. The purpose of the oversight activities is to ensure that approved survey vendors follow ALL the CAHPS Hospice Survey administration protocols; and thereby, ensure the comparability of CAHPS Hospice Survey data across hospices.
 - In order for the CAHPS Hospice Survey Project Team to perform the required oversight activities, organizations that are approved to administer the CAHPS Hospice Survey must conduct all of their business operations within the United States. This requirement applies to all staff and subcontractors.
 - In order to ensure the confidentiality of data, survey vendors may not use home-based or virtual interviewers to conduct the CAHPS Hospice Survey, nor may they conduct any survey administration processes (e.g. mailings) from a residence
- Approved survey vendors are expected to maintain active contract(s) for CAHPS Hospice Survey administration with client hospice(s). An “active contract” is one in which the CAHPS Hospice Survey vendor is authorized by hospice client(s) to submit CAHPS Hospice Survey data to the CAHPS Hospice Survey Data Warehouse. ***If a CAHPS Hospice Survey vendor does not have any contracted hospice client(s) for the CAHPS Hospice Survey within two years (a consecutive 24 months) of the date the survey vendor received approval to administer the CAHPS Hospice Survey, then that survey vendor’s “Approved” status for CAHPS Hospice Survey administration will be withdrawn.*** If approval status is withdrawn, the survey vendor must once again follow the steps to apply for consideration of approval to administer the CAHPS Hospice Survey. The first step is to complete a participation form and submit it to the CAHPS Hospice Survey Project Team for consideration. Once conditionally approved, the survey vendor must then participate in the Introduction to CAHPS Hospice Survey Training.
- In reviewing Participation Forms from potential CAHPS Hospice Survey vendors, the CAHPS Hospice Survey Project Team will take into consideration the applicant’s prior experience administering CAHPS Surveys, if any

Note: If a survey vendor is non-compliant with program requirements, the non-compliant action could affect a hospice’s APU for a given fiscal year.

A survey vendor must meet **ALL** of the Survey Vendor Minimum Business Requirements. In addition, subcontractors performing major CAHPS Hospice Survey administration functions (e.g., mail/telephone operations) must also meet all of the CAHPS Hospice Survey Minimum Business Requirements that pertain to that role. The minimum business requirements for an organization to become approved to administer the CAHPS Hospice Survey are as follows:

Relevant Survey Experience:

Criteria	Survey Vendor
Number of Years in Business	➤ Minimum four years
Number of Years Conducting Surveys in the Requested Mode	➤ Minimum three years in conducting surveys in the selected mode(s) of administration
Number of Years Conducting Patient-Specific Surveys	➤ Minimum two years conducting patient-specific surveys as an organization
Sampling Experience	➤ Two years prior experience selecting random sample based on specific eligibility criteria: <ul style="list-style-type: none"> • Work with contracted client(s) to obtain patient data for sampling via HIPAA-compliant electronic data transfer processes • Adequately document sampling process • Survey vendors are responsible for conducting the sampling process and must not subcontract this activity

Survey Capability and Capacity:

Criteria	Survey Vendor
Personnel	➤ Designated CAHPS Hospice Survey personnel: <ul style="list-style-type: none"> • Project Director with minimum two years prior experience conducting patient-specific surveys in the requested mode • Staff with minimum one year prior experience in sample frame development and sample selection • Programmer (subcontractor designee, if applicable) with minimum one year prior experience receiving large encrypted data files in different formats/software packages electronically from an external organization; processing survey data needed for survey administration and survey response data; preparing data files for electronic submission; and submitting data files to an external organization • Call Center/Mail Center Supervisor (subcontractor designee, if applicable) with minimum one year prior experience in role ➤ Have appropriate organizational back-up staff for coverage of key staff ➤ Volunteers are not permitted to be involved in any aspect of the CAHPS Hospice Survey administration process

Criteria	Survey Vendor
Physical Plant and System Resources	<ul style="list-style-type: none"> ➤ Physical plant resources available to handle the volume of surveys being administered, including computer and technical equipment: <ul style="list-style-type: none"> • A secure commercial work environment • Home-based or virtual interviewers cannot be used to administer the CAHPS Hospice Survey nor used to conduct any survey administration processes • Physical facilities and electronic equipment and software to collect, process and report data securely • If offering telephone surveys, must have the equipment, software and facilities to conduct CATI interviews and to monitor interviewers ➤ Electronic or alternative survey management system to: <ul style="list-style-type: none"> • Track fielded surveys throughout the protocol, avoiding respondent burden and losing respondents • Assign random, unique, de-identified identification number (Tracking ID) to track each sampled patient/primary informal caregiver (i.e., family member or friend of the hospice patient) ➤ Organizations that are approved to administer the CAHPS Hospice Survey must conduct all of their business operations within the United States. This requirement applies to all staff and subcontractors. ➤ All System Resources are subject to oversight activities, including site visits to physical locations
Sample Frame Creation	<ul style="list-style-type: none"> ➤ Two years prior experience selecting random sample based on specific eligibility criteria: <ul style="list-style-type: none"> • Generate the sample frame data file that contains all individuals who meet the eligible population criteria • Draw random sample of individuals for the survey, who meet the eligible population criteria
Mail Administration	<ul style="list-style-type: none"> ➤ Mail survey administration activities are not to be conducted from a residence, nor from a virtual office ➤ Obtain and update addresses of sampled patients/primary informal caregivers ➤ Produce and print professional quality survey instruments and materials according to guidelines; a sample of all mailing materials must be submitted for review ➤ Merge and print sample name and address on personalized mail survey cover letters, and print unique Tracking ID on the survey questionnaire ➤ Mail out of survey materials ➤ Receive and process (key-entry or scanning) completed questionnaires ➤ Track and identify non-respondents for follow-up mailing ➤ Assign final survey status codes to describe the final result of each sampled case

Criteria	Survey Vendor
Telephone Administration	<ul style="list-style-type: none"> ➤ Telephone interviews are not to be conducted from a residence nor from a virtual office ➤ Obtain, verify and update telephone numbers ➤ Develop computer programs for electronically administering the survey (CATI) ➤ Collect telephone interview data for the survey, using CATI system; a sample of the telephone script and interviewer screen shots must be submitted for review ➤ Identify non-respondents for follow-up telephone calls ➤ Schedule and conduct callbacks to non-respondents at varying times of the day and different days of the week ➤ Assign final status codes to reflect results of attempts to obtain completed interview with sampled cases
Mixed Mode Administration (Mail with Telephone Follow-up)	<ul style="list-style-type: none"> ➤ Mail survey administration and telephone interviews are not to be conducted from a residence nor from a virtual office ➤ Adhere to all Mail Only and Telephone Only survey administration requirements (described above). ➤ Track cases from mail survey through telephone follow-up activities
Data Submission	<ul style="list-style-type: none"> ➤ Survey vendors are responsible for conducting data submission and must not subcontract this process ➤ Scan or key data from completed mail surveys ➤ Import (as necessary) data from CATI system into a data file ➤ Develop data files, edit and clean data according to standard protocols ➤ Follow all data cleaning and data submission rules, including verifying that data files are de-identified and contain no duplicate cases ➤ Export data from the electronic data collection system to the required format for data submission, confirm that the data were exported correctly, that the data submission files are formatted correctly and contain the correct data headers and data records ➤ Submit data electronically in the specified format to the CAHPS Hospice Survey Data Warehouse ➤ Work with CMS' contractor to resolve data problems and data submission problems

Criteria	Survey Vendor
Technical Assistance/ Customer Support	<ul style="list-style-type: none"> ➤ Two years prior experience providing telephone customer support ➤ Provide toll-free customer support line: <ul style="list-style-type: none"> • Customer support must be offered in all languages that the survey vendor administers the survey in • Respond to calls within 24-48 hours

Participation in Quality Control Activities and Documentation Requirements:

Criteria	Survey Vendor
Demonstrated Quality Control Procedures	<ul style="list-style-type: none"> ➤ Incorporate well-documented quality control procedures (as applicable) for: <ul style="list-style-type: none"> • In-house training of staff and subcontractors involved in survey operations • Printing, mailing and recording receipt of survey questionnaires, if applicable • Telephone administration of survey, if applicable • Coding and verifying of survey data and survey-related materials • Scanning or keying in survey data • Preparation of final person-level data files for submission • All other functions and processes that affect the administration of the CAHPS Hospice Survey ➤ Participate in any conference calls and site visits as part of overall quality monitoring activities: <ul style="list-style-type: none"> • Provide documentation as requested for site visits and conference calls, including but not limited to: staff training records, telephone interviewer monitoring records and file construction documentation
Documentation Requirements	<ul style="list-style-type: none"> ➤ Keep electronic or hard copy files of staff training and training dates ➤ Maintain electronic documentation of telephone monitoring, if applicable ➤ Maintain documentation of mail production quality checks, if applicable ➤ Maintain documentation of all survey administration activities and related quality checks for review during site visits

Adhere to all Protocols, Specifications and Agree to Participate in Training Sessions:

Survey Training	<ul style="list-style-type: none"> ➤ Attend all CMS Introduction and Vendor Update training sessions (subcontractors assigned key roles must attend training)
Administer the Survey According to all Survey Specifications	<ul style="list-style-type: none"> ➤ Review and follow all procedures described in the CAHPS Hospice Survey Quality Assurance Guidelines that are applicable to the selected survey data collection mode ➤ Fully comply with the CAHPS Hospice Survey oversight activities ➤ Approved survey vendors are expected to maintain active contract(s) for CAHPS Hospice Survey administration with client hospice(s). An “active contract” is one in which the CAHPS Hospice Survey vendor is authorized by hospice client(s) to collect and submit CAHPS Hospice data to the CAHPS Hospice Survey Data Warehouse. If a CAHPS Hospice Survey vendor does not have any contracted hospice clients within two years (a consecutive 24 months) of the date they received approval to administer the CAHPS Hospice Survey, then that survey vendor’s “Approved” status for CAHPS Hospice Survey administration will be withdrawn. If approval status is withdrawn, the organization must once again follow the steps to apply for reconsideration for approval to administer the CAHPS Hospice Survey.

CAHPS Hospice Survey Rules of Participation

Survey vendors agree to the following Rules of Participation as found in the CAHPS Hospice Survey Participation Forms:

➤ **Submit Participation Form**

Before attending the Introduction to CAHPS Hospice Survey Training, new survey vendors must complete and submit a Participation Form online. Participation Forms are available on the CAHPS Hospice Survey Web site at www.hospicecahpsurvey.org.

Note: Approval of the survey vendors’ participation status to administer the CAHPS Hospice Survey is contingent upon successful completion of teleconference call(s) with the CAHPS Hospice Survey Project Team, if requested, to discuss relevant survey experience, organizational survey capability and capacity and quality control procedures.

➤ **Attend CAHPS Hospice Survey Training**

Survey vendors that intend to administer the survey must attend the Introduction to CAHPS Hospice Survey Training and subsequent CAHPS Hospice Survey Update Training sessions sponsored by CMS. At a minimum, the survey vendor’s Project Manager must participate in the CAHPS Hospice Survey training sessions. **Subcontractors who are responsible for major functions of CAHPS Hospice Survey administration (e.g., mail/telephone) must attend CAHPS Hospice Survey training.**

- **Change in key personnel**

A survey vendor must immediately notify the CAHPS Hospice Survey Project Team of changes in its contact person or key staff and organizational structure (i.e., changes in ownership, name, and address) via email (hospicecahpssurvey@HCQIS.org)
- **Participation in a CAHPS Hospice Survey Dry Run**

During the first quarter of CY 2015, hospices will be required to conduct a dry run of the survey for at least one month of patient deaths (deaths which occurred in January 2015, February 2015, or March 2015). The one “dry run month,” plus the nine months of April 2015 to December 2015 participation, will be required to meet the requirement of the Hospice Quality Reporting Program for the FY 2017 APU.
- **Review and Follow the *CAHPS Hospice Survey Quality Assurance Guidelines* and Policy Protocols**

The *CAHPS Hospice Survey Quality Assurance Guidelines* manual has been developed to assure the standardization of the survey data collection process and the comparability of reported data. Survey vendors must review and follow the *CAHPS Hospice Quality Assurance Guidelines*. In addition, survey vendors must follow all policy protocols, including *CAHPS Hospice Survey Bulletins*, posted on the CAHPS Hospice Survey Web site at www.hospicecahpssurvey.org.
- **Attest to the Accuracy of the Organization’s Data Collection Process**

The survey vendor must review and attest (as determined by CMS) to the accuracy of the organization’s data collection process and conformance with the *CAHPS Hospice Survey Quality Assurance Guidelines*
- **Survey vendors are responsible for sampling and data submission and these processes cannot be subcontracted**

Any variations from the survey administration protocols must be reported to CMS immediately upon discovery (except those that have been pre-approved by CMS through the Exception Request process). CMS may determine that data collected in a non-approved manner may not be reported.
- **Develop Survey Vendor CAHPS Hospice Survey QAP**

Survey vendors must develop a QAP for survey administration in accordance with the *CAHPS Hospice Survey Quality Assurance Guidelines* and update the QAP as part of their participation status. The Model QAP document (see Appendix H) must be used for developing the QAP. The QAP must be updated, as necessary, to reflect changes in key personnel, resources and processes (see *Oversight Activities* chapter for more information).

Upon request, each survey vendor must submit their QAP and materials relevant to that year’s CAHPS Hospice Survey administration (as determined by CMS), including mailing materials (e.g., cover letters and questionnaires) and/or telephone scripts (including screen shots and skip pattern logic, if applicable) to hospicecahpssurvey@HCQIS.org for review by the CAHPS Hospice Survey Project Team.

*Note: The CAHPS Hospice Survey Project Team’s acceptance of a submitted QAP and corresponding survey materials **does not** constitute or imply approval or endorsement of the survey vendor’s CAHPS Hospice Survey administration processes. Additionally, any*

materials submitted with the QAP (e.g., questionnaires, cover letters, tracking forms, etc.) must be templates and **must not** contain any decedent/caregiver protected health information (PHI) or personal identifying information (PII).

➤ **Participate in Oversight Activities Conducted by the CAHPS Hospice Survey Project Team**

Survey vendors, including subcontractors, must be prepared to participate in all oversight activities, such as site visits and/or teleconference calls, as requested by the CAHPS Hospice Survey Project Team, to confirm that correct survey protocols are followed. ***Failure to comply with oversight activities may result in the revocation of approval to administer the CAHPS Hospice Survey.*** All materials relevant to survey administration are subject to review. Non-compliance with CAHPS Hospice Survey program requirements (including, but not limited to, participation and cooperation in oversight activities), may result in the contracted hospice's CAHPS Hospice Survey scores not being reported, which could affect the hospice's APU, and/or other sanctions (see the *Oversight Activities* chapter for more information on non-compliance and sanctions).

➤ **Review and Acknowledge Agreement with the Rules of Participation**

By signing the CAHPS Hospice Survey Participation Form, survey vendors signify agreement with all of the Rules of Participation, including all CAHPS Hospice Survey oversight activities and survey administration due dates.

Communications and Technical Support

Overview

Organizations and individuals have access to a number of sources of information regarding the CAHPS Hospice Survey. Several of these sources are listed below.

CAHPS Hospice Survey Information and Technical Assistance

For information and technical assistance, contact CAHPS Hospice Survey Information and Technical Support.

- Via email at hospicecahpssurvey@HCQIS.org
- Via telephone 1-844-472-4621

When contacting the CAHPS Hospice Survey Project Team regarding a specific hospice, **be sure to provide** the following information in your email or telephone voice mail:

- Survey vendor name
- Hospice six-digit CMS Certification Number (CCN)
- Hospice name

For additional information and technical assistance related to the use of the CAHPS Hospice Survey Data Warehouse or data submission issues, contact the CAHPS Hospice Survey Data Coordination Team via email only at:

- cahpshospicetechsupport@rand.org

General Information, Announcements and Updates

To learn more about the CAHPS Hospice Survey and to view important new updates and announcements, please visit the CAHPS Hospice Survey Web site at:

www.hospicecahpssurvey.org.

To Communicate with CMS Regarding the CAHPS Hospice Survey

- Via email at hospicesurvey@cms.hhs.gov

Sampling Protocol

Overview

This chapter describes the procedures survey vendors should use to request the decedent/caregiver list from their hospices, identify decedents/caregivers eligible for the survey, construct a sampling frame, and select a sample each month. The sampling procedures described in this chapter were developed to ensure standardized administration of the CAHPS Hospice Survey by all approved survey vendors and to ensure the comparability of the data and survey results that are reported.

Eligibility for the CAHPS Hospice Survey

The following groups of decedents/caregivers are eligible for inclusion in the sample frame:

- Decedents age 18 and over
- Decedents with death at least 48 hours following last admission to hospice care
- Decedents for whom there is a caregiver of record
- Decedents whose caregiver is someone other than a non-familial legal guardian
- Decedents for whom the caregiver has a U.S. or U.S. Territory home address

Decedents/caregivers who request 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) will be excluded from the sample frame. Patients whose last admission to hospice resulted in a live discharge will be excluded.

*Note: Decedents/caregivers must be included in the CAHPS Hospice Survey sample frame unless the survey vendor has positive evidence that a decedent/caregiver is ineligible. If information is missing on **any** variable that affects survey eligibility when the sample frame is constructed, the decedent/caregiver must be included in the sample frame.*

Monthly Decedents/Caregivers List

Data collection on the CAHPS Hospice Survey is conducted on a monthly basis. Survey vendors select monthly samples of all decedents/caregivers who meet survey eligibility criteria for each contracted hospice. For each monthly sample, the survey administration must be initiated two calendar months after the patient’s death. Submission to the CAHPS Hospice Survey Data Warehouse is done on a quarterly basis.

Month of Death	Initial Contact with Sampled Decedents/Caregivers	Data Submission to the CAHPS Hospice Survey Data Warehouse
January 2015	April 1, 2015	August 12, 2015
February 2015	May 1, 2015	
March 2015	June 1, 2015	
April 2015	July 1, 2015	November 1, 2015
May 2015	August 1, 2015	
June 2015	September 1, 2015	

Month of Death	Initial Contact with Sampled Decedents/Caregivers	Data Submission to the CAHPS Hospice Survey Data Warehouse
July 2015	October 1, 2015	February 10, 2016
August 2015	November 1, 2015	
September 2015	December 1, 2015	
October 2015	January 1, 2016	May 11, 2016
November 2015	February 1, 2016	
December 2015	March 1, 2016	

Hospice Information Submission Requirements

Each hospice must submit monthly:

- The decedent/caregiver list
- Counts of cases ineligible due to:
 - Live discharge
 - Requests for no contact (i.e., decedent or caregiver signed “no publicity” requests or otherwise directly requested not to be contacted) to the survey vendor in time for the survey vendor to initiate the survey data collection protocols

Decedent/Caregiver List

Hospices are required to supply monthly decedent/caregiver lists to their survey vendors containing the following data elements for each decedent who died within a calendar month while under the care of the hospice program (first day of month through last day of month).

- Decedent name (first, middle [if available], last) and prefix/suffix
- Decedent date of birth
- Decedent date of death
- Decedent sex
- Decedent race/ethnicity
- Decedent primary diagnosis
- Decedent admission date for final episode of hospice care
- Decedent payers (primary, secondary, other)
- Decedent last location/setting of care (i.e., home, assisted living facility, nursing home, acute care hospital, freestanding hospice inpatient unit)
- Caregiver name (first, middle [if available], last) and prefix/suffix
- Caregiver contact information, including mailing address, telephone number(s), email address (if available)
- Caregiver relationship to decedent (i.e., spouse/partner, child, sibling, other, etc.)

The information that the hospice provides will be used by the survey vendor to identify survey-eligible decedents/caregivers and survey the sampled decedents/caregivers.

Note: Each contracted hospice is required to submit its entire decedent/caregiver list to its survey vendor, excluding no-publicity decedents/caregivers.

Counts of Ineligibles

The hospice must submit to its survey vendor a count for each of the following ineligibility categories:

- Patient(s) discharged alive. This includes patients who have the following Patient Status codes (FL17):
 - 01 Discharged to home, revoked, or decertified
 - 50 Discharged/transferred to hospice – home (routine or CHC)
 - 51 Discharged/transferred to hospice – medical facility (respite or GIP)
- Decedents or caregivers who requested not to be contacted (i.e., signed “no publicity” requests or otherwise directly requested not to be contacted)

Note: With the exception of no-publicity decedents/caregivers, hospices are required to document the complete list of all decedents/caregivers for whom information has been withheld from the survey vendor for any reason.

Sample Frame Creation

Survey vendors participating in the CAHPS Hospice Survey are responsible for generating complete, accurate and valid sample frame data files each month that contain all administrative information on all decedents/caregivers who meet the eligible population criteria.

Prior to generating the CAHPS Hospice Survey sample frame, survey vendors must apply the eligibility criteria and remove ineligible decedents/caregivers. The following steps must be followed when creating the sample frame:

- Decedents/Caregivers whose eligibility status is uncertain must be included in the sample frame
- The sample frame for a particular month must include all survey-eligible decedents/caregivers from the first through the last day of the month (e.g., for January, any qualifying patient deaths from the 1st through 31st)
- Decedents with missing or incomplete caregiver addresses and/or telephone numbers must not be removed from the sample frame. Instead, every attempt must be made to find the correct address and/or telephone number. If the necessary contact information is not found, the “Final Survey Status” must be coded as “10 – Non-response: Bad address” or as “11 – Non-response: Bad/No Phone Number.” (For more information, see the *Data Coding and Data File Preparation* chapter.)

Survey vendors are required to provide counts of (a) patients discharged alive (provided by the hospice), (b) no publicity patients (provided by the hospice), and (c) total number of ineligible decedents/caregivers as determined by the survey vendor applying the following criteria:

- Decedent was under the age of 18
- Decedent’s death was less than 48 hours following last admission to hospice care
- Decedent has no caregiver of record
- Decedent’s caregiver is a non-familial legal guardian
- Decedent’s caregiver has an address outside the U.S. or U.S. Territories

Note: Survey vendors must retain counts of the number of ineligible decedents/caregivers in each of the above categories. This documentation is subject to review.

The survey vendor must retain the original decedent/caregiver lists, the sample frames (the entire list of eligible CAHPS Hospice Survey decedents/caregivers from which each hospice's sample is drawn) and ineligibility counts for three years.

Sampling Procedure

Hospices with fewer than 50 survey-eligible decedents/caregivers during the prior calendar year are exempt from the survey data collection and reporting requirements. Hospices with 50 to 699 survey-eligible decedents/caregivers in the prior year are required to survey all cases (conduct a census) and attempt to obtain as many completes as possible. Hospices with 700 or more survey-eligible decedents/caregivers in the prior year are required to survey a minimum sample of 700 using an equal-probability design. While there is no requirement for census administration, hospices with 700 or more survey-eligible decedents/caregivers may conduct a census, if desired. Survey-eligible decedents/caregivers are defined as that group of decedent and caregiver pairs that meet all the criteria for inclusion in the survey sample.

For national implementation, the CAHPS Hospice Survey Project Team has assumed an eligibility rate of 85% and a response rate of 50%, based on the experience in the 2013 field test of the CAHPS Hospice Survey instrument. These rates will result in an estimated 300 completed surveys for each hospice with 700 or more survey-eligible decedents/caregivers in the calendar year and between 21 and 300 completed surveys for hospices with between 50 and 699 survey-eligible decedents/caregivers during the calendar year.

Note: Hospices that share a common CCN (formerly known as the Medicare Provider Number [MPN]) must calculate the total number of survey-eligible decedents/caregivers per CCN, not per individual hospice program.

Consistent Monthly Sampling

For ease of sampling within hospices large enough to conduct non-census sampling, CMS recommends that survey vendors sample an approximately equal number of decedents/caregivers each month, unless adjustments are required. Adjustments should take place between quarters only. Survey vendors have the option to allocate the yearly sample proportionately to each month according to the expected proportional distribution of total survey-eligible decedents/caregivers over the 4 rolling quarters (12-month reporting period). Survey vendors must sample from every month in the reporting period, even if they have already achieved the required number of sampled decedents/caregivers.

Final Survey Sample

The final sample drawn each month must reflect a *random* sample of decedents/caregivers from the survey sample frame, or for those hospices conducting a census, all decedents/caregivers from the survey sample frame.

Note: When a census is conducted, the "Type of Sampling" field in the Header Record must be coded "2 – Census Sample."

Method of Sampling

Sampling for the CAHPS Hospice Survey is based on the survey-eligible decedents/caregivers (CAHPS Hospice Survey sample frame) for a calendar **month**. If every survey-eligible decedent/caregiver for a given month has the same probability of being sampled, then an **equiprobable** approach is being used.

Simple Random Sampling (SRS)

SRS is the most basic sampling technique. Here, a group of decedents/caregivers (a sample) is randomly selected from a larger group of survey-eligible decedents/caregivers. Each decedent/caregiver is chosen entirely by chance, and each survey-eligible decedent/caregiver has an equal chance of being included in the sample. For the CAHPS Hospice Survey, a census sample is also considered to be a simple random sample.

SRS Example 1: End of month % random sample selection

- Sampling for **Hospice C** is conducted only once for a given month at the end of the month
 - Suppose **Hospice C** has 150 survey-eligible decedents/caregivers for a given month and wishes to use a 50% sampling rate
 - **Randomly sort** all 150 survey-eligible decedents/caregivers prior to sampling
 - Then select 50% of the 150 survey-eligible decedents/caregivers for a monthly sample size of 75 decedents/caregivers. Since the survey-eligible decedents/caregivers list is already randomly sorted, the first 75 decedents may be selected to form the monthly random sample.

SRS Example 2: Census sampling

- **Hospice D** is required, or if a hospice with more than 700 survey-eligible decedents/caregivers per year chooses to sample all survey-eligible decedents/caregivers
 - A census sample is SRS because each decedent/caregiver has an equal chance (100%) of being included in the sample and the decedents/caregivers are not stratified in any manner
 - Suppose **Hospice D** has 40 survey-eligible decedents/caregivers for a given month. Since this hospice is using census sampling, each of the 40 survey-eligible decedents/caregivers is included in the hospice's CAHPS Hospice Survey sample.

Note: Other sampling scenarios may exist and the survey vendor should contact CAHPS Hospice Survey Information and Technical Support with questions at: hospicecahpsurvey@HCOIS.org or call 1-844-472-4621.

Mail Only Survey Administration

Overview

This chapter describes guidelines for the Mail Only Mode of the CAHPS Hospice Survey administration.

Data collection for sampled decedents/caregivers must be initiated two months following the month of patient death. Survey vendors will send sampled caregivers a first questionnaire with a cover letter within the first seven days of the field period. A second questionnaire with a follow-up cover letter **must** be sent to all sampled caregivers who did not respond to the first questionnaire, approximately 21 calendar days after the first questionnaire mailing.

*Note: If after the first mailing the survey vendor learns that a sampled decedent/caregiver is ineligible for the CAHPS Hospice Survey, the survey vendor must not send the caregiver the second questionnaire. After the sample has been drawn, any decedents/caregivers who are found to be ineligible **must not** be removed or replaced in the sample. Instead, these decedents/caregivers are assigned a “Final Survey Status” code of ineligible (2, 3, 4, 5, or 6 as applicable). An administrative record must be submitted for these decedents/caregivers.*

Data collection must be closed out for a sampled caregiver by six weeks (42 calendar days) following the mailing of the first questionnaire (initial contact). Caregivers who receive the CAHPS Hospice Survey must not be offered incentives of any kind. Caregivers who do not respond to the survey are assigned a “Final Survey Status” code of non-response.

Survey vendors must include the “Number Survey Attempts – Mail” field in the Decedent/Caregiver Administrative Data Record. This field is required when “Survey Mode” in the Header Record is “1 – Mail Only.” This field captures the mail wave attempt in which the final disposition of the survey is determined. More information regarding the coding of the survey attempts field is presented in the *Data Coding and Data File Preparation* chapter.

Survey vendors must make every reasonable effort to achieve optimal survey response rates and to pursue contacts with potential respondents until the data collection protocol is completed.

The basic tasks and timing for conducting the CAHPS Hospice Survey using the Mail Only Mode of survey administration are summarized below.

Activity	Timing
Mail initial questionnaire with cover letter to sampled caregivers	Two months after the month of patient death within the first seven days of the field period
Mail second questionnaire with cover letter to all sampled caregivers who do not respond to the first survey mailing	Approximately 21 calendar days after the first survey mailing
Complete data collection	Within six weeks (42 calendar days) of the first survey mailing
Submit data files to the CAHPS Hospice Survey Data Warehouse by the data submission deadline. No files will be accepted after the submission deadline date.	See the quarterly data submission deadlines in the <i>Sampling Protocol</i> chapter

To reiterate, the first mail attempt must occur two months after the month of patient death within the first seven days of the field period. Data collection must then be completed no later than six weeks (42 calendar days) after the initial mail-out. To illustrate the timing of the survey mail-out, the example below is provided of a patient who died on April 18 while in hospice care.

Example:

- The first survey is mailed out on July 1 (two months after month of patient’s death)
- If the caregiver has not returned the survey by July 22 (21 days after the initial mailing on July 1), a second survey is mailed out
- Data collection must be closed out on August 12 for this caregiver, which is six weeks (42 days) from the July 1 initial mail-out date:
 - If the survey is returned **on or before** August 12, which is the last day of the survey administration time period for this caregiver, then the survey is included in the final survey data file and assigned a “Final Survey Status” code of either “1 – Completed survey” or “7 – Non-response: Break off” based on the calculation of percent complete as described in the *Data Coding and Data File Preparation* chapter
 - If the survey is returned **after** August 12 (August 13, for example), which is beyond the six weeks (42 days) survey administration time period for this caregiver, then the survey data are **not** included in the final survey data file (**however, an administrative data record is submitted for this caregiver**) and a “Final Survey Status” code of “9 – Non-response: Non-response after maximum attempts” is assigned

Production of Questionnaire and Related Materials

The Mail Only Mode of survey administration may be conducted in English, Spanish and Chinese. Survey vendors are provided with the CAHPS Hospice Survey questionnaires in English, Spanish and Chinese and initial and follow-up cover letters in English, Spanish and Chinese. Survey vendors are not permitted to make or use any other translations of the CAHPS Hospice Survey cover letters or questionnaires. We strongly encourage hospices with a significant caregiver population that speaks Spanish or Chinese to offer the CAHPS Hospice

Survey in that language(s). We encourage hospices that serve patient populations that speak languages other than those noted to request CMS to create an official translation of the CAHPS Hospice Survey in those languages.

Mailings must include a personalized cover letter, a questionnaire, and a business reply envelope. The cover letters may be sent in both English and Spanish or both English and Chinese, and may be two-sided (English on one side and Spanish on the other or English on one side and Chinese on the other). Cover letters sent to respondents must be personalized with the decedent's name, the caregiver's name and the hospice's name. The letter must also provide a toll-free number for respondents to call if they have questions. The cover of the questionnaire must include a label indicating the name of the hospice, and if applicable, may include the specific hospice inpatient unit, acute care hospital or nursing home facility in which their family member or friend resided.

For CAHPS Hospice Survey administration, the OMB Paperwork Reduction Act language must appear in the mailing, either on the cover letter or on the front or back of the questionnaire. In addition, the OMB control number must appear on the front page of the questionnaire.

To increase the likelihood that the respondent is the person within the sampled caregiver's household who is most knowledgeable about the decedent's hospice care, language must be included in the questionnaire, and optionally in the cover letter, clearly stating that the survey should be given to the person in the household who knows the most about the hospice care received by the decedent.

Each survey vendor must submit a sample of their CAHPS Hospice Survey mailing materials (e.g., questionnaires and cover letters) by the specified due date for review by the CAHPS Hospice Survey Project Team.

Required for the Mail Questionnaire

The CAHPS Hospice Survey Core questions (Q1 – Q40) must be placed at the beginning of the survey. The order of the Core questions must not be altered and all the Core questions must remain together. The “About Your Family Member” and “About You” questions must be placed after the Core questions and cannot be eliminated from the questionnaire. The “About You” questions must follow the “About Your Family Member” questions.

Survey vendors must adhere to the following specifications for questionnaire formatting and the production of mail materials:

- Question and answer category wording must not be changed
- No changes are permitted in the order of the Core questions
- No changes are permitted in the order of the “About Your Family Member” questions
- No changes are permitted in the order of the “About You” questions
- No changes are permitted in the order of the response categories for the Core, “About Your Family Member” or “About You” questions
- The Core questions must remain together
- The “About Your Family Member” and “About You” questions must remain together
- Each question and answer categories must remain together in the same column and on the same page

- Response options must be listed vertically (see examples in Appendix M and N). Response options that are listed horizontally or in a combined vertical and horizontal format are not allowed.

Formatting

- Wording that is **bolded** or underlined in the questionnaire provided in the *CAHPS Hospice Survey Quality Assurance Guidelines* must be emphasized in the same manner in the survey vendor's questionnaire
- Arrow (i.e., ➔) placement in the questionnaire instructions and answer categories that specifies skip patterns must not be changed
- Section headings (e.g., "Your Family Member's Hospice Care," etc.) must be included on the questionnaire and must be capitalized
- Survey materials must be in a readable font (i.e. Arial) with a font size of 10 point at a minimum

Other Requirements

- All survey instructions written at the top of the questionnaire must be printed verbatim
- Randomly generated, unique identifiers must be placed on the first or last page of the questionnaire, at a minimum. Survey vendors may add other identifiers on the questionnaire for tracking purposes (e.g., unit identifiers, etc.). Neither the decedent's nor the caregiver's name may be printed on the questionnaire.
- The text indicating the purpose of the unique identifier ["You may notice a number on the survey. This number is used to let us know if you returned your survey so we do not have to send you reminders."] must be printed either immediately after the survey instructions on the questionnaire or on the cover letter, and may appear on both.
- The survey vendor's return address must be printed on the last page of the questionnaire to make sure that the questionnaire is returned to the correct address in the event that the enclosed return envelope is misplaced by the caregiver
- If the survey vendor's name is included in the return address, then the survey vendor's business name must be used, not an alias or tag line
- A mail wave indicator must be included on the survey

Optional for the Mail Questionnaire

Survey vendors have some flexibility in formatting the CAHPS Hospice Survey questionnaire by following the guidelines described below.

- Small coding numbers, preferably in superscript, may be included next to the response choices on the questionnaire
- Hospice logos may be included on the questionnaire; however, other images and tag lines are not permitted
- The phrase "Use only blue or black ink" may be printed on the questionnaire
- The name of the hospice may be printed on the questionnaire in Questions 2, 4 and 39, as indicated below
 - Question 2 – "In what locations did your family member receive care from [ABC Hospice]?"
 - Question 4 – "As you answer the rest of the questions in this survey, please think only about your family member's experience with [ABC Hospice]."

- Question 39 – “Please answer the following questions about your family member’s care from [ABC Hospice]. Do not include care from other hospices in your answers.”
- Page numbers may be included on the questionnaire
- Color may be incorporated in the questionnaire

Survey vendors should consider incorporating the following recommendations in formatting the CAHPS Hospice Survey questionnaire to increase the likelihood of receiving a returned survey:

- Two-column format that is used in Appendices M and N
- Wide margins (at least 3/4 inch) so that the survey has sufficient white space to enhance its readability

Supplemental Questions

Survey vendors may add up to 15 hospice-specific supplemental questions to the CAHPS Hospice Survey, following the guidelines described below:

- Hospice-specific supplemental questions are added immediately after the Core questions (Questions 1 – 40) or at the end of all the CAHPS Hospice Survey questions (Questions 1 – 47)
 - When supplemental questions are placed in between the Core questions and the “About Your Family Member” questions, the “ABOUT YOUR FAMILY MEMBER” heading must still be placed prior to the “About Your Family Member” questions
 - When adding supplemental questions after the “About You” questions, a transition phrase must be placed before the supplemental questions
- Phrases must be added to indicate a transition from the CAHPS Hospice Survey questions to the hospice-specific supplemental questions regardless of whether the supplemental questions are placed between the Core questions and the “About Your Family Member” questions and/or after the “About You” questions. Examples of transitional phrases are as follows:
 - *“Now we would like to gather some additional detail on topics we have asked you about before. These items use a somewhat different way of asking for your response since they are getting at a slightly different way of thinking about the topics.”*
 - *“The following questions focus on additional care your family member may have received from Hospice X.”*
 - *“This next set of questions is to provide the hospice additional feedback about your family member’s hospice care.”*

In addition, one supplemental question must be included in the mail questionnaire **if** the hospice wishes to view the survey responses linked to respondents’ name and other identifying information. The survey question, referred to as the Consent to Share Responses, must be printed in the mail questionnaire, and the respondent must check the “Yes” response option for the vendor to provide the hospice with the respondent’s answers linked to the respondent’s name and identifying information. The question is typically placed at the end of the questionnaire, as the last question.

Survey vendors must avoid hospice-specific supplemental questions that:

- pose a burden to the caregiver (e.g., length and complexity of supplemental questions, etc.)
- are worded very similarly to the Core CAHPS Hospice Survey questions

- may cause the caregiver to terminate the survey (e.g., items that ask about sensitive medical, health or personal topics, etc.)
- jeopardize decedent/caregiver confidentiality (other than the “Consent to Share Responses” item above)
- ask the caregiver to explain why he or she chose a specific response; for example, it is not acceptable to ask caregivers why they indicated that they would not recommend the hospice to friends and family

Cover Letters

Survey vendors may adapt the sample cover letters provided (see Appendices M and N). Survey vendors must follow the guidelines described below when altering the cover letter templates provided in this manual.

Required for the Cover Letter

- The cover letter must be printed on the hospice’s or survey vendor’s letterhead and must include the signature of the hospice administrator or survey vendor project director
- The language indicating the purpose of the unique identifier (“You may notice a number on the survey. This number is used to let us know if you returned your survey so we don’t have to send you reminders.”) must be printed immediately after the survey instructions on the questionnaire or on the cover letter, and may appear on both.
- The following items must be included in the body of the cover letter:
 - name and address of the sampled caregiver. “To Whom It May Concern” is not an acceptable salutation.
 - name of the decedent

Note: There may be instances in which a decedent and caregiver have the same name. Quality control activities must be implemented to ensure the names on the cover letter for the decedent and caregiver are correct.

- language indicating that answers will be shared, if the survey responses will be shared with the hospice for the purpose of quality improvement
- an explanation that participation in the survey is voluntary
- the hospice name to make certain that the caregiver completes the survey based on the care received from that hospice only
- a toll-free customer support telephone number for survey vendors
 - Customer support must be offered in all languages in which the survey vendor administers the survey
 - Vendors must be ready to support calls from deaf or the hearing impaired, including, but not limited to TTY
- The OMB language must appear on either the questionnaire or cover letter, and may appear on both, in a readable font at a minimum of 10 point
- Cover letters must NOT:
 - be attached to the survey; doing so could compromise confidentiality
 - attempt to bias, influence or encourage caregivers to answer CAHPS Hospice Survey questions in a particular way

- imply that the hospice, its personnel or its agents will be rewarded or gain benefits if caregivers answer CAHPS Hospice Survey questions in a particular way
- ask or imply that caregivers should choose certain responses; indicate that the hospice is hoping for a given response, such as a “10,” “Definitely yes,” or an “Always”
- indicate that the hospice’s goal is for all caregivers to rate them as a “10,” “Definitely yes” or an “Always”
- offer incentives of any kind for participation in the survey
- include any content that attempts to advertise or market the hospice’s mission or services
- offer caregivers the opportunity to complete the survey over the telephone
- include extraneous titles for caregiver (e.g., Aunt, Uncle)

Optional for the Cover Letter

- Cover letters may be double sided (English/Spanish or English/Chinese)
- Use of the Spanish or Chinese cover letters is allowed if the survey vendor is sending a Spanish or Chinese questionnaire to the caregiver
- Information may be added to the English cover letters (in English, Spanish or Chinese) that indicates that the caregiver may request a mail survey in Spanish or Chinese
- English should be the default language in the continental United States and Spanish should be the default language in Puerto Rico
- Survey vendor’s return address may be included on the cover letter to make sure the questionnaire is returned to the correct address in the event that the enclosed return envelope is misplaced by the caregiver. If the survey vendor’s name is included in the return address, then the survey vendor’s business name must be used, not an alias or tag line.
- Any instructions that appear on the survey may be repeated in the cover letter

Note: Any variations to the questionnaire and/or cover letters, other than the optional items listed above, will require an approved Exception Request prior to survey administration (see the Exception Request Process and the Discrepancy Report Process chapters).

Mailing of Materials

Survey vendors must mail materials following the guidelines described below:

- Attempts must be made to contact every survey-eligible decedent/caregiver drawn into the sample, whether or not they have a complete mailing address. Survey vendors must use commercial software or other means to update addresses provided by the hospice for sampled decedents/caregivers. (Mailings returned as undeliverable and for which no updated address is available must be coded “10 – Non-response: Bad address.”) Survey vendors must retain a record of attempts made to acquire missing addresses. All materials relevant to survey administration are subject to review.
 - Survey vendors must first make every reasonable attempt to obtain a caregiver’s address including re-contacting the hospice client to inquire about an address update for caregivers with no mailing address. Attempts to obtain the caregivers address must be documented.
- Self-addressed, stamped business return envelopes must be enclosed in the survey envelope along with the cover letter and questionnaire. The CAHPS Hospice Survey

cannot be administered without both a cover letter and self-addressed, stamped business return envelope.

- All mailings must be sent to each caregiver by name, and to the caregiver's most current address listed in the hospice record or retrieved by other means
- For caregivers who request to be sent an additional questionnaire (either after the first or second mailing) survey vendors must follow the guidelines below:
 - It is acceptable to mail a replacement survey at the caregiver's request within the 42 calendar day survey administration period; however, the survey administration timeline does not restart
 - After 42 calendar days from the first mailing, a replacement CAHPS Hospice Survey must NOT be mailed-out, as the data collection timeframe of 42 calendar days after the first mailing has expired

Hospices and survey vendors are **not** allowed to:

- show or provide the CAHPS Hospice Survey or cover letters to caregivers prior to the administration of the survey, including while the patient is still under hospice care
- mail any pre-notification letters or postcards after patient death to inform caregivers about the CAHPS Hospice Survey

Notes:

- *In instances where returned mail surveys have all missing responses (i.e., without any questions answered – blank questionnaires), send a second survey to the caregiver if the data collection time period has not expired. If the second mailing is returned with all missing responses, then code the Final Survey Status as “8 – Non-response: Refusal.” If the second mailing is not returned, then code the Final Survey Status as “9 – Non-response: Non-response after maximum attempts.”*
- *When the first survey is not returned, the second survey is mailed and subsequently the second mailed survey is returned with all missing responses, then code the Final Survey Status as “8 – Non-response: Refusal.”*

It is strongly recommended that all mailings be sent with first class postage or indicia to ensure delivery in a timely manner and to maximize response rates, as first class mail is more likely to be opened.

Data Receipt and Retention

Survey vendors may use key-entry or scanning to record returned survey data in their data collection systems. Returned questionnaires must be tracked by date of receipt as well as key-entered or scanned in a timely manner. If a caregiver returns two survey questionnaires, the survey vendor must use only the first CAHPS Hospice Survey received.

Survey vendors must maintain a crosswalk of their interim disposition codes to the CAHPS Hospice Survey Final Survey Status codes and include the crosswalk in the survey vendor's QAP.

Survey vendors must follow the data entry decision rules and data storage requirements described below.

Key-entry

Survey vendors' key-entry processes must incorporate the following features:

- Unique record verification system: The survey management system performs a check to verify that the caregiver response data have not already been entered in the survey management system
- Valid range checks: The data entry system identifies responses/entries that are invalid or out-of-range
- Validation: Survey vendors must have a plan and process in place to verify the accuracy of key-entered data. Survey vendors must confirm that key-entered data accurately capture the responses on the original survey. A different staff member (preferably the data entry supervisor) must reconcile any discrepancies.

Scanning

Survey vendors' scanning software must accommodate the following:

- Unique record verification system: The survey management system performs a check to confirm that the caregiver's survey responses have not already been entered in the survey management system
- Valid *range checks*: The software identifies invalid or out-of-range responses
- Validation: Survey vendors must have a plan and process in place to confirm the accuracy of scanned data. Survey vendors must make certain that scanned data accurately capture the responses on the original survey. A staff member must reconcile any responses not recognized by the scanning software.

Decision Rules

Whether employing scanning or key-entry of mail questionnaires, survey vendors must use the following decision rules to resolve common ambiguous situations. Survey vendors must follow these guidelines to ensure standardization of data entry across hospices.

- If a mark falls between two response options but is obviously closer to one than the other, then select the choice to which the mark is closest
- If a mark falls equidistant between two response options, then code the value for the item as "M – Missing/Don't know"
- If a mark is missing, code the value for the item as "M – Missing/Don't know." Survey vendors must not impute a response (see *Data Coding and Data File Preparation* chapter for information on coding skip pattern questions)
- For other than multi-mark questions, when more than one response option is marked, code the value as "M – Missing/Don't know"

*Note: In instances where there are multiple marks **but** the caregiver's intent is clear, survey vendors should code the survey with the caregiver's **clearly identified** intended response.*

Personnel Training

Training of personnel in the CAHPS Hospice Survey data collection protocols is key to successful survey administration. The following section addresses training provided to:

- Project staff
- Customer support personnel

- Mail data entry personnel
- Subcontractors

Training of Project Staff

At a minimum, the survey vendor's Project Manager and any subcontractor(s) with responsibility for major survey administration functions must participate in the CAHPS Hospice Survey Training sponsored by CMS. Individuals who are involved and work on any aspect of CAHPS Hospice Survey operations (e.g., account managers, sampling specialists, quality assurance managers, programmers and information technology staff, etc.), must be thoroughly trained by the survey vendor on CAHPS Hospice Survey protocols and methodology to guarantee standardization of survey administration. Survey vendors must also provide training to their hospice clients on preparation of the decedents/caregivers lists.

Survey vendors must establish a process for training new project team members on CAHPS Hospice Survey administration in a timely fashion. It is strongly recommended that staff members are cross-trained in all aspects of the CAHPS Hospice Survey administration process in case of unforeseen staffing turnover or absence. Back-up staff for CAHPS Hospice Survey administration responsibilities must be assigned to staff employed by the survey vendor.

Note: Volunteers are not permitted to be involved in any aspect of the CAHPS Hospice Survey administration process.

Training of Customer Support Personnel

Survey vendors train customer support personnel in CAHPS Hospice Survey protocols and methodology to answer questions appropriately. Survey vendors must periodically (at a minimum on a quarterly basis) assess the reliability and consistency of customer support personnel responses. In addition, questions posed by surveyed caregivers should be reviewed regularly to determine if there is a need to develop additional FAQs. All inquiries received and responses provided through customer support must be documented. This documentation must be available for review upon request by the CAHPS Hospice Survey Project Team.

- Distressed Respondent Procedures:

Of critical importance is the need for survey vendors to develop a "distressed respondent protocol," to be incorporated into all interviewer and help desk training. Handling distressed respondent situations requires balancing keeping personally identifying information (PII) and private health information (PHI) confidential and helping a person who needs assistance. For survey research organizations, best interviewing practices recommend having a distressed respondent protocol in place for handling distressed respondents, which balances the respondent's right to confidentiality and privacy and providing assistance, if the situation indicates that the respondent's health and safety are in jeopardy.

If a respondent experiences distress significant enough for him or her to request additional support, CMS and the CAHPS Hospice Survey Project Team recommend that survey vendors' telephone staff put the respondent in contact with the appropriate local resource (generally a bereavement counselor or social worker on the hospice team that

provided care to their family member or friend). This visit and support groups for bereavement are part of the services covered under the Medicare Hospice Benefit.

Training of Mail Data Entry Personnel

Survey vendors will address the following items when training data entry personnel:

- Use of data entry equipment and programs
- Survey specifications and protocols
- Survey instrument, question flow, and skip patterns
- Data key-entry procedures
- Validation programs
- Decision rules/ambiguous responses

Training of survey vendor staff must be documented. This documentation must be available for review upon request by the CAHPS Hospice Survey Project Team.

Quality Control Guidelines

Survey vendors are responsible for the quality of work performed by any staff members and subcontractor(s). Survey vendors must conduct site verification of printing and mailing processes, regardless of whether they are using internal staff or subcontractor(s) to perform this work.

To avoid mail administration errors and to make certain that questionnaires are delivered as required, survey vendors must:

- perform interval checking of printed mailing pieces for:
 - fading, smearing, and misalignment of printed materials
 - appropriate survey contents, accurate address information, and proper postage on the survey sample packet
 - assurance that all printed materials in a mailing envelope have the same unique identifier
 - inclusion of all eligible sampled decedents in the sample mailing for that month
- include seeded mailings in mail-outs at a minimum on a quarterly basis
 - Seeded mailings are sent to designated survey vendor CAHPS Hospice Survey project staff (other than the staff producing the materials) to check for timeliness of delivery, accuracy of addresses, content of the mailing, and the quality of the printed materials
 - Seeded mailings must be integrated into the hospice's batched survey mailings, not sent as a stand-alone mailing to CAHPS Hospice Survey project staff
- perform address updates for missing or incorrect information
 - Attempts must be made to update address information to confirm accuracy and correct formatting
 - In addition to working with client hospices to obtain the most current caregiver contact information, survey vendors must employ other options, such as the National Change of Address (NCOA) and the United States Postal Service (USPS) CASS Certified Zip+4 software. Other means are also available to update addresses for accurate mailings, such as:

- Commercial software
- Internet search engines

Survey vendors **must** retain a record of all quality control activities and document these activities in the survey vendor's QAP. All materials relevant to survey administration are subject to review.

Monitoring and Quality Oversight

Survey vendors must establish a system for providing and documenting quality oversight and monitoring of their CAHPS Hospice Survey administration and CAHPS Hospice Survey project staff, including subcontractors. Quality checking activities must be performed by a different staff member than the individual who originally performed the specific project task(s). In addition, survey vendors must:

- perform and document quality checks of all key events in survey administration including, but not limited to: sample frame creation; sampling procedures; data receipt; data entry; data submission; backup systems; etc.
- monitor the performance of all staff involved with any aspect of programming, sample frame creation, sampling, processing of response data (from receipt and handling of returned surveys, through data entry, validation and edit checking) on an ongoing basis, and verify that staff and subcontractors are compliant with HIPAA regulations
- monitor the performance of all subcontractor(s)
- provide performance feedback to all staff and subcontractor(s), through regular assessments, to include special emphasis placed on the detection and correction of identified performance problems

The CAHPS Hospice Survey Project Team will conduct site visits to survey vendors and to their subcontractors, if applicable, to review survey vendors' operations, monitoring, quality oversight practices, and documentation. As noted earlier, if a survey vendor is non-compliant with program requirements for any of their contracted hospices, the hospice survey data may not be reported.

Safeguarding Decedent/Caregiver Confidentiality

Survey vendors must take the following actions to further protect the confidentiality of decedent/caregivers:

- Prevent unauthorized access to confidential electronic and hard copy information by restricting physical access to confidential data (use locks or password-protected entry systems on rooms, file cabinets and areas where confidential data are stored)
- Develop CAHPS Hospice Survey or survey specific confidentiality agreements and obtain signatures from all personnel with access to survey information, including staff and all subcontractors involved in survey administration and data collection
- Confirm that staff and subcontractors are compliant with HIPAA regulations in regard to decedent/caregiver protected health information (PHI)
- Establish protocols for secure file transmission. Emailing of PHI via unsecure email is prohibited.
- Establish protocols for identifying security breaches and instituting corrective actions
- Store returned mail paper questionnaires and/or electronically scanned questionnaires in a secure and environmentally safe location for a minimum of three years

*Note: It is strongly recommended that the method used by contracted hospices to transmit information (e.g., decedents/caregivers lists) to the survey vendor be reviewed by the hospice's HIPAA/privacy officer to confirm compliance with HIPAA regulations. Any materials (e.g., QAP, questionnaires, cover letters, tracking forms) submitted by the survey vendor to the CAHPS Hospice Survey Project Team must be blank templates and **must not** contain any decedent/caregiver PHI.*

Survey vendors must have physical plant resources available to handle the volume of surveys being administered, in addition to systematic processes that effectively track sampled decedents' progress through the data collection protocol and caregivers' responses to the survey. System resources are subject to oversight activities including site visits to physical locations.

Data Security

Survey vendors must securely store caregiver identifying electronic data and responses to the survey. Survey vendors must take the following actions to secure the data:

- Use a firewall and/or other mechanisms for preventing unauthorized access to the electronic files
- Implement access levels and security passwords so that only authorized users have access to sensitive data
- Implement daily data backup procedures that adequately safeguard system data
- Test backup files at a minimum on a quarterly basis to make sure the files are easily retrievable and working
- Perform frequent saves to media to minimize data losses in the event of power interruption

Data Retention and Storage

Survey vendors must store all CAHPS Hospice Survey administration lists and data in a secure and environmentally controlled location for a minimum of three years.

Telephone Only Survey Administration

Overview

This chapter describes guidelines for the Telephone Only Mode of the CAHPS Hospice Survey administration.

Data collection for sampled decedents/caregivers must be initiated two months following the month of patient death.

*Note: If the survey vendor learns that a sampled decedent/caregiver is ineligible for the CAHPS Hospice Survey, the survey vendor must not make further attempts to contact that caregiver. After the sample has been drawn, any decedents/caregivers who are found to be ineligible **must not be removed or replaced in the sample. Instead, these decedents/caregivers are assigned the “Final Survey Status” code of ineligible (2, 3, 4, 5, and 6, as applicable). An administrative record must be submitted for these decedents/caregivers.***

Data collection may be completed by telephone only. Outbound calling must be scheduled in a manner to ensure all cases have a first attempt within 7 days of the start of the field period (initial contact). Data collection must be closed out for a sampled caregiver by six weeks (42 calendar days) following the first call attempt. If it is known that the caregiver may be available in the latter part of the 42 calendar day data collection time period (e.g., caregiver is on vacation the first 2 or 3 weeks of the 42 calendar day field period and there would be an opportunity to reach the caregiver closer to the end of the field period), then survey vendors must use the entire field time period to schedule telephone calls. Telephone call attempts are to be made between the hours of 9 AM and 9 PM respondent time. Caregivers who receive the CAHPS Hospice Survey must not be offered incentives of any kind. Caregivers who do not respond to the survey are assigned a “Final Survey Status” code of non-response.

Survey vendors must include the “Number Survey Attempts – Telephone” field in the Decedent/Caregiver Administrative Data Record. This field is required when “Survey Mode” in the Header Record is “2 – Telephone Only.” This field captures the telephone attempt in which the final disposition of the survey is determined. More information regarding the coding of the survey attempts field is presented in the *Data Coding and Data File Preparation* chapter.

Survey vendors must make every reasonable effort to achieve optimal survey response rates and to pursue contact with potential respondents until the data collection protocol is completed.

The basic tasks and timing for conducting the CAHPS Hospice Survey using the Telephone Only Mode of survey administration are summarized below.

Activity	Timing
Initiate systematic telephone contact with sampled caregivers	Two months after the month of patient death within the first seven days of the field period
Complete telephone data collection	Within six weeks (42 calendar days) after the first attempt
Submit data files to the CAHPS Hospice Survey Data Warehouse by the data submission deadline. No files will be accepted after the submission deadline date.	See the quarterly data submission deadlines in the <i>Sampling Protocol</i> chapter

To reiterate, the first telephone attempt must occur two months after the month of patient death within the first seven days of the field period. Data collection must then be completed no later than six weeks (42 calendar days) after the initial telephone attempt. To illustrate the timing of the attempts, the following example is provided of a patient who died on April 1 while in hospice care.

Example:
<ul style="list-style-type: none"> ➤ The first telephone attempt is made on July 1 (two months after the month of patient’s death) ➤ Data collection must be closed out by August 12 for this caregiver, which is six weeks (42 days) from the July 1 first telephone attempt date: <ul style="list-style-type: none"> • If a telephone interview is completed on or before August 12, which is the last day of the survey administration time period for this caregiver, then the survey data are included in the final survey data file and assigned a “Final Survey Status” code of either “1 – Completed survey” or “7 – Non-response: Break off” based on the calculation of percent complete as described in the <i>Data Coding and Data File Preparation</i> chapter <ul style="list-style-type: none"> ○ If the survey is mistakenly completed after August 12 (August 13, for example), which is beyond the six weeks (42 days) survey administration time period for this caregiver, then the survey data are not included in the final survey data file (however, an administrative data record is submitted for this caregiver) and a “Final Survey Status” code of “9 – Non-response: Non-response after maximum attempts” is assigned

Survey vendors must make every reasonable effort to achieve optimal telephone response rates by thoroughly familiarizing interviewers with the study purpose; carefully supervising interviewers; retraining those interviewers having difficulty enlisting cooperation; and re-contacting reluctant respondents with different interviewers at different times until the final data collection protocol is completed.

Telephone Interviewing Systems

Telephone Script

Telephone data collection must be available in both English and Spanish. English should be the default language in the continental United States and Spanish should be the default language in Puerto Rico. Survey vendors are provided standardized telephone scripts in both English and Spanish (Appendices O and P) for CAHPS Hospice Survey administration. These telephone

scripts must be read verbatim without adding any other scripting or tag questions, such as “How are you?” Survey vendors are not permitted to make or use any other language translations of the CAHPS Hospice Survey telephone scripts. We strongly encourage hospices with a significant caregiver population that speaks Spanish to offer the CAHPS Hospice Survey in this language. We encourage hospices that serve patient populations that speak languages other than those noted to request CMS to create an official translation of the CAHPS Hospice Survey in those languages.

Each survey vendor must submit a copy of its CAHPS Hospice Survey telephone script and interviewer CATI screen shots (including skip pattern logic) by the specified due date for review by the CAHPS Hospice Survey Project Team.

Required for the Telephone Script

The CAHPS Hospice Survey Core questions (Q1 – Q40) must be placed at the beginning of the survey. The order of the Core questions must not be altered and all the Core questions must remain together. The “About Your Family Member” and “About You” questions must be placed after the Core questions and cannot be eliminated from the questionnaire. The “About You” questions must follow the “About Your Family Member” questions.

Programming of the telephone scripts must follow the guidelines described below:

- Question and answer category wording must not be changed
- No changes are permitted in the order of the Core questions
- No changes are permitted in the order of the “About Your Family Member” CAHPS Hospice Survey questions
- No changes are permitted in the order of the “About You” questions
- No changes are permitted in the order of the answer categories for the Core, “About Your Family Member” or “About You” questions
- The Core questions must remain together
- The “About Your Family Member” and “About You” questions must remain together
- All underlined content must be emphasized
 - No other script content is to be emphasized; in particular, response options must be read at the same even pace without any additional emphasis on any particular response category
- Only one language (English or Spanish) may appear on the electronic interviewing system screen
- The survey vendor is responsible for programming the scripts and specifications into their electronic telephone interviewing system software or an alternative system
 - The transitional statements found throughout the telephone script are part of the structured script and must be read. An example of a transitional phrase that must be read can be found before Question 39 (Q 39 Intro): “Please answer the following questions about your family member’s care from [ABC Hospice]. Do not include care from other hospices in your answers.”
 - Do not program a specific response category as the default option

Survey vendors must have a process in place to address caregivers’ requests to verify the survey legitimacy or to answer questions about the survey.

Supplemental Questions

Survey vendors may add up to 15 hospice-specific supplemental questions to the CAHPS Hospice Survey, following the guidelines described below:

- Hospice-specific supplemental questions are added immediately after the Core CAHPS Hospice Survey questions (Questions 1 – 40) or at the end of all the CAHPS Hospice Survey questions (Questions 1 – 47).
 - When supplemental questions are placed in between the Core questions and the “About Your Family Member” questions, the “ABOUT YOUR FAMILY MEMBER” heading must still be placed prior to the “About Your Family Member” questions
 - When adding supplemental questions after the “About You” questions, a transition phrase must be placed before the supplemental questions
- Phrases must be added to indicate a transition from the CAHPS Hospice Survey questions to the hospice-specific supplemental questions regardless of whether the supplemental questions are placed between the Core questions and the “About Your Family Member” questions and/or after the “About You” questions. Examples of transitional phrases are as follows:
 - *“Now we would like to gather some additional detail on topics we have asked you about before. These items use a somewhat different way of asking for your response since they are getting at a slightly different way of thinking about the topics.”*
 - *“The following questions focus on additional care your family member may have received from Hospice X.”*
 - *“This next set of questions is to provide the hospice additional feedback about your family member’s hospice care.”*

In addition, one supplemental question must be included in the telephone questionnaire **if** the hospice wishes to view the survey responses linked to respondents’ name and other identifying information. The survey question, referred to as the Consent to Share Responses, must be included in the telephone questionnaire, and the respondent must answer “Yes” for the vendor to provide the hospice with the respondent’s answers linked to the respondent’s name and identifying information. The question is typically placed at the end of the interview as the last question.

Survey vendors must avoid hospice-specific supplemental questions that:

- pose a burden to the respondent (e.g., number, length, and complexity of supplemental questions, etc.)
- are worded very similarly to the Core CAHPS Hospice Survey questions
- may cause the respondent to terminate the survey (e.g., items that ask about sensitive medical, health or personal topics, etc.)
- jeopardize decedent/caregiver confidentiality (other than the “Consent to Share Responses” item above)
- ask the caregiver to explain why he or she chose a specific response; for example, it is not acceptable to ask caregivers why they indicated that they would not recommend the hospice to friends and family

Interviewing Systems

Telephone data collection must be computer-assisted using live interviewers. Paper surveys administered by phone and the use of Touch-tone or Speech-enabled IVR are not acceptable.

Therefore, an electronic telephone interviewing system **is required for survey vendors**. An electronic telephone interviewing system uses standardized scripts and design specifications. The survey vendor is responsible for programming the scripts and specifications into their electronic telephone interviewing software. Regardless of caregiver response, the interviewer must record all responses in the telephone interview. Predictive dialing may be used as long as there is a live interviewer to interact with the caregiver, and the system is compliant with Federal Trade Commission (FTC) and Federal Communications Commission (FCC) regulations.

- Survey vendors may program the caller ID to display “on behalf of [HOSPICE NAME],” with the permission and compliance of the hospice’s HIPAA/Privacy Officer. Survey vendors **must not** program the caller ID to display only [HOSPICE NAME].

Monitoring/Recording Telephone Calls

When calling caregivers who reside in California, Connecticut, Delaware, Florida, Illinois, Maryland, Massachusetts, Michigan, Montana, New Hampshire, Pennsylvania, and Washington, survey vendors may begin the monitoring/recording of telephone calls after the interviewer states, “*This call may be monitored [recorded] for quality improvement purposes.*” This statement is found at the end of the INTRO section of the CAHPS Hospice Survey Telephone Script located in Appendices O and P.

Telephone Attempts

Survey vendors must attempt to reach each and every caregiver in the sample. Telephone call attempts are to be made between the hours of 9 AM and 9 PM respondent time. Repeated attempts must be made until the caregiver is contacted, found ineligible or five attempts have been made. After five attempts to contact the caregiver have been made, no further attempts are to be made. A telephone attempt is defined as one of the following:

- The telephone rings six times with no answer
- The interviewer reaches a wrong number
- An answering machine/voicemail is reached. In this case the interviewer must not leave a message.
- The interviewer reaches a household member and is told that the caregiver is not available to come to the telephone or has a new telephone number. The interviewer must not leave a message.
- The interviewer reaches the caregiver but is asked to call back at a more convenient time
 - The call back should be scheduled at the caregiver’s convenience, if at all possible
- The interviewer gets a busy signal on each of three consecutive telephone attempts
 - When systems permit, the three consecutive telephone attempts are to be made at approximately 20-minute intervals
- The interviewer reaches a disconnected number

If, during a telephone attempt, the sampled caregiver indicates that someone within the household is more knowledgeable about the hospice care that the decedent received, the more knowledgeable person may be a proxy respondent. If a sampled caregiver indicates that he or she never oversaw, was not involved in, or is unknowledgeable about the hospice care provided to the decedent, interviewers may ask if someone else in the household is knowledgeable about the decedent’s hospice care. If such a person exists, he or she may be a proxy respondent. Interviewers must not accept individuals outside of the sampled caregiver’s household as proxy

respondents. Should no knowledgeable individual be identified within the household, the case should be coded as ineligible using code “6 – Ineligible: Never involved in decedent care.”

Sampled caregivers are to be called up to five times unless the sampled caregiver (or an eligible proxy caregiver) completes the survey, is found to be ineligible or explicitly refuses to complete the survey (or if someone refuses on behalf of the caregiver).

- If the survey vendor learns that a decedent/caregiver is ineligible for the CAHPS Hospice Survey, the caregiver must not receive any further telephone attempts

Survey vendors must adhere to the following guidelines in their attempts to contact caregivers:

- Telephone attempts are made at various times of the day, on different days of the week, and in different weeks to maximize the probability that the survey vendor will contact the caregiver

Note: More than one telephone attempt may be made in a week (7 calendar days). However, the five telephone attempts cannot be made in just one week (7 calendar days). The five call attempts must span more than one week (eight or more days) to account for caregivers who are temporarily unavailable.

- Caregivers who call back after an initial contact can be scheduled for interviews or forwarded to an available CAHPS Hospice Survey interviewer
- Interviewers must not leave messages on answering machines or with household members, since this could violate a caregiver’s privacy. Survey vendors must instead attempt to re-contact the caregiver to complete the CAHPS Hospice Survey.
- When a caregiver requests to complete at a later date a telephone survey already in progress, a call back should be scheduled. At the time of the call back, the interview should resume with the next question where the caregiver left off from the previous call.
- If on the fifth attempt, the caregiver requests to schedule an appointment to complete the survey, it is permissible to schedule that appointment and call the caregiver back provided that the appointment is within the 42 calendar day data collection time period. If on the call back at the scheduled time, no connection is made with the caregiver, then no further contact may be attempted. This additional (sixth) call attempt would be coded as “5 – Fifth Telephone attempt” in the “Number Survey Attempts – Telephone” for data file submission.

Note: The CAHPS Hospice Survey Project Team strongly recommends that, when requested, telephone call back scheduling accommodates a caregiver’s request for a specific day and time in order to ensure a reasonable response rate for the hospice.

Survey vendors must take the following steps to contact difficult-to-reach caregivers:

- If the caregiver’s telephone number is incorrect, make every effort to find the correct telephone number. If the person answering the telephone knows how to reach the caregiver, the new information must be used.
- If the caregiver is away temporarily, he or she must be contacted upon return, provided that it is within the data collection time period. If it is known that the caregiver may be available in the latter part of the 42 calendar day data collection time period (e.g.,

caregiver is on vacation the first 2 or 3 weeks of the 42 calendar day data collection time period and there would be an opportunity to reach the caregiver closer to the end of the data collection time period), then survey vendors must use the entire data collection time period to schedule telephone calls.

- If the caregiver does not speak the language in which the survey is being administered, the interviewer must thank the caregiver for his or her time and terminate the interview
- If the call is inadvertently dropped and the interview is interrupted, the caregiver should be re-contacted immediately to complete the remainder of the survey. This re-contact does not constitute an additional call attempt.

Obtaining and Updating Telephone Numbers

Survey vendors normally obtain telephone numbers from the hospice's records. Survey vendors must use commercial software or other means to update telephone numbers provided by the hospice for sampled caregivers. Requisite attempts must be made to contact every eligible caregiver in the sample, whether or not there is a complete and correct telephone number for the caregiver when the sample is created. Survey vendors must retain a record of attempts to acquire missing telephone numbers. All materials relevant to survey administration are subject to review.

Hospices/Survey vendors should attempt to obtain updated telephone numbers prior to the start of telephone attempts through commercial locating services, Internet or other means. To obtain the most current caregiver contact information, survey vendors must employ various options for updating telephone numbers:

- Running update program software against the sample file just before or after uploading data to survey management systems
- Utilizing commercial software, Internet directories, and/or directory assistance

Data Receipt and Retention

Survey vendors must record the date of the telephone interview and must link survey responses from the telephone interview to their survey management system, regardless of the interviewing system employed. Survey vendors must maintain a crosswalk of their interim disposition codes to the CAHPS Hospice Survey Final Survey Status codes and include the crosswalk in the survey vendor's QAP.

Electronic Telephone Interviewing System

The electronic telephone interviewing system employed by survey vendors must be electronically linked to their survey management system to enable responses obtained from the electronic telephone interviewing system to be automatically added to the survey management system.

Data Storage

Survey vendors must retain all CAHPS Hospice Survey data collected through an electronic telephone interviewing system in a secure and environmentally controlled location for a minimum of three years.

Quality Control Guidelines

Survey vendors are responsible for the quality of work performed by any staff members and subcontractor(s). Survey vendors must employ the following guidelines for proper interviewer training, monitoring and oversight regardless of whether they are using internal staff or subcontractor(s) to perform this work.

Interviewer Training

Consistent monitoring of interviewers' work is essential to achieve standardized and accurate results. Properly trained and supervised interviewers ensure that standardized, non-directive interviews are conducted. Interviewers conducting the telephone survey must be trained prior to interviewing (see Appendix F for more information on interviewing guidelines).

- Training must direct interviewers to read questions exactly as worded in the script, use non-directive probes and maintain a neutral and professional relationship with the respondent
- Interviewers must be trained to read response options exactly as worded and at an even pace without emphasis on any particular response category
- Interviewers must be trained to record responses to survey questions only after the caregiver has responded to the questions; that is, interviewers must not pre-code response choices
- In organizations where interviewers assign interim or final call disposition codes, they must be trained in the definition of each disposition code
- Interviewers must be trained in a process for redirecting calls to another interviewer when the respondent is personally known to the initial interviewer
- Distressed Respondent Procedures:

Of critical importance is the need for survey vendors to develop a "distressed respondent protocol," to be incorporated into all interviewer and help desk training. Handling distressed respondent situations requires balancing keeping personally identifying information (PII) and private health information (PHI) confidential and helping a person who needs assistance. For survey research organizations, best interviewing practices recommend having a distressed respondent protocol in place for handling distressed respondents, which balances the respondent's right to confidentiality and privacy and providing assistance, if the situation indicates that the respondent's health and safety are in jeopardy.

If a respondent experiences distress significant enough for him or her to request additional support, CMS and the CAHPS Hospice Survey Project Team recommend that survey vendors' telephone staff put the respondent in contact with the appropriate local resource (generally a bereavement counselor or social worker on the hospice team that provided care to their family member or friend). This visit and support groups for bereavement are part of the services covered under the Medicare Hospice Benefit.

Note: If a survey vendor uses a subcontractor to conduct telephone interviewing, then the survey vendor is responsible for attending/participating in the subcontractor's telephone interviewer training to confirm compliance with CAHPS Hospice Survey protocols and guidelines.

Telephone Monitoring and Oversight

Each survey vendor employing the Telephone Only Mode of survey administration must institute a telephone monitoring and evaluation program. The telephone monitoring and evaluation program must include, but is not limited to, the following oversight activities:

- Survey vendors must monitor at least 10 percent of all CAHPS Hospice Survey interviews, dispositions and call attempts in their entirety (both English and Spanish) through silent monitoring of interviewers using the electronic telephone interviewing system software or an alternative system. Silent monitoring capability must include the ability to monitor calls onsite and from remote locations. All staff conducting CAHPS Hospice Survey interviews must be included in the monitoring. Additionally, it is strongly encouraged that survey vendors provide “floor rounding” in their call-center(s) to visually observe and ensure the professionalism of the telephone interviewers.
- **Survey vendors using a subcontractor must monitor at least 10 percent of the subcontractor’s CAHPS Hospice Survey telephone interviews and call attempts in their entirety, provide feedback to the subcontractor’s interviewers about their performance and confirm that the subcontractor’s interviewers correct any areas that need improvement. Feedback must be provided to interviewers as soon as possible following a monitoring session.**

Note: CAHPS Hospice Survey protocols currently require that approved CAHPS Hospice Survey vendors who subcontract the task of CAHPS Hospice Survey telephone interviewing monitor at least 10% of all CAHPS Hospice Survey calls/attempts/completed surveys. The CAHPS Hospice Survey Project Team also expects that a survey vendor’s subcontractor will conduct internal monitoring of their telephone interviewers as a matter of good business practice that incorporates quality checks. While it is preferred that each organization continue to monitor 10% of CAHPS Hospice Survey interviews (for an overall total of 20%), it is permissible for the survey vendor and its subcontractor to conduct a combined total of at least 10% monitoring, as long as each organization conducts a portion of the monitoring. Therefore, the survey vendor and its subcontractor can determine the ratio of monitoring that each organization conducts, as long as the combined total meets or exceeds 10%. Please note that CAHPS Hospice Survey interviews monitored concurrently by the survey vendor and its subcontractor do not contribute separately to each organization’s monitoring time.

- Staff who are found to be consistently unable to follow the script verbatim, employ proper probes, remain objective and courteous, be clearly understood, or operate the electronic telephone interviewing system competently, must be identified and retrained or, if necessary, replaced
- In organizations where interviewers assign interim or final disposition codes, the assignment of codes must be reviewed by a supervisor
- Organizations must monitor interviewer survey response coding by, at a minimum, reviewing the frequency of missing responses in the surveys administered by interviewers

Survey vendors **must** retain a record of all quality control activities and document these activities in the survey vendor’s QAP. All materials relevant to survey administration are subject to review.

Safeguarding Decedent/Caregiver Confidentiality

Survey vendors must take the following actions to further protect the confidentiality of decedents/caregivers:

- Prevent unauthorized access to confidential electronic and hard copy information by restricting physical access to confidential data (use locks or password-protected entry systems on rooms, file cabinets and areas where confidential data are stored)
- Develop CAHPS Hospice Survey or survey specific confidentiality agreements and obtain signatures from all personnel with access to survey information, including staff and all subcontractors involved in survey administration and data collection
- Confirm that staff and subcontractors are compliant with HIPAA regulations in regard to decedent/caregiver protected health information (PHI)
- Establish protocols for secure file transmission. Emailing of PHI via unsecure email is prohibited.
- Establish protocols for identifying security breaches and instituting corrective actions

*Note: It is strongly recommended that the method used by contracted hospices to transmit information (e.g., decedents/caregivers lists) to the survey vendor be reviewed by the hospice's HIPAA/privacy officer to confirm compliance with HIPAA regulations. Any materials (e.g., QAP, questionnaires, cover letters, tracking forms) submitted by the survey vendor to the CAHPS Hospice Survey Project Team must be blank templates and **must not** contain any decedent/caregiver PHI.*

Survey vendors must have physical plant resources available to handle the volume of surveys being administered, in addition to systematic processes that effectively track sampled caregivers' progress through the data collection protocol and caregivers' responses to the survey. System resources are subject to oversight activities including site visits to physical locations.

Mixed Mode Survey Administration

Overview

This chapter describes guidelines for the Mixed Mode of the CAHPS Hospice Survey administration, which is a combination of an initial mailing of the questionnaire with telephone follow-up.

Data collection for sampled decedents/caregivers must be initiated two months following the month of patient death within the first seven days of the field period. Survey vendors must send sampled caregivers a questionnaire with a cover letter within the first seven days of the field period, then beginning approximately 21 calendar days after mailing the questionnaire conduct a maximum of five telephone attempts to non-respondents.

Notes:

- Reversing the protocol (telephone attempts followed by mail attempt) is not allowed
- *If the survey vendor learns that a sampled decedent/caregiver is ineligible for the CAHPS Hospice Survey, no further attempts should be made to contact that caregiver. After the sample has been drawn, any decedents/caregivers who are found to be ineligible **must not** be removed or replaced in the sample. Instead, these decedents/caregivers are assigned the “Final Survey Status” code of ineligible (2, 3, 4, 5, or 6, as applicable). An administrative record must be submitted for these decedents/caregivers.*

Data collection must be closed out for a sampled caregiver by six weeks (42 calendar days) following the mailing of the questionnaire (initial contact). If the caregiver did not return a mail survey and it is known that the caregiver may be available in the latter part of the 21 calendar day telephone component of the field period, and there would be an opportunity to reach the caregiver closer to the end of the telephone component of the field period, then survey vendors must use the entire 21 calendar day telephone component field period to schedule telephone calls. Telephone call attempts are to be made between the hours of 9 AM and 9 PM, respondent time. Caregivers who receive the CAHPS Hospice Survey must not be offered incentives of any kind. Caregivers who do not respond to the survey are assigned a “Final Survey Status” code of non-response.

Note: Should a caregiver call the toll-free number to do the interview by phone, they cannot complete the interview prior to the start of the telephone follow-up window and should be scheduled for a callback during the telephone data collection time period.

Survey vendors must include the “Number Survey Attempts – Telephone” field in the Decedent Administrative Data Record. This field is required when “Survey Mode” in the Header Record is “3 – Mixed Mode” and “Survey Completion Mode” is “2 – Mixed Mode-phone.” If the survey is completed/dispositioned during the telephone phase of the Mixed Mode, the “Number Survey Attempts – Telephone” captures the telephone attempt in which the final disposition of the survey is determined. More information regarding the survey attempts field is presented in the *Data Coding and Data File Preparation* chapter.

Survey vendors must make every reasonable effort to achieve optimal survey response rates and to pursue contact with potential respondents until the data collection protocol is completed.

The basic tasks and timing for conducting the CAHPS Hospice Survey, using the Mixed Mode of survey administration, are summarized below.

Activity	Timing
Send mail questionnaire with cover letter to sampled caregiver	Two months after the month of patient death within the first seven days of the field period
Initiate systematic telephone contact for all non-respondents	Approximately 21 calendar days after mailing of the questionnaire
Complete data collection activities	Over the next 21 calendar days
Submit data files to the CAHPS Hospice Survey Data Warehouse by the data submission deadline. No files will be accepted after the submission deadline date.	See the quarterly data submission deadlines in the <i>Sampling Protocol</i> chapter

To reiterate, the mail-out of the survey must occur two months after the month of patient death within the first seven days of the field period. Data collection then must be completed no later than six weeks (42 calendar days) after the mailing of the questionnaire. To illustrate the timing of survey mail-out and telephone follow-up the following example is provided of a patient who died on April 30 while in hospice care.

Example:
<ul style="list-style-type: none"> ➤ The survey is mailed out on July 1 (two months after patients death) ➤ If the caregiver has not returned the survey by July 22 (21 days after the initial mailing on July 1) telephone contact must be initiated ➤ Data collection must be closed out on August 12 for this caregiver, which is six weeks (42 days) from the July 1 initial mail-out date: <ul style="list-style-type: none"> • If a telephone interview is completed on or before August 12, which is the last day of the survey administration time period for this caregiver, then the survey data are included in the final survey data file and assigned a “Final Survey Status” code of either “1 – Completed survey” or “7 – Non-response: Break off” based on the calculation of percent complete as described in the <i>Data Coding and Data File Preparation</i> chapter • If the survey is mistakenly completed after August 12 (August 13, for example), which is beyond the six weeks (42 days) survey administration time period for this caregiver, then the survey data are not included in the final survey data file (however, an administrative data record is submitted for this caregiver) and a “Final Survey Status” code of “9 – Non-response: Non-response after maximum attempts” is assigned

Mail Protocol

This section describes guidelines for the mail phase of the Mixed Mode of survey administration.

Production of Questionnaire and Related Materials

The mail phase of the Mixed Mode of survey administration can be conducted in English and Spanish. Survey vendors are provided with the CAHPS Hospice Survey questionnaires in English and Spanish, and cover letters in English and Spanish (Appendices M and N). Survey vendors are not permitted to make or use any other translations of the CAHPS Hospice Survey cover letter or questionnaire. We strongly encourage hospices with a significant caregiver population that speaks Spanish to offer the CAHPS Hospice Survey in this language. We encourage hospices that serve patient populations that speak languages other than those noted to request CMS to create an official translation of the CAHPS Hospice Survey in those languages.

Mailings must include a personalized cover letter, a questionnaire, and a business reply envelope. The cover letters may be sent in both English and Spanish and may be two-sided, English on one side and Spanish on the other. Cover letters sent to respondents must be personalized with the decedent's name, the caregiver's name and the hospice's name. The letter must also provide a toll-free number for respondents to call if they have questions. The cover of the questionnaire must include a label indicating the name of the hospice, and if applicable, may include the specific hospice inpatient unit, acute care hospital or nursing home facility in which their family member or friend resided.

For CAHPS Hospice Survey administration, the OMB Paperwork Reduction Act language must appear in the mailing, either on the cover letter or on the front or back of the questionnaire. In addition, the OMB control number must appear on the front page of the questionnaire.

To increase the likelihood that the respondent is the person within the sampled caregiver's household who is most knowledgeable about the decedent's hospice care, language must be included in the questionnaire, and optionally in the cover letter, clearly stating that the survey should be given to the person in the household who knows the most about the hospice care received by the decedent.

Each survey vendor must submit a sample of their CAHPS Hospice Survey mailing materials (e.g., questionnaire and cover letter) by the specified due date for review by the CAHPS Hospice Survey Project Team.

Required for the Mail Questionnaire

The CAHPS Hospice Survey Core questions (Q1 – Q40) must be placed at the beginning of the survey. The order of the Core questions must not be altered and all the Core questions must remain together. The “About Your Family Member” and “About You” questions must be placed after the Core questions and cannot be eliminated from the questionnaire. The “About You” questions must follow the “About Your Family Member,” or “About You” questions.

Survey vendors must adhere to the following specifications for questionnaire formatting and the production of mailing materials.

- Question and answer category wording must not be changed
- No changes are permitted in the order of the Core questions
- No changes are permitted in the order of the “About Your Family Member” questions
- No changes are permitted in the order of the “About You” questions
- No changes are permitted in the order of the response categories for the Core, “About Your Family Member” or “About You” questions
- The Core questions must remain together
- The “About Your Family Member” and “About You” questions must remain together
- Each question and answer categories must remain together in the same column and on the same page
- Response options must be listed vertically (see examples in Appendix M and N). Response options that are listed horizontally or in a combined vertical and horizontal format are not allowed.

Formatting

- Wording that is **bolded** or underlined in the questionnaire provided in the *CAHPS Hospice Survey Quality Assurance Guidelines* must be emphasized in the same manner in the survey vendor’s questionnaire
- Arrow (i.e., ➔) placement in the questionnaire instructions and answer categories that specifies skip patterns must not be changed
- Section headings (e.g., “Your Family Member’s Hospice Care,” etc.) must be included on the questionnaire and must be capitalized
- Survey materials must be in a readable font (i.e. Arial) with a font size of 10 point at a minimum

Other Requirements

- All survey instructions written at the top of the questionnaire must be printed verbatim
- Randomly generated, unique identifiers must be placed on the first or last page of the questionnaire, at a minimum. Survey vendors may add other identifiers on the questionnaire for tracking purposes (e.g., unit identifiers, etc.). Neither the decedent nor the caregiver’s name may be printed on the questionnaire.
- The text indicating the purpose of the unique identifier [“You may notice a number on the survey. This number is used to let us know if you returned your survey so we do not have to send you reminders.”] must be printed immediately after the survey instructions or on the cover letter, and may appear on both.
- The survey vendor’s return address must be printed on the last page of the questionnaire in order to verify that the questionnaire is returned to the correct address in the event that the enclosed return envelope is misplaced by the caregiver
- If the survey vendor’s name is included in the return address, then the survey vendor’s business name must be used, not an alias or tag line

Optional for the Mail Questionnaire

Survey vendors have some flexibility in formatting the CAHPS Hospice Survey questionnaire by following the guidelines described below:

- Small coding numbers, preferably in superscript, may be included next to the response choices on the questionnaire
- Hospice logos may be included on the questionnaire; however, other images and tag lines are not permitted
- The phrase “Use only blue or black ink” may be printed on the questionnaire
- The name of the hospice may be printed on the questionnaire in Questions 2, 4 and 39, as indicated below
 - Question 2 – “In what locations did your family member receive care from [ABC Hospice]?”
 - Question 4 – “As you answer the rest of the questions in this survey, please think only about your family member’s experience with [ABC Hospice].”
 - Question 39 – “Please answer the following questions about your family member’s care from [ABC Hospice]. Do not include care from other hospices in your answers.”
- Page numbers may be included on the questionnaire
- Color may be incorporated in the questionnaire

Survey vendors should consider incorporating the following recommendations in formatting the CAHPS Hospice Survey questionnaire to increase the likelihood of receiving a returned survey:

- Two-column format that is used in Appendices M and N
- Wide margins (at least 3/4 inch) so that the survey has sufficient white space to enhance its readability

Supplemental Questions

Survey vendors may add up to 15 hospice-specific supplemental questions to the CAHPS Hospice Survey following the guidelines described below:

- For Mixed Mode, the same survey questions added to the mail survey for a given hospice must be added to the telephone CATI script
- Hospice-specific supplemental questions are added immediately after the Core questions (Questions 1 – 40) or at the end of all the CAHPS Hospice Survey questions (Questions 1 – 47)
 - When supplemental questions are placed in between the Core questions and the “About Your Family Member” questions, the “ABOUT YOUR FAMILY MEMBER” heading must still be placed prior to the “About Your Family Member” questions
 - When adding supplemental questions after the “About You” questions, a transition phrase must be placed before the supplemental questions
- Phrases must be added to indicate a transition from the CAHPS Hospice Survey questions to the hospice-specific supplemental questions regardless of whether the supplemental questions are placed between the Core questions and the “About Your Family Member” questions and/or after the “About You” questions. Example of transitional phrases are as follows:
 - *“Now we would like to gather some additional detail on topics we have asked you about before. These items use a somewhat different way of asking for your response since they are getting at a slightly different way of thinking about the topics.”*

- “The following questions focus on additional care your family member may have received from Hospice X.”
- “This next set of questions is to provide the hospice additional feedback about your family member’s hospice care.”

In addition, one supplemental question must be included in the mail **if** the hospice wishes to view the survey responses linked to respondents’ name and other identifying information. The survey question, referred to as the Consent to Share Responses, must be printed on the mail questionnaire. The respondent must check the “Yes” response option in the mail questionnaire for the vendor to provide the hospice with the respondent’s answers linked to the respondent’s name and identifying information. The question is typically placed at the end of the questionnaire or interview, as the last question.

Survey vendors must avoid hospice-specific supplemental questions that:

- pose a burden to the caregiver (e.g., number, length, and complexity of supplemental questions, etc.)
- are worded very similarly to the Core CAHPS Hospice Survey questions
- may cause the respondent to terminate the survey (e.g., items that ask about sensitive medical, health or personal topics, etc.)
- jeopardize decedent/caregiver confidentiality (other than the “Consent to Share Responses” item above)
- ask the caregiver to explain why he or she chose a specific response; for example, it is not acceptable to ask respondents why they indicated that they would not recommend the hospice to friends and family

Cover Letter

Survey vendors may adapt the sample cover letters provided (see Appendices M and N). Survey vendors must follow the guidelines described below when altering the cover letter templates provided in this manual.

Required for the Cover Letter

- The cover letter must be printed on the hospice’s or survey vendor’s letterhead and must include the signature of the hospice administrator or survey vendor project director
- The language indicating the purpose of the unique identifier (“You may notice a number on the survey. This number is used to let us know if you returned your survey so we don’t have to send you reminders.”) must be printed immediately after the survey instructions on the questionnaire or on the cover letter, and may appear on both.
- The following items must be included in the body of the cover letter:
 - name and address of the sampled caregiver. “To Whom It May Concern” is not an acceptable salutation.
 - name of decedent

Note: There may be instances in which a decedent and caregiver have the same name. Quality control activities must be implemented to ensure the names on the cover letter for the decedent and caregiver are correct.

- language indicating that answers will be shared, if the survey responses will be shared with the hospice for the purpose of quality improvement
- an explanation that participation in the survey is voluntary
- the hospice name to make certain that the caregiver completes the survey based on the care received from that hospice only
- a toll-free customer support telephone number for survey vendors
 - Customer support must be offered in all languages in which the survey vendor administers the survey
 - Vendors must be ready to support calls from deaf or the hearing impaired, including but not limited to TTY
- The OMB language must appear on either the questionnaire or cover letter, and may appear on both, in a readable font at a minimum of 10 point.
- Cover letter must NOT:
 - be attached to the survey; doing so could compromise confidentiality
 - attempt to bias, influence or encourage caregivers to answer CAHPS Hospice Survey questions in a particular way
 - imply that the hospice, its personnel or its agents will be rewarded or gain benefits if caregivers answer CAHPS Hospice Survey questions in a particular way
 - ask or imply that caregivers should choose certain responses; indicate that the hospice is hoping for a given response, such as a “10,” “Definitely yes,” or an “Always”
 - indicate that the hospice’s goal is for all caregivers to rate them as a “10,” “Definitely yes” or an “Always”
 - offer incentives of any kind for participation in the survey
 - include any content that attempts to advertise or market the hospice’s mission or services
 - offer caregivers the opportunity to complete the survey over the telephone
 - include extraneous titles for caregiver (e.g., Aunt, Uncle)

Optional for the Cover Letter

- Cover letters may be double sided (English on one side and Spanish on the other)
- Use of the Spanish cover letter is allowed if the survey vendor is sending a Spanish questionnaire to the caregiver
- Information may be added to the English cover letter (in English or Spanish) that indicates that the caregiver may request a mail survey in Spanish
- English should be the default language in the continental United States and Spanish should be the default language in Puerto Rico
- Survey vendor’s return address may be included on the cover letter to make sure that the questionnaire is returned to the correct address in the event that the enclosed return envelope is misplaced by the caregiver. If the survey vendor’s name is included in the return address, then the survey vendor’s business name must be used, not an alias or tag line.
- Any instructions that appear on the survey may be repeated in the cover letter

Note: Any variations to the questionnaire and/or cover letter, other than the optional items listed above, will require an approved Exception Request prior to survey administration (see the Exception Request Process and Discrepancy Report Process chapters).

Mailing of Materials

Survey vendors must mail materials following the guidelines described below:

- Attempts must be made to contact every survey-eligible decedent/caregiver drawn into the sample, whether or not they have a complete mailing address. Survey vendors must use commercial software or other means to update addresses provided by the hospice for sampled decedents/caregivers. (Mailings returned as undeliverable and for which no updated address is available must be coded as “10 – Non-response: Bad address.”) Survey vendors must retain a record of attempts made to acquire missing addresses. All materials relevant to survey administration are subject to review.
 - Survey vendors must first make every reasonable attempt to obtain a caregiver’s address including re-contacting the hospice client to inquire about an address update for caregivers with no mailing address. Attempts to obtain the caregivers address must be documented.
- Self-addressed, stamped business return envelopes must be enclosed in the survey envelope along with the cover letter and questionnaire. The CAHPS Hospice Survey cannot be administered without both a cover letter and self-addressed, stamped business return envelope.
- All mailings must be sent to each caregiver by name, and to the caregiver’s most current address listed in the hospice record or retrieved by other means
- For caregivers who request to be sent an additional questionnaire (either after the first or second mailing) survey vendors must follow the guidelines below:
 - It is acceptable to mail a replacement survey at the caregiver’s request within the first 21 calendar days of the 42 calendar day survey administration period; however, the survey administration timeline does not restart
 - After 21 calendar days from the mailing, a replacement CAHPS Hospice Survey must NOT be mailed-out, as the telephone portion of the Mixed Mode protocol must be initiated

Hospices and survey vendors are **not** allowed to:

- show or provide the CAHPS Hospice Survey or cover letters to patients or caregivers prior to the administration of the survey, including while the patient is still under hospice care
- mail any pre-notification letters or postcards after patient death to inform caregivers about the CAHPS Hospice Survey

Note: In instances where returned mail surveys have all missing responses (i.e., without any questions answered – blank questionnaire), initiate telephone contact after 21 days of mailing the questionnaire.

It is strongly recommended that the mailing be sent with first class postage or indicia to ensure delivery in a timely manner and to maximize response rates, as first class mail is more likely to be opened.

Data Receipt and Retention of Mailed Questionnaires

Survey vendors utilizing the Mixed Mode of survey administration must keep track of the mode in which each survey was completed (i.e., mail or telephone). If a caregiver returned the CAHPS

Hospice Survey mail questionnaire with enough of the questions applicable to all caregivers answered for the survey to be considered a completed survey (based on the calculation of percent complete; for more information see the *Data Coding and Data File Preparation* chapter), then the survey vendor must: 1. retain documentation in their survey management system that the caregiver completed the survey in the **mail** phase of the Mixed Mode of survey administration; and, 2. assign the appropriate “Survey Completion Mode” in the administrative record for this decedent/caregiver (see the *Data Coding and Data File Preparation* chapter on “Survey Completion Mode” for more information).

Survey vendors may use key-entry or scanning to record returned survey data in their data collection systems. Returned questionnaires must be tracked by date of receipt and key-entered or scanned in a timely manner. If a caregiver completes the CAHPS Hospice Survey via the telephone and a questionnaire is subsequently returned by the caregiver, the survey vendor must use the telephone CAHPS Hospice Survey responses since they were received first.

Survey vendors must maintain a crosswalk of their interim disposition codes to the CAHPS Hospice Survey Final Survey Status codes and include the crosswalk in the survey vendor’s QAP.

Survey vendors must follow the data entry decision rules and data storage requirements described below.

Key-entry

Survey vendors’ key-entry processes must incorporate the following features:

- **Unique record verification system:** The survey management system performs a check to verify that the caregiver response data have not already been entered in the survey management system
- **Valid range checks:** The data entry system identifies responses/entries that are invalid or out-of-range
- **Validation:** Survey vendors must have a plan and process in place to verify the accuracy of the key-entered data. Survey vendors must confirm that key-entered data accurately capture the responses on the original survey. A different staff member (preferably the data entry supervisor) must reconcile any discrepancies.

Scanning

Survey vendors’ scanning software should accommodate the following:

- **Unique record verification system:** The survey management system performs a check to confirm that the caregiver’s survey responses have not already been entered in the survey management system
- **Valid range checks:** The software identifies invalid or out-of-range responses
- **Validation:** Survey vendors must have a plan and process in place to confirm the accuracy of scanned data. Survey vendors must make certain that scanned data accurately capture the responses on the original survey. A staff member must reconcile any responses not recognized by the scanning software.

Decision Rules for Mail Data

Whether employing scanning or key-entry of mail questionnaires, survey vendors must use the following decision rules to resolve common ambiguous situations. Survey vendors must follow these guidelines to ensure standardization of data entry across hospices.

- If a mark falls between two response options but is obviously closer to one than the other, then select the choice to which the mark is closest
- If a mark falls equidistant between two response options, then code the value for the item as “M – Missing/Don’t know”
- If a mark is missing, code the value for the item as “M – Missing/Don’t know.” Survey vendors must not impute a response. (see *Data Coding and Data File Preparation* chapter for information on coding skip pattern questions)
- For other than multi-mark questions, when more than one response option is marked, code the value as “M – Missing/Don’t know”

*Note: In instances where there are multiple marks **but** the caregiver’s intent is clear, survey vendors should code the survey with the caregiver’s **clearly identified** intended response.*

Storage of Mail Data

Survey vendors must store returned paper questionnaires or scanned images of paper questionnaires in a secure and environmentally controlled location for a minimum of three years. Paper questionnaires or scanned images must be easily retrievable.

Quality Control Guidelines for Mail Data

Survey vendors are responsible for the quality of work performed by any staff members and subcontractor(s). Survey vendors must conduct site verification of printing and mailing processes, regardless of whether they are using internal staff or subcontractor(s) to perform this work.

To avoid mail administration errors and to make certain the questionnaires are delivered as required, survey vendors must:

- perform interval checking of printed mailing pieces for:
 - fading, smearing, and misalignment of printed materials
 - appropriate survey contents, accurate address information, and proper postage on the survey sample packet
 - assurance that all printed materials in a mailing envelope have the same unique identifier
 - inclusion of all eligible sampled caregivers in the sample mailing for that month
- include seeded mailings in mail-outs at a minimum on a quarterly basis
 - seeded mailings are sent to designated survey vendor CAHPS Hospice Survey project staff (other than the staff producing the materials) to check for timeliness of delivery, accuracy of addresses, content of the mailing, and quality of the printed materials
 - seeded mailings must be integrated into the hospice’s batched survey mailings, not sent as a stand-alone mailing to CAHPS Hospice Survey project staff

- perform address updates for missing or incorrect information
 - Attempts must be made to update address information to confirm accuracy and correct formatting
 - In addition to working with client hospices to obtain the most current caregiver contact information, survey vendors must employ other options, such as the National Change of Address (NCOA) and the United States Postal Service (USPS) CASS Certified Zip+4 software. Other means are also available to update addresses for accurate mailings, such as:
 - Commercial software
 - Internet search engines

Survey vendors **must** retain a record of all quality control activities and document these activities in the survey vendor's QAP. All materials relevant to survey administration are subject to review.

Telephone Protocol

If the mail questionnaire has not been returned within 21 calendar days following the mail-out to sampled caregivers, survey vendors must follow the CAHPS Hospice Survey telephone survey protocol. This section describes guidelines for the telephone phase of the Mixed Mode of survey administration. Survey vendors must conduct a maximum of five telephone attempts to non-respondents from the questionnaire mailing.

Survey vendors should make every reasonable effort to achieve optimal telephone response rates, such as thoroughly familiarizing interviewers with the study purpose, carefully supervising interviewers, retraining those interviewers having difficulty enlisting cooperation, and re-contacting reluctant respondents with different interviewers at different times, until the data collection protocol is completed.

Telephone Interviewing Systems

Telephone Script

Telephone data collection must be available in both English and Spanish. English should be the default language in the continental United States and Spanish should be the default language in Puerto Rico. Survey vendors are provided standardized telephone scripts in both English and Spanish (Appendices O and P) for CAHPS Hospice Survey administration. These telephone scripts must be read verbatim without adding any other scripting, or tag questions such as "How are you?" Survey vendors are not permitted to make or use any other language translations of the CAHPS Hospice Survey telephone scripts. We strongly encourage hospices with a significant caregiver population that speaks Spanish to offer the CAHPS Hospice Survey in this language. We encourage hospices that serve patient populations that speak languages other than those noted to request CMS to create an official translation of the CAHPS Hospice Survey in those languages.

Each survey vendor must submit a copy of its CAHPS Hospice Survey telephone script and interviewer screen shots (including skip pattern logic) by the specified due date for review by the CAHPS Hospice Survey Project Team.

Required for the Telephone Script

The CAHPS Hospice Survey Core questions (Q1 – Q40) must be placed at the beginning of the survey. The order of the Core questions must not be altered and all the Core questions must remain together. The “About Your Family Member” and “About You” questions must be placed after the Core questions and cannot be eliminated from the questionnaire. The “About You” questions must follow the “About Your Family Member” questions.

Programming of the telephone scripts must follow the guidelines described below:

- Question and answer category wording must not be changed
- No changes are permitted in the order of the Core questions
- No changes are permitted in the order of the “About Your Family Member” questions
- No changes are permitted in the order of the “About You” questions
- No changes are permitted in the order of the answer category for the Core, “About Your Family Member” or “About You” questions
- The Core questions must remain together
- The “About Your Family Member” and “About You” questions must remain together
- All underlined content must be emphasized
 - No other script content is to be emphasized; in particular, response options must be read at the same even pace without any additional emphasis on any particular response category
- Only one language (English or Spanish) may appear on the electronic interviewing system screen
- The survey vendor is responsible for programming the scripts and specifications into their electronic telephone interviewing system software or an alternative system
 - The transitional statements found throughout the telephone script are part of the structured script and must be read. An example of a transitional phrase that must be read can be found before Question 39 (Q39 Intro): “Please answer the following questions about your family member’s care from [ABC Hospice]. Do not include care from other hospices in your answers.”
 - Do not program a specific response category as the default option

Survey vendors must have a process in place to address caregivers’ requests to verify the survey legitimacy or to answer questions about the survey.

Supplemental Questions

Survey vendors may add up to 15 hospice-specific supplemental questions to the CAHPS Hospice Survey following the guidelines described below:

- For Mixed Mode, the same survey questions added to the mail survey for a given hospice must be added to the telephone CATI script
- Hospice-specific supplemental questions are added immediately after the Core CAHPS Hospice Survey questions (Questions 1 – 40) or at the end of all the CAHPS Hospice Survey questions (Questions 1 – 47)
 - When supplemental questions are placed in between the Core questions and the “About Your Family Member” questions, the “ABOUT YOUR FAMILY MEMBER” heading must still be placed prior to the “About Your Family Member” questions

- When adding supplemental questions after the “About You” questions a transition phrase must be placed before the supplemental questions
- Phrases must be added to indicate a transition from the CAHPS Hospice Survey questions to the hospice-specific supplemental questions, regardless of whether the supplemental questions are placed between the Core questions and the “About Your Family Member” questions and/or after the “About You” questions. Examples of transitional phrases are as follows:
 - *“Now we would like to gather some additional detail on topics we have asked you about before. These items use a somewhat different way of asking for your response since they are getting at a slightly different way of thinking about the topics.”*
 - *“The following questions focus on additional care your family member may have received from Hospice X.”*
 - *“This next set of questions is to provide the hospice additional feedback about your family member’s hospice care.”*

In addition, one supplemental question must be included in the telephone questionnaire **if** the hospice wishes to view the survey responses linked to respondents’ name and other identifying information. The survey question, referred to as the Consent to Share Responses, must be included in the telephone script. The respondent must answer “Yes” for the vendor to provide the hospice with the respondent’s answers linked to the respondent’s name and identifying information. The question is typically placed at the end of the interview.

Survey vendors must avoid the following types of hospice-specific supplemental questions that:

- pose a burden to the respondent (e.g., number, length, and complexity of supplemental questions, etc.)
- may affect responses to the CAHPS Hospice Survey
- may cause the caregiver to terminate the survey (e.g., items that ask about sensitive medical, health or personal topics, etc.)
- jeopardize decedent/caregiver confidentiality (other than the “Consent to Share Responses” item above)
- ask the caregiver to explain why he or she chose a specific response; for example, it is not acceptable to ask caregivers why they indicated that they would not recommend the hospice to friends and family

Interviewing Systems

Telephone data collection must be computer-assisted using live interviewers. Paper survey administered by phone and the use of Touch-tone or Speech-enabled IVR are not acceptable. Therefore, an electronic telephone interviewing system **is required for survey vendors**. An electronic telephone interviewing system uses standardized scripts and design specifications. The survey vendor is responsible for programming the scripts and specifications into their electronic telephone interviewing software. Regardless of caregiver response, the interviewer must record all responses in the telephone interview. Predictive dialing may be used as long as there is a live interviewer to interact with the caregiver, and the system is compliant with Federal Trade Commission (FTC) and Federal Communications Commission (FCC) regulations.

- Survey vendors may program the caller ID to display “on behalf of [HOSPICE NAME],” with the permission and compliance of the hospice’s HIPAA/Privacy Officer. Survey vendors **must not** program the caller ID to display only [HOSPICE NAME].

Monitoring/Recording Telephone Calls

When calling caregivers who reside in California, Connecticut, Delaware, Florida, Illinois, Maryland, Massachusetts, Michigan, Montana, New Hampshire, Pennsylvania, and Washington, survey vendors may begin the monitoring/recording of telephone calls after the interviewer states, “*This call may be monitored [recorded] for quality improvement purposes.*” This statement is found at the end of the INTRO section of the CAHPS Hospice Survey Telephone Script located in Appendices O and P.

Telephone Attempts

Survey vendors must attempt to reach each and every non-respondent to the mail survey. Telephone call attempts are to be made between the hours of 9 AM and 9 PM respondent time. Repeated attempts must be made until the caregiver is contacted, found ineligible or five attempts have been made. After five attempts to contact the caregiver have been made, no further attempts are to be made. A telephone attempt is defined as one of the following:

- The telephone rings six times with no answer
- The operator reaches a wrong number
- An answering machine/voice mail is reached. In this case the interviewer must not leave a message.
- The interviewer reaches a household member and is told that the caregiver is not available to come to the telephone or has a new telephone number. The interviewer must not leave a message.
- The interviewer reaches the caregiver but is asked to call back at a more convenient time
 - The call back should be scheduled at the caregiver’s convenience, if at all possible
- The interviewer gets a busy signal during each of three consecutive telephone attempts
 - When systems permit, the three consecutive telephone attempts are to be made at approximately 20-minute intervals
- The interviewer reaches a disconnected number

If, during a telephone attempt, the sampled caregiver indicates that someone within the household is more knowledgeable about the hospice care that the decedent received, the more knowledgeable person may be a proxy respondent. If a sampled caregiver indicates that he or she never oversaw, was not involved in, or is unknowledgeable about the hospice care provided to the decedent, interviewers may ask if someone else in the household is knowledgeable about the decedent’s hospice care. If such a person exists, he or she may be a proxy respondent. Interviewers must not accept individuals outside of the sampled caregiver’s household as proxy respondents. Should no knowledgeable individual be identified within the household, the case should be coded as ineligible using code “6 – Ineligible: Never involved in decedent care.”

Sampled caregivers are to be called up to five times unless the sampled caregiver (or an eligible proxy caregiver) completes the survey, is found to be ineligible or explicitly refuses to complete the survey (or is someone refuses on behalf of the caregiver).

- If the survey vendor learns that a decedent/caregiver is ineligible for the CAHPS Hospice Survey, that caregiver **must not** receive any further telephone attempts

Survey vendors must adhere to the following guidelines in their attempts to contact caregivers:

- Telephone attempts are made at various times of the day, on different days of the week, and in different weeks to maximize the probability that the survey vendor will contact the caregivers

Note: More than one telephone attempt may be made in a week (7 calendar days). However, the five telephone attempts cannot be made in just one week (7 calendar days). The five call attempts must span more than one week to account for caregiver who are temporarily unavailable.

- Caregivers who call back after an initial contact can be scheduled for an interview or forwarded to an available interviewer
- Interviewers must not leave messages on answering machines or with household members, since this could violate a caregiver's privacy. Survey vendors must instead attempt to re-contact the caregiver to complete the CAHPS Hospice Survey.
- When a caregiver requests to complete at a later date a telephone survey already in progress, a call back should be scheduled. At the time of the call back, the interview should resume with the next question where the caregiver left off from the previous call.
- If on the fifth attempt, the caregiver requests to schedule an appointment to complete the survey, it is permissible to schedule that appointment and call the caregiver back provided that the appointment is within the 42 calendar day data collection time period. If on the call back at the scheduled time, no connection is made with the caregiver, then no further contact may be attempted. This additional (sixth) call attempt would be coded as "5 – Fifth Telephone attempt" in "Number Survey Attempts – Telephone" for data file submission.

Note: The CAHPS Hospice Survey Project Team strongly recommends that, when requested, telephone call back scheduling accommodate a caregiver's request for a specific day and time in order to ensure a reasonable response rate for the hospice.

Survey vendors take the following steps to contact difficult-to-reach caregivers:

- If the caregiver's telephone number is incorrect, make every effort to find the correct telephone number. If the person answering the telephone knows how to reach the caregiver, the new information must be used.
- If the caregiver is away temporarily, he or she must be contacted upon return, provided that it is within the data collection time period. If it is known that the caregiver may be available in the latter part of the 42 calendar day data collection time period (e.g., caregiver is on vacation the first 2 or 3 weeks of the 42 calendar day data collection time period and there would be an opportunity to reach the caregiver closer to the end of the data collection time period), then survey vendors must use the entire data collection time period to schedule telephone calls.
- If the caregiver does not speak the language in which the survey is being administered, the interviewer must thank the caregiver for his or her time and terminate the interview

- If the call is inadvertently dropped and the interview is interrupted, the caregiver should be re-contacted immediately to complete the remainder of the survey. This re-contact does not constitute an additional call attempt.

Obtaining and Updating Telephone Numbers

Survey vendors normally obtain telephone numbers from the hospice's records. Survey vendors must use commercial software or other means to update telephone numbers provided by the hospice for the sampled caregivers. Requisite attempts must be made to contact every non-respondent to the mail survey, whether or not there is a complete and correct telephone number for the caregiver when the sample is created. Survey vendors must retain a record of attempts to acquire missing telephone numbers. All materials relevant to survey administration are subject to review.

Hospices/Survey vendors should attempt to obtain updated telephone numbers prior to the start of telephone attempts through commercial locating services, Internet or other means. To obtain the most current caregiver contact information, survey vendors must employ various options for updating telephone numbers:

- Running update program software against the sample file just before or after uploading data to survey management systems
- Utilizing commercial software, Internet directories, and directory assistance

Receipt and Retention of Telephone Data

Survey vendors utilizing the Mixed Mode of survey administration must keep track of the Mode in which the survey was completed (i.e., mail or telephone). If a caregiver completed the CAHPS Hospice Survey by telephone with enough of the questions applicable to all caregivers answered for the survey to be considered a completed survey (based on the calculation of percent complete; for more information see the *Data Coding and Data File Preparation* chapter), then the survey vendor must:

- retain documentation in their survey management system that the caregiver completed the survey in the telephone phase of the Mixed Mode of survey administration
- assign the appropriate "Survey Completion Mode" in the administrative record for this decedent/caregiver (see the *Data Coding and Data File Preparation* chapter on "Survey Completion Mode" for more information)
- survey vendors must also document the telephone attempt "Number Survey Attempts – Telephone" in which the Final Survey Status is determined. For example, if the interview was conducted and finished with the caregiver on the fourth telephone attempt then the survey vendor must document the "Number Survey Attempts – Telephone" as "4 – Fourth Telephone attempt." Please see the *Data Coding and Data File Preparation* chapter for more information on coding the "Number Survey Attempts – Telephone" field.

Survey vendors must record the date of the telephone interview and must link survey responses from the telephone interview to their survey management system, regardless of the interviewing system employed. Survey vendors must maintain a crosswalk of their interim disposition codes to the CAHPS Hospice Survey Final Survey Status codes and include the crosswalk in the survey vendor's QAP.

Electronic Telephone Interviewing System

The electronic telephone interviewing systems employed by survey vendors must be electronically linked to their survey management system to enable responses obtained from the electronic telephone interviewing system to be automatically added to the survey management system.

Storage of Telephone Data

Survey vendors must retain all CAHPS Hospice Survey data collected through an electronic telephone interviewing system in a secure and environmentally controlled location for a minimum of three years.

Quality Control Guidelines for Telephone Data Collection

Survey vendors are responsible for the quality of work performed by any staff members and subcontractor(s). Survey vendors must employ the following guidelines for proper interviewer training, monitoring, and oversight regardless of whether they are using internal staff or subcontractor(s) to perform this work.

Interviewer Training

Consistent monitoring of interviewers' work is essential to achieve standardized and accurate results. Properly trained and supervised interviewers ensure that standardized, non-directive interviews are conducted. Interviewers conducting the telephone survey must be trained prior to interviewing (see Appendix G for more information on interviewing guidelines).

- Training must direct interviewers to read questions exactly as worded in the script, use non-directive probes and maintain a neutral and professional relationship with the respondent
- Interviewers must be trained to read response options exactly as worded and at an even pace without emphasis on any particular response category
- Interviewers must be trained to record responses to survey questions only after the caregiver has responded to the questions; that is, interviewers must not pre-code response choices
- In organizations where interviewers assign interim or final call disposition codes, they must be trained in the definition of each disposition code
- Interviewers must be trained in a process for redirecting calls to another interviewer when the respondent is personally known to the initial interviewer
- Distressed Respondent Procedures:

Of critical importance is the need for survey vendors to develop a "distressed respondent protocol," to be incorporated into all interviewer and help desk training. Handling distressed respondent situations requires balancing keeping personally identifying information (PII) and private health information (PHI) confidential and helping a person who needs assistance. For survey research organizations, best interviewing practices recommend having a distressed respondent protocol in place for handling distressed respondents, which balances the respondent's right to confidentiality and privacy and providing assistance, if the situation indicates that the respondent's health and safety are in jeopardy.

If a respondent experiences distress significant enough for him or her to request additional support, CMS and the CAHPS Hospice Survey Project Team recommend that survey vendors' telephone staff put the respondent in contact with the appropriate local resource (generally a bereavement counselor or social worker on the hospice team that provided care to their family member or friend). This visit and support groups for bereavement are part of the services covered under the Medicare Hospice Benefit.

Note: If the survey vendor uses a subcontractor to conduct telephone interviewing, then the survey vendor is responsible for attending/participating in the subcontractor's telephone interviewer training to confirm compliance with CAHPS Hospice Survey protocols and guidelines.

Telephone Monitoring and Oversight

Each survey vendor employing the Mixed Mode of survey administration must institute a telephone monitoring and evaluation program, during the telephone phase of the protocol. The telephone monitoring and evaluation program must include, but is not limited to, the following oversight activities:

- Survey vendors must monitor at least 10 percent of all CAHPS Hospice Survey interviews, dispositions and call attempts in their entirety (both English and Spanish) through silent monitoring of interviewers using the electronic telephone interviewing system software or an alternative system. Silent monitoring capability must include the ability to monitor calls onsite and from remote locations. All staff conducting CAHPS Hospice Survey interviews must be included in the monitoring. Additionally, it is strongly encouraged that survey vendors provide "floor rounding" in their call-center(s) to visually observe and ensure the professionalism of the telephone interviewers.
- **Survey vendors using a subcontractor must monitor at least 10 percent of the subcontractor's CAHPS Hospice Survey telephone interviews and call attempts in their entirety, provide feedback to the subcontractor's interviewers about their performance, and confirm that the subcontractor's interviewers correct any areas that need improvement. Feedback must be provided to interviewers as soon as possible following a monitoring session.**

Note: CAHPS Hospice Survey protocols currently require that approved CAHPS Hospice Survey vendors who subcontract the task of CAHPS Hospice Survey telephone interviewing monitor at least 10% of all CAHPS Hospice Survey calls/attempts/completed surveys. The CAHPS Hospice Survey Project Team also expects that a survey vendor's subcontractor will conduct internal monitoring of their telephone interviewers as a matter of good business practice that incorporates quality checks. While it is preferred that each organization continue to monitor 10% of CAHPS Hospice Survey interviews (for an overall total of 20%), it is permissible for the survey vendor and its subcontractor to conduct a combined total of at least 10% monitoring, as long as each organization conducts a portion of the monitoring. Therefore, the survey vendor and its subcontractor can determine the ratio of monitoring that each organization conducts, as long as the combined total meets or exceeds 10%. Please note that CAHPS Hospice Survey interviews monitored concurrently by the survey vendor and its subcontractor do not contribute separately to each organization's monitoring time.

- Staff who are found to be consistently unable to follow the script verbatim, employ proper probes, remain objective and courteous, be clearly understood, or operate the electronic telephone interviewing system competently must be identified and retrained or, if necessary, replaced
- In organizations where interviewers assign interim or final disposition codes, the assignment of codes must be reviewed by a supervisor
- Organizations must monitor interviewer survey response coding by, at a minimum, reviewing the frequency of missing responses in the surveys administered by interviewers

Survey vendors **must** retain a record of all quality control activities and document these activities in the survey vendor's QAP. All materials relevant to survey administration are subject to review.

Safeguarding Decedent/Caregiver Confidentiality

Survey vendors must take the following actions to further protect the confidentiality of decedents/caregivers:

- Prevent unauthorized access to confidential electronic and hard copy information by restricting physical access to confidential data (use locks or password-protected entry systems on rooms, file cabinets and areas where confidential data are stored)
- Develop CAHPS Hospice Survey or survey specific confidentiality agreements and obtain signatures from all personnel with access to survey information, including staff and all subcontractors involved in survey administration and data collection
- Confirm that staff and subcontractors are compliant with HIPAA regulations in regard to decedent/caregiver protected health information (PHI)
- Establish protocols for secure file transmission. Emailing of PHI via unsecure email is prohibited.
- Establish protocols for identifying security breaches and instituting corrective actions
- Store returned mail paper questionnaires and/or electronically scanned questionnaires in a secure and environmentally safe location for a minimum of three years

*Note: It is strongly recommended that the method used by contracted hospices to transmit information (e.g., decedents/caregivers lists) to the survey vendor be reviewed by the hospice's HIPAA/privacy officer to confirm compliance with HIPAA regulations. Any materials (e.g., QAP, questionnaires, cover letters, tracking forms) submitted by the survey vendor to the CAHPS Hospice Survey Project Team must be blank templates and **must not** contain any decedent/caregiver PHI.*

Survey vendors must have physical plant resources available to handle the volume of surveys being administered, in addition to systematic processes that effectively track sampled decedents' progress through the data collection protocol and caregivers' responses to the survey. System resources are subject to oversight activities including site visits to physical locations.

Data Coding and Data File Preparation

Overview

The CAHPS Hospice Survey uses standardized protocols for file specifications, coding and submission of data. This chapter provides information about preparing data files for submission to the CAHPS Hospice Survey Data Warehouse including requirements for assigning the random, unique, de-identified decedent/caregiver identification number; XML file specifications; coding and interpreting ambiguous or missing data elements in returned surveys; survey disposition codes; and determining the rate of response.

Random, Unique, De-identified Tracking Number

The survey vendor must assign each decedent/caregiver in the sample a random, unique, de-identified number (Decedent ID). This Decedent ID is used to follow cases through the data collection process and report whether the survey for each decedent/caregiver has been returned, or needs a repeat mailing or telephone follow-up. Any de-identified combination of up to 16 letters and numbers may be used. The Decedent ID must not include any combination of letters or numbers that can otherwise identify the decedent or caregiver. For example, the date of death (month, date and/or year), the birth date (month, date and/or year) and hospice ID number (e.g., decedent hospice record number, etc.) must not be combined in any manner to generate the Decedent ID. Each month, sampled decedents/caregivers must be assigned a new Decedent ID; numbers must not be repeated from month to month, or used in a sequential numbering order unless the decedent/caregiver list is randomized prior to the assignment of the Decedent ID.

File Specifications

The survey vendor must organize survey data into monthly files and then submit the files to the CAHPS Hospice Survey Data Warehouse either monthly or quarterly. Survey vendors are required to submit their data files to the CAHPS Hospice Survey Data Warehouse in the XML file format.

Hospices with zero survey-eligible decedents/caregivers (zero cases) in a month must still submit a CAHPS Hospice Survey Header Record.

Note: “Zero cases” submissions must not be used when hospices or survey vendors missed surveying eligible decedents/caregivers, such as when hospices do not submit their decedents/caregiver lists for the month to their survey vendor in a timely manner. In situations such as these, a Discrepancy Report must be completed and submitted.

XML File Specifications

The XML format allows a hospice’s sampled decedent/caregiver records to be submitted in one file. If a hospice’s data file contains a decedent/caregiver record that has been submitted more than once, the most recently submitted record will completely overwrite any previous record for that decedent/caregiver, and only the most recently submitted file will be stored in the data warehouse. No substitutions for valid data element values are acceptable. For the full listing of valid values, details on the XML file specifications, and for a sample XML file layout, see Appendix E.

Each XML file consists of three parts:

1. Header Record
2. Decedent/Caregiver Administrative Record
3. Survey Results Record

1. Header Record

Each monthly data file submitted by a survey vendor begins with the Header Record. The Header Record contains identification and sampling information that is applicable to every survey record in that month. The Header Record includes such variables as: hospice name; CMS Certification Number (CCN), formerly known as the Medicare Provider Number; National Provider Identifier (NPI), which is an optional field; survey mode; the total number of decedent/caregiver cases received from the hospice in the month; the number of live discharge patients reported by the hospice in the month; the number of no-publicity decedents/caregivers reported by the hospice in the month; the number of decedents/caregivers determined by the vendor to be ineligible for all other reasons in the month; the number of sampled decedents/caregivers; and sample type.

A critical component in the Header Sub-Record is the “Type of Sampling” used. See the *Sampling Protocol* chapter for information on sampling options.

Each field of the Header Record requires an entry for a valid data submission, with the exceptions of the optional “NPI;” field.

2. Decedent/Caregiver Administrative Record

The second part of the data submission file is the Decedent/Caregiver Administrative Record. This contains de-identified information on each sampled decedent/caregiver in the file including the Decedent ID; final survey status; survey completion mode, if applicable; survey received/completion date, if applicable; language in which the survey was administered or attempted to be administered; and lag time. In addition, this section should contain the following information for the decedent: date of birth, date of death, sex, race/ethnicity, primary diagnosis, admission date for final episode of hospice care, payers, last location/setting of care, and caregiver relationship to decedent. The decedent/caregiver Decedent/Caregiver Administrative Record also includes:

- The “Number Survey Attempts – Telephone” is required when “Survey Mode” in the Header Record is “2 – Telephone Only.” It is also required when “Survey Mode” in the Header Record is “3 – Mixed mode” **and** “Survey Completion Mode” is “2 – Mixed mode-phone.”
- The “Number Survey Attempts – Mail” is required when “Survey Mode” in the Header Record is “1 – Mail Only.”

A Decedent/Caregiver Administrative Record is required for each decedent/caregiver sampled for the CAHPS Hospice Survey, whether or not the caregiver responded to the survey. For successful submission of the monthly data file, each field of the Decedent/Caregiver Administrative Record must contain a valid value. Use a code for “Not Applicable” if appropriate.

3. Survey Results Record

The third part of the monthly data submission file is the Survey Results Record. This set of records contains the actual survey responses from each caregiver who responded to the CAHPS Hospice Survey.

The Survey Results Record is required only when “Final Survey Status” in the Decedent/Caregiver Administrative Record is coded either “1 – Completed Survey” or “7 – Non-Response: Break-off.” When the Survey Results Record is included, all response fields must have a valid value, which may include “M – Missing/Don’t Know” and “88 – Not Applicable.” The opening and closing <caregiverresponse> XML tags (which enclose the Survey Results Record) are not necessary when there are no survey responses to submit for a given decedent/caregiver.

- The decision on whether to key the responses to open-ended survey items, specifically, the “Other” in Question 1 (response option 9) and Question 2 (response option 6), and “Some other language” (response option 4) in Q47, is up to each individual hospice. Vendors will not be required to key and include responses to open-ended survey items on the data files submitted to the CAHPS Hospice Survey Data Warehouse. CMS, however, encourages survey vendors to review the open-ended entries so that they can provide feedback to the CAHPS Hospice Survey Project Team about adding additional preprinted response options to these survey items in the future, if needed.
- If the vendor includes the Consent to Share Responses question in the mail survey questionnaire or telephone interview, we recommend that the vendor key the response to that question. However, responses to the Consent to Share question will not be included on the data files submitted to the CAHPS Hospice Survey Data Warehouse.

Note: The Survey Results Record is not required for “Final Survey Status” of anything other than “1 – Completed survey” or “7 – Non-Response: Break-off,” however, if the Survey Results Record is included, then all fields must have a valid value.

Decision Rules and Coding Guidelines

The CAHPS Hospice Survey decision rules and coding guidelines have been developed to address situations in which survey responses are ambiguous, missing or incorrectly provided, and to capture appropriate information for data submission. Survey vendors must adhere to the following guidelines to ensure valid and consistent coding of these situations.

Mail Surveys

Survey vendors must employ the following decision rules for resolving common ambiguous situations when scanning or key-entering mail surveys in order to ensure uniformity in data coding:

- If a mark falls between two response options but is obviously closer to one than the other, then select the choice to which the mark is closest
- If a mark falls equidistant between two response options, then code the value of the item as “M – Missing/Don’t Know”
- If a value is missing, then code as “M – Missing/Don’t Know.” Survey vendors must not impute a response; in other words, do not try to determine what the caregiver would have

responded for the missing value based on answers to other questions (see information below with regard to coding skip pattern questions).

- When more than one response option is marked, code the value as “M – Missing/Don’t Know”
 - Exception: Question 2, *“In what locations did your family member receive care from this hospice? Please choose one or more.”* For Question 2, enter responses for ALL of the categories that the respondent has selected.
 - Exception: Question 43, *“What was your family member’s race? Please choose one or more.”* For Question 43, enter responses for ALL of the categories that the respondent has selected.

In instances where there are multiple marks **but** the caregiver’s intent is clear, survey vendors should code the survey with the caregiver’s **clearly identified** intended response.

CATI

When a caregiver breaks off the interview and subsequent questions aren’t asked, then use “M – Missing” to code the unanswered questions.

Survey Skip Patterns

There are several items in the CAHPS Hospice Survey that can and should be skipped by certain respondents. These items form skip patterns. Ten questions in the CAHPS Hospice Survey serve as screener questions (Questions 3, 4, 13, 15, 17, 21, 24, 26, 28, and 32) that determine whether the associated dependent questions require an answer. The following decision rules are provided to assist in the coding of caregiver responses to skip pattern questions.

Skip Patterns

- Do not correct a screener question by imputing a response based on the caregiver’s answers to the dependent questions. Enter the value provided by the caregiver.
- For mail questionnaire skip patterns
 - If the screener question is left blank, code it as “M – Missing/Don’t Know.” In this scenario, code any appropriately skipped dependent questions as “M – Missing/Don’t Know.” Do not impute responses based on how the caregiver answers questions.
 - In instances where the caregiver made an error in the skip pattern, dependent questions are coded with the response provided by the caregiver. That is, survey vendors must not “clean” or correct skip pattern errors on surveys completed by a caregiver.
 - Dependent questions that are appropriately skipped should be coded as “88 - Not Applicable”
- For CATI questionnaire skip patterns
 - In instances where the caregiver answers “I don’t know” or refuses to answer the screener question, code response option of “M – Missing/Don’t know”
 - When answer options of “M – Missing/Don’t know” are used for coding screener questions, the skip pattern should be programmed into the electronic telephone interviewing system. The resulting associated dependent questions should be coded as “88 – Not Applicable.”

- Appropriately skipped dependent questions should be coded as “88 – Not Applicable”

Note: For telephone follow-up via CATI, skip patterns should be programmed into the electronic telephone interviewing system. Coding may be done automatically by the telephone interviewing system or later during data preparation.

Header Record

- All fields in the Header Record must have a valid value entered with the exception of “NPI field.”
- Once the “Survey Mode” field has been defined for the first month in a quarter, the survey mode for the quarter can be changed by resubmitting this file **ONLY** if the data files for another month in the quarter have not yet been submitted.
- In calculating the “Eligible Sample” field, the number of survey-eligible decedents/caregivers in the sample frame in the month must not include decedents/caregivers who are determined to be ineligible or excluded, regardless of whether they are selected for the survey sample
 - “Sample Size” can therefore be larger than the “Eligible Sample”. For example, if a decedent/caregiver was selected for the survey sample and later determined to be ineligible (i.e., “Final Survey Status” code of “3 – Ineligible: Not in eligible population” or “6 – Ineligible: Never involved in decedent care”), then the decedent/caregiver must be subtracted from the number of survey-eligible decedents/caregivers in the month. However, this does NOT apply to “Final Survey Status” codes of “2 – Ineligible: Deceased,” “4 – Ineligible: Language barrier” or “5 – Ineligible: Mental/Physical incapacity.”
 - If a decedent/caregiver is not selected for the survey sample and is later determined to be ineligible, then the decedent/caregiver must be subtracted from the number of survey-eligible decedents/caregivers in the month
 - The “Eligible Sample” field must include the count of decedents/caregivers who are eligible for the CAHPS Hospice Survey
- Once the “Type of Sampling” field has been defined for the first month in a quarter, the sample type for the quarter can be changed by resubmitting this file **ONLY** if the data files for another month in the quarter have not yet been submitted
- When hospices sample 100% of the survey-eligible decedents/caregivers (i.e., a census), the “Type of Sampling” must be coded as “2 – Census Sample”

Note: Hospices with zero survey-eligible decedents/caregivers (zero cases) in a month must still submit a CAHPS Hospice Survey Header Record.

Decedent/Caregiver Administrative Record

- All fields in the Decedent/Caregiver Administrative Record must have a valid value. Use code “M – Don’t Know” for all missing fields, with the following exceptions:
 - The “language” field must be completed with the appropriate valid value indicating the survey language in which the survey was administered (English, Spanish or Chinese), even if a caregiver does not complete the survey

- Decedent/Caregiver Administrative Record information must be submitted for all decedents/caregivers selected for the survey sample, including decedents/caregivers found to be ineligible prior to survey administration
 - If a decedent/caregiver is found to be ineligible or excluded after the sample is drawn, the decedent/caregiver should be assigned a “Final Survey Status” code of “3 – Ineligible: Not in eligible population”
 - If the decedent/caregiver is selected for the CAHPS Hospice Survey and the 42-day initial contact period has lapsed prior to any contact attempt, then the decedent/caregiver should be assigned a “Final Survey Status” code of “9 – Non-Response: Non- response after maximum attempts”
- The “Survey Completion Mode” field must be submitted if the “Survey Mode” in the Header Record is “3 – Mixed mode” and the “Final Survey Status” is “1 – Completed survey” or “7 – Non-response: Break off.” For other “Final Survey Status” codes, code “Survey Completion Mode” as “88 – Not applicable.”

Note: “Survey Completion Mode” is not a required field for “Survey Mode” of “1 – Mail Only” and “2 – Telephone Only.”

- The “Number Survey Attempts – Telephone” field must be submitted when:
 - the “Survey Mode” in the Header Record is “2 – Telephone Only”
 - the “Survey Mode” in the Header Record is “3 – Mixed mode” and “Survey Completion Mode” is “2 – Mixed mode-phone”
 - the “Number Survey Attempts - Telephone” field is coded with the attempt that corresponds to the time of final survey status determination

Note: “Number Survey Attempts – Telephone” is not a required field for “Survey Mode” of “1 – Mail Only.” If this field (Number Survey Attempts – Telephone) is included with “Survey Mode” of “1 – Mail Only,” then code “Number Survey Attempts – Telephone” as “88 – Not applicable.”

- The “Number Survey Attempts – Mail” field must be submitted when:
 - the “Survey Mode” in the Header Record is “1 – Mail Only”
 - the “Number Survey Attempts – Mail” field is coded with the attempt that corresponds to the time of final survey status determination

Note: “Number Survey Attempts – Mail” is not a required field for “Survey Mode” of “2 – Telephone Only” or “3 – Mixed mode.” If this field (Number Survey Attempts – Mail)” is included with “Survey Mode” of “2 – Telephone Only” or “3 – Mixed mode” then code “Number Survey Attempts – Mail” as “88 – Not applicable.”

Note: The “Number Survey Attempts – Telephone” and the “Number Survey Attempts – Mail” fields are submitted in accordance with the requirements identified above for all CAHPS Hospice Survey Final Status Codes.

- The “Lag Time” is calculated for each decedent/caregiver in the sample and is defined as the number of days between the decedent’s date of death and the date that data collection activities ended for the decedent/caregiver
 - All surveys (i.e., “Final Survey Status” codes of 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, or M) **must contain** the actual lag time.

Note: Although a completed or break-off survey may have a lag time of as much as 140 days, survey administration must be completed within 6 weeks (42 days) of initial contact (first mailing of the mail survey or first telephone attempt).

- The following are brief illustrations of how lag time would be determined for each Final Survey Status (<survey-status> or “Disposition of survey”):
 - **Completed survey** (code 1): Lag time is the number of days between the decedent’s date of death and the receipt of a completed mail survey or the completion of a telephone survey
 - **Ineligible: Deceased** (code 2): Lag time is the number of days between the decedent’s date of death and the date it is determined that the caregiver is deceased
 - **Ineligible: Not in eligible population** (code 3): Lag time is the number of days between the decedent’s date of death and the date it is determined that the decedent/caregiver is not eligible for the CAHPS Hospice Survey
 - **Ineligible: Language barrier** (code 4): Lag time is the number of days between the decedent’s date of death and the date it is determined that a language barrier prevents the caregiver from completing the CAHPS Hospice Survey
 - **Ineligible: Mental/physical incapacity** (code 5): Lag time is the number of days between the decedent’s date of death and the date it is determined that a mental or physical incapacity prevents the caregiver from completing the CAHPS Hospice Survey
 - **Ineligible: Never involved in decedent care** (code 6): Lag time is the number of days between the decedent’s date of death and the date it is determined that the caregiver was never involved in hospice care for the decedent
 - **Non-response: Break off** (code 7): Lag time is the number of days between the decedent’s date of death and the date the caregiver “breaks off” or fails to complete the CAHPS Hospice Survey after the survey has started
 - **Non-response: Refusal** (code 8): Lag time is the number of days between the decedent’s date of death and the date the caregiver (or someone on the caregiver’s behalf) refuses to take the CAHPS Hospice Survey
 - **Non-response: Non-response after maximum attempts** (code 9): Lag time is the number of days between the decedent’s date of death and the date of the maximum attempt (Mail: non-return of the second mailing of survey; Telephone: fifth call attempt) to administer the CAHPS Hospice Survey
 - **Non-response: Bad address** (code 10): Lag time is the number of days between the decedent’s date of death and the date it is determined that the caregiver’s actual mailing address is not viable
 - **Non-response: Bad/no phone number** (code 11): Lag time is the number of days between the decedent’s date of death and the date it is determined that the caregiver’s actual telephone number is not viable

To illustrate the calculation of lag time where a caregiver did not respond to the survey, two examples are provided:

Example A: Lag Time Calculation Mail	
Mode of Survey Administration	Mail Only
Decedent Date of Death	January 15
Date of First Mail Attempt	April 1 (75 days after death)
Date of Follow-up Mail Attempt	April 22 (21 days after first mail attempt)
Date Data Collection Activities Ended for this Decedent/Caregiver	May 12 (42 days after first mail attempt) Caregiver never returned the CAHPS Hospice Survey
CAHPS Hospice Survey Final Status	Code as “9 – Non-response: non-response after maximum attempts” because the data collection protocol of 42 days has been reached and the caregiver has not returned the CAHPS Hospice Survey
Lag Time	Calculated as 117 Days (number of days between the patient’s death [January 15] to the date data collection activities ended [May 12])

Example B: Lag Time Calculation Telephone	
Mode of Survey Administration	Telephone Only
Decedent Date of Death	January 15
Date of First Attempt	April 1 (75 days after decedent death)
Date Data Collection Activities Ended for this	May 12 (42 days after the first telephone attempt)
CAHPS Hospice Survey Final Status	Code as “9 – Non-response: non-response after maximum attempts” because the data collection protocol of 42 days had ended and the caregiver had not been reached although five attempts were made
Lag Time	Calculated as 117 Days (number of days between the decedent’s death [January 15] to the date data collection activities ended [May 12])

To illustrate the calculation of lag time when a caregiver responds and completes the survey, one example is provided:

Example C: Lag Time Calculation Mail	
Mode of Survey Administration	Mail Only
Decedent Date of Death	January 15
Date of First Mail Attempt	April 1 (75 days after death)
Date of Response	April 15
CAHPS Hospice Survey Final Status	Code as “1 – Completed survey
Lag Time	Calculated as 90 Days (number of days between the patient’s death [January 15] to the date response was received [April 15])

- The “Supplemental Question Count” field must be submitted when the “Final Survey Status” is “1 – Completed survey” or “7 – Non-response: Breakoff.” The value submitted is the count of supplemental questions included in the survey for the given decedent/caregiver (whether or not the supplemental questions were asked/responded to).
- Decedent/Caregiver Administrative Record information must be submitted for all decedents/caregivers selected for the survey sample, including decedents/caregivers found to be ineligible prior to survey administration

Survey Results Record

- Enter all survey responses as provided by the caregiver for each survey item
- All survey questions must have a valid value. For “Final Survey Status” of “1 – Completed survey” or “7 – Non-Response: Break-off,” code missing answers as “M – Missing/Don’t Know” or “88 – Not Applicable.”
- For Question 41, “*What is the highest grade or level of school that your family member completed?*” if a caregiver indicates that he or she does not know the decedent’s education, the interviewer should code “<7> Respondent indicates that he or she does not know family member’s level of education.” This should not be recoded to “M – Missing/Don’t Know” in the data file.
- Caregivers may select more than one response category in Question 2, “*In what locations did your family member receive care from this hospice? Please choose one or more*” and in Question 43, “*What was your family member’s race? Please choose one or more.*”
 - Mail Survey
 - Enter **all** of the categories that the caregiver has selected. For any category not selected, enter “0.” If **no** categories are selected, enter “M – Missing/Don’t Know” for all categories.
 - Telephone Surveys
 - Enter **all** of the categories that the caregiver has selected. If the caregiver responds “Yes” to a category, enter “1.” If the caregiver responds “No” to a category, enter “0.” If the caregiver does not provide a response to any of the categories or skips the question, enter “M – Missing/Don’t Know.”

Note: A valid value must be submitted for each category in Question 2 and Question 43.

- If the same caregiver completes two surveys for the same decedent (i.e., the caregiver returns both mail surveys), the survey vendor uses the first CAHPS Hospice Survey received

Disposition of Survey Codes

Maintaining up-to-date dispositions of survey codes is a required part of the CAHPS Hospice Survey administration process. Using the random, unique, de-identified Decedent ID, the survey vendor assigns each decedent/caregiver in the sample a survey status code, which is used to track and report whether the caregiver has completed a questionnaire or requires further follow-up. Typically, survey status codes are either interim (which indicate the status of each sampled decedent/caregiver during the data collection period), or final (which indicate the final outcome of each decedent/caregiver surveyed at the end of data collection, that is – “Final Survey Status”).

Interim disposition codes are to be used only for internal tracking purposes. The data files that are submitted to the CAHPS Hospice Survey Data Warehouse must contain the CAHPS Hospice Survey final survey status codes. Interim survey status codes allow the survey vendor to calculate and report the number of completed questionnaires and the response rate at any time during the data collection period. After data collection is completed, the survey vendor assigns each sampled decedent/caregiver a final survey status code.

The following provides details on the assignment of the “Final Survey Status” field.

Code Description

1 Completed survey

Survey vendors assign a “Final Survey Status” code of “1 – Completed survey” when the caregiver answers at least 50 percent of the questions applicable to all decedents/caregivers. For detailed information on a completed survey, refer to *Definition of a Completed Survey* in this section.

2 Ineligible: Deceased

Survey vendors assign a “Final Survey Status” code of “2 – Ineligible: Deceased” when the caregiver is deceased by time of survey administration.

3 Ineligible: Not in Eligible Population

Survey vendors assign a “Final Survey Status” code of “3 – Ineligible: Not in eligible population” when there is evidence that the decedent/caregiver does not meet the following eligibility criteria:

- Decedents age 18 and over
- Decedents with death at least 48 hours following last admission to hospice care
- Decedents for whom there is a caregiver of record
- Decedents whose caregiver is someone other than a non-familial legal guardian
- Decedents for whom the caregiver has a U.S. or U.S. Territory home address

4 Ineligible: Language Barrier

Survey vendors assign a “Final Survey Status” code of “4 – Ineligible: Language barrier” when there is evidence that the caregiver does not read or speak the language in which the survey is being administered.

5 Ineligible: Mental or Physical Incapacity

Survey vendors assign a “Final Survey Status” code of “5 – Ineligible: Mental/physical incapacity” when the caregiver is unable to complete the survey because he/she is mentally or physically incapacitated. This includes caregivers who are visually/hearing impaired.

6 Ineligible: Never Involved in Decedent Care

Survey vendors assign a “Final Survey Status” code of “6 – Ineligible: Never involved in decedent care” when the answer to Question 3, “*While your family member was in hospice care, how often did you take part in or oversee care for him or her?*” is “Never” or when calling the household the sampled caregiver indicates that he/she was not involved in the patient’s hospice care and no alternative caregiver respondent resides in the household (coded “NOT INVOLVED IN CARE AND NO PROXY IDENTIFIED” on INTRO of the CATI script).

7 Non-response: Break-off

Survey vendors assign a “Final Survey Status” code of “7 – Non-response: Break-off” when a caregiver provides a response to at least one CAHPS Hospice Survey Core question, but answered too few Core questions to meet the criteria for a completed survey.

8 Non-response: Refusal

Survey vendors assign a “Final Survey Status” code of “8 – Non-response: Refusal” when a caregiver returns an incomplete survey with a note stating they do not wish to participate, or when a caregiver verbally refuses to respond to the survey. Surveys completed by a respondent outside of the sampled caregiver household are coded as “8 – Non-response: Refusal.” In the CATI survey, if a sampled caregiver disavows knowledge of the Hospice the case should be coded “8 – Non-response: Refusal.”

Note: Respondents who reside outside of the household of the sampled caregiver are not permitted. In the event that it is determined a survey has been completed by a respondent outside of the sampled caregiver household, the decedent/caregiver is assigned a “Final Survey Status” code of “8 – Non-Response: Refusal.” The survey vendor submits the decedent/caregiver administrative record but does not submit the survey responses. The survey vendor retains a copy of such a survey and any accompanying documentation. If a survey is returned with a note or someone verbally refuses on behalf of the decedent/caregiver, the vendor should code the survey as “8 – Non-Response: Refusal.”

9 Non-response: Non-response after Maximum Attempts

Survey vendors assign a “Final Survey Status” code of “9 – Non-response: Non-response after maximum attempts” when one of the following occurs:

- there is no evidence to suggest that a caregiver's contact information is bad (e.g., bad address in Mail Only methodology, bad telephone number in Telephone Only, and both bad address and bad telephone number in a Mixed mode methodology), or
- if after the maximum number of attempts (two mail attempts for Mail Only; five telephone attempts for Telephone Only; and one mail attempt and five telephone attempts for Mixed mode), the caregiver has not completed the survey by the end of the survey administration time period (i.e., 42 days from initial contact), or
- if the survey is returned by mail or completed by telephone more than 42 days from initial contact

10 Non-response: Bad Address

This disposition code applies only to the Mail Only mode. Survey vendors assign a "Final Survey Status" code of "10 – Non-response: Bad address" when there is evidence that a caregiver's address is bad (e.g., the post office returns the questionnaire to the hospice/survey vendor, etc.).

11 Non-response: Bad/No Telephone Number

This disposition code applies to the Telephone Only and Mixed modes of administration. For the Telephone Only mode, survey vendors assign a "Final Survey Status" code of "11 – Non-response: Bad/no phone number" when there is evidence that a caregiver's telephone number is bad (e.g., no telephone number available or a disconnected telephone number, etc.). For the Mixed mode, "11 – Non-response: Bad/no phone number" is used when there is evidence that a caregiver's address and telephone number are both bad.

Assigning Bad Address and/or Bad Telephone Number Disposition Codes

The "Final Survey Status" codes of "9 – Non-response after maximum attempts," "10 – Non-response: Bad address," and "11 – Non-response: Bad/no phone number" are assigned based on the viability of the address and telephone number for the caregiver. Survey vendors must track the viability of the mailing address and telephone number for each caregiver during survey administration. In general, the contact information is assumed to be viable unless there is sufficient evidence to suggest otherwise. If the evidence is insufficient, the survey vendor must continue attempting to contact the caregiver until the required number of attempts has been exhausted.

Note: Attempts must be made to contact every survey-eligible decedent/caregiver drawn into the sample, whether or not they have a complete mailing address and/or telephone number. Survey vendors have flexibility in not sending mail surveys to caregivers without mailing addresses, such as the homeless. However, survey vendors must first make every reasonable attempt to obtain a caregiver's address including re-contacting the hospice client to inquire about an address update for decedent/caregivers with no mailing address. Survey vendors must use commercial software or other means to update addresses and/or telephone numbers provided by the hospice for sampled decedent/caregivers. If the survey vendor is unsuccessful in obtaining a viable mailing address and/or telephone number, they must retain a record of their attempts to acquire the missing information. All materials relevant to survey administration are subject to review by CMS.

The following examples illustrate what constitutes sufficient or insufficient evidence of viability. For a Mail Only survey, sufficient evidence regarding the viability of a caregiver’s address includes:

- The hospice does not provide an address in the decedent/caregiver list, and the survey vendor is unable to obtain an address for the caregiver
- Mail is returned marked “Address Unknown”
- Mail is returned marked “Moved – No Forwarding Address”

For a Mail Only survey, insufficient evidence regarding the viability of a caregiver’s address includes:

- Address updating search does not result in an exact “match.” If the search does not result in an exact “match,” the survey vendor must attempt to mail using the address that is available.

For all modes of administration **except** Mail Only, sufficient evidence regarding the viability of caregiver’s telephone number includes:

- The hospice does not provide a telephone number in the decedent/caregiver list, and the survey vendor is unable to obtain a telephone number for the caregiver
- The telephone interviewer dials the caregiver’s telephone number and receives a message that the telephone number is non-working or out of order, and no updated number is available or obtained
- The telephone interviewer dials the caregiver’s telephone number, speaks to a person, and is informed that he/she has the wrong telephone number and other attempts to obtain the correct telephone number are not successful

For all modes of administration **except** Mail Only, insufficient evidence regarding the viability of a caregiver’s telephone number includes:

- The survey vendor obtains a busy signal every time a telephone attempt is made

The following table summarizes how survey vendors assign the “Final Survey Status” codes of “9 – Non-response: Non-response after maximum attempts,” “10 – Non-response: Bad address,” and “11 – Non-response: Bad/no phone number” after assessing the caregiver’s contact information for viability. Due to the nature of the information available in the three modes of survey administration, different coding rules apply for surveys administered in each mode.

Mail Only Methodology		
Assigning Final Survey Status/Disposition Codes 9, 10, and 11		
	Viable Address and No Response After Maximum Attempts	Evidence of a Bad Address
<i>Final Survey Status Code</i>	9	10

Telephone Only Methodology Assigning Final Survey Status/Disposition Codes 9, 10, and 11		
	Viable Telephone Number and No Response After Maximum Attempts	Evidence of a Bad/No Telephone Number
<i>Final Survey Status Code</i>	9	11

Mixed Mode Methodology Assigning Final Survey Status/Disposition Codes 9, 10, and 11		
	Viable Address and/or Telephone Number <u>and</u> No Response After Maximum Attempts	Evidence of Both a Bad Address and a Bad/No Telephone Number
<i>Final Survey Status Code</i>	9	11

Definition of a Completed Survey

Survey vendors should be aware that a survey can be considered “complete” for CAHPS Hospice Survey purposes even if a caregiver did not answer all items. Survey vendors assign a decedent/caregiver’s survey a “Final Survey Status” code of “1 – Completed survey” when at least 50 percent of the questions applicable to all decedents/caregivers (questions 1 – 4, 6 – 13, 15, 17, 21, 24, 26, 28, 30 – 32, and 35 – 47) are answered. Appropriately skipped questions and the following questions are not included in the calculation of percentage complete: 5, 14, 16, 18 – 20, 22, 23, 25, 27, 29, 33, and 34.

The following steps describe how to determine if a survey is completed:

Step 1 – Sum the number of questions that have been answered by the caregiver that are applicable to all decedents/caregivers

R = total number of questions answered

Step 2 – Divide the total number of questions answered by 34, which is the total number of questions applicable to all decedents/caregivers, and then multiply by 100

Percentage Complete = $(R/34) \times 100$

Step 3 – If the Percentage Complete is at least 50 percent, then assign the survey a “Final Survey Status” code of “1 – Completed survey”

Survey Response Rate

The following formula is included for informational purposes only; survey vendors are not required to perform this calculation.

$$\text{Response Rate} = \frac{\text{Total Number of Completed Surveys}}{\text{Total Number of Surveys Fielded} - \text{Total Number of Ineligible Surveys}}$$

- **Total Number of Completed Surveys** is the total number of surveys with a “Final Survey Status” of 1
- **Total Number of Surveys Fielded** is the total sample, which includes “Final Survey Status” codes of 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, and M
- **Total Number of Ineligible Surveys** is the total number of surveys with a “Final Survey Status” code of 2, 3, 4, 5, or 6

It is important to emphasize that the remaining Non-Response disposition codes (i.e., “7 – Break-off,” “8 – Refusal,” “9 – Non-response after maximum attempts,” “10 – Bad address,” and “11 – Bad/No telephone number”) are **not** removed from the denominator of the response rate calculation.

Data Submission

Overview

The CAHPS Hospice Survey will use a standardized protocol for the preparation and submission of all data. This section describes the preparation, registration, and submission of survey data files to the CAHPS Hospice Survey Data Warehouse. If any problems occur when submitting data to the CAHPS Hospice Survey Data Warehouse, the CAHPS Hospice Survey Data Coordination Team can be reached by sending an email message to cahphospicetechsupport@rand.org.

Data Submission Process

The CAHPS Hospice Survey Data Coordination Team has developed a secure data warehouse hosted by the RAND Corporation. This data warehouse will operate as a secure file transfer system that survey vendors will use to submit survey data to CMS and where survey vendors and hospices may review CAHPS Hospice Survey Data Submission Reports. Use of the CAHPS Hospice Survey Data Warehouse for data submission does not require installation of special software or a licensing fee on the part of survey vendors, except for the purchase of PGP for file encryption. The interface for the data warehouse is user friendly and will require minimal training.

Data File Submission Dates

As previously specified in this manual, survey vendors are required to submit data quarterly. Survey vendors may submit an interim data file prior to the final submission date. Submitting an interim data file will provide survey vendors an opportunity to test the data submission process and correct any data file errors/problems before they have to submit the final data file and correct any data file errors/problems.

Note: Survey vendors may submit interim data any time during the quarter; however, a fully correct data file must be submitted by 11:59 PM Eastern Time on the required submission date.

Survey Vendor Authorization Process

Hospices must submit documentation to the CAHPS Hospice Survey Data Coordination Team authorizing survey vendors to collect and submit data on their behalf before survey vendors can access the data submission application hosted by RAND. Upon receipt of the CAHPS Hospice Survey Vendor Authorization Form (see Appendix B), the CAHPS Hospice Survey Data Coordination Team will confirm the authenticity of the authorizing entity verifying contact information at both the hospice and survey vendor level. Only then will the survey vendor be contacted and provided an account for the CAHPS Hospice Survey Data Warehouse.

Preparation for Data Submission

As mentioned earlier in this manual, each survey vendor participating in the CAHPS Hospice Survey is required to designate a primary Data Administrator within their organization responsible for submitting survey data to the CAHPS Hospice Survey Data Warehouse on behalf of hospice clients. In addition to the primary Data Administrator, each survey vendor must designate a second person within the organization to act as the Back-up Data Administrator who

will also have access to the CAHPS Hospice Survey Data Warehouse. The Data Administrator will be designated as the main point of contact between the CAHPS Hospice Survey Data Coordination Team and the survey vendor regarding issues related to uploading files to the CAHPS Hospice Survey Data Warehouse. In addition, the Data Administrator will have primary responsibility for ensuring that the survey vendor follows procedures for preparing and submitting survey data according to CMS requirements as outlined in this manual. The CAHPS Hospice Survey Data Coordination Team must be notified of any personnel changes to the survey vendor's Data Administrator role. The new Data Administrator will be required to create a new password for the survey vendor's CAHPS Hospice Survey Data Warehouse account.

The CAHPS Hospice Survey Data Warehouse allows for data submission by vendors and review of data submission reports by both hospices and vendors. Hospices may designate an individual within their organization who will have access to CAHPS Hospice Survey Data Submission Reports. The CAHPS Hospice Survey Data Coordination Team must be notified of any personnel changes to the hospice's designee. The new designee will be required to create a new password for the hospice's CAHPS Hospice Survey Data Warehouse account.

Each survey vendor's Data Administrator, as well as the Back-up Administrator and the hospice designee, will be required to register with the CAHPS Hospice Survey Data Coordination Team by completing a CAHPS Hospice Survey Data Warehouse Access Form (see Appendix D) and emailing or faxing it to the CAHPS Hospice Survey Data Coordination Team. Once the CAHPS Hospice Survey Data Coordination Team has verified the information on the form and, for survey vendors, confirmed that a survey vendor has been authorized by one or more hospice contracts to submit data on their behalf, unique ID and passwords will be assigned (created by the CAHPS Hospice Survey Data Coordination Team). The CAHPS Hospice Survey Data Coordination Team will contact each survey vendor or hospice designee by telephone to communicate the password by speaking directly to the designated individual. The passwords will not be transmitted through email, Internet or other electronic methods and will not be left on voice mail.

The CAHPS Hospice Survey Data Coordination Team will copy the Data Administrator, Back-up Data Administrator and the hospice designee on all email communications related to the data warehouse on data submission.

Survey File Submission Naming Convention

In submitting CAHPS Hospice Survey data files, survey vendors must use the following file naming convention:

Vendorname.submissionN.mmddyy.txt.pgp

Where

N = number within day to count the number of submissions; can be any number of characters. If more than one submission is made on the same day this number must be different for each submitted file.

mm = number of month of submission (justify leading zero)

dd = day of the month of submission (justify leading zero)

yy = 2 digit year of submission

Example: XYZResearch.submission1.051514.txt.pgp

Notes:

- *Survey vendors must submit all records for all decedents/caregivers in a single file*
- *Files submitted must include a record for every decedent/caregiver in the CAHPS Hospice Survey sample frame file (for the interim data submission, the record for a decedent/caregiver for whom the vendor has not yet completed a survey must be coded with disposition code “33 – No response collected”)*

Password Authentication

Upon successful authentication of the survey vendor’s or hospice designee’s username and password, users will have access to their organization’s designated folder in the CAHPS Hospice Survey Data Warehouse. Survey vendors and hospice designees will be provided instructions for re-authenticating their password, including the requirements and recommended guidelines for creating a password (passwords must be at least 7 characters in length and contain at least one character from 3 of the 5 classes of characters: uppercase letters, lowercase letters, digits, punctuation or symbols).

Organization of the CAHPS Hospice Survey Data Warehouse

Vendors will upload data files to a secure CAHPS Hospice Survey Data Warehouse at the RAND Corporation. Each survey vendor will have its own folder in the CAHPS Hospice Survey Data Warehouse and won’t be able to see, locate, or access another survey vendor’s folder. Hospices will have its their own folders in the CAHPS Hospice Survey Data Warehouse and won’t be able to see, locate, or access survey vendors’ or other hospices’ folders. Documents and files of interest to all vendors and hospices will be placed in the top level folder of the CAHPS Hospice Survey Data Warehouse and will be visible and available for download by any authorized user of the CAHPS Hospice Survey Data Warehouse.

File Encryption

All survey vendors must adhere to file format specifications and, as an additional security precaution, are required to encrypt survey data files using PGP software (www.pgp.com) prior to submitting files to the CAHPS Hospice Survey Data Warehouse. PGP is a widely used, commercially available data encryption computer program that provides cryptographic privacy and authentication for data communication. Each survey vendor is responsible for purchasing a PGP license if they do not already use PGP.

Files must be encrypted using the CAHPS Hospice Survey PGP Public Key before they are uploaded to the CAHPS Hospice Survey Data Warehouse. The CAHPS Hospice Survey Data Coordination Team will provide all survey vendors with the PGP Public Key by placing a copy of the Public Key in the top level folder of the CAHPS Hospice Survey Data Warehouse. Data files submitted to the CAHPS Hospice Survey Data Warehouse that are not encrypted will be rejected and must be resubmitted.

Any file uploaded to the survey vendor’s folder that does not have the “.pgp” extension, indicating the prescribed PGP encryption, will be quarantined and automatically deleted. An

automated email will be sent to the survey vendor's data administrator and backup data administrator, informing them they have uploaded a file that does not comply with the established naming standards and that the file therefore will not be processed and will need to be resubmitted correctly. The CAHPS Hospice Survey Data Coordination Team will also be notified by automated email that the event occurred.

Instructions for Accessing the CAHPS Hospice Survey Data Warehouse

Refer to Appendix C for detailed instructions for survey vendors and hospices on accessing the CAHPS Hospice Survey Data Warehouse. In brief, the process is as follows:

1. The Data Administrator will receive an email from the CAHPS Hospice Survey Data Coordination Team with an invitation to the CAHPS Hospice Survey Data Warehouse. This email will contain a link that will allow the Data Administrator to login to the CAHPS Hospice Survey Data Warehouse.
2. After clicking the link the Data Administrator will be routed to the login page where he/she will be prompted for his/her user ID and a password
3. On the first login only, the Data Administrator will be presented with a page to change his/her password
4. Once the password has been updated, the Data Administrator will be transferred to the File Manager tab of the CAHPS Hospice Survey Data Warehouse
5. Selecting the workspace name link in the File Manager tab will allow the user to Download and Add Files

Note: These instructions should be followed for each authorized user of the CAHPS Hospice Survey Data Warehouse.

Data Auditing and Validation Checks

The CAHPS Hospice Survey Data Coordination Team will audit the data files as they are submitted by survey vendors for compliance with the file specifications outlined in the chapter on Data Coding and Data Preparation in this manual.

The data audit process conducted by the CAHPS Hospice Survey Data Coordination Team involves conducting various data checks of the survey data submitted by survey vendors. The first check will be integrated into the CAHPS Hospice Survey Data Warehouse and involves testing for the appropriate file extension .pgp to indicate that a survey file has been encrypted. As described above, any file uploaded to the CAHPS Hospice Survey Data Warehouse that does not have the “.pgp” extension will be automatically deleted. In such instances, an automated email will be sent to the survey vendor's Data Administrator and Back-up Data Administrator informing them that they have uploaded a file that does not comply with the established naming standards, and that the file will not be processed; and therefore, needs to be resubmitted correctly. Properly encrypted files will receive additional edit checks on submitted data files, including:

- Morphological tests (appropriate character set, naming conventions, etc.)
- Checks for the presence of required data fields
- Range checks of data fields

Survey vendors (Data Administrator and Back-up Data Administrator) and hospices will receive a second email that contains the full detail of the edit check report by 8:00 PM Eastern Time on the next business day after submission. If the submitted data file fails the edit checks described above, the email notification to survey vendors and hospices will indicate that they are required to resubmit a corrected survey data file and will include details of the discrepancies found during the edit checking. If the data file they submitted passes the edit checks, the email notification will indicate that no additional action is required and will include a summary of the submitted data file for vendor verification. Survey vendors are responsible for submitting a corrected file by the deadline for submission. Survey vendors and hospices will receive emailed reports until their entire dataset has passed all edit checks.

Data Submission Reports

Three CAHPS Hospice Survey Data Submission Reports are accessible by hospices and survey vendors. The reports will contain information related to each data submission as well as a summary of submissions for each hospice. The reports and content are as follows:

- **Survey Status Summary Report** – includes the number of surveys submitted for a hospice for each month in the submission quarter. This report lists the accepted administrative data records (which includes the number of respondents and non-respondents to the survey) and the accepted survey results records (which includes only the respondents to the survey).
- **Data Submission Detail Report** – includes the upload date and status of files (accepted or rejected) under a given Batch ID, and lists Decedent IDs and any error codes with messages.
- **Review and Correction Report** – contains the frequency of valid values submitted for a hospice for each month in the submission quarter. Hospices/survey vendors are strongly encouraged to review this report for possible data errors.

Data Submission Reports for hospices will include information only for their hospice; reports for survey vendors will include information for all hospices for which they submit data.

Note: All hospices should review the Survey Status Summary and Data Submission Detail reports on a regular basis.

Oversight Activities

Overview

In order to verify compliance with CAHPS Hospice Survey protocols, the CMS-sponsored CAHPS Hospice Survey Project Team conducts oversight of participating survey vendors. This chapter describes the oversight activities for the CAHPS Hospice Survey. All materials and procedures relevant to survey administration are subject to review. **Signing the CAHPS Hospice Survey Participation Form signifies agreement with all of the Rules of Participation, including all CAHPS Hospice Survey oversight activities.**

Oversight Activities

Survey vendors are required to participate in CAHPS Hospice Survey oversight. The purpose of the oversight activities is to ensure that approved survey vendors follow the CAHPS Hospice Survey administration protocols; and thereby, ensure the comparability of CAHPS Hospice Survey data across hospices. These oversight activities include but are not limited to the following:

➤ CAHPS Hospice Survey Model QAP

The CAHPS Hospice Survey Model QAP is a comprehensive working document that is developed, and periodically revised, by survey vendors in order to document their current processes for the administration of the CAHPS Hospice Survey and correct implementation of standard protocols. The QAP should also be used as a training tool for project staff and subcontractors. The CAHPS Hospice Survey Project Team will review survey vendor QAPs to ensure that the survey vendor's stated processes are compliant with CAHPS Hospice Survey protocols. Any approved Exception Requests must be thoroughly discussed in the QAP. In addition, materials relevant to the CAHPS Hospice Survey administration, including mailing materials (e.g., cover letters and questionnaires) and/or telephone scripts and interviewer screen shots are required to be submitted for each approved mode of survey administration. CMS may also request additional survey-related materials for review as needed.

➤ Analysis of Submitted Data

All survey data submitted to the CAHPS Hospice Survey Data Warehouse by survey vendors are reviewed by the CAHPS Hospice Survey Data Coordination Team. This review includes, but is not limited to, statistical and comparative analyses; preparation of data for reporting; and other activities as required by CMS. If data anomalies are found, this will result in follow-up with the survey vendor.

➤ Site Visits/Conference Calls

All survey vendors (and their subcontractors, as applicable) are required to participate in site visits and/or conference calls conducted by the CAHPS Hospice Survey Project Team. The site visits allow the CAHPS Hospice Survey Project Team to review and observe systems, procedures, facilities, resources, and documentation related to administering the CAHPS Hospice Survey. The conference calls allow the CAHPS Hospice Survey Project Team to discuss issues with the survey vendor related to administration of the CAHPS Hospice Survey.

➤ Additional Activities

Additional activities as specified by CMS may be conducted in addition to the above.

Note: If the site visit/conference call, or any other oversight activity conducted by the CAHPS Hospice Survey Project Team, suggests that actual survey processes differ from CAHPS Hospice Survey protocols, immediate corrective actions may be required and sanctions may be applied.

CAHPS Hospice Survey Model Quality Assurance Plan (QAP)

Survey vendors approved to administer the CAHPS Hospice Survey are obligated to develop and continually update a QAP. The QAP is a comprehensive working document that outlines the survey vendor's implementation of, and compliance with, the CAHPS Hospice Survey guidelines. The main purposes of the Model QAP are as follows:

- Provide documentation of survey vendors' understanding, application and compliance with the *CAHPS Hospice Survey Quality Assurance Guidelines*. The following components must be addressed:
 1. Organizational background and structure for project
 2. Work plan for survey administration
 3. Role of subcontractor(s), if applicable
 4. Survey and data management system
 - Include a detailed description of the following:
 - For Telephone Only and the Telephone component of Mixed Mode, how interviewers redirect the call when the respondent is personally known by the initial interviewer
 5. Quality Controls for survey administration activities
 6. Confidentiality, privacy and security procedures in accordance with HIPAA
 7. Annual reporting of the results from quality control activities
 8. CAHPS Hospice Survey materials
- Serve as the organization-specific guide for administering the CAHPS Hospice Survey, training project staff to conduct the survey and conducting quality control and oversight. **The QAP should be developed in enough step-by-step detail, including flow charts, tracking forms and diagrams, such that the survey methodology is easily replicable by a new staff member assigned to the organization's survey operations.**
- Ensure high quality data collection and continuity in survey processes

The QAP should provide sufficient detail so that the project team can determine the survey vendor's adherence to survey administration guidelines and that rigorous quality checks or controls have been put in place.

The CAHPS Hospice Survey Project Team will notify survey vendors of the due date to submit a QAP to the CAHPS Hospice Survey Project Team. All QAPs must be dated and all changes from prior versions must be clearly identified (i.e., use Microsoft Word track changes).

Along with the QAP, survey vendors may be required to submit other materials relevant to the CAHPS Hospice Survey administration, when requested by CMS. The CAHPS Hospice Survey Project Team's **acceptance** of a submitted QAP and corresponding survey materials **does not** constitute or imply approval or endorsement of the survey vendor's CAHPS Hospice Survey administration processes.

The Model QAP can be found in Appendix H. It is required that survey vendors use the Model QAP as a template for developing and updating their own QAP. The Model QAP can be downloaded from the CAHPS Hospice Survey Web site (www.hospicecahpsurvey.org).

Analysis of Submitted Data

The CAHPS Hospice Survey Data Coordination Team reviews and analyzes all survey data submitted to the CAHPS Hospice Survey Data Warehouse in order to ensure the integrity of the data. If significant issues are identified, the survey vendor may be contacted. Survey vendors must adhere to all submission requirements as specified in the *CAHPS Hospice Survey Quality Assurance Guidelines V1.0*; posted on www.hospicecahpsurvey.org, as well as the deadline dates as posted on the CAHPS Hospice Survey Web site. Please monitor the CAHPS Hospice Survey Web site for additional data submission information and updates.

Site Visits/Conference Calls

The CAHPS Hospice Survey Project Team will conduct site visits and/or conference calls with survey vendors to verify compliance with the CAHPS Hospice Survey protocols. The size and composition of the review team will vary.

The CAHPS Hospice Survey Project Team conducts its site reviews in the presence of the survey vendor's staff, and a confidentiality agreement is signed by all parties at the start of the site visit. The CAHPS Hospice Survey Project Team works with the visited organization to cover agenda items presented in advance to the survey vendor. The CAHPS Hospice Survey Project Team may also review any additional information or facilities determined to be necessary to complete the site visit, including work performed by subcontractors, if applicable. **Survey vendors must make their subcontractors available to participate in the site visits and conference calls.**

In addition to other activities, the CAHPS Hospice Survey Project Team will observe and review data systems and processes, which may require access to confidential records and/or protected health information. The site review includes a review of sampling procedures. The survey vendor must retain CAHPS Hospice-related Survey data files, including decedents/caregivers lists and de-identified electronic data files (e.g., CAHPS Hospice Survey sampling frame) for three years. The CAHPS Hospice Survey Project Team will review specific data records and trace the documentation of activities from the receipt of the decedent/caregiver list through the uploading of the data to the CAHPS Hospice Survey Data Warehouse. The Project Director/Project Manager at a minimum must be physically present during the site visit. The site review may also include interviews with key staff members and interactions with project staff and subcontractors, if applicable. Any information observed or obtained during the site visit review will remain confidential, as per CMS guidelines. After the site visit, the CAHPS Hospice Survey Project Team will provide the survey vendor with a summary of findings from the site visit, and may pose follow-up questions and/or request additional information as needed.

Site visits may be announced and scheduled in advance, or they may be unannounced. Survey vendors will be given a three-day window during which an unannounced site visit may be conducted.

During the site visit and/or conference call, the CAHPS Hospice Survey Project Team will review the survey vendor's survey systems and will assess protocols based upon the *CAHPS Hospice Survey Quality Assurance Guidelines*. All materials relevant to survey administration will be subject to review. The systems and program review includes, but is not necessarily limited to:

- Survey management
- Staff training
- Data systems
- Sampling procedures
- Printed materials
- Printing, mailing and other related facilities
- Telephone materials, interview areas and other related facilities
- Telephone interviews
- Data receipt and entry
- Storage facilities
- Confidentiality, privacy and security
- Written documentation of survey processes
- Specific and/or randomly selected records covering a time period to include the data in the most recent report period, or earlier

After the site visit or conference call, survey vendors will be given a defined time period in which to correct any problems and provide follow-up documentation of corrections for review. Survey vendors will be subject to follow-up site visits and/or conference calls, as needed.

Non-compliance and Sanctions

Non-compliance with CAHPS Hospice Survey protocols including program requirements, timely submission of the QAP as requested, and participation and cooperation in oversight activities, may result in sanctions being applied to a survey vendor including:

- increased oversight activities
- loss of approved status to administer the CAHPS Hospice Survey
- other sanctions as deemed appropriate by CMS

Note: Hospices that contract with a survey vendor should be aware that non-compliance by either hospices or survey vendors could result in these, or other, sanctions.

Exception Request Process

Overview

The exception request process and Exception Request Form have been established to handle alternative methodologies that vary from standard CAHPS Hospice Survey protocols. The proposed alternative methodology(ies) must not be implemented until the submitted Exception Request Form has been approved.

Exception Request Process

The Exception Request process has been created to provide survey vendors with more flexibility to meet individual organizations' need for certain variations from protocol, while still maintaining the integrity of the data for standardized reporting. The Exception Request Form must be completed with sufficient detail, including clearly defined timeframes, for the CAHPS Hospice Survey Project Team to make an informed decision. The requested exception from protocol must not be implemented prior to receiving approval from the CAHPS Hospice Survey Project Team.

- Exception Requests will be limited to a two-year approval timeframe. The two-year time period will begin from the date of approval.

To request an exception, survey vendors are required to complete and submit an Exception Request Form online via the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org). The form is designed to capture information on the proposed alternative to the standard protocol(s). Hospice CCNs (formerly known as Medicare Provider Numbers [MPNs]) **must be included on the form.**

- Survey vendors must complete and submit all Exception Request Forms on behalf of their client hospice(s)
- Survey vendors may submit one Exception Request Form on behalf of multiple hospices with the same exception request. Survey vendors must include a list of contracted hospices and each hospice CCN on whose behalf they are submitting the exception request. Please be sure to include the information in the specified section of the Exception Request Form.
- A new Exception Request Form must be submitted for hospices not included in the original request.

Exception Request Category

Survey vendors must request an exception for alternative strategies not identified in the *CAHPS Hospice Survey Quality Assurance Guidelines V1.0* manual

Note: No alternative modes of survey administration will be permitted other than those prescribed for the survey (Mail Only, Telephone Only, and Mixed [mail with telephone follow-up] Modes).

Review Process

The Exception Request will be reviewed by the CAHPS Hospice Survey Project Team. These reviews will include an assessment of the methodological soundness of the proposed alternative and the potential for introducing bias. Depending on the type of exception, a review of procedures and/or a site visit or conference call may be required. The CAHPS Hospice Survey Project Team will notify survey vendors whether or not their exception has been approved. If the request is not approved, the CAHPS Hospice Survey Project Team will provide an explanation. Survey vendors then have the option of appealing the decision.

Survey vendors have five business days from the date of the Exception Request denial notification email to submit an appeal. To request an appeal, survey vendors must resubmit the Exception Request Form (checking the box marked “Appeal of Exception Denial”) and provide further information that addresses the explanation for the denial. The appeal is then submitted to the CAHPS Hospice Survey Project Team for re-review. The second review will take approximately 10 business days.

Discrepancy Report Process

Overview

The discrepancy process and the Discrepancy Report Form have been established for use by survey vendors to notify the CAHPS Hospice Survey Project Team of any discrepancies in following standard CAHPS Hospice Survey protocols. Survey vendors are required to notify the CAHPS Hospice Survey Project Team of any discrepancies in following the standard CAHPS Hospice Survey protocols which have been encountered during survey administration. Survey vendors **must** notify the CAHPS Hospice Survey Project Team as soon as the discrepancy is identified.

Discrepancy Report Process

On occasion, a survey vendor may identify discrepancies from CAHPS Hospice Survey protocols that require corrections to procedures and/or electronic processing to realign the activity to comply with CAHPS Hospice Survey protocols. Survey vendors are required to notify CMS of these discrepancies. In its oversight role, the CAHPS Hospice Survey Project Team may also identify discrepancies that require correction. Examples of discrepancies include, but are not limited to, missing survey-eligible decedents/caregivers from a particular month, or computer programming that caused an otherwise survey-eligible decedent/caregiver to be excluded from the sample frame.

- Survey vendors must complete and submit all Discrepancy Reports on behalf of their client hospices
- Survey vendors are required to complete and submit a Discrepancy Report to formally notify CMS immediately upon discovery of the discrepancy. The Discrepancy Report Form must be submitted online via the CAHPS Hospice Survey Web site (www.hospicecahpsurvey.org). This report notifies the CAHPS Hospice Survey Project Team of the nature, timing, cause, and extent of the discrepancy, as well as the proposed correction and timeline to correct the discrepancy. Hospice CCNs (formerly known as Medicare Provider Numbers [MPNs]) must be included on the form.

Discrepancy Report Review Process

The Discrepancy Report will be thoroughly reviewed by the CAHPS Hospice Survey Project Team, to assess the actual or potential impact of the discrepancy on reported CAHPS Hospice Survey results. Notification of the outcome of the review may not be forthcoming until all the data for the affected reporting periods have been submitted and reviewed, and the impact of the discrepancy has been ascertained. Email notification will be distributed to the organization submitting the Discrepancy Report once the outcome of the review has been determined.

Depending on the nature and extent of the discrepancy, a formal review of the survey vendor's procedures, and/or a site visit or conference call may be conducted. The CAHPS Hospice Survey Project Team will notify survey vendors if additional information is required to document and correct the issue.

Data Quality Checks

Overview

Survey vendors must implement quality assurance processes to verify the integrity of the collected and submitted CAHPS Hospice Survey data. This chapter describes suggested quality check activities that survey vendors may implement, and should not be considered an exhaustive list of possible quality check activities that can be used by survey vendors. It is important to note that quality check activities must be performed by a different staff member than the individual who originally performed the specific project task(s). The goals of conducting quality check activities are to minimize the probability of errors occurring in the handling of the data throughout the various steps of data processing; to verify that required fields are present and protocols are met; and to identify and explain unusual or unexpected changes in the data files. Therefore, quality checks must be operationalized for all of the key components or steps of survey administration and data processing.

Traceable Data File Trail

Survey vendors should save both original and processed CAHPS Hospice Survey data files. This allows for easier identification of issues. The information below provides suggestions regarding CAHPS Hospice Survey related file retention:

- Preserve a copy of every file received in original form and leave unchanged (including files received from hospice clients)
- Institute version controls for datasets, reports, and any software code and programs used for collecting and processing CAHPS Hospice Survey data records
 - Do not delete old data files
 - Keep intermediate data files, not just original and final versions

Review of Data Files

Survey vendors should examine their own data files and all clients' data files for any unusual or unexpected changes, including missing data. Trending or comparing data elements for individual hospices over different time periods is one technique that can be used to determine whether any unusual or unexpected changes have occurred. Listed below are suggested activities:

- Investigate data for notable changes in the counts of decedents/caregivers. Prior to processing the decedents/caregivers list, run frequency/percentage tables for all administrative variables received from the hospice, and compare to same-variable tables from previous months. If notable differences are discovered, investigate to determine the reason for the differences.
 - Look for missing administrative data elements, and follow-up with the hospice immediately upon receipt of the decedents/caregivers list
- Prior to preparing data files for submission to the CAHPS Hospice Survey Data Warehouse, run frequency/percentage tables for all survey variables stored for a given hospice and month. Compare to same-variable tables from previous months; if notable differences are found, investigate and determine if the data are accurate.
 - Verify that the number of administrative records matches the value for sample size for the given month

- Check that header record variables match back to raw data summary statistics for the time period
 - Review a random selection of administrative records as a quality check against original raw decedent/caregiver data. This same activity can be performed for actual survey records.
- Verify that required data elements for all decedents/caregivers in the CAHPS Hospice Survey sample frame are submitted to the CAHPS Hospice Survey Data Warehouse

Appendix A

CAHPS[®] Hospice Survey Minimum Business Requirements

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix A

CAHPS[®] Hospice Survey Minimum Business Requirements

A survey vendor must meet **ALL** of the Survey Vendor Minimum Business Requirements. In addition, subcontractors performing major CAHPS Hospice Survey administration functions (e.g., mail/telephone operations) must also meet all of the CAHPS Hospice Survey Minimum Business Requirements that pertain to that role. The minimum business requirements for an organization to become approved to administer the CAHPS Hospice Survey are as follows:

Relevant Survey Experience:

Criteria	Survey Vendor
Number of Years in Business	➤ Minimum four years
Number of Years Conducting Surveys in the Requested Mode	➤ Minimum three years in conducting surveys in the selected mode(s) of administration
Number of Years Conducting Patient-Specific Surveys	➤ Minimum two years conducting patient-specific surveys as an organization
Sampling Experience	➤ Two years prior experience selecting random sample based on specific eligibility criteria: <ul style="list-style-type: none">• Work with contracted client(s) to obtain patient data for sampling via HIPAA-compliant electronic data transfer processes• Adequately document sampling process• Survey vendors are responsible for conducting the sampling process and must not subcontract this activity

Survey Capability and Capacity:

Criteria	Survey Vendor
Personnel	<ul style="list-style-type: none"> ➤ Designated CAHPS Hospice Survey personnel: <ul style="list-style-type: none"> • Project Director with minimum two years prior experience conducting patient-specific surveys in the requested mode • Staff with minimum one year prior experience in sample frame development and sample selection • Programmer (subcontractor designee, if applicable) with minimum one year prior experience receiving large encrypted data files in different formats/software packages electronically from an external organization; processing survey data needed for survey administration and survey response data; preparing data files for electronic submission; and submitting data files to an external organization • Call Center/Mail Center Supervisor (subcontractor designee, if applicable) with minimum one year prior experience in role ➤ Have appropriate organizational back-up staff for coverage of key staff ➤ Volunteers are not permitted to be involved in any aspect of the CAHPS Hospice Survey administration process
Physical Plant and System Resources	<ul style="list-style-type: none"> ➤ Physical plant resources available to handle the volume of surveys being administered, including computer and technical equipment: <ul style="list-style-type: none"> • A secure commercial work environment • Home-based or virtual interviewers cannot be used to administer the CAHPS Hospice Survey nor may conduct any survey administration processes • Physical facilities and electronic equipment and software to collect, process, and report data securely • If offering telephone surveys, must have the equipment, software and facilities to conduct CATI interviews and to monitor interviewers ➤ Electronic or alternative survey management system to: <ul style="list-style-type: none"> • Track fielded surveys throughout the protocol, avoiding respondent burden and losing respondents • Assign random, unique, de-identified identification number (Tracking ID) to track each sampled patient/primary informal caregiver (i.e., family member or friend of the hospice patient) ➤ Organizations that are approved to administer the CAHPS Hospice Survey must conduct all of their business operations within the United States. This requirement applies to all staff and subcontractors. ➤ All System Resources are subject to oversight activities, including site visits to physical locations

Criteria	Survey Vendor
Sample Frame Creation	<ul style="list-style-type: none"> ➤ Two years prior experience selecting random sample based on specific eligibility criteria: <ul style="list-style-type: none"> • Generate the sample frame data file that contains all individuals who meet the eligible population criteria • Draw random sample of individuals for the survey, who meet the eligible population criteria
Mail Administration	<ul style="list-style-type: none"> ➤ Mail survey administration activities are not to be conducted from a residence, nor from a virtual office ➤ Obtain and update addresses of sampled patients/primary informal caregivers ➤ Produce and print professional quality survey instruments and materials according to guidelines; a sample of all mailing materials must be submitted for review ➤ Merge and print sample name and address on personalized mail survey cover letters and print unique Tracking ID on the survey questionnaire ➤ Mail out of survey materials ➤ Receive and process (key-entry or scanning) completed questionnaires ➤ Track and identify non-respondents for follow-up mailing ➤ Assign final survey status codes to describe the final result of work on each sampled case
Telephone Administration	<ul style="list-style-type: none"> ➤ Telephone interviews are not to be conducted from a residence, nor from a virtual office ➤ Obtain, verify and update telephone numbers ➤ Develop computer programs for electronically administering the survey (CATI) ➤ Collect telephone interview data for the survey, using CATI system; a sample of the telephone script and interviewer screen shots must be submitted for review ➤ Identify non-respondents for follow-up telephone calls ➤ Schedule and conduct callbacks to non-respondents at varying times of the day and different days of the week ➤ Assign final status codes to reflect results of attempts to obtain completed interview with sampled cases
Mixed Mode Administration (Mail with Telephone Follow-up)	<ul style="list-style-type: none"> ➤ Mail survey administration and telephone interviews are not to be conducted from a residence, nor from a virtual office ➤ Adhere to all Mail Only and Telephone Only survey administration requirements (described above). ➤ Track cases from mail survey through telephone follow-up activities

Criteria	Survey Vendor
Data Submission	<ul style="list-style-type: none"> ➤ Survey vendors are responsible for conducting data submission and must not subcontract this process ➤ Scan or key data from completed mail surveys ➤ Import (as necessary) data from CATI system into a data file ➤ Develop data files and edit and clean data according to standard protocols ➤ Follow all data cleaning and data submission rules, including verifying that data files are de-identified and contain no duplicate cases ➤ Export data from the electronic data collection system to the required format for data submission, confirm that the data were exported correctly, that the data submission files are formatted correctly and contain the correct data headers and data records ➤ Submit data electronically in the specified format to the CAHPS Hospice Survey Data Warehouse ➤ Work with CMS' contractor to resolve data problems and data submission problems
Technical Assistance/ Customer Support	<ul style="list-style-type: none"> ➤ Two years prior experience providing telephone customer support ➤ Provide toll-free customer support line: <ul style="list-style-type: none"> • Customer support must be offered in all languages that the survey vendor administers the survey in • Respond to calls within 24-48 hours

Participation in Quality Control Activities and Documentation Requirements:

Criteria	Survey Vendor
Demonstrated Quality Control Procedures	<ul style="list-style-type: none"> ➤ Incorporate well-documented quality control procedures (as applicable) for: <ul style="list-style-type: none"> • In-house training of staff and subcontractors involved in survey operations • Printing, mailing and recording receipt of survey questionnaires, if applicable • Telephone administration of survey, if applicable • Coding and verifying of survey data and survey-related materials • Scanning or keying in survey data • Preparation of final person-level data files for submission • All other functions and processes that affect the administration of the CAHPS Hospice Survey ➤ Participate in any conference calls and site visits as part of overall quality monitoring activities: <ul style="list-style-type: none"> • Provide documentation as requested for site visits and conference calls, including but not limited to: staff training records, telephone interviewer monitoring records, and file construction documentation

Criteria	Survey Vendor
Documentation Requirements	<ul style="list-style-type: none"> ➤ Keep electronic or hard copy files of staff training and training dates ➤ Maintain electronic documentation of telephone monitoring, if applicable ➤ Maintain documentation of mail production quality checks, if applicable ➤ Maintain documentation of all survey administration activities and related quality checks for review during site visits

Adhere to all Protocols, Specifications and Agree to Participate in Training Sessions:

Criteria	Survey Vendor
Survey Training	<ul style="list-style-type: none"> ➤ Attend all CMS Introduction and Vendor Update training sessions (subcontractors assigned key roles must attend training)
Administer the survey according to all Survey Specifications	<ul style="list-style-type: none"> ➤ Review and follow all procedures described in the CAHPS Hospice Survey Quality Assurance Guidelines that are applicable to the selected survey data collection mode ➤ Fully comply with the CAHPS Hospice Survey oversight activities ➤ Approved survey vendors are expected to maintain active contract(s) for CAHPS Hospice Survey administration with client hospice(s). An “active contract” is one in which the CAHPS Hospice Survey vendor is authorized by hospice client(s) to collect and submit CAHPS Hospice data to the CAHPS Hospice Data Warehouse. If a CAHPS Hospice Survey vendor does not have any contracted hospice clients within two years (a consecutive 24 months) of the date they received approval to administer the CAHPS Hospice Survey, then that survey vendor’s “Approved” status for CAHPS Hospice Survey administration will be withdrawn. If approval status is withdrawn, the organization must once again follow the steps to apply for reconsideration for approval to administer the CAHPS Hospice Survey.

Appendix B

CAHPS[®] Hospice Survey Vendor Authorization Form

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix B

CAHPS[®] Hospice Survey Survey Vendor Authorization Form

Hospice agencies must authorize an approved CAHPS^{®1} Hospice Survey vendor to submit data on their behalf for the 2015 administration of the CAHPS Hospice Survey.

In order to authorize a survey vendor, a Hospice representative must complete the CAHPS Hospice Survey Vendor Authorization Form and submit it to the RAND Corporation by May 1, 2015. The individual who completes this form for the Hospice will be considered the CAHPS Hospice Survey Administrator for that Hospice. Hospices should also designate, on the form, an individual within the hospice organization to serve as the main point of contact with the CAHPS Hospice Survey Project Team and to review data submissions by the vendor.

This form must be signed and dated in the presence of a notary public, notarized, and sent to the RAND Corporation. Please note, when completing a Survey Vendor Authorization Form pertaining to multiple hospice agencies, it would be appropriate to attach a list to the form (signed and dated by the Survey Administrator) of all the hospices (names and CMS Certification Numbers [CCN]). On the form itself, please note that “a document containing a list of “XX” number of hospice agencies is attached to the form” in the spaces provided.

If sent via U.S. Mail, send to:

RAND Corporation
ATTN: Melissa A. Bradley
CAHPS Hospice Survey
1200 South Hayes Street
Arlington, VA 22202

If sent via Federal Express, UPS or other overnight delivery service, send to:

RAND Corporation
ATTN: Melissa A. Bradley
CAHPS Hospice Survey
1200 South Hayes Street
Arlington, VA 22202
Phone: 703-413-1100, extension 5614

Please note: After submission of the Survey Vendor Authorization Form, no further action is required by the hospice to notify CMS of their survey vendor selection. RAND Corporation communicates to CMS which hospice agencies have authorized a survey vendor to administer the CAHPS Hospice Survey on their behalf.

¹ CAHPS[®] is a registered trademark of the Agency for Healthcare Research and Quality, a U.S. Government agency.

CAHPS[®] Hospice Survey 2015 Survey Vendor Authorization Form

I, _____ (Print Hospice Administrator's name), acknowledge and accept the role and all of the responsibilities of the CAHPS Hospice Survey Administrator for _____ (Print Name of Hospice **and CMS CCN Number**). For multiple hospice agencies, notate "See listing of "XX [include count]" hospice names and CCNs."

In this role I will be responsible for:

- 1) Authorizing a survey vendor to collect data for _____ (Print Name of Hospice or "See Listing Attached") as part of the 2015 CAHPS Hospice Survey and to submit data to CMS on behalf of the hospice.
- 2) Notifying CMS and RAND immediately if the hospice de-authorizes a survey vendor.
- 3) Designating an individual within the hospice organization to serve as the main point of contact with the CAHPS Hospice Survey Project Team and who will review data submissions by the vendor.
- 4) Notifying the CAHPS Hospice Survey Project Team if my role as the CAHPS Hospice Survey Administrator for the hospice will no longer be valid and identifying my successor.

By signing this form, I authorize _____ (Print Survey Vendor Name) to collect data for the hospice I represent as part of the 2015 CAHPS Hospice Survey and to submit data to CMS on behalf of the hospice.

Hospice Administrator First and Last Name: _____

Hospice Administrator Signature: _____

Title: _____

Phone Number: () _____ Email: _____

Hospice Administrator Mailing Address: _____

City: _____ State: _____ Zip Code: _____

Hospice Point of Contact for the CAHPS Hospice Survey Project Team:

First and last name: _____

Phone number: () _____

Email address: _____

Name of Survey Vendor authorizing:

Survey Vendor Name: _____

Survey Vendor Mailing Address: _____

City: _____ State: _____ Zip Code: _____

Notary Public Signature: _____

Stamp: _____

Notary Public Date: _____

Appendix C

CAHPS[®] Hospice Survey Data Warehouse Access

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix C

CAHPS[®] Hospice Survey 2015 Vendor Access to CAHPS Hospice Survey Data Warehouse

The CAHPS^{®1} Hospice Survey Data Warehouse is maintained by RAND. All vendors contracting with hospices to implement the 2015 CAHPS Hospice Survey must have a user account on the Data Warehouse. Complete this form and submit it as an email attachment to CAHPShospicetechsupport@rand.org or by fax to CAHPS Hospice Survey Data Support Team (703) 413-8111. **Your form must be received by July 1, 2015.**

Provide contact information for your organization's Data Administrator, and Back-up Data Administrator. Both are required to authorize a user account on the Data Warehouse.

Your Organization's Name: _____

Data Administrator

First and last name: _____

Phone number: () _____

Data administrator email address: _____

Back-up Data Administrator

First and last name: _____

Phone number: () _____

Back-up administrator email address: _____

¹ CAHPS[®] is a registered trademark of the Agency for Healthcare Research and Quality, a U.S. Government Agency.

Appendix D

CAHPS[®] Hospice Survey Sample File Layout

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix D

CAHPS Hospice Survey Sample File Layout

Below is an example of a sample file layout. **Please note the following:**

1. The Sample File Layout is for internal hospice/survey vendor use only. The file is used to facilitate the standardized administration of the CAHPS Hospice Survey and includes the data elements necessary for data submission, sampling and proper recording keeping. The patient identifying information and other *italicized Data Element* fields will **not** be submitted to the CAHPS Hospice Survey Data Warehouse.
2. CMS strongly recommends that hospices/survey vendors collect all data elements whether or not they are required for data submission.

Sample File Layout			
Data Element	Length	Value Labels and Use	Required for Data Submission
Provider Name	100	Name of the Hospice	Yes
Provider ID	10	CMS Certification Number (formerly known as Medicare Provider Number)	Yes
NPI	10	National Provider Identifier (optional)	No
Facility Name	100	Name of hospice, inpatient or nursing home facility, if applicable (optional)	No
Total Number of Live Discharges	10	Number of patients who were discharged alive during the month	Yes
Total Number of Decedents/Caregivers	10	Number of decedents/caregivers during the month	Yes
“No-Publicity” decedents/caregivers	10	Number of “no-publicity” decedents/caregivers during the month who were excluded from the file	Yes
Decedent/Caregiver Unique ID	16	Hospice/Survey vendor generated, random, unique, de-identified Decedent/Caregiver ID used to de-duplicate the file, and to track the decedent/caregiver’s survey status through the survey administration process	Yes

Sample File Layout

<i>Caregiver First Name</i>	30	Name information used to personalize materials to caregiver	No
<i>Caregiver Middle Initial</i>	1		
<i>Caregiver Last Name</i>	30		
<i>Caregiver Prefix</i>	6		
<i>Caregiver Suffix Name</i>	10		
<i>Decedent First Name</i>	30	Name information used to personalize materials to caregiver	No
<i>Decedent Middle Initial</i>	1		
<i>Decedent Last Name</i>	30		
<i>Decedent Prefix Name</i>	6		
<i>Decedent Suffix Name</i>	10		
Decedent Sex	1	1 = Male 2 = Female M = Unknown/Missing	Yes
Decedent Hispanic	1	1 = Hispanic/Latino/Spanish 2 = Not Hispanic/Latino/Spanish M = Unknown/Missing	Yes
Decedent Race	1	1 = White 2 = Black or African American 3 = Asian 4 = Native Hawaiian or Pacific Islander 5 = American Indian or Alaska Native 6 = More than one race 7 = Other M = Unknown/Missing	Yes
Decedent Date of Birth	8	MMDDYYYY Used by hospice/survey vendor to calculate patient age to confirm patient meets eligibility criteria	Yes
Decedent Date of Death	8	MMDDYYYY Used by hospice/survey vendor to calculate patient age to confirm patient meets eligibility criteria	Yes
Decedent Hospice Admission Date	8	MMDDYYYY Decedent admission date for his/her final episode of hospice care. Used by hospice/survey vendor to confirm caregiver/decendent meets eligibility criteria	Yes

Sample File Layout

Decedent Last Location/Setting of Care	2	1 = Home 2 = Assisted living 3 = Long-term care facility or non-skilled nursing facility 4 = Skilled nursing facility 5 = Inpatient hospital 6 = Inpatient hospice facility 7 = Long-term care facility 8 = Inpatient psychiatric facility 9 = Location not otherwise specified 10 = Hospice facility M = Unknown/Missing	Yes
Decedent Payer Primary	1	1 = Medicare 2 = Medicaid 3 = Private 4 = Uninsured/no payer 5 = Program for All Inclusive Care for the Elderly (PACE) 6 = Other M = Unknown/Missing	Yes
Decedent Payer Secondary	1	1 = Medicare 2 = Medicaid 3 = Private 4 = Uninsured/no payer 5 = Program for All Inclusive Care for the Elderly (PACE) 6 = Other M = Unknown/Missing	Yes
Decedent Payer Other	1	1 = Medicare 2 = Medicaid 3 = Private 4 = Uninsured/no payer 5 = Program for All Inclusive Care for the Elderly (PACE) 6 = Other M = Unknown/Missing	Yes
Decedent Primary Diagnosis	10	ICD-9 codes (ICD-10 codes anticipated to be implemented October 1, 2015)	Yes
<i>Caregiver Mailing Address 1</i>	50	Street address or post office box Address information used in protocols that have a mail mode of survey administration	No

Sample File Layout

<i>Caregiver Mailing Address 2</i>	50	Mailing address 2 nd line (if needed)	No
<i>Caregiver Mailing City</i>	50	Mailing city	No
<i>Caregiver Mailing State</i>	2	2-character state abbreviation	No
<i>Caregiver Mailing Zip Code</i>	9	9-digit zip code; no hyphen, separators or de-limiters (i.e., 5 digit zip code followed by 4 digit extension)	No
<i>Caregiver Telephone Number 1</i>	10	3-digit area code plus 7-digit telephone number; no dashes, separators or de-limiters Telephone information used in protocols that involve a telephone component as part of the mode of administration	No
<i>Caregiver Telephone Number 2</i>	10	3-digit area code plus 7-digit telephone number; no dashes, separators or de-limiters Telephone information used in protocols that involve a telephone component as part of the mode of administration	No
<i>Caregiver Telephone Number 3</i>	10	3-digit area code plus 7-digit telephone number; no dashes, separators or de-limiters Telephone information used in protocols that involve a telephone component as part of the mode of administration	No
<i>Caregiver Email Address</i>	30	Email address of caregiver	No
Caregiver relationship to the decedent	1	1 = Spouse / partner 2 = Parent 3 = Child 4 = Other family member 5 = Friend 6 = Legal guardian 7 = Other M=Missing	YES

Appendix E

CAHPS[®] Hospice Survey XML File Specification

THIS PAGE
INTENTIONALLY
LEFT BLANK

CAHPS Hospice Survey XML File Specification Version 1.0

This XML file specification (Version 1.0) applies to **January 1, 2015 and forward decedent/caregiver data collection.**

Each file submission will represent one month of survey data for each hospice.

The CAHPS Hospice Survey XML file is made up of 3 parts: **1) Header Record; 2) Decedent/Caregiver Administrative; Record 3) Survey Results Record.**

There should be only one header record for each CAHPS Hospice Survey xml file. Each decedent/caregiver sampled and included in the CAHPS Hospice Survey XML file should have a decedent/caregiver administrative record, and if survey results are being submitted for the decedent/caregiver there should be a survey results record.

Each field (except **npi, facility name and several conditional items** - see data element description for more details) of the header record and decedent/caregiver administrative data requires an entry for a valid data submission.

Survey results records are not required for a valid data submission but if survey results are included, then all answers must have an entry. Survey results records are required if the final <survey-status> is "1 - Completed survey" or "7 - Non-response: Break off".

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<monthlydata> Opening Tag, defines the monthly survey data	This is the opening element of the file. The closing tag for this element will be at the end of the file. Attributes describe the element and are included within the opening and closing <>					
	See example.	N/A	N/A	NA	N/A	Yes
The following section defines the format of the header record.						
<header> Opening Tag, defines the header record of monthly survey data	This is the opening element of the header record. The closing tag for this element will be at the end of the header record. Note: This tag is required in the XML document, however, it contains no data. This header element should only occur once per file.					
	None	N/A	N/A	NA	N/A	Yes
<provider-name> Sub-element of header	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This header element should only occur once per file. Example: <provider-name>Sample Hospice</provider-name>					
	None	Name of the hospice represented by the survey.	N/A	Alphanumeric Character	100	Yes
<provider-id> Sub-element of header	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This header element will occur again as an administration data element in the patient level data record. Example: <provider-id>123456</provider-id>					
	None	ID number of the hospice represented by the survey.	Valid 6 digit CMS Certification Number (formerly known as Medicare Provider Number).	Alphanumeric Character	10	Yes
<npi> Sub-element of header	Each element must have a closing tag that is the same as the opening tag, but with a forward slash. This header element should only occur once per file. This is an optional data element at this time but may be required in the future. Example: <npi>1234567890</npi>					
	None	National Provider Identifier	Valid 10 digit National Provider Identifier.	Numeric	10	No

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<survey-mode> Sub-element of header	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This header data element should only occur once per file. Note: The Survey Mode must be the same for all three months within a quarter. Example: <survey-mode>1</survey-mode>					
	None	Mode of survey administration. Survey Mode must be the same for all three months within a quarter. Once you have uploaded your first month of data, you have the ability to re-upload that month and change the survey mode if you'd like. However, once you have uploaded data for two months within a given quarter, you are locked into that survey mode and cannot change it for that quarter.	1 - Mail only 2 - Telephone only 3 - Mixed mode	Alphanumeric Character	1	Yes
<decedents-caregivers> Sub-element of header	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This header element should only occur once per file. Example: <decedents-caregivers>150</decedents-caregivers>					
	None	The total number of decedent/caregiver cases received from the hospice in the month	N/A	Numeric	10	Yes
<live-discharges> Sub-element of header	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This header element should only occur once per file. Example: <live-discharges>150</live-discharges>					
	None	Number of patients who were discharged alive during the month.	N/A	Numeric	10	Yes
<no-publicity> Sub-element of header	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This header element should only occur once per file. Example: <no-publicity>150</no-publicity>					
	None	Number of "no-publicity" decedents/caregivers during the month who were excluded from the file	N/A	Numeric	10	Yes

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<number-ineligible> Sub-element of header		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This header element should only occur once per file. Example: <number-ineligible>650</number-ineligible>				
	None	The number of decedents/caregivers determined to be ineligible for all other reasons in the month.	N/A	Numeric	10	Yes
<sample-size> Sub-element of header		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This header element should only occur once per file. Example: <sample-size>600</sample-size>				
	None	Number of eligible decedents/caregivers drawn into the sample for survey administration.	N/A	Numeric	10	Yes
<sample-type> Sub-element of header		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This header element should only occur once per file. Sampled decedents/caregivers must be age 18 or above at the time of death. Example: <sample-type>2</sample-type>				
	None	Sample type must be the same for all three months within a quarter. Once you have uploaded your first month of data, you have the ability to re-upload that month and change the sample type if you'd like. However, once you have uploaded data for two months within a given quarter, you are locked into that sample type and cannot change it for that quarter.	1 - Simple random sample	Numeric	1	Yes
			2 - Census Sample			
</header> Closing tag for header	None	Note: This closing element for the header is required in the XML document, however, it contains no data. This header element should only occur once per file.				

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
The following section defines the format of the decedent/caregiver level data record.						
<decedentleveldata> Opening Tag, defines the patient level data record of monthly survey data	This is the opening element of the decedent/caregiver level data record. The closing tag for this element will be at the end of the decedent/caregiver level data record. Note: The <decedentleveldata> section includes the opening and closing <decedentleveldata> tags and all the tags between these two tags. The <decedentleveldata> section is required in the XML file, if at least one decedent/caregiver is being submitted. If the <sample-size> is 0, and no decedent/caregiver data is being submitted, the <decedentleveldata> section should not be included in the XML file. This decedent/caregiver level data element should only occur once per decedent/caregiver.					
	None	N/A	N/A	NA	N/A	Yes
<provider-id> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata element also occurs in the previous header record. Example: <provider-id>123456</provider-id>					
	None	ID number of the hospice represented by the survey.	Valid 6 digit CMS Certification Number (formerly known as Medicare Provider Number).	Alphanumeric Character	10	Yes
<decedent-id> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata element will occur again as a data element in the caregiver response record. Example: <decedent-id>12345</decedent-id>					
	None	Unique de-identified decedent/caregiver id assigned by the survey vendor to uniquely identify the survey.	N/A	Alphanumeric Character	16	Yes
<birth-yr> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <birth-yr>1940</birth-yr>					
	None	Year decedent was born provided by the hospice	YYYY YYYY (cannot be 9999)	Numeric	4	Yes
<birth-month> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <birth-month>1</birth-month>					
	None	Month decedent was born provided by the hospice	MM MM = (1 - 12) (cannot be 00, 13 - 99)	Numeric	2	Yes

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<birth-day> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <birth-day>1</birth-day>					
	None	Day decedent was born provided by the hospice	DD DD = (1 - 31) (cannot be 00, 32 - 99)	Numeric	2	Yes
<death-yr> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <death-yr>2015</death-yr>					
	None	Year decedent died provided by the hospice	YYYY YYYY = (2015 or greater) (cannot be 9999)	Numeric	4	Yes
<death-month> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <death-month>1</death-month>					
	None	Month decedent died provided by the hospice	MM MM = (1 - 12) (cannot be 00, 13 - 99)	Numeric	2	Yes
<death-day> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <death-day>1</death-day>					
	None	Day decedent died provided by the hospice	DD DD = (1 - 31) (cannot be 00, 32 - 99)	Numeric	2	Yes
<admission-yr> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <admission-yr>2015</admission-yr>					
	None	Year decedent was admitted for final episode of hospice care provided by the hospice	YYYY YYYY = (2014 or later) (cannot be 9999)	Numeric	4	Yes

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<admission-month> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <admission-month>1</admission-month>					
	None	Month decedent was admitted for final episode of hospice care provided by the hospice	MM MM = (1 - 12) (cannot be 00, 13 - 99)	Numeric	2	Yes
<admission-day> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <admission-day>1</admission-day>					
	None	Day decedent was admitted for final episode of hospice care provided by the hospice	DD DD = (1 - 31) (cannot be 00, 32 - 99)	Numeric	2	Yes
<sex> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <sex>1</sex>					
	None	Decedent sex provided by the hospice	1 - Male	Alphanumeric Character	1	Yes
			2 - Female			
			M - Missing			
<decedent-hispanic> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <decedent-hispanic>1</decedent-hispanic>					
	None	Indication whether on not decedent is hispanic provided by the hospice	1 - Hispanic	Alphanumeric Character	1	Yes
			2 - Non-hispanic			
			M - Missing			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<p><decedent-race> Sub-element of decedentleveldata</p>	None	<p>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <decedent-race>1</decedent-race> Decedent's race provided by the hospice</p>	<p>1 - White 2 - Black or African American 3 - Asian 4 - Native Hawaiian or Pacific Islander 5 - American Indian or Alaska Native 6 - More than one race 7 - Other M -Missing</p>	Alphanumeric Character	1	Yes
<p><caregiver-relationship> Sub-element of decedentleveldata</p>	None	<p>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <caregiver-relationship>1</caregiver-relationship> Caregiver relationship to decedent provided by the hospice</p>	<p>1 - Spouse/partner 2 - Parent 3 - Child 4 - Other family member 5 - Friend 6 - Legal guardian 7 - Other M - Missing</p>	Alphanumeric Character	1	Yes

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<decedent-payer-primary> Sub-element of decedentleveldata		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <decedent-payer-primary>1</decedent-payer-primary>				
	None	Decedent's primary payer for healthcare services provided by the hospice	1 - Medicare 2 - Medicaid 3 - Private 4 - Uninsured/no payer 5 - Program for All Inclusive Care for the Elderly (PACE) 6 - Other M - Missing	Alphanumeric Character	1	Yes
<decedent-payer-secondary> Sub-element of decedentleveldata		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <decedent-payer-secondary>1</decedent-payer-secondary>				
	None	Decedent's secondary payer for healthcare services provided by the hospice	1 - Medicare 2 - Medicaid 3 - Private 4 - Uninsured/no payer 5 - Program for All Inclusive Care for the Elderly (PACE) 6 - Other M - Missing	Alphanumeric Character	1	Yes
<decedent-payer-other> Sub-element of decedentleveldata		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <decedent-payer-other>1</decedent-payer-other>				
	None	Decedent's other payer for healthcare services provided by the hospice	1 - Medicare 2 - Medicaid 3 - Private 4 - Uninsured/no payer 5 - Program for All Inclusive Care for the Elderly (PACE) 6 - Other	Alphanumeric Character	1	Yes

CMS

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
			M - Missing			
<last-location> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <last-location>1</last-location>					
	None	Decedent's last location/setting of hospice care provided by the hospice	1 - Home 2 - Assisted living 3 - Long-term care facility or non-skilled nursing facility 4 - Skilled nursing facility 5 - Inpatient hospital 6 - Inpatient hospice facility 7 - Long-term care facility 8 - Inpatient psychiatric facility 9 - Location not otherwise specified 10 - Hospice facility M - Missing	Alphanumeric Character	2	Yes
<facility-name> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This is an optional data element at this time but may be required in the future. Example: <facility-name>Facility</facility-name>					
	None	Name of hospice, inpatient or nursing home facility, if applicable (optional)	N/A	Alphanumeric Character	100	No
<decedent-primary-diagnosis> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <decedent-primary-diagnosis>310.11</decedent-primary-diagnosis>					
	None	The decedent's primary diagnosis provided by the hospice	ICD-9 codes (ICD-10 codes anticipated to be implemented October 1, 2015)	Numeric	10	Yes

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<survey-status> Sub-element of decedentleveldata		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per caregiver/decedent. Example: <survey-status>10</survey-status>				
	None	Disposition of survey.	1 - Completed survey	Alphanumeric Character	2	Yes
			2 - Ineligible: Deceased			
			3 - Ineligible: Not in eligible population			
			4 - Ineligible: Language barrier			
			5 - Ineligible: Mental/physical incapacity			
			6 - Ineligible: Not involved in decedent care			
			7 - Non-response: Break off			
			8 - Non-response: Refusal			
			9 - Non-response: Non-response after maximum attempts			
			10 - Non-response: Bad address			
			11 - Non-response: Bad/no phone number			
			33- No response collected (used only for interim data file submission)			
			M - Missing			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<survey-completion-mode> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This tag is required if the Survey Mode is Mixed and the Survey Status is 1 - Completed Survey or 7 - Non-response: Break off. The values entered must match a value corresponding to the Survey Mode defined in the header section of the XML file. If the XML Element <Survey Mode> is other than Mixed, this tag should not be included in the XML file. Example: <survey-completion-mode>1</survey-completion-mode>					
	None	Survey Mode used to complete a survey administered via the Mixed mode.	1 - Mixed mode-mail	Numeric	2	No. Required only if Survey Mode is Mixed and Survey Status is 1- Completed Survey or 7- Non-response: Break off.
			2 - Mixed mode-phone			
			88 - Not applicable			
<number-survey-attempts-telephone> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This tag is required if the Survey Mode is Telephone Only or Mixed Mode with a survey completion mode answer of 2 - Mixed Mode - Phone. If the XML Element <Survey Mode> is other than Telephone only or Mixed Mode (phone), this tag does not need to be included in the XML file. Example: <number-survey-attempts-telephone>1</number-survey-attempts-telephone>					
	None	Number of telephone contact attempts per survey with a survey mode of Telephone Only or Mixed.	1 - First Telephone attempt	Numeric	2	No, conditionally required only if the Survey Mode is Telephone Only Mode or Mixed Mode with survey completion mode = 2- Mixed mode-phone.
			2 - Second Telephone attempt			
			3 - Third Telephone attempt			
			4 - Fourth Telephone attempt			
			5 - Fifth Telephone attempt			
			88 - Not applicable			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<number-survey-attempts-mail> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This tag is required if the Survey Mode is Mail Only. If the XML Element <Survey Mode> is other than Mail only, this tag does not need to be included in the XML file. Example: <number-survey-attempts-mail>1</number-survey-attempts-mail>					
	None	Mail wave per survey for which final survey status code is determined. Mail Only mode.	1 - First wave mailing	Numeric	2	No, conditionally required only if the Survey Mode is Mail Only
			2 - Second wave mailing			
			88 - Not applicable			
<language> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <language>1</language>					
	None	Identify survey language in which the survey was administered (English, Spanish, Chinese)	1 - English	Numeric	2	Yes
			2 - Spanish			
			3 - Chinese			
			88 - Not applicable			
<lag-time> Sub-element of decedentleveldata	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Note: The Lag Time should not be coded as "Missing." Example: <lag-time>84</lag-time>					
	None	Number of days between decedent date of death and the date that data collection activities ended for the decedent/caregiver.	0-365	Numeric	3	Yes
			888 - Not applicable (use only for interim data file submission)			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<p><supplemental-question-count> Sub-element of decedentleveldata</p>	<p>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. Example: <supplemental-question-count>4</supplemental-question-count></p>					
	None	A count of supplemental questions added to the questionnaire.	0-15 M - Missing	Alphanumeric Character	2	No. Required only if Survey Status is 1- Completed Survey or 7- Non-response: Break off.
<p>A survey results (caregiver response) record is defined as the <caregiverresponse> and is defined as follows: (Note: Survey results (caregiver response) records are not required for a valid data submission, however if survey results are included then all answers must have an entry. Survey results (caregiver response) record is required, if the final <survey-status> is "1 - Completed survey" or "7 - Non-response: Break off".)</p>						
<p><caregiverresponse> Opening Tag, defines the patient response data record within the caregiver level data record of monthly survey data</p>	<p>This is the opening element of the caregiver response record. The closing tag for this element will be at the end of the caregiver response record. Note: There will be one <caregiverresponse> section for each caregiver if survey results are being submitted for the caregiver The <caregiverresponse> section includes the opening and closing <caregiverresponse> tags and all the tags between these two tags. This <caregiverresponse> section is required in the XML file only if survey results are being submitted for the caregiver If survey results are not being submitted for the caregiver the <caregiverresponse> section should not be submitted. This caregiver response element should only occur once per patient.</p>					
	None	N/A	N/A	NA	N/A	Yes

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<decedent-id> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This element also occurs in the previous decedent level data record. Example: <decedent-id>12345</decedent-id>					
	None	Unique de-identified decedent/caregiver id assigned by the survey vendor to uniquely identify the survey.	N/A	Alphanumeric Character	16	Yes
<related> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver Example: <related>4</related>					
	None	Question 1: Related.	1 - My spouse or partner	Alphanumeric Character	1	Yes
			2 - My parent			
			3 - My mother-in-law or father-in-law			
			4 - My grandparent			
			5 - My aunt or uncle			
			6 - My sister or brother			
			7 - My child			
			8 - My friend			
			9 - Other			
			M - Missing/Don't know			
<location-home> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. If the check box for 'Home' is selected, enter value '1' for this data element If the check box for 'Home' is not selected (and at least one other check box for race is selected), enter value '0' for this data element If none of the check boxes for this question are selected on the survey, enter the value 'M' for this data element and for all other data elements Example: <location-home>0</location-home>					
	None	Question 2: Location: at home.	1 - Home	Alphanumeric Character	1	Yes
			0 - Not home			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<location-assisted> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. If the check box for 'Assisted living facility' is selected, enter value '1' for this data element If the check box for 'Assisted living facility' is not selected (and at least one other check box for race is selected), enter value '0' for this data element If none of the check boxes for this question are selected on the survey, enter the value 'M' for this data element and for all other data elements Example: <location-assisted>0</location-assisted>					
	None	Question 2: Location: assisted living facility.	1 - Assisted living facility	Alphanumeric Character	1	Yes
			0 - Not assisted living facility			
			M - Missing/Don't know			
<location-nursinghome> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. If the check box for 'Nursing Home' is selected, enter value '1' for this data element If the check box for 'Nursing Home' is not selected (and at least one other check box for race is selected), enter value '0' for this data element If none of the check boxes for this question are selected on the survey, enter the value 'M' for this data element and for all other data elements Example: <location-nursinghome>0</location-nursinghome>					
	None	Question 2: Location: nursing home.	1 - Nursing Home	Alphanumeric Character	1	Yes
			0 - Not nursing home			
			M - Missing/Don't know			
<location-hospital> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. If the check box for 'Hospital' is selected, enter value '1' for this data element If the check box for 'Hospital' is not selected (and at least one other check box for race is selected), enter value '0' for this data element If none of the check boxes for this question are selected on the survey, enter the value 'M' for this data element and for all other data elements Example: <location-hospital>0</location-hospital>					
	None	Question 2: Location: hospital	1 - Hospital	Alphanumeric Character	1	Yes
			0 - Not hospital			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
			M - Missing/Don't know			
<location-hospice-facility> Sub-element of caregiverresponse		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. If the check box for 'Hospice facility/hospice house' is selected, enter value '1' for this data element If the check box for 'Hospice facility/hospice house' is not selected (and at least one other check box for race is selected), enter value '0' for this data element If none of the check boxes for this question are selected on the survey, enter the value 'M' for this data element and for all other data elements Example: <location-hospice-facility>0</location-hospice-facility>				
	None	Question 2: Location: hospice facility/hospice house	1 - Hospice facility/hospice house	Alphanumeric Character	1	Yes
			0 - Not hospice facility/hospice house			
			M - Missing/Don't know			
<location-other> Sub-element of caregiverresponse		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. If the check box for 'Other' is selected, enter value '1' for this data element If the check box for 'Other' is not selected (and at least one other check box for race is selected), enter value '0' for this data element If none of the check boxes for this question are selected on the survey, enter the value 'M' for this data element and for all other data elements Example: <location-other>0</location-other>				
	None	Question 2: Location: other	1 - Other	Alphanumeric Character	1	Yes
			0 - Not other			
			M - Missing/Don't know			
<oversee> Sub-element of caregiverresponse		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver Example: <oversee>4</oversee>				
	None	Question 3: Oversee.	1 - Never	Alphanumeric Character	1	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			CMS			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
			M - Missing/Don't know			
<needhelp> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <needhelp>1</needhelp>					
	None	Question 4: Need help.	1 - Yes	Alphanumeric Character	2	Yes
			2 - No			
			88 - Not applicable			
			M - Missing/Don't know			
<gethelp> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <gethelp>4</gethelp>					
	None	Question 5: Get help.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			
<h_informtime> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver Example: <h_informtime>4</h_informtime>					
	None	Question 6: Hospice inform.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<helpasan> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <helpasan>4</helpasan>					
	None	Question 7: Help As Soon as Need.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			
<h_explain> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <h_explain>4</h_explain>					
	None	Question 8: Hospice explain.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			
<h_inform> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <h_inform>4</h_inform>					
	None	Question 9: Hospice inform.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<h_confuse> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <h_confuse>4</h_confuse>					
	None	Question 10: Hospice confuse.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			
<h_dignity> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <h_dignity>4</h_dignity>					
	None	Question 11: Hospice dignity.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			
<h_cared> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <h_cared>4</h_cared>					
	None	Question 12: Hospice cared.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			

CMS

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<h_talk> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <h_talk>1</h_talk>					
	None	Question 13: Hospice talk.	1 - Yes	Alphanumeric Character	2	Yes
			2 - No			
			88 - Not applicable			
			M - Missing/Don't know			
<h_talklisten> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <h_talklisten>4</h_talklisten>					
	None	Question 14: Hospice talk and listen.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			
<pain> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <pain>1</pain>					
	None	Question 15: Pain.	1 - Yes	Alphanumeric Character	2	Yes
			2 - No			
			88 - Not applicable			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<painhlp> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <painhlp>1</painhlp>					
	None	Question 16: Pain help.	1 - Yes, definitely	Alphanumeric Character	2	Yes
			2 - Yes, somewhat			
			3 - No			
			88 - Not applicable			
			M - Missing/Don't know			
<painrx> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <painrx>1</painrx>					
	None	Question 17: Pain medicine.	1 - Yes	Alphanumeric Character	2	Yes
			2 - No			
			88 - Not applicable			
			M - Missing/Don't know			
<painrxside> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <painrxside>1</painrxside>					
	None	Question 18: Pain medication info	1 - Yes, definitely	Alphanumeric Character	2	Yes
			2 - Yes, somewhat			
			3 - No			
			88 - Not applicable			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<painrxwatch> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <painrxwatch>1</painrxwatch>					
	None	Question 19: Pain medicine watch.	1 - Yes, definitely	Alphanumeric Character	2	Yes
			2 - Yes, somewhat			
			3 - No			
			88 - Not applicable			
			M - Missing/Don't know			
<painrxtrain> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <painrxtrain>4</painrxtrain>					
	None	Question 20: Pain medicine train.	1 - Yes, definitely	Alphanumeric Character	2	Yes
			2 - Yes, somewhat			
			3 - No			
			4 - I did not need to give pain medicine to my family member			
			88 - Not applicable			
			M - Missing/Don't know			
<breath> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <breath>1</breath>					
	None	Question 21: Breath.	1 - Yes	Alphanumeric Character	2	Yes
			2 - No			
			88 - Not applicable			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<breathhlp> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <breathhlp>4</breathhlp>					
	None	Question 22: Breath help.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			
<breathtrain> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <breathtrain>4</breathtrain>					
	None	Question 23: Breath train.	1 - Yes, definitely	Alphanumeric Character	2	Yes
			2 - Yes, somewhat			
			3 - No			
			4 - I did not need to help my family member with trouble breathing.			
			88 - Not applicable			
			M - Missing/Don't know			
<constip> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <constip>1</constip>					
	None	Question 24: Constipation.	1 - Yes	Alphanumeric Character	2	Yes
			2 - No			
			88 - Not applicable			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<constiphlp> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <constiphlp>4</constiphlp>					
	None	Question 25: Constipation Help.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			
<sad> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <sad>1</sad>					
	None	Question 26: Sad.	1 - Yes	Alphanumeric Character	2	Yes
			2 - No			
			88 - Not applicable			
			M - Missing/Don't know			
<sadgethlp> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <sadgethlp>4</sadgethlp>					
	None	Question 27: Sad Get Help.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
		M - Missing/Don't know				

CMS

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<restless> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <restless>1</restless>					
	None	Question 28: Restless.	1 - Yes	Alphanumeric Character	2	Yes
			2 - No			
			88 - Not applicable			
			M - Missing/Don't know			
<restlesstrain> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <restlesstrain>1</restlesstrain>					
	None	Question 29: Restless train.	1 - Yes, definitely	Alphanumeric Character	2	Yes
			2 - Yes, somewhat			
			3 - No			
			88 - Not applicable			
		M - Missing/Don't know				
<movetrain> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <movetrain>4</movetrain>					
	None	Question 30: Move train.	1 - Yes, definitely	Alphanumeric Character	2	Yes
			2 - Yes, somewhat			
			3 - No			
			4 - I did not need to move my family member			
		88 - Not applicable				
		M - Missing/Don't know				

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<expectinfo> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <expectinfo>1</expectinfo>					
	None	Question 31: Expect info.	1 - Yes, definitely	Alphanumeric Character	2	Yes
			2 - Yes, somewhat			
			3 - No			
			88 - Not applicable			
			M - Missing/Don't know			
<receivednh> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <receivednh>1</receivednh>					
	None	Question 32: Received nursing home.	1 - Yes	Alphanumeric Character	2	Yes
			2 - No			
			88 - Not applicable			
			M - Missing/Don't know			
<cooperatehnh> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <cooperatehnh>4</cooperatehnh>					
	None	Question 33: Cooperate hospice and nursing home.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<differhnh> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <differhnh>4</differhnh>					
	None	Question 34: Difference between hospice and nursing home.	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			
<h_clisten> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <h_clisten>4</h_clisten>					
	None	Question 35: Hospice listening carefully to caregiver	1 - Never	Alphanumeric Character	2	Yes
			2 - Sometimes			
			3 - Usually			
			4 - Always			
			88 - Not applicable			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<cbeliefrespect> Sub-element of caregiverresponse		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <cbeliefrespect>1</cbeliefrespect>				
	None	Question 36: Caregiver beliefs respected.	1 - Too little	Alphanumeric Character	2	Yes
			2 - Right amount			
			3 - Too much			
			88 - Not applicable			
			M - Missing/Don't know			
<cemotion> Sub-element of caregiverresponse		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <cemotion>1</cemotion>				
	None	Question 37: Caregiver emotion.	1 - Too little	Alphanumeric Character	2	Yes
			2 - Right amount			
			3 - Too much			
			88 - Not applicable			
			M - Missing/Don't know			
<cemotionafter> Sub-element of caregiverresponse		Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <cemotionafter>1</cemotionafter>				
	None	Question 38: Caregiver emotion after.	1 - Too little	Alphanumeric Character	2	Yes
			2 - Right amount			
			3 - Too much			
			88 - Not applicable			
			M - Missing/Don't know			

CMS

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<ratehospice> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <ratehospice>4</ratehospice>					
	None	Question 39: Rate hospice.	0 - Worst hospice care possible	Alphanumeric Character	2	Yes
			1			
			2			
			3			
			4			
			5			
			6			
			7			
			8			
			9			
			10 - Best hospice care possible			
			88 - Not applicable			
		M - Missing/Don't know				
<h_recommend> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <h_recommend>4</h_recommend>					
	None	Question 40: Hospice recommended.	1 - Definitely no	Alphanumeric Character	2	Yes
			2 - Probably no			
			3 - Probably yes			
			4 - Definitely yes			
			88 - Not applicable			
			M - Missing/Don't know			

CMS

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<pEdu> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <pEdu>4</pEdu>					
	None	Question 41: Patient educaton.	1 - 8th grade or less	Alphanumeric Character	1	Yes
			2 - Some high school, but did not graduate			
			3 - High school graduate or GED			
			4 - Some college or 2-year degree			
			5 - 4-year college graduate			
			6 - More than 4-year college degree			
			7- Don't know			
			M - Missing/Don't know			
<pLatino> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <pLatino>1</pLatino>					
	None	Question 42: Patient Latino.	1 - No, not Spanish/Hispanic/Latino	Alphanumeric Character	1	Yes
			2 - Yes, Puerto Rican			
			3 - Yes, Mexican, Mexican American, Chicano/a			
			4 - Yes, Cuban			
			5 - Yes, other Spanish/Hispanic/Latino			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<p><race-white> Sub-element of caregiverresponse</p>		<p>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <race-white>1</race-white> If the check box for the race 'White' is selected, enter value '1' for this data element If the check box for the race 'White' is not selected (and at least one other check box for race is selected), enter value '0' for this data element If none of the check boxes for the race question are selected on the survey, enter the value 'M' for this data element and for all other race data elements</p>				
	None	Question 43: Race, White.	1 - White	Alphanumeric Character	1	Yes
			0 - Not White			
			M - Missing/Don't know			
<p><race-african-amer> Sub-element of caregiverresponse</p>		<p>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <race-african-amer>0</race-african-amer> If the check box for the race 'Black or African-American' is selected, enter value '1' for this data element If the check box for the race 'Black or African-American' is not selected (and at least one other check box for race is selected), enter value '0' for this data element If none of the check boxes for the race question are selected on the survey, enter the value 'M' for this data element and for all other race data elements</p>				
	None	Question 43: Race, African-American.	1 - Black or African-American	Alphanumeric Character	1	Yes
			0 - Not Black or African-American			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<p><race-asian> Sub-element of caregiverresponse</p>		<p>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <race-asian>0</race-asian> If the check box for the race 'Asian' is selected, enter value '1' for this data element If the check box for the race 'Asian' is not selected (and at least one other check box for race is selected), enter value '0' for this data element If none of the check boxes for the race question are selected on the survey, enter the value 'M' for this data element and for all other race data elements</p>				
	None	Question 43: Race, Asian.	1 - Asian	Alphanumeric Character	1	Yes
			0 - Not Asian			
			M - Missing/Don't know			
<p><race-hi-pacific-islander> Sub-element of caregiverresponse</p>		<p>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <race-hi-pacific-islander>0</race-hi-pacific-islander> If the check box for the race 'Native Hawaiian or Pacific Islander' is selected, enter value '1' for this data element If the check box for the race 'Native Hawaiian or Pacific Islander' is not selected (and at least one other check box for race is selected), enter value '0' for this data element If none of the check boxes for the race question are selected on the survey, enter the value 'M' for this data element and for all other race data elements</p>				
	None	Question 43: Race, Pacific Islander.	1 - Native Hawaiian or Pacific Islander	Alphanumeric Character	1	Yes
			0 - Not Native Hawaiian or Pacific Islander			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<race-amer-indian-ak> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <race-amer-indian-ak>0</race-amer-indian-ak> If the check box for the race 'American Indian or Alaska native' is selected, enter value '1' for this data element If the check box for the race 'American Indian or Alaska native' is not selected (and at least one other check box for race is selected), enter value '0' for this data element If none of the check boxes for the race question are selected on the survey, enter the value 'M' for this data element and for all other race data elements					
	None	Question 43: Race, American Indian/Alaska Native.	1 - American Indian or Alaska native	Alphanumeric Character	1	Yes
			0 - Not American Indian or Alaska native			
			M - Missing/Don't know			
<cAge> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <cAge>1</cAge>					
	None	Question 44: Caregiver, age.	1 - 18 to 24	Alphanumeric Character	1	Yes
			2 - 25 to 34			
			3 - 35 to 44			
			4 - 45 to 54			
			5 - 55 to 64			
			6 - 65 to 74			
			7 - 75 to 84			
			8 - 85 or older			
			M - Missing/Don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<cSex> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <cSex>1</cSex>					
	None	Question 45: Caregiver, Sex.	1 - Male	Alphanumeric Character	1	Yes
			2 - Female			
			M - Missing/Don't know			
<cEdu> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <cEdu>4</cEdu>					
	None	Question 46: Caregiver Education.	1 - 8th grade or less	Alphanumeric Character	1	Yes
			2 - Some high school, but did not graduate			
			3 - High school graduate or GED			
			4 - Some college or 2-year degree			
			5 - 4-year college graduate			
			6 - More than 4-year college degree			
			M - Missing/don't know			

XML Element	Attributes	Description	Valid Values	Data Type	Max Field Size	Data Element Required
<cHomeLang> Sub-element of caregiverresponse	Each element must have a closing tag that is the same as the opening tag but with a forward slash. This caregiver response data element should only occur once per caregiver. Example: <cHomeLang>4</cHomeLang>					
	None	Question 47: Language spoken at home.	1 - English	Alphanumeric Character	1	Yes
			2 - Spanish			
			3 - Chinese			
			4 - Some other language			
			M - Missing/don't know			
</caregiverresponse> Closing tag for caregiverresponse	None	Note: This tag is required in the XML file, however, it contains no data. This caregiver response element should only occur once per caregiver				
</decedentleveldata> Closing tag for decedentleveldata	None	Note: This tag is required in the XML file, however, it contains no data. This administration element should only occur once per caregiver.				
</monthlydata> Closing tag, defines the monthly survey data	None	Note: This tag is required in the XML file, however, it contains no data. This monthly data element should only occur once per caregiver				

CAHPS Hospice Survey Sample XML File Layout Version 1

```
<?xml version="1.0"?>
<!-- CAHPS Hospice Survey XML File Specification Version 1.0 -->
<monthlydata>
  - <header>
    <provider-name>Sample Hospice</provider-name>
    <provider-id>123456</provider-id>
    <npi>1234567890</npi>
    <survey-mode>1</survey-mode>
    <decedents-caregivers>150</decedents-caregivers>
    <live-discharges>150</live-discharges>
    <no-publicity>150</no-publicity>
    <number-ineligible>650</number-ineligible>
    <sample-size>600</sample-size>
    <sample-type>2</sample-type>
  </header>
  - <decedentleveldata>
    <provider-id>123456</provider-id>
    <decedent-id>12345</decedent-id>
    <birth-yr>1940</birth-yr>
    <birth-month>1</birth-month>
    <birth-day>1</birth-day>
    <death-yr>2015</death-yr>
    <death-month>1</death-month>
    <death-day>1</death-day>
    <admission-yr>2015</admission-yr>
    <admission-month>1</admission-month>
    <admission-day>1</admission-day>
    <sex>1</sex>
    <decedent-hispanic>1</decedent-hispanic>
    <decedent-race>1</decedent-race>
    <caregiver-relationship>1</caregiver-relationship>
    <decedent-payer-primary>1</decedent-payer-primary>
    <decedent-payer-secondary>1</decedent-payer-secondary>
    <decedent-payer-other>1</decedent-payer-other>
    <last-location>1</last-location>
    <facility-name>Facility</facility-name>
    <decedent-primary-diagnosis>310.11</decedent-primary-diagnosis>
    <survey-status>1</survey-status>
```

<survey-completion-mode>1</survey-completion-mode>
 <number-survey-attempts-telephone>1</number-survey-attempts-telephone>
 <number-survey-attempts-mail>1</number-survey-attempts-mail>
 <language>1</language>
 <lag-time>125</lag-time>
 <supplemental-question-count>4</supplemental-question-count>
 - <caregiverresponse>
 <decedent-id>12345</decedent-id>
 <related>4</related>
 <location-home>0</location-home>
 <location-assisted>0</location-assisted>
 <location-nursinghome>0</location-nursinghome>
 <location-hospital>0</location-hospital>
 <location-hospice-facility>0</location-hospice-facility>
 <location-other>0</location-other>
 <oversee>4</oversee>
 <needhelp>1</needhelp>
 <gethelp>4</gethelp>
 <h_informtime>4</h_informtime>
 <helpasan>4</helpasan>
 <h_explain>4</h_explain>
 <h_inform>4</h_inform>
 <h_confuse>4</h_confuse>
 <h_dignity>4</h_dignity>
 <h_cared>4</h_cared>
 <h_talk>1</h_talk>
 <h_talklisten>4</h_talklisten>
 <pain>1</pain>
 <painhlp>1</painhlp>
 <painrx>1</painrx>
 <painrxside>1</painrxside>
 <painrxwatch>1</painrxwatch>
 <painrxtrain>4</painrxtrain>
 <breath>1</breath>
 <breathhlp>4</breathhlp>
 <breathtrain>4</breathtrain>
 <constip>1</constip>

<constiphlp>4</constiphlp>
<sad>1</sad>
<sadgethlp>4</sadgethlp>
<restless>1</restless>
<restlesstrain>1</restlesstrain>
<movetrain>4</movetrain>
<expectinfo>1</expectinfo>
<receivednh>1</receivednh>
<cooperatehnh>4</cooperatehnh>
<differhnh>4</differhnh>
<h_clisten>4</h_clisten>
<cbeliefrespect>1</cbeliefrespect>
<cemotion>1</cemotion>
<cemotionafter>1</cemotionafter>
<ratehospice>4</ratehospice>
<h_recommend>4</h_recommend>
<pEdu>4</pEdu>
<pLatino>1</pLatino>
<race-white>1</race-white>
<race-african-amer>0</race-african-amer>
<race-asian>0</race-asian>
<race-hi-pacific-islander>0</race-hi-pacific-islander>
<race-amer-indian-ak>0</race-amer-indian-ak>
<cAge>1</cAge>
<cSex>1</cSex>
<cEdu>4</cEdu>
<cHomeLang>4</cHomeLang>
</caregiverresponse>
</decendentleveldata>
</monthlydata>

Appendix F

CAHPS[®] Hospice Survey Interviewing Guidelines for Telephone Surveys

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix F

CAHPS[®] Hospice Survey Interviewing Guidelines for Telephone

Overview

These guidelines address expectations for interviewers conducting the CAHPS^{®1} Hospice Survey by telephone. To collect the highest quality data possible, telephone interviewers must follow these guidelines while conducting telephone interviews.

As an interviewer, your role in the success of this survey is important. You will interact with many respondents and you are the person who assures the respondents that their participation is important.

Due to the nature of this survey you may experience a little more resistance on behalf of the respondent; therefore, it will be necessary for you to familiarize yourself with the organizations Distressed Respondent Procedures.

General Interviewing Techniques

As an Interviewer you must:

- study and thoroughly familiarize yourself with the Frequently Asked Questions (FAQ) list before you begin conducting telephone interviews so that you are knowledgeable about the CAHPS Hospice Survey
- read all questions and response choices in the indicated order and exactly as worded, so that all respondents are answering the same question. Questions that are re-worded can bias the respondent's response and the overall survey results.
- not attempt to increase the likelihood of the respondent providing one answer over another answer
- read all transitional statements
- never skip over a question because you think the respondent has answered it already
- speak in an upbeat and courteous tone
- maintain a professional and neutral relationship with the respondent at all times
- not provide personal information or opinions about the survey
- listen carefully to any respondent questions and offer concise responses. You may not provide extra information or lengthy explanations.
- tell the respondent that there are no more questions and thank the respondent for his or her time at the end of the survey
- not administer the CAHPS Hospice Survey to any respondent whom you know personally

¹ CAHPS[®] is a registered trademark of the Agency for Healthcare Research and Quality, a U.S. Government agency.

Introduction and Refusal Avoidance

For optimal response rates, it is important that telephone interviewers attempt to avoid telephone refusals from the respondent. The introduction and initial moments of the interview are critical to gaining cooperation from the respondent.

Interviewers/Operators must:

- read the telephone script introductions verbatim, unless the respondent/respondent interrupts to ask a question or voices a concern
- speak clearly and politely to establish a rapport with the respondent
- avoid long pauses
- not rush through the introduction
- be prepared to answer questions about the survey by familiarizing themselves with the survey and the FAQ document
- attempt to gain cooperation, but if the respondent refuses, the interviewer should politely end the call. The interviewer should not argue with or antagonize the respondent.

Answering Questions and Probing

Telephone interviewers need to probe when a respondent fails to give a complete or an adequate answer. Interviewers must never interpret respondent answers. Interviewers must not ask the respondent probing questions about their health such as “How are you feeling today?” or “Are you having any pain?” before asking the CAHPS Hospice Survey questions.

- Interviewer probes must be neutral and must not increase the likelihood of the respondent providing one answer over another answer. Probes should stimulate the respondent to give answers that meet the question objectives.
- Types of probes:
 - Repeat the question or the answer categories
 - Interviewer says:
 - “Take a minute to think about it.” REPEAT QUESTION, IF APPROPRIATE
 - “So, would you say that it is...” REPEAT ANSWER CATEGORIES
 - “Which would be closer?” REPEAT ANSWER CATEGORIES THAT ARE CLOSEST TO THE CAREGIVER’S RESPONSE
- Interviewers must not interpret survey questions for the respondent

Conventions on Telephone Survey Instruments

- All text that appears in lowercase letters must be read out loud
- Text in UPPERCASE letters must not be read out loud
- Text that is underlined must be emphasized
- Characters in < > must not be read
- [Square brackets] are used to show programming instructions that must not actually appear on electronic telephone interviewing system screens
- MISSING/DON’T KNOW (DK) is a valid response option for each item in the electronic telephone interviewing system scripts. This allows the telephone interviewer to go to the next question if a respondent is unable to provide a response for a given question (or refuses to provide a response). In the survey file layouts, a value of MISSING/DK is coded as “M – Missing/Don't know.”
- Skip patterns should be programmed into the electronic telephone system

- Appropriately skipped questions should be coded as “88 – Not applicable.” For example, if a respondent answers “No” to Question 4 of the CAHPS Hospice Survey, the program should skip Question 5, and go to Question 6. Question 5 must then be coded as “88 – Not applicable.” Coding may be done automatically by the telephone system or later during data preparation.
- When a response to a screener question is not obtained, the screener question and any questions in the skip pattern should be coded as “M – Missing/Don't know.” For example, if the respondent does not provide an answer to Question 17 of the CAHPS Hospice Survey and the interviewer selects “M – Missing/Don't know” to Question 17, then the telephone system should be programmed to skip Questions 18, 19, & 20 and go to Question 21. Questions 18, 19 & 20 must then be coded as “M – Missing/Don't know.” Coding may be done automatically by the telephone interviewing system or later during data preparation.
- There must be only one language (i.e., English or Spanish) that appears on the electronic telephone interviewing system screen

Appendix G

CAHPS[®] Hospice Survey Frequently Asked Questions For Customer Support

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix G

CAHPS[®] Hospice Survey Frequently Asked Questions for Customer Support

Overview

This document provides survey customer support personnel guidance on responding to frequently asked questions (FAQs) from caregivers answering the CAHPS[®]¹ Hospice Survey. It provides answers to general questions about the survey, concerns about participating in the survey, and questions about completing/returning the survey. Survey vendors may amend the document to be specific to their operations, or revise individual responses for clarity.

Note: Survey vendors conducting the CAHPS Hospice Survey must NOT attempt to influence or encourage caregivers to answer items in a particular way. For example, the survey vendor conducting the CAHPS Hospice Survey must NOT say, imply or persuade caregivers to respond to items in a particular way. In addition, survey vendors must NOT indicate or imply in any manner that the hospice, its personnel or its agents will appreciate or gain benefits if caregivers respond to the items in a particular way. Please refer to the “Program Requirements” section of the CAHPS Hospice Survey Quality Assurance Guidelines V1.0 for more information on communicating with caregivers.

I. General Questions About the Survey

➤ **Who is conducting this survey? Who is sponsoring this survey?**

[SURVEY VENDOR:] I’m an interviewer from the research organization [SURVEY VENDOR NAME]. [HOSPICE NAME] has asked our organization to help conduct this survey to enable them to get feedback from caregivers whose family member or friend recently died while in hospice care.

➤ **What is the purpose of the survey? How will the data be used?**

The survey is part of a national initiative by the United States Department of Health and Human Services to measure the quality of care in hospices.

The survey is designed to measure caregiver’s perspectives on hospice care for public reporting. The data collected from the survey will be provided to consumers to help them make informed choices when selecting a hospice. It will also be used to help improve the quality of care provided by hospices. Your participation is important.

¹ CAHPS[®] is a registered trademark of the Agency for Healthcare Research and Quality, a U.S. Government agency.

➤ **How can I verify this survey is legitimate?**

You can contact [HOSPICE NAME] at [TELEPHONE NUMBER] for information about the survey.

NOTE: SURVEY VENDORS OBTAIN CONTACT INFORMATION FROM THE HOSPICE ABOUT WHO TO CONTACT TO VERIFY THE LEGITIMACY OF THE SURVEY.

➤ **Is there a government agency that I can contact to find out more about this survey?**

Yes, you can contact the Centers for Medicare & Medicaid Services, a federal agency within the Department of Health and Human Services through the CAHPS Hospice Survey Technical Assistance telephone number at 1-844-472-4621 or by email at hospicecahpsurvey@HCQIS.org.

➤ **Are my answers confidential? Who will see my answers?**

Your answers will be seen by the research staff, and may be shared with the hospice for purposes of quality improvement.

➤ **How long will this take?**

The survey takes about 10 minutes [OR SURVEY VENDOR SPECIFY].

NOTE: THE NUMBER OF MINUTES WILL DEPEND ON WHETHER SURVEY IS INTEGRATED WITH HOSPICE-SPECIFIC SUPPLEMENTAL QUESTIONS.

➤ **What questions will be asked?**

The survey asks questions about the experiences your family member or friend had receiving care and services from the hospice. There will be questions asking you about any problems they may have had receiving care or services. It asks you to rate different types of care and services your family member or friend may have received.

➤ **How did you get my name? How was I chosen for the survey?**

Your name was randomly selected from all recent patient deaths from [HOSPICE NAME].

II. Concerns About Participating in the Survey

➤ **I don't do surveys.**

I understand, however I hope you will consider participating. This is a very important study for [HOSPICE NAME]. The results of the survey will help them understand what they are doing well and what needs improvement.

➤ **I'm not interested.**

[HOSPICE NAME] could really use your help. Could you tell me why you're not interested in participating?

➤ **I'm extremely busy. I don't really have the time.**

I know your time is limited; however, it is a very important survey, and I really appreciate your help today. The interview will take about 10 minutes [OR SURVEY VENDOR SPECIFY]. Perhaps we could get started, and see what the questions are like. We can stop any time you like.

[IF NECESSARY:] The interview can be broken into parts, if necessary; you don't have to do the whole thing in one sitting.

[IF NECESSARY:] I can schedule it for any time that is convenient for you, including evenings or weekends if you prefer.

NOTE: THE NUMBER OF MINUTES WILL DEPEND ON WHETHER THE HOSPICE SURVEY IS INTEGRATED WITH HOSPICE-SPECIFIC SUPPLEMENTAL QUESTIONS.

➤ **You called my cell phone. Can you call back after [CAREGIVER SPECIFY TIME]?**

Yes, we can call you back at [CAREGIVER SPECIFY]?

[IF "NO":] Set future date/time.

NOTE: TELEPHONE CALL ATTEMPTS ARE TO BE MADE BETWEEN THE HOURS OF 9 AM AND 9 PM, RESPONDENT TIME, UNLESS AN ALTERNATIVE TIME IS REQUESTED BY CAREGIVER.

➤ **I don't want to answer a lot of personal questions.**

I understand your concern. This is a very important survey. If a question bothers you, just tell me you'd rather not answer it, and I'll move on to the next question. Why don't we get started and you can see what the questions are like?

➤ **I'm very unhappy with [HOSPICE NAME] and I don't see why I should help them with this survey.**

I'm sorry you're unhappy. This is a good reason for you to participate. Your responses will help the hospice understand what improvements are needed.

➤ **Do I have to complete the survey? What happens if I do not? Why should I?**

Your participation is voluntary. There are no penalties for not participating. But, it is a very important survey and your answers will help us to improve the quality of care [HOSPICE NAME] provides and will also help other consumers make informed decisions when they choose a hospice for themselves or their family members or friends.

➤ **Will I get junk mail if I answer this survey?**

No, you will not get any junk mail as a result of answering this survey.

➤ **I am on the *Do Not Call List*. Are you supposed to be calling me?**

The *Do Not Call List* prohibits sales and telemarketing calls. We're not selling anything nor asking for money. We are a survey research firm. Your hospice has asked us to help conduct this survey.

➤ **I don't want to buy anything.**

We're not selling anything or asking for money. We want to ask you some questions about the care and services provided by [HOSPICE NAME].

III. Questions About Completing/Returning the Survey

➤ **Is there a deadline to fill out the survey?**

[FOR MAIL SURVEY:] Since we need to contact so many people, it would really help if you could return it within the next several days.

[FOR TELEPHONE SURVEY:] We need to finish all the interviews as soon as possible, but since we need to contact so many people, it would really help if we could do the interview right now. If you don't have the time, maybe I could schedule an appointment for sometime within the next several days.

➤ **Where do I put my name and address on the questionnaire?**

You should not write your name or address on the questionnaire. Each survey has been assigned an identification number that allows us to keep track of which respondents have returned a completed questionnaire.

Appendix H

CAHPS[®] Hospice Survey Model Quality Assurance Plan

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix H

CAHPS[®] Hospice Survey Model Quality Assurance Plan

Overview and Background

Survey vendors that are approved to administer the CAHPS Hospice Survey will be required to submit an annual Quality Assurance Plan (QAP). The QAP must describe the survey vendor's implementation of and compliance with all required protocols to administer the CAHPS Hospice Survey.

The purpose of this document is to serve as a model or guide in the preparation of a survey vendor's QAP in order to ensure that all required items are addressed in sufficient detail for review by the CAHPS Hospice Survey Project Team. Following review by the project team, the survey vendor will be provided with feedback that indicates whether the QAP has been accepted, conditionally accepted (pending completion of follow-up of required items – usually minor) or requires revision (major changes needed in order for the QAP to be considered complete).

It will be important that sufficient detail is provided in the QAP so that the project team can determine a survey vendor's adherence to survey administration guidelines and that rigorous quality checks or controls have been put in place. All survey materials (mail materials and screen shots of the telephone script in English and Spanish) must be submitted for review. In addition, examples of templates, logs, tracking tools or other relevant documentation should be included as appendices to the QAP.

The following sections below outline the required content to be addressed and the specified sequence that must be followed in the survey vendor's QAP.

Organizational Background and Structure

1. *Provide survey vendor contact information on the first page of the QAP. Please include:*
 - A. Survey vendor name
 - B. Survey vendor's mailing address
 - C. Physical location, if mailing address is different
 - D. Web site address, if one is available
 - E. Name of contact person, his or her direct telephone number and email address
 - F. Number of contracted client hospices, if applicable
 - G. Survey vendor's approved survey mode(s)
 - H. Date of the QAP
2. *Briefly describe the survey vendor's history and affiliations, including the scope of business and number of years in business*
3. *Describe the survey vendor's survey experience with all patient populations, including a description of the mode(s) of survey administration and the number of years conducted, for each mode the survey vendor is approved to administer the CAHPS Hospice Survey*

4. *Provide and attach a CAHPS Hospice Survey **organizational chart** that identifies, by name and title, the staff and subcontractors, if applicable, responsible for each of the major project tasks. Include in the organizational chart the reporting relationships for all CAHPS Hospice Survey project staff, and identify any key staff who work from remote locations. Also, please specify the name and title of the staff members (primary and secondary/backup) who perform the following project tasks:*
 - A. Overall project management, including training and supervision
 - B. Tracking of key survey events
 - C. Creation of the sample frame
 - D. Drawing the sample
 - E. Assignment of the random, unique de-identified decedent/caregiver identification numbers
 - F. Administering the survey by the approved mode (Mail Only, Telephone Only, Mixed Mode)
 - G. Data receipt and data entry
 - H. Data submission; list all staff members authorized to upload data to the CAHPS Hospice Survey Data Warehouse
 - I. Quality checks of all key events including, but not limited to, survey administration, sample frame creation, data entry, data submission, electronic backup systems, etc.
5. *Describe the background and qualifications of all key personnel (e.g., Project Director, Project Manager, Programmer, Call Center/Mail Center Supervisor) involved in the CAHPS Hospice Survey, including a description of the capabilities of all subcontractors and the survey vendor's experience with its subcontractors, if applicable. Background and qualifications of all key personnel and subcontractor(s) should include experience in conducting patient-specific surveys and experience in the appropriate project task(s) assigned to the project staff. Staff resumes are not required; however, these resumes may be requested during oversight activities.*
6. *Identify who participated in the CAHPS Hospice Survey webinar training in the current year. Describe the training that has been or will be provided to all personnel involved in CAHPS Hospice Survey processes, including subcontractors, if subcontractors are used during the CAHPS Hospice Survey process. Survey vendors should also describe training that they provide to their client hospices.*

Work Plan for Survey Administration

This section of the QAP should be written in a manner so that a new member of the CAHPS Hospice Survey team could carry out the processes necessary to administer the CAHPS Hospice Survey. The QAP should provide sufficient detail for this person to completely understand and accurately follow the processes to administer the survey, and should include a comprehensive timeline of key events (number of days between key events), showing who will do what, when they will do it, and how they will get it done. The QAP should be free of extraneous information. The emphasis should be on providing concise explanations of required CAHPS Hospice Survey processes.

Note: If survey vendors are approved for multiple modes of survey administration, they must separately list responses for each mode.

7. *Provide the information requested below for the survey vendor's approved mode of survey administration, including a timeline of key survey administration events.*
 - A. Mail Only Mode – describe the process for updating addresses, producing mailing materials, and process for mailing out the surveys (Mail Only Survey Administration chapter)
 - B. Telephone Only Mode – describe the process for updating telephone numbers, programming and operating the interviewing systems, and contacting sampled caregivers (Telephone Only Survey Administration chapter)
 1. Describe how interviewers respond to respondents who request or are in need of bereavement services
 - C. Mixed Mode – see above for Mail Only and Telephone Only (Mixed Mode Survey Administration chapter)
 - D. describe your organization's Distressed Respondent Procedures

8. *Describe the steps involved in creating the sample frame and selecting the sample size. (Do not include programming code.)*
 - A. Describe the process for receiving and updating the decedent/caregiver information, including electronic security utilized for exchange of decedent/caregiver lists between client hospices and survey vendors. Describe what the hospice will provide for sample frame creation.
 1. Include a list of all data elements the hospice will provide
 - B. Describe the database(s)/document(s) that will be used to identify the eligible decedents/caregivers
 - C. Describe the method of sampling to be used, including the process for selecting the sample size (Sampling Protocol chapter)
 - D. Describe the procedure for ensuring hospices with sufficient eligible population sizes sample at least 700 decedents/caregivers in a 12-month timeframe
 - E. List the CAHPS Hospice Survey eligibility and exclusion criteria and describe the process for applying them to determine decedent/caregiver eligibility for inclusion in the CAHPS Hospice Survey sample frame (Sampling Protocol chapter)
 - F. If administering the survey in multiple languages identify the language(s) and describe how the survey language to be administered to the eligible caregiver is chosen

9. *Describe the process and steps used to assign the random, unique de-identified decedent/caregiver identification numbers. (NOTE: Identification numbers must not be based on a coding structure that could potentially reveal decedent/caregiver identities, such as those that incorporate the decedent's/caregiver's last name, initials, date of birth, hospice account number, month, date, etc.)*

10. *List all Exceptions Requests for which the survey vendor has received approval and describe how these approved exceptions requests are incorporated into the CAHPS Hospice Survey process*

11. *Describe the data receipt and data entry procedures. (Do not include programming code.)*
 - A. Describe how the surveys are handled and recorded when they are returned by mail (if applicable) or completed by telephone (if applicable)
 - B. Describe the use of the decision rules, if applicable
 - C. Describe the scanning procedure, if applicable
 - D. Describe how and when in the process the final survey status code is assigned

- E. Provide the crosswalk of your organization’s interim disposition codes to final CAHPS Hospice Survey disposition codes, if applicable
12. *Describe the data preparation and submission procedures. (Do not include programming code.)*
- A. Describe the process of updating the eligibility status of decedents/caregivers (i.e., process for updating any missing fields in the decedent/caregiver list received from the hospice), if applicable
 - B. Describe the process for converting data into XML files and uploading the data to the CAHPS Hospice Survey Data Warehouse, if applicable
 - C. Describe the time frames for completing data submission

Survey and Data Management System and Quality Controls

13. *Describe the system resources (hardware and software) available, if not previously described in sections above, such as:*
- A. Telephone (CATI) interviewing systems
 - B. Mailing equipment
 - C. Scanning systems
 - D. Software used for tracking, assigning de-identifying numbers, generating sample frame, producing mail survey packets, telephone survey administration, XML file generation
 - E. Address and telephone number updating resources
14. *Describe the customer support telephone line and how it will be operated*
- A. Identify who is responsible for responding to questions regarding the CAHPS Hospice Survey
 - B. Specify the customer support telephone number
 - C. Include a written transcript of the voice mail message that specifies the caller can leave a message about the survey
 - D. Include the hours of live/voice mail operations for the customer support line and the time frame for returning voice mail messages
 - E. Describe how survey vendor will provide customer support in all languages that the survey vendor administers the survey in
 - F. Describe how survey vendor will handle respondents who request or are in need of bereavement services
15. *Tracking of key events should be part of a survey vendor’s quality oversight processes. Describe how key events are tracked throughout the survey process, including, but not limited to:*
- A. Receipt of the decedent/caregiver list
 - B. Creation of the sample frame
 - C. Drawing the sample
 - D. Assignment of random, unique de-identified decedent/caregiver identification numbers
 - E. Administering the survey by the approved mode(s) of administration
 - F. Data receipt
 - G. Data entry
 - H. Data submission
 - I. Data Retention

For items 14 –19, please be sure to include the following in your description.

- ◆ Identify who performs the checks
 - ◆ Identify what checks are performed
 - ◆ Identify how the checks are performed
 - ◆ Identify how frequently the checks occur
 - ◆ Identify the number or percentage of records that are checked
 - ◆ Identify the documentation that provides evidence that the checks are performed
16. Describe the process for monitoring on-site work and subcontractors' work to ensure high quality results. Include monitoring of telephone interviewers, and checks of printed mailing materials.
17. Describe the quality control checks implemented to validate that eligibility and exclusion criteria are applied correctly and that sample frame creation is accurate
- A. Describe the method used to verify the sample is a random selection (unless using 100% census sample)
18. Describe the quality control process to validate the accuracy of manual data entry and/or electronic scanning procedures. Include the quality control process to verify the accuracy of the application of CAHPS Hospice Survey decision rules (mail surveys).
19. Describe the quality control checks of telephone (CATI) procedures to confirm that programming is accurate and in accordance with CAHPS Hospice Survey protocols, and that data integrity is maintained (if applicable to your CAHPS Hospice Survey processes)
20. Describe the quality control process to validate the accuracy of data submission including the review of the CAHPS Hospice Survey Data Warehouse Submission Reports
21. Describe the process for electronic back-up, including the quality control checks that are in place to ensure the backup files are retrievable

Confidentiality, Privacy and Security Procedures

22. Describe the confidentiality agreements with staff and subcontractors involved in any aspect of survey administration. Be sure to include information as to whether the confidentiality agreement contains content for surveys in general or if CAHPS Hospice Survey-specific language is included in the confidentiality agreement.
23. Describe the physical and electronic security and storage procedures to protect decedent/caregiver-identified files, survey questionnaires, audio-recorded interviews, and sample files, including the length of time that the survey materials will be retained

QAP Update: Discussion of Results of Quality Control Activities

24. Discuss the results and “lessons learned” from the quality review activities listed below. Describe in detail the outcomes of these reviews.
- A. Describe CAHPS Hospice Survey administration challenges and how these were handled

- B. Describe the discovery of any variations from CAHPS Hospice Survey protocols and how these variations were corrected
- C. Describe the process for communicating the results of your quality checks to upper management
- D. Describe any opportunities for improvement to your CAHPS Hospice Survey administration processes that were identified
- E. Document in the QAP any changes in survey administration resulting from quality process improvement activities

Other

- 25. *Include any forms used in CAHPS Hospice Survey administration that may assist the CAHPS Hospice Survey Project Team in reviewing the survey vendor's processes (e.g., tracking logs, sample frame format, etc.). **NOTE: These items should be templates only and must not contain any Protected Health Information (PHI).***

Appendix I

CAHPS[®] Hospice Survey Exception Request Form

**THIS PAGE
INTENTIONALLY
LEFT BLANK**

Appendix I

CAHPS[®] Hospice Survey Exception Request Form

To complete and submit the Exception Request Form online, visit the CAHPS^{®1} Hospice Survey Web site at www.hospicecahpsurvey.org. Section I is to be completed by the survey vendor submitting this form. The hospice(s) for which this Exception Request relates to must be listed in Section II along with each hospice's CMS Certification Number (CCN). All required fields are indicated with an asterisk (*). *NOTE: This form does not accept any special characters or symbols in the text boxes. Use only alphanumeric characters when completing this form.*

I. General Information

Tracking ID

[Auto Populated]

Submission Date

[Auto Populated]

Name of Survey Vendor submitting the Exception Request *

II. Contact Person for this Exception Request (Confirmation email will be sent to the Contact Person.)

2a. First Name: *

2b. Middle Initial:

2c. Last Name: *

2d. Title:*

2e. Mailing Address 1: *

2f. Mailing Address 2:

2g. City: *

2h. State: *

2i. Zip Code: *

2j. Telephone: * (xxx-xxx-xxxx)

EXT:

2k. Fax Number:

2l. Email Address: *

III. Exception Request

Please complete items 1, 2 and 3 below for each requested exception

1. Exception Request For (Check one in each category):

- 1a. New Exception
 Appeal of Exception Denial

1b. Exception (specify)

¹ CAHPS[®] is a registered trademark of the Agency for Healthcare Research and Quality, a U.S. Government agency.

2. List of Hospices applicable to this Exception Request

Hospice Name: *	CCN: *

3. Description of Exception Request

3a. Purpose of Proposed Exception Request (e.g., sampling, other): *

3b. Rationale for Proposed Exception Request: *

3c. Explanation of Implementation of Proposed Exception Request: *

3d. Evidence that Exception Will Not Affect Survey Results: *

The Exception Request Form must be completed and submitted online at www.hospicecahpsurvey.org.

Appendix J

CAHPS[®] Hospice Survey Discrepancy Report Form

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix J

CAHPS[®] Hospice Survey Discrepancy Request Form

Section 1 is to be completed by the survey vendor submitting this form. The requested information regarding the affected hospices must be provided in Section 4 in order to complete the CAHPS^{®1} Hospice Survey Discrepancy Report. THIS FORM MUST BE SUBMITTED ONLINE (www.hospicecahpsurvey.org). All required fields are indicated with an asterisk (*). *NOTE: This form does not accept any special characters or symbols in the text boxes. Use only alphanumeric characters when completing this form.*

1. General Information

Tracking ID

[Auto Populated]

Submission Date

[Auto Populated]

Name of Survey Vendor submitting Discrepancy Report *

2. Contact Person for this Discrepancy Report (Confirmation email will be sent to the Contact Person.)

2a. First Name: *

2b. Middle Initial:

2c. Last Name: *

2d. Title:*

2e. Mailing Address 1: *

2f. Mailing Address 2:

2g. City: *

2h. State: *

2i. Zip Code: *

2j. Telephone: * (xxx-xxx-xxxx)

EXT:

2k. Fax Number:

2l. Email Address: *

3. Information About the Discrepancy

3a. Description of the discrepancy: *

3b. Description of how the discrepancy was identified: *

3c. Description of the corrective action to fix the discrepancy, including estimated time for implementation: *

¹ CAHPS[®] is a registered trademark of the Agency for Healthcare Research and Quality, a U.S. Government agency.

3d. Additional information that would be helpful that has not been included above: *

4. List of Hospices Applicable to this Discrepancy

4a. Total number of affected hospices: *

4b. Add the information for the affected hospices by populating the following 10 fields. A hospice may be added more than once if there are multiple time frames for the hospice. It is important that the impact of the discrepancy is quantified; however “unknown” will be accepted as a valid response in the fields below, if the requested information is not known at the time this form is completed.

Name of Hospice	CCN	Hospice Contact Person	Email Address	Eligible Decedents/ Caregivers Affected	Avg. Eligible Decedents/ Caregivers/ Month	Sampled Decedents/ Caregivers Affected	Avg. Surveys Admin/ Month	Time Frame Begin Date xx/xx/xx	Time Frame End Date xx/xx/xx

This form must be submitted online via the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org).

Appendix K

CAHPS[®] Hospice Survey Participation Exemption for Size Form

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix K

CAHPS[®] Hospice Survey Participation Exemption for Size Form

To complete and submit the Participation Exemption for Size Form online, visit the CAHPS^{®1} Hospice Survey Web site at www.hospicecahpssurvey.org. All required fields are indicated with an asterisk (*). *Note: For multiple hospice programs sharing one CCN, the survey-eligible decedent/caregiver count is the total from all programs.*

I. General Information

CCN Number: *	Submission Date [Auto Populated]	Name of Hospice: *
<input type="text"/>	<input type="text"/>	<input type="text"/>

II. Contact Person at Hospice for this Exemption for Size Request (Confirmation email will be sent to the Contact Person)

2a. First Name: *	2b. Middle Initial:	2c. Last Name: *
<input type="text"/>	<input type="text"/>	<input type="text"/>
2d. Title:*	2e. Mailing Address 1: *	2f. Mailing Address 2:
<input type="text"/>	<input type="text"/>	<input type="text"/>
2g. City: *	2h. State: *	2i. Zip Code: *
<input type="text"/>	<input type="text"/>	<input type="text"/>
2j. Telephone: * (xxx-xxx-xxxx)	EXT:	2k. Fax Number:
<input type="text"/>	<input type="text"/>	<input type="text"/>
2l. Email Address: *		
<input type="text"/>		

III. Participation Exemption for Size Request (Do not leave any fields blank – enter 0 [zero] if applicable)

1. Enter the total number of patients who died while in hospice care between January 1, 2014 and December 31, 2014 (CY 2014)*	<input type="text"/>
2. Enter the total number of patients during CY 2014 who fall into the following categories. Do not include a patient in more than one of the following categories:	
a. Enter the number of patients who were discharged alive*	<input type="text"/>
b. Enter the number of decedents:	
i. who were under the age of 18*	<input type="text"/>
ii. who died within 48 hours of admission to hospice care*	<input type="text"/>
iii. for whom there is no caregiver of record*	<input type="text"/>
iv. for whom the caregiver is a non-familial legal guardian*	<input type="text"/>
v. for whom the caregiver has a foreign (non-US or US Territory) home address*	<input type="text"/>
vi. for whom the caregiver requested not to be contacted*	<input type="text"/>

The Participation Exemption for Size Form must be completed and submitted online at www.hospicecahpssurvey.org.

¹ CAHPS[®] is a registered trademark of the Agency for Healthcare Research and Quality, a U.S. Government agency.

Appendix L

CAHPS[®] Hospice Survey Examples of Additional Supplemental Questions For Survey Vendor Use

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix L

CAHPS[®] Hospice Survey Examples of Additional Supplemental Questions For Survey Vendor Use

S1. 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?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

S2. 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.

Special Medical Equipment¹

S3. Special medical equipment includes things like hospital beds, wheelchairs, or oxygen. While your family member was in hospice care, did your family member need special medical equipment?

- ¹ Yes
- ² No → If No, please go to Question S5.

¹ The items regarding special medical equipment were designed and tested to assess care within a home setting. Care should be taken when interpreting results from respondents whose family members did not receive care in a home setting. It is recommended that Question S3 be used as a screener for the subsequent Special Medical Equipment items.

S4. Did your family member get the equipment as soon as he or she needed it?

¹ Yes

² No

S5. Was the equipment picked up in a timely manner when your family member no longer needed it?

¹ Yes

² No

Personal Care Needs²

S6. 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?

¹ Never

² Sometimes

³ Usually

⁴ Always

Hospice Care Received in a Hospital or Hospice Facility

S7. Some people receive hospice care while they are in a hospital or hospice facility. Did your family member receive care from this hospice while he or she was in a hospital or hospice facility?

¹ Yes

² No

S8. While your family member was in hospice care, did you speak to a doctor as often as you needed?

¹ Yes, definitely

² Yes, somewhat

³ No

² Note: The item regarding personal care needs was designed and tested to assess care within nursing home or inpatient settings. Care should be taken when interpreting results from respondents whose family members received care only in a home setting.

S9. While your family member was in hospice care, were his or her room and bathroom kept clean?

- ¹ Yes, definitely
- ² Yes, somewhat
- ³ No

Consent to Share Responses

In addition, one supplemental question must be included in the mail and telephone questionnaire **if** the hospice wishes to view the survey responses linked to respondents' name and other identifying information. The survey question, referred to as the Consent to Share Responses, must be printed in the mail questionnaire and included in the telephone questionnaire. The respondent must check the "Yes" response option in the mail questionnaire or answer "Yes" to the question during the telephone interview for the vendor to provide the hospice with the respondent's answers linked to the respondent's name and identifying information. The question is typically placed at the end of the questionnaire or interview, as the last question.

The hospice that provided care to your family member may want to review your answers so that they can decide how to address any concerns that you have. We will not share your answers to this survey linked to your name unless you give your permission for this information to be shared with the hospice.

Do you give your permission to provide your answers to this survey linked to your name to the hospice?

- Yes, I give my permission to share my name and survey responses with the hospice.
- No, I do not give permission to share my name and survey responses with the hospice.

Appendix M

CAHPS[®] Hospice Survey Mail Survey Materials (English)

THIS PAGE
INTENTIONALLY
LEFT BLANK

CAHPS[®] Hospice Survey

Please answer the survey questions about the care the patient received from this hospice:

[NAME OF HOSPICE]

All of the questions in this survey will ask about the experiences with this hospice.

If you want to know more about this survey, please call [TOLL FREE NUMBER]. All calls to that number are free.

OMB#XXXX-XXXX

CAHPS[®] Hospice Survey

SURVEY INSTRUCTIONS

◆ Please give this survey to the person in your household who knows the most about the hospice care received by the person listed on the survey cover letter.

◆ Use a dark colored pen to fill out the survey.

◆ Place an X directly inside the square indicating a response, like in the sample below.

Yes
 No

◆ To indicate an answer selected was in error clearly draw a line through the square and select another square.

◆ You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

Yes → ***If Yes, Go to Question 1***
 No

THE HOSPICE PATIENT

1. How are you related to the person listed on the survey cover letter?

- ¹ My spouse or partner
- ² My parent
- ³ My mother-in-law or father-in-law
- ⁴ My grandparent
- ⁵ My aunt or uncle
- ⁶ My sister or brother
- ⁷ My child
- ⁸ My friend
- ⁹ Other (please print):

2. For this survey, the phrase "family member" refers to the person listed on the survey cover letter. In what locations did your family member receive care from this hospice? Please choose one or more.

- ¹ Home
- ² Assisted living facility
- ³ Nursing home
- ⁴ Hospital
- ⁵ Hospice facility/hospice house
- ⁶ Other (please print):

YOUR ROLE

3. While your family member was in hospice care, how often did you take part in or oversee care for him or her?

- Never → If Never, go to Question 41
- Sometimes
- Usually
- Always

YOUR FAMILY MEMBER'S HOSPICE CARE

As you answer the rest of the questions in this survey, please think only about your family member's experience with the hospice named on the survey cover.

4. For this survey, the hospice team includes all the nurses, doctors, social workers, chaplains and other people who provided hospice care to your family member. 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?

- Yes
- No → If No, go to Question 6

5. How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?

- Never
- Sometimes
- Usually
- Always

6. While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?

- Never
- Sometimes
- Usually
- Always

7. 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?

- Never
- Sometimes
- Usually
- Always

8. While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?

- Never
- Sometimes
- Usually
- Always

9. While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?

- Never
- Sometimes
- Usually
- Always

10. 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?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

11. While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

12. While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

13. 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?

- ¹ Yes
- ² No → If No, go to Question 15

14. How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?

- ¹ Never
- ² Sometimes
- ³ Usually
- ⁴ Always

15. While your family member was in hospice care, did he or she have any pain?

- ¹ Yes
- ² No → If No, go to Question 17

16. Did your family member get as much help with pain as he or she needed?

- ¹ Yes, definitely
- ² Yes, somewhat
- ³ No

17. While your family member was in hospice care, did he or she receive any pain medicine?

- ¹ Yes
- ² No → If No, go to Question 21

18. 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?

- ¹ Yes, definitely
- ² Yes, somewhat
- ³ No

19. Did the hospice team give you the training you needed about what side effects to watch for from pain medicine?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No

20. Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No
- 4 I did not need to give pain medicine to my family member

21. While your family member was in hospice care, did your family member ever have trouble breathing or receive treatment for trouble breathing?

- 1 Yes
- 2 No → If No, go to Question 24

22. How often did your family member get the help he or she needed for trouble breathing?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

23. Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No
- 4 I did not need to help my family member with trouble breathing

24. While your family member was in hospice care, did your family member ever have trouble with constipation?

- 1 Yes
- 2 No → If No, go to Question 26

25. How often did your family member get the help he or she needed for trouble with constipation?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

26. While your family member was in hospice care, did he or she show any feelings of anxiety or sadness?

- 1 Yes
- 2 No → If No, go to Question 28

27. How often did your family member get the help he or she needed from the hospice team for feelings of anxiety or sadness?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

28. While your family member was in hospice care, did he or she ever become restless or agitated?

- Yes
- No → If No, go to Question 30

29. Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?

- Yes, definitely
- Yes, somewhat
- No

30. 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 the training you needed about how to safely move your family member?

- Yes, definitely
- Yes, somewhat
- No
- I did not need to move my family member

31. Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?

- Yes, definitely
- Yes, somewhat
- No

HOSPICE CARE RECEIVED IN A NURSING HOME

32. Some people receive hospice care while they are living in a nursing home. Did your family member receive care from this hospice while he or she was living in a nursing home?

- Yes
- No → If No, go to Question 35

33. 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?

- Never
- Sometimes
- Usually
- Always

34. 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?

- Never
- Sometimes
- Usually
- Always

YOUR OWN EXPERIENCE WITH HOSPICE

35. While your family member was in hospice care, how often did the hospice team listen carefully to you?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

36. 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?

- 1 Too little
- 2 Right amount
- 3 Too much

37. While your family member was in hospice care, how much emotional support did you get from the hospice team?

- 1 Too little
- 2 Right amount
- 3 Too much

38. In the weeks after your family member died, how much emotional support did you get from the hospice team?

- 1 Too little
- 2 Right amount
- 3 Too much

OVERALL RATING OF HOSPICE CARE

39. Please answer the following questions about your family member's care from the hospice named on the survey cover. Do not include care from other hospices in your answers.

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?

- 0 0 Worst hospice care possible
- 1 1
- 2 2
- 3 3
- 4 4
- 5 5
- 6 6
- 7 7
- 8 8
- 9 9
- 10 10 Best hospice care possible

40. Would you recommend this hospice to your friends and family?

- 1 Definitely no
- 2 Probably no
- 3 Probably yes
- 4 Definitely yes

ABOUT YOUR FAMILY MEMBER

41. What is the highest grade or level of school that your family member completed?

- 1 8th grade or less
- 2 Some high school but did not graduate
- 3 High school graduate or GED
- 4 Some college or 2-year degree
- 5 4-year college graduate
- 6 More than 4-year college degree
- 7 Don't know

42. Was your family member of Hispanic, Latino, or Spanish origin or descent?

- 1 No, not Spanish/Hispanic/Latino
- 2 Yes, Puerto Rican
- 3 Yes, Mexican, Mexican American, Chicano/a
- 4 Yes, Cuban
- 5 Yes, Other Spanish/Hispanic/Latino

43. What was your family member's race? Please choose one or more.

- 1 White
- 2 Black or African American
- 3 Asian
- 4 Native Hawaiian or other Pacific Islander
- 5 American Indian or Alaska Native

ABOUT YOU

44. What is your age?

- 1 18 to 24
- 2 25 to 34
- 3 35 to 44
- 4 45 to 54
- 5 55 to 64
- 6 65 to 74
- 7 75 to 84
- 8 85 or older

45. Are you male or female?

- 1 Male
- 2 Female

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

- 1 8th grade or less
- 2 Some high school but did not graduate
- 3 High school graduate or GED
- 4 Some college or 2-year degree
- 5 4-year college graduate
- 6 More than 4-year college degree

47. What language do you mainly speak at home?

- 1 English
- 2 Spanish
- 3 Chinese
- 4 Some other language (please print):

THANK YOU

Please return the completed survey in the postage-paid envelope.

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]

CAHPS[®] Hospice Survey

Please answer the survey questions about the care the patient received from this hospice:

[NAME OF HOSPICE]

All of the questions in this survey will ask about the experiences with this hospice.

If you want to know more about this survey, please call [TOLL FREE NUMBER]. All calls to that number are free.

OMB#XXXX-XXXX

CAHPS[®] Hospice Survey

SURVEY INSTRUCTIONS

◆ Please give this survey to the person in your household who knows the most about the hospice care received by the person listed on the survey cover letter.

◆ Use a dark colored pen to fill out the survey.

◆ Place an X directly inside the square indicating a response, like in the sample below.

Yes
 No

◆ To indicate an answer selected was in error clearly draw a line through the square and select another square.

◆ You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

Yes → ***If Yes, Go to Question 1***
 No

THE HOSPICE PATIENT

1. How are you related to the person listed on the survey cover letter?

- My spouse or partner
 My parent
 My mother-in-law or father-in-law
 My grandparent
 My aunt or uncle
 My sister or brother
 My child
 My friend
 Other (please print):

2. For this survey, the phrase "family member" refers to the person listed on the survey cover letter. In what locations did your family member receive care from this hospice? Please choose one or more.

- Home
 Assisted living facility
 Nursing home
 Hospital
 Hospice facility/hospice house
 Other (please print):

YOUR ROLE

3. While your family member was in hospice care, how often did you take part in or oversee care for him or her?
- ¹0 Never → If Never, go to Question 41
 - ²0 Sometimes
 - ³0 Usually
 - ⁴0 Always

YOUR FAMILY MEMBER'S HOSPICE CARE

As you answer the rest of the questions in this survey, please think only about your family member's experience with the hospice named on the survey cover.

4. For this survey, the hospice team includes all the nurses, doctors, social workers, chaplains and other people who provided hospice care to your family member. 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?
- ¹0 Yes
 - ²0 No → If No, go to Question 6
5. How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?
- ¹0 Never
 - ²0 Sometimes
 - ³0 Usually
 - ⁴0 Always

6. While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?
- ¹0 Never
 - ²0 Sometimes
 - ³0 Usually
 - ⁴0 Always
7. 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?
- ¹0 Never
 - ²0 Sometimes
 - ³0 Usually
 - ⁴0 Always
8. While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?
- ¹0 Never
 - ²0 Sometimes
 - ³0 Usually
 - ⁴0 Always
9. While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?
- ¹0 Never
 - ²0 Sometimes
 - ³0 Usually
 - ⁴0 Always

10. 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?

- ¹0 Never
- ²0 Sometimes
- ³0 Usually
- ⁴0 Always

11. While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

- ¹0 Never
- ²0 Sometimes
- ³0 Usually
- ⁴0 Always

12. While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?

- ¹0 Never
- ²0 Sometimes
- ³0 Usually
- ⁴0 Always

13. 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?

- ¹0 Yes
- ²0 No → If No, go to Question 15

14. How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?

- ¹0 Never
- ²0 Sometimes
- ³0 Usually
- ⁴0 Always

15. While your family member was in hospice care, did he or she have any pain?

- ¹0 Yes
- ²0 No → If No, go to Question 17

16. Did your family member get as much help with pain as he or she needed?

- ¹0 Yes, definitely
- ²0 Yes, somewhat
- ³0 No

17. While your family member was in hospice care, did he or she receive any pain medicine?

- ¹0 Yes
- ²0 No → If No, go to Question 21

18. 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?

- ¹0 Yes, definitely
- ²0 Yes, somewhat
- ³0 No

19. Did the hospice team give you the training you needed about what side effects to watch for from pain medicine?

- ¹0 Yes, definitely
- ²0 Yes, somewhat
- ³0 No

20. Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?

- ¹0 Yes, definitely
- ²0 Yes, somewhat
- ³0 No
- ⁴0 I did not need to give pain medicine to my family member

21. While your family member was in hospice care, did your family member ever have trouble breathing or receive treatment for trouble breathing?

- ¹0 Yes
- ²0 No → If No, go to Question 24

22. How often did your family member get the help he or she needed for trouble breathing?

- ¹0 Never
- ²0 Sometimes
- ³0 Usually
- ⁴0 Always

23. Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?

- ¹0 Yes, definitely
- ²0 Yes, somewhat
- ³0 No
- ⁴0 I did not need to help my family member with trouble breathing

24. While your family member was in hospice care, did your family member ever have trouble with constipation?

- ¹0 Yes
- ²0 No → If No, go to Question 26

25. How often did your family member get the help he or she needed for trouble with constipation?

- ¹0 Never
- ²0 Sometimes
- ³0 Usually
- ⁴0 Always

26. While your family member was in hospice care, did he or she show any feelings of anxiety or sadness?

- ¹0 Yes
- ²0 No → If No, go to Question 28

27. How often did your family member get the help he or she needed from the hospice team for feelings of anxiety or sadness?

- ¹0 Never
- ²0 Sometimes
- ³0 Usually
- ⁴0 Always

28. While your family member was in hospice care, did he or she ever become restless or agitated?

- ¹0 Yes
- ²0 No → If No, go to Question 30

29. Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?

- ¹0 Yes, definitely
- ²0 Yes, somewhat
- ³0 No

30. 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 the training you needed about how to safely move your family member?

- ¹0 Yes, definitely
- ²0 Yes, somewhat
- ³0 No
- ⁴0 I did not need to move my family member

31. Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?

- ¹0 Yes, definitely
- ²0 Yes, somewhat
- ³0 No

HOSPICE CARE RECEIVED IN A NURSING HOME

32. Some people receive hospice care while they are living in a nursing home. Did your family member receive care from this hospice while he or she was living in a nursing home?

- ¹0 Yes
- ²0 No → If No, go to Question 35

33. 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?

- ¹0 Never
- ²0 Sometimes
- ³0 Usually
- ⁴0 Always

34. 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?

- ¹0 Never
- ²0 Sometimes
- ³0 Usually
- ⁴0 Always

YOUR OWN EXPERIENCE WITH HOSPICE

35. While your family member was in hospice care, how often did the hospice team listen carefully to you?

- ¹0 Never
- ²0 Sometimes
- ³0 Usually
- ⁴0 Always

36. 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?

- ¹0 Too little
- ²0 Right amount
- ³0 Too much

37. While your family member was in hospice care, how much emotional support did you get from the hospice team?

- ¹0 Too little
- ²0 Right amount
- ³0 Too much

38. In the weeks after your family member died, how much emotional support did you get from the hospice team?

- ¹0 Too little
- ²0 Right amount
- ³0 Too much

OVERALL RATING OF HOSPICE CARE

39. Please answer the following questions about your family member's care from the hospice named on the survey cover. Do not include care from other hospices in your answers.

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?

- ⁰0 0 Worst hospice care possible
- ¹0 1
- ²0 2
- ³0 3
- ⁴0 4
- ⁵0 5
- ⁶0 6
- ⁷0 7
- ⁸0 8
- ⁹0 9
- ¹⁰0 10 Best hospice care possible

40. Would you recommend this hospice to your friends and family?

- ¹0 Definitely no
- ²0 Probably no
- ³0 Probably yes
- ⁴0 Definitely yes

ABOUT YOUR FAMILY MEMBER

41. What is the highest grade or level of school that your family member completed?

- ¹0 8th grade or less
- ²0 Some high school but did not graduate
- ³0 High school graduate or GED
- ⁴0 Some college or 2-year degree
- ⁵0 4-year college graduate
- ⁶0 More than 4-year college degree
- ⁷0 Don't know

42. Was your family member of Hispanic, Latino, or Spanish origin or descent?

- ¹0 No, not Spanish/Hispanic/Latino
- ²0 Yes, Puerto Rican
- ³0 Yes, Mexican, Mexican American, Chicano/a
- ⁴0 Yes, Cuban
- ⁵0 Yes, Other Spanish/Hispanic/Latino

43. What was your family member's race? Please choose one or more.

- ¹0 White
- ²0 Black or African American
- ³0 Asian
- ⁴0 Native Hawaiian or other Pacific Islander
- ⁵0 American Indian or Alaska Native

ABOUT YOU

44. What is your age?

- ¹0 18 to 24
- ²0 25 to 34
- ³0 35 to 44
- ⁴0 45 to 54
- ⁵0 55 to 64
- ⁶0 65 to 74
- ⁷0 75 to 84
- ⁸0 85 or older

45. Are you male or female?

- ¹0 Male
- ²0 Female

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

- ¹0 8th grade or less
- ²0 Some high school but did not graduate
- ³0 High school graduate or GED
- ⁴0 Some college or 2-year degree
- ⁵0 4-year college graduate
- ⁶0 More than 4-year college degree

47. What language do you mainly speak at home?

- ¹0 English
- ²0 Spanish
- ³0 Chinese
- ⁴0 Some other language (please print):

THANK YOU

Please return the completed survey in the postage-paid envelope.

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]

Sample Initial Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]

[ADDRESS]

[CITY, STATE ZIP]

Dear [SAMPLED CAREGIVER NAME]:

[HOSPICE NAME] is conducting a survey about the hospice services that patients and their families receive. You were selected for this survey because you were identified as the caregiver of [DECEDENT NAME]. We realize this may be a difficult time for you, but we hope that you will help us learn about the quality of care that you and your family member or friend received from the hospice.

Questions [NOTE THE QUESTION NUMBERS] in the enclosed survey are part of a national initiative sponsored by the United States Department of Health and Human Services (HHS) to measure the quality of care in hospices. The Centers for Medicare & Medicaid Services (CMS), which is part of HHS, is conducting this survey to improve hospice care. CMS pays for most of the hospice care in the U.S. It is CMS's responsibility to ensure that hospice patients and their family members and friends get high quality care. One of the ways they can fulfill this responsibility is to find out directly from you about the hospice care your family member or friend received. Your participation is voluntary and will not affect any health care or benefits you receive.

We hope that you will take the time to complete the survey. After you have completed the survey, please return it in the pre-paid envelope. Your answers will be combined with other respondents and may be shared with the hospice for purposes of quality improvement. [OPTIONAL: You may notice a number on the survey. This number is used to let us know if you returned your survey so we don't have to send you reminders.]

If you have any questions about the enclosed survey, please call the toll-free number 1-800-xxx-xxxx. Thank you for helping to improve hospice care for all consumers.

Sincerely,

[HOSPICE ADMINISTRATOR]

[HOSPICE NAME]

Sample Follow-up Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[HOSPICE OR VENDOR LETTERHEAD]
[SAMPLED CAREGIVER NAME]
[ADDRESS]
[CITY, STATE ZIP]

Dear [SAMPLED CAREGIVER NAME]:

Our records show that you were recently a caregiver for [DECEDENT NAME] at [NAME OF HOSPICE]. Approximately three weeks ago, we sent you a survey regarding the care you and your family member or friend received from this hospice. If you have already returned the survey to us, please accept our thanks and disregard this letter. However, if you have not done so already, we would greatly appreciate it if you would take the time to complete this important questionnaire.

We hope that you will take this opportunity to help us learn about the quality of care your family member or friend received. The results from this survey will be used to help ensure that all Americans get the highest quality hospice care.

Questions [NOTE THE QUESTION NUMBERS] in the enclosed survey are part of a national initiative sponsored by the United States Department of Health and Human Services (HHS) to measure the quality of care in hospices. Your participation is voluntary and will not affect any health care or benefits you receive.

Please take a few minutes and complete the enclosed survey. After you have completed the survey, please return it in the pre-paid envelope. Your answers will be combined with other respondents and may be shared with the hospice for purposes of quality improvement. [OPTIONAL: You may notice a number on the survey. This number is used to let us know if you returned your survey so we don't have to send you reminders.]

If you have any questions about the enclosed survey, please call the toll-free number 1-800-xxx-xxxx. Thank you for helping to improve hospice care for all consumers.

Sincerely,
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]

Appendix N

CAHPS[®] Hospice Survey Mail Survey Materials (Spanish)

THIS PAGE
INTENTIONALLY
LEFT BLANK

CAHPS[®] Hospice Survey

Por favor conteste las preguntas en esta encuesta sobre la atención que recibió este paciente de este hospicio:

NAME OF HOSPICE

Todas las preguntas en esta encuesta se tratan sobre las experiencias de este paciente con este hospicio.

Si desea saber más sobre este estudio, llama a [TOLL FREE NUMBER}. Todas las llamadas son gratis.

OMB# XXXX-XXXX

CAHPS[®] Hospice Survey

INSTRUCCIONES PARA LA ENCUESTA

- Por favor entréguele esta encuesta a la persona de su hogar que sepa más sobre los cuidados que recibió de este centro la persona cuyo nombre aparece en la carta de presentación de esta encuesta.
- Use un bolígrafo de tinta negra para completar el cuestionario
- Marque con una 'X' el cuadrado para indicar su respuesta. Vea el siguiente ejemplo:
 - Sí
 - No
- Si quiere cambiar una respuesta, tache con una línea el cuadrado que usted quiere cambiar y en su lugar marque con una 'X' el cuadrado que desea escoger, así:
- A veces hay que saltarse alguna pregunta. Cuando esto ocurra, una flecha a la derecha de la respuesta le indicará a qué pregunta hay que pasar. Por ejemplo:
 - Sí → **Si contestó Sí, pase a la Pregunta 1 en la Página 1.**
 - No

EL PACIENTE DEL HOSPICIO

1. ¿Qué relación tiene con usted la persona cuyo nombre aparece en la carta de presentación de esta encuesta?

¹ Es mi esposo/a o pareja

² Es mi padre/madre

³ Es mi suegro/a

⁴ Es mi abuelo/a

⁵ Es mi tío/a

⁶ Es mi hermano/a

⁷ Es mi hijo/a

⁸ Es un/a amigo/a

⁹ Otro (por favor imprima):

2. Para esta encuesta, utilizaremos las palabras “su familiar” para referirnos a la persona cuyo nombre aparece en la carta de presentación de esta encuesta. ¿En qué lugar o lugares recibió su familiar los cuidados de este hospicio? Marque uno o más

¹ En su casa

² En un hogar de asistencia parcial

³ En una casa de ancianos y convalecencia

⁴ En un hospital

⁵ En un centro u hogar de hospicio

⁶ Otro (Por favor imprima):

SU PAPEL

3. Mientras su familiar estuvo bajo los cuidados del hospicio, ¿con qué frecuencia supervisó usted o participó en dichos cuidados?

¹ Nunca → Si contestó Nunca, pase a la Pregunta 41.

² A veces

³ La mayoría de las veces

⁴ Siempre

LOS CUIDADOS QUE EL HOSPICIO PROPORCIONÓ A SU FAMILIAR

Al responder el resto de las preguntas de esta encuesta, por favor piense sólo en la experiencia de su familiar con el hospicio nombrado en la en la portada de esta encuesta.

4. Para esta encuesta, el equipo del hospicio incluye a todos los doctores, enfermeras, trabajadores sociales, religiosos y demás personas que le proporcionaron cuidados paliativos a su familiar.

Mientras su familiar estaba bajo los cuidados del hospicio, ¿tuvo usted que ponerse en contacto con el equipo del hospicio durante la noche, en fin de semana o en día festivo porque tenía alguna duda o necesitaba ayuda para el cuidado de su familiar?

¹ Sí

² No → Si contestó No, pase a la Pregunta 6.

5. **¿Con qué frecuencia obtuvo la ayuda que necesitaba del equipo del hospicio durante la noche, en fin de semana o en día festivo?**

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

6. **Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo de personal del hospicio lo mantuvo a usted informado de cuando iban a llegar a cuidar a su familiar?**

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

7. **Mientras su familiar estaba bajo los cuidados de este hospicio, cuando usted o un miembro de su familia le pedían ayuda al equipo del hospicio, ¿con qué frecuencia obtenían la ayuda tan pronto como la necesitaban?**

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

8. **Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio explicaba las cosas de un modo fácil de entender?**

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre.

9. **Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio lo mantenía a usted informado sobre el estado de su familiar?**

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

10. **Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia alguien del equipo del hospicio le dio a usted informes confusos o contradictorios sobre el estado o los cuidados de su familiar?**

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

11. Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del centro trataba a su familiar con dignidad y respeto?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

12. Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia sintió usted que al equipo del hospicio realmente le importaba su familiar?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

13. Mientras su familiar estaba bajo los cuidados del hospicio, ¿habló usted con el equipo del hospicio sobre algún problema relacionado con los cuidados de su familiar?

- 1 Sí
- 2 No → Si contestó No, pase a la Pregunta 15.

14. ¿Con qué frecuencia el equipo del hospicio lo escuchó con atención cuando usted les habló sobre problemas relacionados con los cuidados de su familiar?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

15. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿tuvo él/ella algún tipo de dolor?

- 1 Sí
- 2 No → Si contestó No, pase a la Pregunta 17.

16. ¿Recibió su familiar toda la ayuda que necesitaba contra el dolor?

- 1 Sí, definitivamente
- 2 Sí, más o menos
- 3 No

17. Mientras su familiar estaba bajo los cuidados del hospicio, ¿le dieron a él o a ella algún medicamento contra el dolor?

- 1 Sí
- 2 No → Si contestó No, pase a la Pregunta 21.

18. Entre los efectos secundarios de la medicina contra el dolor está la somnolencia. ¿Algún personal del equipo del hospicio habló con usted o su familiar sobre los efectos secundarios del medicamento contra el dolor?

¹ Sí, definitivamente

² Sí, más o menos

³ No

19. ¿El equipo del hospicio le dio la capacitación que usted necesitaba para saber de qué efectos secundarios del medicamento contra el dolor tenía usted que estar pendiente?

¹ Sí, definitivamente

² Sí, más o menos

³ No

20. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber si había que darle a su familiar más medicamento contra el dolor y, si sí, cuándo dárselo?

¹ Sí, definitivamente

² Sí, más o menos

³ No

⁴ No tuve necesidad de dar medicamento para el dolor a mi familiar

21. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿en algún momento tuvo su familiar dificultad para respirar o recibió tratamiento para su dificultad para respirar?

¹ Sí

² No → Si contestó No, pase a la Pregunta 24.

22. ¿Con qué frecuencia su familiar recibió la ayuda que necesitaba para su dificultad para respirar?

¹ Nunca

² A veces

³ La mayoría de las veces

⁴ Siempre

23. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber cómo ayudar a su familiar si él/ella tenía problemas para respirar?

¹ Sí, definitivamente

² Sí, más o menos

³ No

⁴ No tuve que ayudar a mi familiar con problemas para respirar

24. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿en algún momento tuvo su familiar problemas de estreñimiento?

¹ Sí

² No → Si contestó No, pase a la Pregunta 26.

25. ¿Con qué frecuencia su familiar recibió la ayuda que necesitaba para sus problemas de estreñimiento?

- ¹ Nunca
- ² A veces
- ³ La mayoría de las veces
- ⁴ Siempre

26. Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento él/ella sintió ansiedad o tristeza?

- ¹ Sí
- ² No → Si contestó No, pase a la Pregunta 28.

27. ¿Con qué frecuencia su familiar recibió del equipo del hospicio la ayuda que necesitaba para su ansiedad o tristeza?

- ¹ Nunca
- ² A veces
- ³ La mayoría de las veces
- ⁴ Siempre

28. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿en algún momento se puso su familiar inquieto o agitado?

- ¹ Sí
- ² No → Si contestó No, pase a la Pregunta 30.

29. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber qué hacer si su familiar se ponía inquieto o agitado?

- ¹ Sí, definitivamente
- ² Sí, más o menos
- ³ No

30. Mover a su familiar incluye acciones como ayudarlo/a a darse la vuelta en la cama, o meterse y salir de la cama o sentarse y levantarse de una silla de ruedas. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber cómo mover a su familiar de manera segura?

- ¹ Sí, definitivamente
- ² Sí, más o menos
- ³ No
- ⁴ No tuve que mover a mi familiar

31. ¿Le dio el equipo del hospicio tanta información como usted quería sobre qué acontecimientos esperar mientras su familiar estuviera muriéndose?

- ¹ Sí, definitivamente
- ² Sí, más o menos
- ³ No

**CUIDADOS DE HOSPICIO
BRINDADOS EN UN HOGAR DE
ANCIANOS Y CONVALECENCIA**

32. Algunas personas que viven en un hogar de ancianos o de convalecencia reciben allí mismo los cuidados de hospicio que necesitan. ¿Su familiar recibió cuidados paliativos de este hospicio cuando vivía en una casa de convalecencia?

- 1 Sí
2 No → Si contestó No, pase a la Pregunta 35.

33. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿con qué frecuencia el equipo del hospicio y el personal del hogar de ancianos y convalecencia se pusieron de acuerdo y acoplaron bien para proporcionarle los cuidados a su familiar?

- 1 Nunca
2 A veces
3 La mayoría de las veces
4 Siempre

34. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿con qué frecuencia los informes que el personal de la casa de convalecencia le daban sobre su familiar eran diferentes de los informes que le daba el equipo del hospicio?

- 1 Nunca
2 A veces
3 La mayoría de las veces
4 Siempre

**SU PROPIA EXPERIENCIA CON EL
CENTRO DE HOSPICIO**

35. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿con qué frecuencia el equipo del hospicio le escuchó a usted con atención?

- 1 Nunca
2 A veces
3 La mayoría de las veces
4 Siempre

36. Apoyo respecto a sus creencias religiosas o espirituales incluye hablar, rezar, momentos de recogimiento, u otras maneras de satisfacer sus necesidades religiosas o espirituales.

Mientras su familiar estaba bajo los cuidados de este hospicio, ¿cuánto apoyo recibió usted respecto a sus creencias religiosas y espirituales por parte del equipo del hospicio?

- 1 Demasiado poco
2 Justo el necesario
3 Demasiado

37. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿cuánto apoyo emocional recibió usted del equipo del hospicio?

- 1 Demasiado poco
2 Justo el necesario
3 Demasiado

38. Durante las semanas posteriores a la muerte de su familiar, ¿recibió usted todo el apoyo emocional que usted quería por parte del equipo del hospicio?

- 1 Demasiado poco
- 2 Justo el necesario
- 3 Demasiado

CALIFICACIÓN GENERAL DE LOS CUIDADOS DEL HOSPICIO

39. Por favor conteste las siguientes preguntas sobre los cuidados paliativos que recibió su familiar por parte del hospicio cuyo nombre aparece en la portada de esta encuesta. No incluya en sus respuestas cuidados proporcionados por otros centros.

Usando un número del 0 al 10, el 0 siendo los peores cuidados de hospicio posibles y 10 los mejores cuidados paliativos posibles de un hospicio, ¿qué número usaría para calificar los cuidados que recibió su familiar por parte de este hospicio?

- 0 Los peores cuidados posibles de un hospicio
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 Los mejores cuidados posibles de un hospicio

40. ¿Le recomendaría este hospicio a sus amigos y familiares?

- 1 Definitivamente no
- 2 Probablemente no
- 3 Probablemente Sí
- 4 Definitivamente Sí

SOBRE SU FAMILIAR

41. ¿Cuál es el grado o nivel escolar más alto que ha completado su familiar?

- 1 8 años de escuela o menos
- 2 Estudios de escuela secundaria, pero sin graduarse
- 3 Graduado de escuela de secundaria, o diploma de la secundaria, o su equivalente (o GED)
- 4 Algunos cursos universitarios o un título universitario de un programa de 2 años
- 5 Título universitario de 4 años
- 6 Título universitario de más de 4 años
- 7 No sé

42. ¿Su familiar es de origen hispano, latino o español?

- 1 No, ni hispano, ni latino, ni español
- 2 Sí, puertorriqueño
- 3 Sí, mexicano, mexicano-americano, chicano
- 4 Sí, cubano
- 5 Sí, de otro origen hispano, latino o español

**43. ¿A qué raza pertenece su familiar?
Marque una o más.**

- 1 Blanca
- 2 Negra o afroamericana
- 3 Asiática
- 4 Nativa de Hawái u otras Islas del Pacífico
- 15 Indígena americana o nativa de Alaska

SOBRE USTED

44. ¿Qué edad tiene usted?

- 1 de 18 a 24 años
- 2 de 25 a 34 años
- 3 de 35 a 44 años
- 4 de 45 a 54 años
- 5 de 55 a 64 años
- 6 de 65 a 74 años
- 7 de 75 a 80 años
- 8 85 años o más

45. ¿Es usted hombre o mujer?

- 1 Hombre
- 2 Mujer

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

- 1 8 años de escuela o menos
- 2 Estudios de escuela secundario, pero sin graduarse
- 3 Graduado de escuela de secundaria o diploma de la secundaria), o su equivalente (o GED)
- 4 Algunos cursos universitarios o un título universitario de un programa de 2 años
- 5 Título universitario de 4 años
- 6 Título universitario de más de 4 años
- 7 No sé

47. ¿En qué idioma habla usted principalmente en casa?

- 1 Inglés
- 2 Español
- 3 Chino
- 4 Otro idioma:

(Por favor imprima.)

Gracias.

Por favor regrese la encuesta completa en el sobre con el porte o franqueo pagado.

[NAME OF SURVEY VENDOR]

[ADDRESS OF SURVEY VENDOR]

CAHPS[®] Hospice Survey

Por favor conteste las preguntas en esta encuesta sobre la atención que recibió este paciente de este hospicio:

NAME OF HOSPICE

Todas las preguntas en esta encuesta se tratan sobre las experiencias de este paciente con este hospicio.

Si desea saber más sobre este estudio, llama a [TOLL FREE NUMBER}. Todas las llamadas son gratis.

OMB# XXXX-XXXX

CAHPS[®] Hospice Survey

INSTRUCCIONES PARA LA ENCUESTA

- Por favor entréguele esta encuesta a la persona de su hogar que sepa más sobre los cuidados que recibió de este centro la persona cuyo nombre aparece en la carta de presentación de esta encuesta.
- Use un bolígrafo de tinta negra para completar el cuestionario
- Marque con una 'X' el cuadrado para indicar su respuesta. Vea el siguiente ejemplo:

0	Si
<input checked="" type="checkbox"/>	No
- Si quiere cambiar una respuesta, tache con una línea el cuadrado que usted quiere cambiar y en su lugar marque con una 'X' el cuadrado que desea escoger, así:
- A veces hay que saltarse alguna pregunta. Cuando esto ocurra, una flecha a la derecha de la respuesta le indicará a qué pregunta hay que pasar. Por ejemplo:

<input checked="" type="checkbox"/>	Si → Si contestó Sí, pase a la Pregunta 1 en la Página 1.
0	No

EL PACIENTE DEL HOSPICIO

1. ¿Qué relación tiene con usted la persona cuyo nombre aparece en la carta de presentación de esta encuesta?

¹ Es mi esposo/a o pareja

² Es mi padre/madre

³ Es mi suegro/a

⁴ Es mi abuelo/a

⁵ Es mi tío/a

⁶ Es mi hermano/a

⁷ Es mi hijo/a

⁸ Es un/a amigo/a

⁹ Otro (Por favor imprima):

(Por favor imprima)

2. Para esta encuesta, utilizaremos las palabras “su familiar” para referirnos a la persona cuyo nombre aparece en la carta de presentación de esta encuesta. ¿En qué lugar o lugares recibió su familiar los cuidados de este hospicio? Marque uno o más

¹ En su casa

² En un hogar de asistencia parcial

³ En una casa de ancianos y convalecencia

⁴ En un hospital

⁵ En un centro u hogar de hospicio

⁶ Otro (Por favor imprima):

SU PAPEL

3. Mientras su familiar estuvo bajo los cuidados del hospicio, ¿con qué frecuencia supervisó usted o participó en dichos cuidados?

¹ Nunca → Si contestó Nunca, pase a la Pregunta 41.

² A veces

³ La mayoría de las veces

⁴ Siempre

LOS CUIDADOS QUE EL HOSPICIO PROPORCIONÓ A SU FAMILIAR

Al responder el resto de las preguntas de esta encuesta, por favor piense sólo en la experiencia de su familiar con el hospicio nombrado en la en la portada de esta encuesta.

4. Para esta encuesta, el equipo del hospicio incluye a todos los doctores, enfermeras, trabajadores sociales, religiosos y demás personas que le proporcionaron cuidados paliativos a su familiar.

Mientras su familiar estaba bajo los cuidados del hospicio, ¿tuvo usted que ponerse en contacto con el equipo del hospicio durante la noche, en fin de semana o en día festivo porque tenía alguna duda o necesitaba ayuda para el cuidado de su familiar?

¹ Sí

² No → Si contestó No, pase a la Pregunta 6.

5. ¿Con qué frecuencia obtuvo la ayuda que necesitaba del equipo del hospicio durante la noche, en fin de semana o en día festivo?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

6. Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo de personal del hospicio lo mantuvo a usted informado de cuando iban a llegar a cuidar a su familiar?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

7. Mientras su familiar estaba bajo los cuidados de este hospicio, cuando usted o un miembro de su familia le pedían ayuda al equipo del hospicio, ¿con qué frecuencia obtenían la ayuda tan pronto como la necesitaban?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

8. Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio explicaba las cosas de un modo fácil de entender?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre.

9. Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio lo mantenía a usted informado sobre el estado de su familiar?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

10. Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia alguien del equipo del hospicio le dio a usted informes confusos o contradictorios sobre el estado o los cuidados de su familiar?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

11. Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del centro trataba a su familiar con dignidad y respeto?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

12. Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia sintió usted que al equipo del hospicio realmente le importaba su familiar?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

13. Mientras su familiar estaba bajo los cuidados del hospicio, ¿habló usted con el equipo del hospicio sobre algún problema relacionado con los cuidados de su familiar?

- 1 Sí
- 2 No → Si contestó No, pase a la Pregunta 15.

14. ¿Con qué frecuencia el equipo del hospicio lo escuchó con atención cuando usted les habló sobre problemas relacionados con los cuidados de su familiar?

- 1 Nunca
- 2 A veces
- 3 La mayoría de las veces
- 4 Siempre

15. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿tuvo él/ella algún tipo de dolor?

- 1 Sí
- 2 No → Si contestó No, pase a la Pregunta 17.

16. ¿Recibió su familiar toda la ayuda que necesitaba contra el dolor?

- 1 Sí, definitivamente
- 2 Sí, más o menos
- 3 No

17. Mientras su familiar estaba bajo los cuidados del hospicio, ¿le dieron a él o a ella algún medicamento contra el dolor?

- 1 Sí
- 2 No → Si contestó No, pase a la Pregunta 21.

18. Entre los efectos secundarios de la medicina contra el dolor está la somnolencia. ¿Algún personal del equipo del hospicio habló con usted o su familiar sobre los efectos secundarios del medicamento contra el dolor?

¹ Sí, definitivamente

² Sí, más o menos

³ No

19. ¿El equipo del hospicio le dio la capacitación que usted necesitaba para saber de qué efectos secundarios del medicamento contra el dolor tenía usted que estar pendiente?

¹ Sí, definitivamente

² Sí, más o menos

³ No

20. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber si había que darle a su familiar más medicamento contra el dolor y, si sí, cuándo dárselo?

¹ Sí, definitivamente

² Sí, más o menos

³ No

⁴ No tuve necesidad de dar medicamentos para el dolor a mi familiar

21. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿en algún momento tuvo su familiar dificultad para respirar o recibió tratamiento para su dificultad para respirar?

¹ Sí

² No → Si contestó No, pase a la Pregunta 24.

22. ¿Con qué frecuencia su familiar recibió la ayuda que necesitaba para su dificultad para respirar?

¹ Nunca

² A veces

³ La mayoría de las veces

⁴ Siempre

23. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber cómo ayudar a su familiar si él/ella tenía problemas para respirar?

¹ Sí, definitivamente

² Sí, más o menos

³ No

⁴ No tuve que ayudar a mi familiar con problemas para respirar

24. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿en algún momento tuvo su familiar problemas de estreñimiento?

¹ Sí

² No → Si contestó No, pase a la Pregunta 26.

25. ¿Con qué frecuencia su familiar recibió la ayuda que necesitaba para sus problemas de estreñimiento?

- ¹ Nunca
- ² A veces
- ³ La mayoría de las veces
- ⁴ Siempre

26. Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento él/ella sintió ansiedad o tristeza?

- ¹ Sí
- ² No → Si contestó No, pase a la Pregunta 28.

27. ¿Con qué frecuencia su familiar recibió del equipo del hospicio la ayuda que necesitaba para su ansiedad o tristeza?

- ¹ Nunca
- ² A veces
- ³ La mayoría de las veces
- ⁴ Siempre

28. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿en algún momento se puso su familiar inquieto o agitado?

- ¹ Sí
- ² No → Si contestó No, pase a la Pregunta 30.

29. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber qué hacer si su familiar se ponía inquieto o agitado?

- ¹ Sí, definitivamente
- ² Sí, más o menos
- ³ No

30. Mover a su familiar incluye acciones como ayudarlo/a a darse la vuelta en la cama, o meterse y salir de la cama o sentarse y levantarse de una silla de ruedas. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber cómo mover a su familiar de manera segura?

- ¹ Sí, definitivamente
- ² Sí, más o menos
- ³ No
- ⁴ No tuve que mover a mi familiar

31. ¿Le dio el equipo del hospicio tanta información como usted quería sobre qué acontecimientos esperar mientras su familiar estuviera muriéndose?

- ¹ Sí, definitivamente
- ² Sí, más o menos
- ³ No

**CUIDADOS DE HOSPICIO
BRINDADOS EN UN HOGAR DE
ANCIANOS Y CONVALECENCIA**

32. Algunas personas que viven en un hogar de ancianos o de convalecencia reciben allí mismo los cuidados de hospicio que necesitan. ¿Su familiar recibió cuidados paliativos de este hospicio cuando vivía en una casa de convalecencia?

¹ Sí

² No → Si contestó No, pase a la Pregunta 35.

33. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿con qué frecuencia el equipo del hospicio y el personal del hogar de ancianos y convalecencia se pusieron de acuerdo y acoplaron bien para proporcionarle los cuidados a su familiar?

¹ Nunca

² A veces

³ La mayoría de las veces

⁴ Siempre

34. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿con qué frecuencia los informes que el personal de la casa de convalecencia le daban sobre su familiar eran diferentes de los informes que le daba el equipo del hospicio?

¹ Nunca

² A veces

³ La mayoría de las veces

⁴ Siempre

**SU PROPIA EXPERIENCIA CON EL
CENTRO DE HOSPICIO**

35. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿con qué frecuencia el equipo del hospicio le escuchó a usted con atención?

¹ Nunca

² A veces

³ La mayoría de las veces

⁴ Siempre

36. Apoyo respecto a sus creencias religiosas o espirituales incluye hablar, rezar, momentos de recogimiento, u otras maneras de satisfacer sus necesidades religiosas o espirituales. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿cuánto apoyo recibió usted respecto a sus creencias religiosas y espirituales por parte del equipo del hospicio?

¹ Demasiado poco

² Justo el necesario

³ Demasiado

37. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿cuánto apoyo emocional recibió usted del equipo del hospicio?

- ¹ 0 Demasiado poco
- ² 0 Justo el necesario
- ³ 0 Demasiado

38. Durante las semanas posteriores a la muerte de su familiar, ¿recibió usted todo el apoyo emocional que usted quería por parte del equipo del hospicio?

- ¹ 0 Demasiado poco
- ² 0 Justo el necesario
- ³ 0 Demasiado

CALIFICACIÓN GENERAL DE LOS CUIDADOS DEL HOSPICIO

39. Por favor conteste las siguientes preguntas sobre los cuidados paliativos que recibió su familiar por parte del hospicio cuyo nombre aparece en la portada de esta encuesta. No incluya en sus respuestas cuidados proporcionados por otros centros.

Usando un número del 0 al 10, el 0 siendo los peores cuidados de hospicio posibles y 10 los mejores cuidados paliativos posibles de un hospicio, ¿qué número usaría para calificar los cuidados que recibió su familiar por parte de este hospicio?

- ⁰ 0 Los peores cuidados posibles de un hospicio
- ¹ 0 1
- ² 0 2
- ³ 0 3
- ⁴ 0 4
- ⁵ 0 5
- ⁶ 0 6
- ⁷ 0 7
- ⁸ 0 8
- ⁹ 0 9
- ¹⁰ 0 10 Los mejores cuidados posibles de un hospicio

40. ¿Le recomendaría este hospicio a sus amigos y familiares?

- ¹ 0 Definitivamente no
- ² 0 Probablemente no
- ³ 0 Probablemente Sí
- ⁴ 0 Definitivamente Sí

SOBRE SU FAMILIAR

41. ¿Cuál es el grado o nivel escolar más alto que ha completado su familiar?

- 1 8 años de escuela o menos
- 2 Estudios de escuela secundaria, pero sin graduarse
- 3 Graduado de escuela de secundaria, o diploma de la secundaria), o su equivalente (o GED)
- 4 Algunos cursos universitarios o un título universitario de un programa de 2 años
- 5 Título universitario de 4 años
- 6 Título universitario de más de 4 años
- 7 No sé

42. ¿Su familiar es de origen hispano, latino o español?

- 1 No, ni hispano, ni latino, ni español
- 2 Sí, puertorriqueño
- 3 Sí, mexicano, mexicano-americano, chicano
- 4 Sí, cubano
- 5 Sí, de otro origen hispano, latino o español

43. ¿A qué raza pertenece su familiar? Marque una o más.

- 1 Blanca
- 2 Negra o afroamericana
- 3 Asiática
- 4 Nativa de Hawái u otras Islas del Pacífico
- 5 Indígena americana o nativa de Alaska

SOBRE USTED

44. ¿Qué edad tiene usted?

- 1 de 18 a 24 años
- 2 de 25 a 34 años
- 3 de 35 a 44 años
- 4 de 45 a 54 años
- 5 de 55 a 64 años
- 6 de 65 a 74 años
- 7 de 75 a 80 años
- 8 85 años o más

45. ¿Es usted hombre o mujer?

- 1 Hombre
- 2 Mujer

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

- ¹ 0 8 años de escuela o menos
- ² 0 Estudios de escuela secundario, pero sin graduarse
- ³ 0 Graduado de escuela de secundaria o diploma de la secundaria), o su equivalente (o GED)
- ⁴ 0 Algunos cursos universitarios o un título universitario de un programa de 2 años
- ⁵ 0 Título universitario de 4 años
- ⁶ 0 Título universitario de más de 4 años
- ⁷ 0 No sé

47. ¿En qué idioma habla usted principalmente en casa?

- ¹ 0 Inglés
- ² 0 Español
- ³ 0 Chino
- ⁴ 0 Otro idioma:

(Por favor imprima.)

Gracias.

Por favor regrese la encuesta completa en el sobre con el porte o franqueo pagado.

[NAME OF SURVEY VENDOR]

[ADDRESS OF SURVEY VENDOR]

Sample Initial Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]

[ADDRESS]

[CITY, STATE ZIP]

Estimado/a [SAMPLED CAREGIVER NAME]:

[HOSPICE NAME] está llevando a cabo una encuesta sobre los servicios de cuidados paliativos que los pacientes y sus familias reciben. Se le ha seleccionado a usted para este estudio porque ha sido identificado como la persona encargada del cuidado de [DECEDENT NAME]. Entendemos que éste debe de ser un momento difícil para usted, pero esperamos que pueda ayudarnos a conocer la calidad de la atención que usted y su familiar o amigo recibieron del hospicio.

Las preguntas [NOTE THE QUESTION NUMBERS] del cuestionario adjunto son parte de una iniciativa nacional patrocinada por el Departamento de Salud y Servicios Humanos (HHS) de los Estados Unidos para evaluar la calidad de la atención de los hospicios. Los Centros de Servicios de Medicare y Medicaid (CMS, por sus siglas en inglés), que es una parte del HHS, está realizando esta encuesta con el fin de mejorar los cuidados paliativos. El CMS paga la mayoría de los cuidados paliativos de los EE.UU. El CMS tiene la responsabilidad de garantizar que los pacientes de los hospicios así como los miembros de su familia y amigos reciban atención de alta calidad. Una de las maneras en que puede cumplir con esta responsabilidad es enterarse directamente por usted de la calidad de los cuidados paliativos que recibió su familiar o amigo. Su participación es voluntaria y no afectará los beneficios o la atención médica que usted recibe.

Esperamos que se tome el tiempo para contestar la encuesta. Después de haber llenado la encuesta, por favor envíela en el sobre con el porte o franqueo pagado. Sus respuestas se combinarán con las de otras personas y, en conjunto, se compartirán con el hospicio con el fin de mejorar la calidad. [OPTIONAL: Podrá ver que hay un número en la encuesta. Ese número sirve para que sepamos si usted devolvió la encuesta y así no tengamos que enviarle recordatorios.]

Si tiene alguna pregunta sobre la encuesta adjunta, no dude en llamarnos a nuestro número gratuito 1-800-XXX-XXXX.

Gracias por ayudar a mejorar los cuidados paliativos para todos los consumidores.

Atentamente,

[HOSPICE ADMINISTRATOR]

[HOSPICE NAME]

Sample Follow-up Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]

[ADDRESS]

[CITY, STATE ZIP]

Estimado/a [SAMPLED CAREGIVER NAME]:

Nuestros registros indican que recientemente usted fue una de las personas encargadas del cuidado de [DECEDENT NAME] en [NAME OF HOSPICE]. Hace aproximadamente tres semanas, le enviamos una encuesta sobre la atención que usted y su familiar o amigo recibieron en ese hospicio. Si ya nos devolvió la encuesta, por favor acepte nuestras disculpas y haga caso omiso de esta carta. Si no lo ha hecho ya, le agradeceríamos que se tomara el tiempo de contestar este importante cuestionario.

Esperamos que usted aproveche esta oportunidad para ayudarnos a saber qué calidad de atención recibió su familiar o amigo. Los resultados de esta encuesta se utilizarán para ayudar a garantizar que todos los estadounidenses reciban la más alta calidad de cuidados paliativos.

Las preguntas [NOTE THE QUESTION NUMBERS] del cuestionario adjunto son parte de una iniciativa nacional patrocinada por el Departamento de Salud y Servicios Humanos (HHS) de los Estados Unidos para evaluar la calidad de la atención de los hospicios. Su participación es voluntaria y no afectará los beneficios o la atención médica que usted recibe.

Por favor, tómese unos minutos para contestar la encuesta adjunta. Después de haber llenado la encuesta, por favor envíela en el sobre con el porte o franqueo pagado. Sus respuestas se combinarán con las de otras personas y, en conjunto, se compartirán con el hospicio con el fin de mejorar la calidad. [OPTIONAL: Podrá ver que hay un número en la encuesta. Ese número sirve para que sepamos si usted devolvió la encuesta y así no tengamos que enviarle recordatorios.]

Si tiene alguna pregunta sobre la encuesta adjunta, no dude en llamarnos a nuestro número gratuito 1-800-XXX-XXXX.

Gracias por ayudar a mejorar los cuidados paliativos para todos los consumidores.

Atentamente,

[HOSPICE ADMINISTRATOR]

[HOSPICE NAME]

Appendix O

CAHPS[®] Hospice Survey Telephone Script (English)

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix O

CAHPS[®] Hospice Survey Telephone Script (English)

Overview

This telephone interview script is provided to assist interviewers while attempting to reach the caregiver of the sampled decedent. The script explains the purpose of the survey and confirms necessary information about the caregiver and decedent.

General Interviewing Conventions and Instructions

- The telephone introduction script must be read verbatim
- All text that appears in lowercase letters must be read out loud
- Text in UPPERCASE letters must not be read out loud, however, YES and NO response options are to be read if necessary
- All questions and all answer categories must be read exactly as they are worded
- No changes are permitted to the order of the question and answer categories for the “Core,” “About Your Family” and “About You” CAHPS Hospice Survey questions
 - The first forty “Core” questions must remain together
 - The next three “About Your Family” questions must remain together and the last four questions “About You” questions must remain together
- All transitional statements must be read
- Text that is underlined must be emphasized
- Characters in < > must not be read
- [Square brackets] are used to show programming instructions that must not actually appear on electronic telephone interviewing system screens
- **Only one language (i.e., English or Spanish) must appear on the electronic interviewing system screen**
- MISSING/DON’T KNOW (DK) is a valid response option for each item in the electronic telephone interviewing system scripts. This allows the telephone interviewer to go to the next question if a patient is unable to provide a response for a given question (or refuses to provide a response). In the survey file layouts, a value of MISSING/DK is coded as “M – Missing/Don't know.”
- Skip patterns should be programmed into the electronic telephone interviewing system
 - Appropriately skipped questions should be coded as “88 - Not applicable.” For example, if a patient answers “No” to Question 4 of the CAHPS Hospice Survey, the program should skip Question 5, and go to Question 6. Question 5 must then be coded as “88 - Not applicable.” Coding may be done automatically by the telephone interviewing system or later during data preparation.

- When a response to a screener question is not obtained, the screener question and any questions in the skip pattern should be coded as “M - Missing/Don't know.” For example, if the patient does not provide an answer to Question 4 of the CAHPS Hospice Survey and the interviewer selects “M – Missing/Don’t Know” to Question 4, then the telephone interviewing system should be programmed to skip Question 5, and go to Question 6. Question 5 must then be coded as “M - Missing/Don't know.” Coding may be done automatically by the telephone interviewing system or later during data preparation.

INITIATING CONTACT

START: Hello, may I please speak to [SAMPLED CAREGIVER NAME]?
 <1> YES [GO TO INTRO]
 <2> PROXY IDENTIFIED – [COLLECT PROXY INFORMATION THEN RETURN TO INTRO]
 <3> NO, REFUSAL [GO TO REFUSAL]
 <4> NO, NOT AVAILABLE RIGHT NOW [SET CALLBACK]
 <5> ALREADY RETURNED SURVEY BY MAIL [GO TO MAILED]
 <6> PATIENT DIDN’T RECEIVE CARE AT NAMED HOSPICE [GO TO DISAVOWAL]

IF ASKED WHO IS CALLING:

This is [INTERVIEWER NAME] calling from [VENDOR NAME]. We are working with [HOSPICE NAME] and the U.S. Department of Health and Human Services to conduct a survey about hospice care.

IF THE SAMPLED CAREGIVER IS NOT AVAILABLE:

Can you tell me a convenient time to call back to speak with (him/her)?

IF THE SAMPLED CAREGIVER SAYS THIS IS NOT A GOOD TIME:

If you don’t have the time now, when is a more convenient time to call you back?

IF SOMEONE OTHER THAN THE SAMPLED CAREGIVER ANSWERS THE PHONE RECONFIRM THAT YOU ARE SPEAKING WITH THE SAMPLED CAREGIVER WHEN HE OR SHE PICKS UP.

INITIATING CONTACT WITH A PROXY RESPONDENT

START: Hello, may I please speak to [PROXY CAREGIVER NAME]?
<1> YES [GO TO INTRO]
<2> NO [REFUSAL]
<3> NO, NOT AVAILABLE RIGHT NOW [SET CALLBACK]

IF ASKED WHO IS CALLING:

This is [INTERVIEWER NAME] calling from [VENDOR NAME].
We are working with [HOSPICE NAME] and the U.S. Department of
Health and Human Services to conduct a survey about hospice care.

IF THE PROXY CAREGIVER IS NOT AVAILABLE:

Can you tell me a convenient time to call back to speak with
(him/her)?

IF THE PROXY CAREGIVER SAYS THIS IS NOT A GOOD TIME:

If you don't have the time now, when is a more convenient time to call
you back?

IF SOMEONE OTHER THAN THE PROXY CAREGIVER ANSWERS THE
PHONE RECONFIRM THAT YOU ARE SPEAKING WITH THE PROXY
CAREGIVER WHEN HE OR SHE PICKS UP.

CALL BACK TO COMPLETE A PREVIOUSLY STARTED SURVEY

START: Hello, may I please speak to [SAMPLED CAREGIVER NAME/PROXY
CAREGIVER NAME]?
<1> YES [GO TO CONFIRM RESPONDENT]
<2> NO [REFUSAL]
<3> NO, NOT AVAILABLE RIGHT NOW [SET CALLBACK]

IF ASKED WHO IS CALLING: This is [INTERVIEWER NAME]
calling from [SURVEY VENDOR]. Is [SAMPLED CAREGIVER
NAME/PROXY CAREGIVER NAME] available to complete
survey that [HE/SHE] started at an earlier date?

CONFIRM RESPONDENT: Before we continue with the survey, I would like to
confirm that I speaking with [SAMPLED CAREGIVER NAME/PROXY
CAREGIVER NAME].

CONTINUE SURVEY WHERE PREVIOUSLY LEFT OFF.

SPEAKING WITH CAREGIVER

INTRO Hi, my name is [INTERVIEWER NAME] and I'm calling from the [VENDOR NAME].

[HOSPICE NAME] is conducting a survey about the hospice services that patients and their families receive. It is part of a national initiative sponsored by the United States Department of Health and Human Services (HHS) to measure the quality of care in hospices. We realize this may be a difficult time for you, but we hope that you will take a few minutes to help us learn about the quality of hospice care that you and your loved one received.

Your participation is voluntary and will not affect any health care or benefits you receive. The interview will take [FILL: approximately 11 minutes /OR SURVEY VENDOR SPECIFY]. Your answers will be combined with other respondents and shared with the hospice for purposes of quality improvement.

IF ASKED WHETHER SOMEONE ELSE CAN SERVE AS **PROXY FOR SAMPLED CAREGIVER:**

For this survey, we need to speak to the person in your household who is the most knowledgeable, **ONCE THE MOST KNOWLEDGEABLE PERSON'S NAME IS PROVIDED:** [Is he/she OR are you] the most knowledgeable about the hospice care received by [DECEDENT NAME]

IF NEEDED AND SPEAKING WITH **THE SAMPLED CAREGIVER:** We received your name from [HOSPICE NAME] because you were listed as the caregiver for [DECEDENT NAME].

IF NEEDED AND SPEAKING WITH **PROXY FOR SAMPLED CAREGIVER:** We received your name from [SAMPLED CAREGIVER] because he/she indicated that you were knowledgeable about the hospice care received by [DECEDENT NAME].

- <1> YES – [GO TO CONTINUE]
- <2> PROXY IDENTIFIED – [COLLECT PROXY INFORMATION THEN RETURN TO PROXY INTRO]
- <3> NO WILL RETURN COMPLETED MAILED SURVEY – [GO TO CALLBACK]
- <4> NO, CALL BACK - [GO TO CALLBACK]
- <5> NO, R UNAVAILABLE DURING FIELD PERIOD – [GO TO ITEM TO CODE ILL, ETC.]

- <6> REFUSE – [GO TO REFUSAL]
- <7> ALREADY RETURNED SURVEY BY MAIL [GO TO MAILED]
- <8> NOT INVOLVED IN CARE AND NO PROXY IDENTIFIED [GO TO INELIGIBLE]
- <9> PATIENT DIDN'T RECEIVE CARE AT NAMED HOSPICE [GO TO DISAVOWAL]

CONTINUE This call may be monitored [OPTIONAL: and/or recorded] for quality improvement purposes. May we begin?

- <1> YES – [BEGIN SURVEY]
- <2> NO, CALL BACK - [GO TO CALLBACK]
- <3> REFUSE – [GO TO REFUSAL]

MAILED Thank you so much for completing the survey by mail. Perhaps we still have not gotten it but we'll check our records again. We may need to contact you again in case we still have not received it. [END CALL]

INELIGIBLE4 I'm sorry, for this project we are only speaking with family members or friends who took part in or oversaw hospice care for their family members. Thank you for your time. Have a good (day/evening). [END CALL]

DISAVOWAL Perhaps there was an error in our records. Thank you for your time. Have a good (day/evening). [END CALL]

BEGIN CAHPS HOSPICE SURVEY QUESTIONS

Q1_INTRO Please answer all questions in this survey about the care the patient received at [HOSPICE NAME]. When thinking about your answers, do not include any other hospice stays.

BE PREPARED TO PROBE IF THE PATIENT ANSWERS OUTSIDE OF THE ANSWER CATEGORIES PROVIDED. PROBE BY REPEATING THE ANSWER CATEGORIES ONLY; DO NOT INTERPRET FOR THE PATIENT.

- Q1 How are you related to [DECEDENT NAME]?
- <1> MY SPOUSE OR PARTNER [GO TO Q2]
 - <2> MY PARENT [GO TO Q2]
 - <3> MY MOTHER-IN-LAW
OR FATHER-IN-LAW [GO TO Q2]
 - <4> MY GRANDPARENT [GO TO Q2]
 - <5> MY AUNT OR UNCLE [GO TO Q2]
 - <6> MY SISTER OR BROTHER [GO TO Q2]
 - <7> MY CHILD [GO TO Q2]
 - <8> MY FRIEND [GO TO Q2]
 - <9> OTHER (PLEASE SPECIFY) [GO TO Q1A]
 - <M> MISSING/DK [GO TO Q2]

Q1A How are you related to [DECEDENT NAME]?

[NOTE: PLEASE DOCUMENT THE RELATIONSHIP AND MAINTAIN IN YOUR INTERNAL RECORDS.]

Q2 For this survey, the phrase “family member” refers to [DECEDENT NAME]. In what locations did your family member receive care from [HOSPICE NAME]? Please answer yes or no to each of the categories.

Q2A At home?

- <1> YES
- <0> NO
- <M> MISSING/DK

Q2B At an assisted living facility?

- <1> YES
- <0> NO
- <M> MISSING/DK

Q2C At a nursing home?

- <1> YES
- <0> NO
- <M> MISSING/DK

Q2D At a hospital?

<1> YES

<0> NO

<M> MISSING/DK

Q2E At a hospice facility or hospice house?

<1> YES

<0> NO

<M> MISSING/DK

Q2F At some other place?

<1> YES [GO TO Q2F]

<0> NO [GO TO Q3]

<M> MISSING/DK [GO TO Q3]

Q2G Where did your family member receive care?

[NOTE: PLEASE DOCUMENT THE OTHER PLACE AND MAINTAIN IN YOUR INTERNAL RECORDS.]

Q3 While your family member was in hospice care, how often did you take part in or oversee care for him or her? Would you say:

<1> Never, [GO TO Q41_INTRO]

<2> Sometimes,

<3> Usually, or

<4> Always?

<M> MISSING/DK

Q4_INTRO As you answer the rest of the questions in this survey, please think only about your family member's experience with [HOSPICE NAME]

Q4 For this survey, the hospice team includes all the nurses, doctors, social workers, chaplains and other people who provided hospice care to your family member. 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?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

<1> YES

<2> NO [GO TO Q6]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO Q6]

Q5 How often did you get the help you needed from the hospice team during evenings, weekends, or holidays? Would you say...

<1> Never,

<2> Sometimes,

<3> Usually, or

<4> Always?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q6 While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member? Would you say...

<1> Never,

<2> Sometimes,

<3> Usually, or

<4> Always?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q7 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? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q8 While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q9 While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q10 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? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q11 While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q12 While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q13 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?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

- <1> YES
- <2> NO [GO TO Q15]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q15]

Q14. How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q15 While your family member was in hospice care, did he or she have any pain?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

<1> YES

<2> NO [GO TO Q17]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO Q17]

Q16 Did your family member get as much help with pain as he or she needed? Would you say...

<1> Yes, definitely,

<2> Yes, somewhat, or

<3> No?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q17 While your family member was in hospice care, did he or she receive any pain medicine?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

<1> YES

<2> NO [GO TO Q21]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO Q21]

Q18 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? Would you say...

<1> Yes, definitely,

<2> Yes, somewhat, or

<3> No?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q19 Did the hospice team give you the training you needed about what side effects to watch for from pain medicine? Would you say...

- <1> Yes, definitely,
- <2> Yes, somewhat, or
- <3> No?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q20 Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member? Would you say...

- <1> Yes, definitely,
- <2> Yes, somewhat,
- <3> No, or
- <4> I did not need to give pain medicine to my family member.

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q21 While your family member was in hospice care, did your family member ever have trouble breathing or receive treatment for trouble breathing?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

- <1> YES
- <2> NO [GO TO Q24]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q24]

Q22 How often did your family member get the help he or she needed for trouble breathing? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q23 Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing? Would you say...

- <1> Yes, definitely,
- <2> Yes, somewhat,
- <3> No, or
- <4> I did not need to help my family member with trouble breathing.

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q24 While your family member was in hospice care, did your family member ever have trouble with constipation?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

- <1> YES
- <2> NO [GO TO Q26]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO Q26]

Q25 How often did your family member get the help he or she needed for trouble with constipation? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q26 While your family member was in hospice care, did he or she show any feelings of anxiety or sadness?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

- <1> YES
- <2> NO [GO TO Q28]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO Q28]

Q27 How often did your family member get the help he or she needed from the hospice team for feelings of anxiety or sadness? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q28 While your family member was in hospice care, did he or she ever become restless or agitated?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

- <1> YES
- <2> NO [GO TO Q30]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q30]

Q29 Did the hospice team give you the training you needed about what to do if your family member became restless or agitated? Would you say...

- <1> Yes, definitely,
- <2> Yes, somewhat, or
- <3> No?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q30 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 the training you needed about how to safely move your family member? Would you say...

- <1> Yes, definitely,
- <2> Yes, somewhat,
- <3> No, or
- <4> I did not need to move my family member.

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q31 Did the hospice team give you as much information as you wanted about what to expect while your family member was dying? Would you say...

- <1> Yes, definitely,
- <2> Yes, somewhat, or
- <3> No?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q32 Some people receive hospice care while they are living in a nursing home. Did your family member receive care from this hospice while he or she was living in a nursing home?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

- <1> YES
- <2> NO [GO TO Q35]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q35]

Q33 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? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q34 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? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q35_INTRO The next set of questions is about you.

Q35 While your family member was in hospice care, how often did the hospice team listen to you? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q36 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? Would you say...

- <1> Too little,
- <2> The right amount, or
- <3> Too much?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q37 While your family member was in hospice care, how much emotional support did you get from the hospice team? Would you say...

- <1> Too little,
- <2> The right amount, or
- <3> Too much?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q38 In the weeks after your family member died, how much emotional support did you get from the hospice team? Would you say...

- <1> Too little,
- <2> The right amount, or
- <3> Too much?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q39 Please answer the following questions about your family member's care from [HOSPICE NAME]. Do not include care from other hospices in your answers.

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?

IF THE RESPONDENT DOES NOT PROVIDE AN APPROPRIATE RESPONSE, PROBE BY REPEATING: 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?

- <0> 0
- <1> 1
- <2> 2
- <3> 3
- <4> 4
- <5> 5
- <6> 6
- <7> 7
- <8> 8
- <9> 9
- <10> 10

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q40 Would you recommend this hospice to your friends and family? Would you say...

- <1> Definitely no,
- <2> Probably no,
- <3> Probably yes, or
- <4> Definitely yes?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q41_INTRO The next questions are about your family member.

Q41 What is the highest grade or level of school that your family member completed? Did he or she...

READ ANSWER CHOICES ONLY IF NECESSARY

- <1> Complete 8th grade or less,
- <2> Complete some high school, but did not graduate,
- <3> Graduate from high school or earn a GED,
- <4> Complete some college or earn a 2-year degree,
- <5> Graduate from a 4-year college, or
- <6> Complete more than 4-year college degree?
- <7> Respondent indicates that he or she does not know family member's level of education

<M> MISSING

ACADEMIC TRAINING BEYOND A HIGH SCHOOL DIPLOMA THAT DOES NOT LEAD TO A BACHELORS DEGREE SHOULD BE CODED AS 4. IF THE RESPONDENT DESCRIBES NON-ACADEMIC TRAINING, SUCH AS TRADE SCHOOL, PROBE TO FIND OUT IF THE FAMILY MEMBER HAS A HIGH SCHOOL DIPLOMA AND CODE 2 OR 3, AS APPROPRIATE.

Q42 Was your family member of Hispanic, Latino, or Spanish origin or descent?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

- <X> YES
- <1> NO

<M> MISSING/DK

IF YES: Would you say you are (READ ALL RESPONSE CHOICES)

- <2> Puerto Rican,
- <3> Mexican, Mexican American, Chicano/a,
- <4> Cuban, or
- <5> Other Spanish/Hispanic/Latino?

<M> MISSING/DK

[FOR TELEPHONE INTERVIEWING, QUESTION 43 IS BROKEN INTO PARTS A-E]

READ ALL RACE CATEGORIES PAUSING AT EACH RACE CATEGORY TO ALLOW PATIENT TO REPLY TO EACH RACE CATEGORY.

IF THE RESPONDENT REPLIES, “WHY ARE YOU ASKING ABOUT MY FAMILY MEMBER’S RACE?:” We ask about your family member’s race for demographic purposes. We want to make sure that the people we include accurately represent the racial diversity in this country.

IF THE RESPONDENT REPLIES, “I ALREADY TOLD YOU ABOUT MY FAMILY MEMBER’S RACE”:

I understand, however the survey requires me to ask about all races so results can include people who are multiracial. If the race does not apply to your family member please answer no. Thanks for your patience.

Q43 When I read the following, please tell me if the category describes your family member’s race. I am required to read all five categories. Please answer yes or no to each of the categories.

Q43A Was your family member White?

- <1> YES/WHITE
- <2> NO/NOT WHITE

- <M> MISSING/DK

Q43B Was your family member Black or African American?

- <1> YES/BLACK OR AFRICAN AMERICAN
- <2> NO/NOT BLACK OR AFRICAN AMERICAN

- <M> MISSING/DK

Q43C Was your family member Asian?

- <1> YES/ASIAN
- <2> NO/NOT ASIAN

- <M> MISSING/DK

Q43D Was your family member Native Hawaiian or other Pacific Islander?
<1> YES/NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER
<2> NO/NOT NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER

<M> MISSING/DK

Q43E Was your family member American Indian or Alaska Native?
<1> YES/AMERICAN INDIAN OR ALASKA NATIVE
<2> NO/NOT AMERICAN INDIAN OR ALASKA NATIVE

<M> MISSING/DK

Q44_INTRO The next questions are about you.

Q44 What is your age?

READ ANSWER CHOICES ONLY IF NECESSARY

<1> 18 to 24
<2> 25 to 34
<3> 35 to 44
<4> 45 to 54
<5> 55 to 64
<6> 65 to 74
<7> 75 to 84
<8> 85 or older

<M>MISSING/DK

Q45 INTERVIEWER ASK ONLY IF NEEDED: Are you male or female?

<1> MALE
<2> FEMALE

<M>MISSING/DK

Q46 What is the highest grade or level of school that you have completed? Did you...

READ ANSWER CHOICES ONLY IF NECESSARY

- <1> Complete 8th grade or less,
- <2> Complete some high school, but did not graduate,
- <3> Graduate from high school or earn a GED,
- <4> Complete some college or earn a 2-year degree,
- <5> Graduate from a 4-year college, or
- <6> Complete more than 4-year college degree?

<M> MISSING/DK

ACADEMIC TRAINING BEYOND A HIGH SCHOOL DIPLOMA THAT DOES NOT LEAD TO A BACHELORS DEGREE SHOULD BE CODED AS 4. IF THE RESPONDENT DESCRIBES NON-ACADEMIC TRAINING, SUCH AS TRADE SCHOOL, PROBE TO FIND OUT IF SHE/HE HAS A HIGH SCHOOL DIPLOMA AND CODE 2 OR 3, AS APPROPRIATE.

Q47 What language do you mainly speak at home? Please listen to all three response choices before you answer. Would you say that you mainly speak...

- <1> English, [GO TO END]
- <2> Spanish, [GO TO END]
- <3> Chinese, or [GO TO END]
- <4> Some other language? [GO TO Q47A]

<M> MISSING/DK [GO TO END]

IF THE PATIENT REPLIES WITH MULTIPLE LANGUAGES, PROBE:

Would you say that you mainly speak [LANGUAGE A] or [LANGUAGE B]?

IF THE PATIENT REPLIES THAT THEY SPEAK AMERICAN PLEASE CODE AS 1-ENGLISH.

Q47A What other language do you mainly speak at home?

[NOTE: PLEASE DOCUMENT THE OTHER LANGUAGE AND MAINTAIN IN YOUR INTERNAL RECORDS]

END Those are all the questions I have. Thank you for your time. [OPTIONAL: Should you like the number for bereavement support at [HOSPICE NAME], I can provide that to you now.]

INTERVIEWER: PROVIDE CONTACT INFORMATION AS NEEDED

Have a good (day/evening). [END CALL]

Appendix P

CAHPS[®] Hospice Survey Telephone Script (Spanish)

THIS PAGE
INTENTIONALLY
LEFT BLANK

Appendix P

CAHPS[®] Hospice Survey Telephone Script (Spanish)

Overview

This telephone interview script is provided to assist interviewers while attempting to reach the caregiver of the sampled decedent. The script explains the purpose of the survey and confirms necessary information about the caregiver and decedent.

General Interviewing Conventions and Instructions

- The telephone introduction script must be read verbatim
- All text that appears in lowercase letters must be read out loud
- Text in UPPERCASE letters must not be read out loud, however, YES and NO response options are to be read if necessary
- All questions and all answer categories must be read exactly as they are worded
- No changes are permitted to the order of the question and answer categories for the “Core”, “About Your Family” and “About You” CAHPS Hospice Survey questions
 - The first forty “Core” questions must remain together
 - The next three “About Your Family” questions must remain together and the last four questions “About You” questions must remain together
- All transitional statements must be read
- Text that is underlined must be emphasized
- Characters in <> must not be read
- [Square brackets] are used to show programming instructions that must not actually appear on electronic telephone interviewing system screens
- **Only one language (i.e., English or Spanish) must appear on the electronic interviewing system screen**
- MISSING/DON'T KNOW (DK) is a valid response option for each item in the electronic telephone interviewing system scripts. This allows the telephone interviewer to go to the next question if a patient is unable to provide a response for a given question (or refuses to provide a response). In the survey file layouts, a value of MISSING/DK is coded as “M – Missing/Don't know.”
- Skip patterns should be programmed into the electronic telephone interviewing system
 - Appropriately skipped questions should be coded as “88 - Not applicable.” For example, if a patient answers “No” to Question 4 of the CAHPS Hospice Survey, the program should skip Question 5, and go to Question 6. Question 5 must then be coded as “88 - Not applicable.” Coding may be done automatically by the telephone interviewing system or later during data preparation.
 - When a response to a screener question is not obtained, the screener question and any questions in the skip pattern should be coded as “M - Missing/Don't know.” For example, if the patient does not provide an answer to Question 4 of the CAHPS Hospice Survey and the interviewer selects “M – Missing/Don't Know” to Question 4,

then the telephone interviewing system should be programmed to skip Question 5, and go to Question 6. Question 5 must then be coded as “M - Missing/Don't know.” Coding may be done automatically by the telephone interviewing system or later during data preparation.

INICIANDO CONTACTO

INICIO: Buenos(as) días(tardes/noches), ¿podría hablar con [SAMPLED CAREGIVER NAME]?

- <1> SÍ [GO TO INTRO]
- <2> PROXY IDENTIFICADO – [COLLECT PROXY INFORMATION THEN RETURN TO INTRO]
- <3> NO, NEGATIVA [GO TO REFUSAL]
- <4> NO, NO ESTÁ DISPONIBLE EN ESTE MOMENTO [SET CALLBACK]
- <5> YA HA VUELTO ENCUESTAS POR CORREO [GO TO MAILED]
- <6> PACIENTE NO RECIBIÓ ATENCIÓN EN EL HOSPICIO NOMBRADO [GO TO DISAVOWAL]

SI LE PREGUNTAN QUIÉN LLAMA:

Soy [INTERVIEWER NAME] de [VENDOR NAME]. Estamos trabajando con [HOSPICE NAME] y con el Departamento de Salud y Servicios Humanos de los Estados Unidos para realizar un estudio sobre los cuidados de hospicio.

SI EL CUIDADOR/PERSONA ENCARGADA DEL CUIDADO DEL PACIENTE NO ESTÁ O NO PUEDE ATENDER LA LLAMADA:

¿Puede decirme a qué hora es conveniente llamar para hablar con él/ella?

SI EL CUIDADOR MUESTRA O DICE QUE NO ES UN BUEN MOMENTO:

Si usted no tiene tiempo ahora, ¿cuándo es más conveniente que vuelva a llamarle?

SI CONTESTA EL TELÉFONO ALGUIEN QUE NO SEA EL CUIDADOR/PERSONA QUE CUIDA DE PACIENTE, CUANDO ÉSTE TOMA LA LLAMADA, CONFIRME QUE EFECTIVAMENTE USTED ESTÁ HABLANDO CON LA PERSONA INDICADA.

INICIANDO CONTACTO CON UN ENTREVISTADO PROXY

INICIO: Buenos(as) días (tardes/noches), ¿podría hablar con [PROXY CAREGIVER NAME]?

- <1> SÍ [GO TO INTRO]
- <2> NO [GO TO REFUSAL]
- <3> NO, NO ESTÁ DISPONIBLE EN ESTE MOMENTO [SET CALLBACK]

SI LE PREGUNTAN QUIÉN LLAMA:

Soy [INTERVIEWER NAME] de [VENDOR NAME]. Estamos trabajando con [HOSPICE NAME] y con el Departamento de Salud y Servicios Humanos de los Estados Unidos para realizar un estudio sobre los cuidados de hospicio.

SI EL CUIDADOR PROXY NO ESTÁ O NO PUEDE ATENDER LA LLAMADA:

¿Puede decirme a qué hora es conveniente llamar para hablar con él(ella)?

SI EL CUIDADOR PROXY DICE QUE NO ES UN BUEN MOMENTO:

Si usted no tiene tiempo ahora, ¿cuándo es más conveniente que vuelva a llamarle?

SI CONTESTA EL TELÉFONO ALGUIEN QUE NO SEA EL CUIDADOR PROXY, CUANDO ÉSTE TOMA LA LLAMADA, CONFIRME QUE EFECTIVAMENTE USTED ESTÁ HABLANDO CON EL CUIDADOR PROXY.

NUEVA LLAMADA PARA TERMINAR LA ENCUESTA INICIADA ANTERIORMENTE

INICIO: Buenos(as) días(tardes/noches), ¿podría hablar con [SAMPLED CAREGIVER NAME/PROXY CAREGIVER NAME]?

- <1> SÍ [GO TO CONFIRM RESPONDENT]
- <2> NO [REFUSAL]
- <3> NO, NO ESTÁ DISPONIBLE EN ESTE MOMENTO [SET CALLBACK]

SI LE PREGUNTAN QUIÉN LLAMA: Soy [INTERVIEWER NAME], y llamo de [VENDOR NAME]. ¿Puedo hablar con [SAMPLED CAREGIVER NAME/PROXY CAREGIVER NAME] para terminar una encuesta que empecé con él(ella) hace poco?

CONFIRMAR QUE ES EL ENTREVISTADO: Antes de continuar con la encuesta, quisiera confirmar que efectivamente estoy hablando con [SAMPLED CAREGIVER NAME/PROXY CAREGIVER NAME].

CONTINUAR CON LA ENCUESTA DONDE SE DEJÓ.

HABLANDO CON EL CUIDADOR

INTRODUCCIÓN — Buenos(as) días(tardes/noches); soy [INTERVIEWER NAME], y llamo de [VENDOR NAME].

[HOSPICE NAME] está llevando a cabo una encuesta sobre los servicios que reciben los pacientes y sus familias en el hospicio. Esta encuesta es parte de una iniciativa nacional patrocinada por el Departamento de Salud y Servicios Humanos de los Estados Unidos (HHS, por sus siglas en inglés) para evaluar la calidad de la atención en los hospicios. Estamos conscientes de que éste debe de ser un momento difícil para usted, pero esperamos que nos dedique unos minutos para ayudarnos a conocer la calidad de la atención que usted y su familiar o amigo recibieron en el hospicio.

Su participación es voluntaria y no afectará los beneficios o la atención médica que usted recibe. La entrevista durará [FILL: aproximadamente 10 minutos /OR SURVEY VENDOR SPECIFY]. Sus respuestas se combinarán con las de otros encuestados y, en conjunto, se compartirán con el hospicio con el fin de mejoramiento de la calidad.

SI LE PREGUNTAN SI OTRA PERSONA PUEDE SERVIR DE PROXY DEL CUIDADOR MUESTRA:

Para este estudio, tenemos que hablar con la persona de su hogar que esté más enterada, **UNA VEZ QUE LE DEN EL NOMBRE DE LA PERSONA QUE ESTÁ MÁS AL TANTO:** ¿Puede decirme si es él(ella OR usted) la persona que está más enterada y al tanto de los cuidados paliativos/de hospicio que recibió [DECEDENT NAME]?

SI ES NECESARIO, Y HABLA CON EL CUIDADOR MUESTRA: Nos dieron su nombre en el [HOSPICE NAME] porque usted aparecía en sus registros como la persona encargada del cuidado de [DECEDENT NAME].

SI ES NECESARIO, Y HABLA CON EL PROXY **DEL CUIDADOR MUESTRA:** Nos dió su nombre [SAMPLED CAREGIVER] porque nos dijo que usted está al tanto de los cuidados paliativos/de hospicio que recibió [DECEDENT NAME].

- <1> SÍ - [GO TO CONTINUE]
- <2> PROXY IDENTIFICADO - [COLLECT PROXY INFORMATION THEN RETURN TO PROXY INTRO]
- <3> NO, VA A ENVIARÁ LA ENCUESTA LLENADA POR CORREO - [GO TO CALLBACK]
- <4> NO, VOLVER A LLAMAR - [GO TO CALLBACK]
- <5> NO, R NO ESTÁ DISPONIBLE DURANTE PERÍODO DE CAMPO - [GO TO ITEM TO CODE ILL, ETC.]
- <6> NEGATIVA - [GO TO REFUSAL]
- <7> YA ENVIÓ LA ENCUESTA POR CORREO [GO TO MAILED]
- <8> NO PARTICIPÓ EN EL CUIDADO Y NO SE IDENTIFICÓ AL PROXY [GO TO INELIGIBLE]
- <9> EL PACIENTE NO RECIBIÓ CUIDADOS EN EL HOSPICIO MENCIONADO [GO TO DISAVOWAL]

CONTINUAR — Esta llamada puede ser monitoreada [OPTIONAL: y/o grabada] con fines de control de calidad. ¿Podemos empezar?

- <1> SÍ -[BEGIN SURVEY]
- <2> NO, VOLVER A LLAMAR - [GO TO CALLBACK]
- <3> REHUSA - [GO TO REFUSAL]

ENCUESTA ENVIADA POR CORREO — Muchas gracias por contestar la encuesta por correo. Quizá no la hayamos recibido todavía, pero que voy a revisar nuestros registros de nuevo. Es posible que tengamos que comunicarnos de nuevo con usted en caso de que aún no lo hayamos recibido. [END CALL]

INELEGIBLE4 — Lo siento, para este proyecto, sólo hablamos con los familiares o amigos que supervisaron o participaron en los cuidados de hospicio de su familiar. Gracias por su tiempo. Que tenga un(una/-) buen(buena/buenas) día(tarde/noches). FINALICE LA LLAMADA [END CALL]

DESCONOCIDO – Debe de haber un error en nuestros registros. Gracias por su tiempo. Que tenga un(una/-) buen(buena/buenas) día(tarde/noches). FINALICE LA LLAMADA [END CALL]

EMPIECE CON LAS PREGUNTAS CAHPS SOBRE EL HOSPICIO

Q1_INTRO Responda a todas las preguntas de esta encuesta sobre la atención recibida por el paciente en [HOSPICE NAME]. Cuando piense en sus respuestas, no incluya ninguna estancia en ningún otro hospicio.

ESTÉ PREPARADO/A PARA TANTEAR EN CASO DE QUE EL ENTREVISTADO DÉ UNA RESPUESTA FUERA DE LAS CATEGORÍAS DE RESPUESTA PROVISTAS. TANTEE REPITIENDO SÓLO LAS CATEGORÍAS DE RESPUESTA; NO TRATE DE INTERPRETAR LO QUE DIGA EL ENTREVISTADO.

Q1 ¿Cuál es su parentesco o relación con [DECEDENT NAME]?

- <1> MI CÓNYUGE O PAREJA [GO TO Q2]
- <2> MI MADRE O PADRE [GO TO Q2]
- <3> MI SUEGRA O SUEGRO [GO TO Q2]
- <4> MI ABUELA O ABUELO [GO TO Q2]
- <5> MI TÍA O TÍO [GO TO Q2]
- <6> MI HERMANA O HERMANO [GO TO Q2]
- <7> MI HIJA O HIJO [GO TO Q2]
- <8> AMIGA O AMIGO [GO TO Q2]
- <9> OTRO (POR FAVOR, ESPECIFIQUE) [GO TO Q1A]

- <M> MISSING/DK [GO TO Q2]

Q1A ¿Cuál es su relación con [DECEDENT NAME]?

[NOTA: POR FAVOR DOCUMENTE EL DATO DE PARENTESCO O RELACIÓN Y CONSÉRVELO EN SU ARCHIVO.]

Q2 Para este estudio, la palabra “familiar” se refiere a [DECEDENT NAME]. ¿En qué lugar o lugares recibió cuidados de [HOSPICE NAME] su familiar? Por favor, responda sí o no para cada una de las categorías.

Q2A ¿En casa?

- <1> SÍ
- <0> NO

- <M> MISSING/DK

Q2B ¿ En un hogar de asistencia parcial?

<1> SÍ
<0> NO

<M> MISSING/DK

Q2C ¿En un hogar de ancianos?

<1> SÍ
<0> NO

<M> MISSING/DK

Q2D ¿En un hospital?

<1> SÍ
<0> NO

<M> MISSING/DK

Q2E ¿En un hospicio o casa hospicio?

<1> SÍ
<0> NO

<M> MISSING/DK

Q2F ¿En algún otro lugar?

<1> SÍ [GO TO Q2F]
<0> NO [GO TO Q3]

<M> MISSING/DK [GO TO Q3]

Q2G ¿Dónde recibió cuidados su familiar?

[NOTA: POR FAVOR DOCUMENTE EL DATO DEL OTRO LUGAR Y CONSÉRVELO EN SU ARCHIVO]

Q3 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia participó usted en dichos cuidados o los supervisó? ¿Diría usted que...

<1> Nunca, [GO TO Q41_INTRO]

<2> A veces,

<3> La mayoría de las veces, o

<4> Siempre?

<M> MISSING/DK

Q4_INTRO Mientras conteste el resto de las preguntas de esta encuesta, por favor piense únicamente en la experiencia de su familiar con [HOSPICE NAME]

Q4 Para este estudio, el equipo del hospicio incluye a todas las enfermeras, médicos, trabajadores sociales, sacerdotes y otras personas que le proporcionaron cuidados paliativos/de hospicio a su familiar.

Mientras su familiar estaba bajo los cuidados del hospicio, ¿necesitó usted ponerse en contacto con el equipo del hospicio durante la noche, en fin de semana o en día festivo porque tenía alguna duda o necesitaba ayuda para el cuidado de su familiar?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*

<1> SÍ

<2> NO [GO TO Q6]

[<88> NOT APLICABLE]

<M> MISSING/DK [GO TO Q6]

Q5 ¿Con qué frecuencia obtuvo la ayuda que necesitaba del equipo del hospicio durante la noche, en fin de semana o en día festivo? ¿Diría usted que...

<1> Nunca,

<2> A veces,

<3> La mayoría de las veces, o

<4> Siempre?

[<88> NOT APLICABLE]

<M> MISSING/DK

- Q6 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio lo(a) mantuvo a usted informado(a) de cuando iban a llegar a cuidar a su familiar? ¿Diría usted que...
- <1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?
- [<88> NOT APPLICABLE]
<M> MISSING/DK
- Q7 Mientras su familiar estaba bajo los cuidados del hospicio, cuando usted o alguno de sus familiares le pedían ayuda al equipo del hospicio, ¿con qué frecuencia obtenían la ayuda tan pronto como la necesitaban? ¿Diría usted que...
- <1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?
- [<88> NOT APPLICABLE]
<M> MISSING/DK
- Q8 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio explicaba las cosas de un modo fácil de entender? ¿Diría usted que...
- <1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?
- [<88> NOT APPLICABLE]
<M> MISSING/DK
- Q9 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio lo(a) mantenía a usted informado(a) sobre el estado de su familiar? ¿Diría usted que...
- <1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?
- [<88> NOT APPLICABLE]
<M> MISSING/DK

Q10 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia alguien del equipo del hospicio le dio a usted informes contradictorios o confusos sobre el estado o los cuidados de su familiar? ¿Diría usted que...

- <1> Nunca,
- <2> A veces,
- <3> La mayoría de las veces, o
- <4> Siempre?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q11 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio trataba a su familiar con dignidad y respeto? ¿Diría usted que...

- <1> Nunca,
- <2> A veces,
- <3> La mayoría de las veces, o
- <4> Siempre?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q12 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia sintió usted que al equipo del hospicio le importaba realmente su familiar? ¿Diría usted que...

- <1> Nunca,
- <2> A veces,
- <3> La mayoría de las veces, o
- <4> Siempre?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q13 Mientras su familiar estaba bajo los cuidados del hospicio, ¿habló usted con el equipo del hospicio sobre algún problema relacionado con la atención o el cuidado de su familiar?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*

- <1> SÍ
- <2> NO [GO TO Q15]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO Q15]

Q14 ¿Con qué frecuencia el equipo del hospicio lo(a) escuchó con atención cuando usted les habló sobre algún problema relacionado con la atención o el cuidado de su familiar? ¿Diría usted que...

- <1> Nunca,
- <2> A veces,
- <3> La mayoría de las veces, o
- <4> Siempre?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q15 Mientras su familiar estaba bajo los cuidados del hospicio, ¿tuvo él(ella) algún tipo de dolor?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*

- <1> SÍ
- <2> NO [GO TO Q17]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO Q17]

Q16 ¿Recibió su familiar toda la ayuda que necesitaba para aliviar el dolor? ¿Diría usted que...

- <1> Sí, definitivamente,
- <2> Sí, más o menos, o
- <3> No?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q17 Mientras su familiar estaba bajo los cuidados del hospicio, ¿le dieron a él(ella) algún medicamento contra el dolor?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*

- <1> SÍ
- <2> NO [GO TO Q21]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO Q21]

Q18 Entre los efectos secundarios de la medicina contra el dolor está la somnolencia. ¿El equipo del hospicio habló con usted o con su familiar sobre los efectos secundarios del medicamento contra el dolor? ¿Diría usted que...

- <1> Sí, definitivamente,
- <2> Sí, más o menos, o
- <3> No?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q19 ¿El equipo del hospicio le dio la capacitación o información que usted necesitaba para saber de qué efectos secundarios del medicamento contra el dolor tenía usted que estar pendiente? ¿Diría usted que...

- <1> Sí, definitivamente,
- <2> Sí, más o menos, o
- <3> No?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q20 ¿El equipo del hospicio le dio a usted la capacitación o información que usted necesitaba para saber si tenía que darle más medicamento contra el dolor a su familiar y, si sí, cuándo dárselo? ¿Diría usted que...

- <1> Sí, definitivamente,
- <2> Sí, más o menos,
- <3> No, o
- <4> No tuve necesidad de darle a mi familiar medicina para el dolor.

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q21 Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento tuvo él(ella) dificultad para respirar o recibió tratamiento para su dificultad para respirar?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO ***SI ES NECESARIO***

- <1> SÍ
- <2> NO [GO TO Q24]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q24]

- Q22 ¿Con qué frecuencia su familiar recibió la ayuda que necesitaba para su dificultad para respirar? ¿Diría usted que...
- <1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?
- [<88> NOT APPLICABLE]
<M> MISSING/DK
- Q23 ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber cómo ayudar a su familiar si él(ella) tenía problemas para respirar? ¿Diría usted que...
- <1> Sí, definitivamente,
<2> Sí, más o menos,
<3> No, o
<4> No tuve necesidad de ayudar a mi familiar con alguna dificultad para respirar.
- [<88> NOT APPLICABLE]
<M> MISSING/DK
- Q24 Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento tuvo él(ella) problemas de estreñimiento?
- LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*
- <1> SÍ
<2> NO [GO TO Q26]
- [<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q26]
- Q25 ¿Con qué frecuencia su familiar recibió la ayuda que necesitaba para sus problemas de estreñimiento? ¿Diría usted que...
- <1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?
- [<88> NOT APPLICABLE]
<M> MISSING/DK

Q26 Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento él(ella) mostró ansiedad o tristeza?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*

<1> SÍ

<2> NO [GO TO Q28]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO Q28]

Q27 ¿Con qué frecuencia su familiar recibió del equipo del hospicio la ayuda que necesitaba para su ansiedad o tristeza? ¿Diría usted que...

<1> Nunca,

<2> A veces,

<3> La mayoría de las veces, o

<4> Siempre?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q28 Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento estuvo su familiar inquieto o agitado?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*

<1> SÍ

<2> NO [GO TO P30]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO P30]

Q29 ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber qué hacer si su familiar estaba inquieto o agitado? ¿Diría usted que...

<1> Sí, definitivamente,

<2> Sí, más o menos, o

<3> No?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q30 Mover a su familiar incluye acciones como ayudarlo(a) a darse la vuelta en la cama, o meterse y salir de la cama o sentarse y levantarse de una silla de ruedas.
¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber cómo mover a su familiar de manera segura? ¿Diría usted que...

- <1> Sí, definitivamente,
- <2> Sí, más o menos,
- <3> No, o
- <4> No tuve necesidad de mover a mi familiar.

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q31 ¿El equipo del hospicio le dio a usted tanta información como usted quería sobre qué acontecimientos esperar mientras su familiar estuviera muriéndose? ¿Diría usted que...

- <1> Sí, definitivamente,
- <2> Sí, más o menos, o
- <3> No?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q32 Algunas personas reciben cuidados paliativos/de hospicio mientras viven en un hogar de ancianos.
¿Su familiar recibió cuidados de este hospicio mientras él(ella) estaba viviendo en un hogar de ancianos?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*

- <1> SÍ
- <2> NO [GO TO Q35]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO Q35]

Q33 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el personal del hogar de ancianos y el equipo del hospicio se pusieron de acuerdo y acoplaron bien para proporcionarle los cuidados a su familiar? ¿Diría usted que...

- <1> Nunca,
- <2> A veces,
- <3> La mayoría de las veces, o
- <4> Siempre?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q34 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia los informes que el personal del hogar de ancianos le daba sobre su familiar eran diferentes de los informes que le daba el equipo del hospicio? ¿Diría usted que...

- <1> Nunca,
- <2> A veces,
- <3> La mayoría de las veces, o
- <4> Siempre?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q35_INTRO El siguiente grupo de preguntas es sobre usted.

Q35 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio lo(a) escuchó a usted? ¿Diría usted que...

- <1> Nunca,
- <2> A veces,
- <3> La mayoría de las veces, o
- <4> Siempre?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q36 El apoyo respecto a sus creencias religiosas o espirituales incluye hablar, rezar, tener momentos de recogimiento, u otras maneras de satisfacer sus necesidades religiosas o espirituales.

Mientras su familiar estaba bajo los cuidados del hospicio, ¿cuánto apoyo recibió usted respecto a sus creencias religiosas y espirituales por parte del equipo del hospicio? ¿Diría usted que...

- <1> Demasiado poco,
- <2> Justo el necesario, o
- <3> Demasiado?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q37 Mientras su familiar estaba bajo los cuidados del hospicio, ¿cuánto apoyo emocional recibió usted del equipo del hospicio? ¿Diría usted que...

- <1> Demasiado poco,
- <2> Justo el necesario, o
- <3> Demasiado?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q38 Durante las semanas posteriores a la muerte de su familiar, ¿recibió usted todo el apoyo emocional que usted quería por parte del equipo del hospicio? ¿Diría usted que...

- <1> Demasiado poco,
- <2> Justo el necesario, o
- <3> Demasiado?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q39 Por favor conteste las siguientes preguntas sobre los cuidados paliativos/de hospicio que su familiar recibió de [HOSPICE NAME]. No incluya ningún cuidado proporcionado por otros hospicios.

Utilizando un número del 0 al 10, siendo 0 los peores cuidados paliativos/de hospicio posibles y 10 los mejores cuidados paliativos/de hospicio posibles, ¿qué número usaría para calificar los cuidados paliativos/de hospicio que recibió su familiar?

SI EL ENTREVISTADO NO DA UNA RESPUESTA ADECUADA, INTENTE DE NUEVO Y REPITA LA PREGUNTA: Utilizando un número del 0 al 10, siendo 0 los peores cuidados paliativos/de hospicio posibles y 10 los mejores cuidados paliativos/de hospicio posibles, ¿qué número usaría para calificar los cuidados paliativos/de hospicio que recibió su familiar?

- <0> 0
- <1> 1
- <2> 2
- <3> 3
- <4> 4
- <5> 5
- <6> 6
- <7> 7
- <8> 8
- <9> 9
- <10> 10

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q40 ¿Le recomendaría este hospicio a sus amigos y familiares? ¿Diría usted que...

- <1> Definitivamente no,
- <2> Probablemente no,
- <3> Probablemente sí, o
- <4> Definitivamente sí?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q41_INTRO Las siguientes preguntas son sobre su familiar.

Q41 ¿Cuál es el grado o nivel escolar más alto que terminó su familiar? ¿Él(ella)...

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*

- <1> Terminó ocho años de escuela o menos,
- <2> Terminó el bachillerato o la preparatoria, pero sin graduarse,
- <3> Obtuvo el diploma de bachillerato, preparatoria, o su equivalente (o GED),
- <4> Terminó algunos cursos universitarios u obtuvo un título universitario de un programa de 2 años,
- <5> Obtuvo un título universitario de 4 años, o
- <6> Terminó estudios universitarios o superiores de más de 4 años
- <7> El entrevistado indica que no sabe el nivel escolar de su familiar

<M> MISSING/DK

CUALQUIER FORMACIÓN ACADÉMICA MÁS ALLÁ DE UN DIPLOMA DE BACHILLERATO, PREPARATORIA O HIGH SCHOOL, QUE NO SEA UNA LICENCIATURA DEBERÁ CODIFICARSE COMO 4. SI EL ENTREVISTADO MENCIONA UNA FORMACIÓN NO ACADÉMICA, COMO UNA ESCUELA DE COMERCIO, TRATE DE AVERIGUAR SI SU FAMILIAR TIENE UN DIPLOMA DE BACHILLERATO, PREPARATORIA O HIGH SCHOOL Y ASIGNE EL CÓDIGO 2 O EL 3, SEGÚN CORRESPONDA.

Q42 ¿Su familiar era de ascendencia u origen hispano, latino o español?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*

- <1> SÍ
- <2> NO

<M> MISSING/DK

SI LA RESPUESTA ES SÍ:
¿Diría usted que su familiar era...

(LEA TODAS OPCIONES DE RESPUESTA)

- <2> Puertorriqueño(a),
- <3> Mexicano(a), estadounidense de origen mexicano, chicano(a),
- <4> Cubano(a), o
- <5> De otro origen español, hispano o latino?

<M> MISSING/DK

PARA LA ENTREVISTA TELEFÓNICA, LA PREGUNTA 43 SE DIVIDE EN PARTES, DE LA “A” A LA “E”

LEER TODAS CATEGORÍAS DE RAZA HACIENDO UNA PAUSA EN CADA CATEGORÍA RACIAL PARA PERMITIRLE AL ENTREVISTADO RESPONDER A CADA CATEGORÍA RACIAL.

SI EL ENTREVISTADO PREGUNTA: “¿POR QUÉ ME PREGUNTA LA RAZA DE MI FAMILIAR?”: Le preguntamos la raza de su familiar para fines demográficos. Queremos estar seguros de que las personas a las que incluimos en el estudio representan efectivamente la diversidad racial de este país.

SI EL ENTREVISTADO RESPONDE: “YA LE DIJE LA RAZA DE MI FAMILIAR”: Sí, ya lo sé; sin embargo, el estudio me obliga a preguntar sobre todas las razas para que en los resultados se pueda incluir a personas que son multirraciales. Si la raza que yo mencione no corresponde al miembro de su familia por favor conteste NO. Gracias por su paciencia.

Q43 Cuando le lea lo siguiente, por favor, dígame si la categoría describe la raza de su familiar. Estoy obligado a leer las cinco categorías. Por favor, responda SÍ o NO a cada una de las categorías.

Q43A ¿Su familiar era blanco(a)?

<1> SÍ/ ERA BLANCO(A)
<2> NO/NO ERA BLANCO(A)

<M> MISSING/DK

Q43B ¿Su familiar era negro(a) o afroamericano(a)?

<1> SÍ/ ERA NEGRO(A)/AFROAMERICANO(A)
<2> NO/NO ERA NEGRO(A) NI AFROAMERICANO(A)

<M> MISSING/DK

Q43C ¿Su familiar era asiático(a)?

<1> SÍ/ ERA ASIÁTICO(A)
<2> NO/NO ERA ASIÁTICO(A)

<M> MISSING/DK

Q43D ¿Su familiar era nativo(a) de Hawai o de otras islas del Pacífico?

<1> SÍ/ERA NATIVO(A) DE HAWAI/DE OTRAS ISLAS DEL PACÍFICO

<2> NO/NO ERA NATIVO(A) DE HAWAI NI DE OTRAS ISLAS DEL
PACÍFICO

<M> MISSING/DK

Q43E ¿Su familiar era Indio(a) Americano(a) o nativo(a) de Alaska?

<1> SÍ/ERA INDIO(A) AMERICANO(A)/NATIVO(A) DE ALASKA

<2> NO/NO ERA INDIO(A) AMERICANO(A) NI NATIVO(A) DE ALASKA

<M> MISSING/DK

Q44_INTRO Las siguientes preguntas son sobre usted.

Q44 ¿Qué edad tiene usted?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*

<1> de 18 a 24 años

<2> de 25 a 34 años

<3> de 35 a 44 años

<4> de 45 a 54 años

<5> de 55 a 64 años

<6> de 65 a 74 años

<7> de 75 a 84 años

<8> 85 años o más

<M> MISSING/DK

Q45 ENTREVISTADOR, PREGUNTE SÓLO *SI ES NECESARIO*:

¿Es usted hombre o mujer?

<1> HOMBRE

<2> MUJER

<M> MISSING/DK

Q46 ¿Cuál es el grado o nivel escolar más alto que terminó? ¿Usted...

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO *SI ES NECESARIO*

- <1> Terminó ocho años de escuela o menos,
- <2> Terminó el bachillerato o la preparatoria, pero sin graduarse,
- <3> Obtuvo el diploma de bachillerato, preparatoria, o su equivalente (o GED),
- <4> Terminó algunos cursos universitarios u obtuvo un título universitario de un programa de 2 años,
- <5> Obtuvo un título universitario de 4 años, o
- <6> Terminó estudios universitarios o superiores de más de 4 años

<M> MISSING/DK

CUALQUIER FORMACIÓN ACADÉMICA MÁS ALLÁ DE UN DIPLOMA DE BACHILLERATO, PREPARATORIA O HIGH SCHOOL, QUE NO SEA UNA LICENCIATURA DEBERÁ CODIFICARSE COMO 4. SI EL ENTREVISTADO MENCIONA UNA FORMACIÓN NO ACADÉMICA, COMO UNA ESCUELA DE COMERCIO, TRATE DE AVERIGUAR SI SU FAMILIAR TIENE UN DIPLOMA DE BACHILLERATO, PREPARATORIA O HIGH SCHOOL Y ASIGNE EL CÓDIGO 2 O EL 3, SEGÚN CORRESPONDA.

Q47 ¿Qué idioma habla usted principalmente en su casa? Por favor, escuche las tres opciones de respuesta antes de contestar. ¿Diría usted que usted habla principalmente...

- <1> Inglés, [GO TO END]
- <2> Español, [GO TO END]
- <3> Chino, o [GO TO END]
- <4> Algún otro idioma? [GO TO Q47A]

<M> MISSING/DK [GO TO END]

SI LA RESPUESTA DEL ENTREVISTADO COMPRENDE VARIOS IDIOMAS, INTENTE PREGUNTÁNDOLE:

¿Diría usted que usted habla sobre todo (IDIOMA A) o (IDIOMA B)?

SI EL ENTREVISTADO CONTESTA QUE HABLA AMERICANO, POR FAVOR ASIGNE EL CÓDIGO 1-INGLÉS.

Q47A ¿Qué otro idioma habla usted mayormente en su casa?

[NOTA: POR FAVOR DOCUMENTE EL DATO DEL OTRO IDIOMA Y CONSÉRVELO EN SU ARCHIVO]

END

Esas son todas las preguntas que tengo. Gracias por su tiempo. (OPCIONAL: Si quiere ayuda para sobrellevar su duelo puedo darle ahora el número de apoyo en el [HOSPICE NAME]).

ENTREVISTADOR: PROPORCIONE LA INFORMACIÓN DE CONTACTO SEGÚN SEA NECESARIO

Que tenga un(una/-) buen(buena/buenas) día(tarde/noches).

FINALICE LA LLAMADA
[END CALL]

