ACKNOWLEDGMENTS

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CMS is pleased to acknowledge the role of the Agency for Healthcare Research and Quality, its CAHPS grantees, and Joan M. Teno, MD, MS 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.
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Quality Assurance Guidelines

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I. Reader’s Guide

Purpose of Quality Assurance Guidelines
The CAHPS Hospice Survey Quality Assurance Guidelines V3.0 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 and hospices with a high-level overview and reference for essential information presented in the CAHPS Hospice Survey Quality Assurance Guidelines V3.0 manual. Readers are directed to the related chapters of the CAHPS Hospice Survey Quality Assurance Guidelines V3.0 manual for more detail.

CAHPS Hospice Survey Quality Assurance Guidelines V3.0 Contents
The CAHPS Hospice Survey Quality Assurance Guidelines V3.0 manual 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, communication with patients and/or their caregivers, the Roles and Responsibilities for participating organizations (i.e., CMS, hospices and survey vendors), survey vendor analysis of CAHPS Hospice Survey data, the Minimum Business Requirements to administer the CAHPS Hospice Survey, and the 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 sample of decedents whose primary informal caregiver (caregiver) may be eligible to receive and respond to the CAHPS Hospice Survey.

Modes of Survey Administration
The CAHPS Hospice Survey Quality Assurance Guidelines V3.0 chapters VI, VII and VIII describe each of the three allowed modes of survey administration: Mail Only, Telephone Only and Mixed Mode (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. 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 and switching survey vendors processes, 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/conference 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 Survey mail materials (English, Spanish, Traditional Chinese, Simplified Chinese, Russian, Portuguese, and Vietnamese); telephone scripts (English and Spanish); suggested supplemental questions; telephone interviewing guidelines; frequently asked questions for customer support; data file layout specifications; survey vendor authorization form; switching survey vendors form; form for accessing the CAHPS Hospice Survey Data Warehouse; the survey vendor model QAP; and the forms for submitting requests for protocol exceptions, discrepancy reports and exemption for size.
For More Information
For program information and to view important updates and announcements, visit the CAHPS Hospice Survey Web site at: www.hospicecahpssurvey.org.

To Provide Comments or Ask Questions
For information and technical assistance, contact the CAHPS Hospice Survey Project Team via email at hospicecahpssurvey@HCQIS.org or call 1-844-472-4621.
II. Introduction and Overview

Background

Before the development of the CAHPS Hospice Survey, there was no official national standardized survey to measure patient and family experiences with hospice care. The CAHPS Hospice Survey uses detailed standardized survey administration protocols to allow for fair comparisons across hospices.

The Centers for Medicare & Medicaid Services (CMS) developed the CAHPS Hospice Survey with input from many stakeholders, including other government agencies, industry stakeholders, consumer groups, and 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 across 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 primary informal caregiver (i.e., family member or friend) identified to receive and respond to the CAHPS Hospice Survey. The primary informal caregiver is referred to as “caregiver” throughout this manual.

CAHPS Hospice Survey Development

The development process for the survey began in 2012 and included: a public request for information about publicly 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 hospital) completed the field test survey. Further information regarding the development and testing of the CAHPS Hospice Survey can be found in the Hospice Experience of Care Survey: Development and Field Test Report available on the Home Page of the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org).

National implementation of the CAHPS Hospice Survey began on January 1, 2015 with a dry run conducted in at least one month (January 2015, February 2015 or March 2015) of the first quarter of 2015. Beginning in April 2015, hospices were required to begin continuous monthly
participation in the CAHPS Hospice Survey. Hospices are 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 (HQRP) requirements. The dry run period was allowed for the initial implementation year only; no further dry run periods will be scheduled.

Office of Management and Budget (OMB) and Public Comment Process
The OMB’s Paperwork Reduction Act clearance process for the CAHPS Hospice Survey required 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. In November 2014, the OMB provided final approval for national implementation of the CAHPS Hospice Survey (42 CFR 418).

Preparation for CAHPS Hospice Survey Data Collection
Survey vendors interested in administering the CAHPS Hospice Survey must apply to participate and must attend all CAHPS Hospice Survey Training sessions. Training is offered via Webinar and there is no associated fee. At a minimum, the survey vendor’s Project Manager must attend all CAHPS Hospice Survey Training sessions. In addition, subcontractors and any other organizations that are responsible for major functions of CAHPS Hospice Survey administration must attend all CAHPS Hospice Survey Training sessions. Survey vendors that meet the CAHPS Hospice Survey Minimum Business Requirements will be eligible to receive conditional approval to be a CAHPS Hospice Survey vendor. Survey vendors will be eligible to receive full approval following participation in the CAHPS Hospice Survey Training session and successful completion of the post-training quiz.

To comply with CMS’ quality reporting requirements, all eligible hospices are required to contract with an approved survey vendor to collect data using the CAHPS Hospice Survey on an ongoing monthly basis. Participation in the CAHPS Hospice Survey is required to meet the pay for reporting requirement of the HQRP for the associated fiscal year (FY) annual payment update (APU).

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

CAHPS Hospice Survey Mode Experiment
In order to achieve the goal of fair comparisons across all hospices that participate in the CAHPS Hospice Survey, it is necessary to adjust for factors that are not directly related to hospice performance but may affect how caregivers answer CAHPS Hospice Survey items. To ensure that CAHPS Hospice Survey scores allow fair and standardized comparisons of hospices, in 2015 CMS conducted a mode experiment to examine whether the mode of survey administration (Mail Only, Telephone Only and Mixed Mode) in which caregivers respond to the survey systematically affects CAHPS Hospice Survey results (42 CFR 418).

This mode experiment enabled CMS to determine if survey mode adjustments are needed, and if they are needed, to develop them. Survey mode adjustments are intended to eliminate any
advantage or disadvantage in CAHPS Hospice Survey scores that might result for a hospice based on the mode in which its caregivers respond to the CAHPS Hospice Survey.

**CAHPS Hospice Survey Instrument**

The CAHPS Hospice Survey mail materials are available in English, Spanish, Chinese, Russian, Portuguese, and Vietnamese. The Chinese mail survey is provided in both traditional and simplified characters and targets both Mandarin and Cantonese speakers. The CAHPS Hospice Survey telephone script is available in English and Spanish.

The CAHPS Hospice Survey is administered using the Mail Only, Telephone Only or Mixed Mode (mail with telephone follow-up). No other modes of survey administration are permitted.

The CAHPS Hospice Survey instrument consists of 47 questions, broken into three sections: Core (Q1 – Q40), About Your Family Member (three questions) and About You (four questions).

**Components of the CAHPS Hospice Survey Instrument**

The standardized 47-question CAHPS Hospice Survey instrument includes the following quality measures:

<table>
<thead>
<tr>
<th>Composite Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hospice Team Communication</strong></td>
</tr>
<tr>
<td>➢ 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?</td>
</tr>
<tr>
<td>➢ While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?</td>
</tr>
<tr>
<td>➢ How often did the hospice team listen carefully to you when you talked with them about problems with your family member’s hospice care?</td>
</tr>
<tr>
<td>➢ While your family member was in hospice care, how often did the hospice team keep you informed about your family member’s condition?</td>
</tr>
<tr>
<td>➢ While your family member was in hospice care, how often did the hospice team listen carefully to you?</td>
</tr>
<tr>
<td>➢ 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?</td>
</tr>
<tr>
<td><strong>Getting Timely Care</strong></td>
</tr>
<tr>
<td>➢ 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?</td>
</tr>
<tr>
<td>➢ How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?</td>
</tr>
<tr>
<td><strong>Treating Family Member with Respect</strong></td>
</tr>
<tr>
<td>➢ While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?</td>
</tr>
<tr>
<td>➢ While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?</td>
</tr>
</tbody>
</table>
### CAHPS Hospice Survey Quality Measures and Constituent Items (Cont’d)

#### Composite Measures (Cont’d)

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting Emotional and Religious Support</td>
</tr>
<tr>
<td>➢ While your family member was in hospice care, how much emotional support did you get from the hospice team?</td>
</tr>
<tr>
<td>➢ In the weeks after your family member died, how much emotional support did you get from the hospice team?</td>
</tr>
<tr>
<td>➢ 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?</td>
</tr>
<tr>
<td>Getting Help for Symptoms</td>
</tr>
<tr>
<td>➢ Did your family member get as much help with pain as he or she needed?</td>
</tr>
<tr>
<td>➢ How often did your family member get the help he or she needed for trouble breathing?</td>
</tr>
<tr>
<td>➢ How often did your family member get the help he or she needed for trouble with constipation?</td>
</tr>
<tr>
<td>➢ How often did your family member get the help he or she needed from the hospice team for feelings of anxiety or sadness?</td>
</tr>
<tr>
<td>Getting Hospice Care Training</td>
</tr>
<tr>
<td>➢ Did the hospice team give you the training you needed about what side effects to watch for from pain medicine?</td>
</tr>
<tr>
<td>➢ Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?</td>
</tr>
<tr>
<td>➢ Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?</td>
</tr>
<tr>
<td>➢ Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?</td>
</tr>
<tr>
<td>➢ 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?</td>
</tr>
<tr>
<td>Global Measures</td>
</tr>
<tr>
<td>Rating of Hospice</td>
</tr>
<tr>
<td>➢ 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?</td>
</tr>
<tr>
<td>Recommend Hospice</td>
</tr>
<tr>
<td>➢ Would you recommend this hospice to your friends and family?</td>
</tr>
</tbody>
</table>
CAHPS Hospice Survey Development and National Implementation Timeline
The following timeline outlines major events in the CAHPS Hospice Survey development process, as well as anticipated dates for future national implementation events.

2012
- September 2012 – CMS selects the RAND Corporation to coordinate the development and field testing of the Hospice Experience of Care Survey instrument. The RAND Corporation assembles a team comprised of Health Services Advisory Group and Joan M. Teno of Brown University, among others, to support these activities.
- December 2012 – Technical Expert Panel convened to discuss main survey content domains and eligibility requirements for the field test.

2013
- January 2013 – A Federal Register Notice is published soliciting comments on the topic areas on the draft pilot instrument.
- November and December 2013 – Field test of Hospice Experience of Care Survey.

2014
- February 2014 – CMS selects the RAND Corporation to support national implementation of the Hospice Experience of Care Survey (subsequently referred to as the CAHPS Hospice Survey, following approval from the Agency for Healthcare Research and Quality [AHRQ] CAHPS Consortium). The RAND Corporation assembles a team comprised of Health Services Advisory Group and Joan M. Teno of Brown University, among others, to support these activities.
- April 2014 – Technical Expert Panel convened to discuss national implementation procedures.
- August 2014 – The FY 2015 Hospice Payment Rate Update Final Rule is published. The rule stipulates that eligible hospices must participate in the CAHPS Hospice Survey to be eligible to receive the APU.
- August 2014 – CAHPS Hospice Survey Quality Assurance Guidelines V1.0 manual is released.
- August 2014 – Hospice Experience of Care Survey: Development and Field Test Report is released.
- October 2014 – The first CAHPS Hospice Survey Training session is conducted via Webinar.
- November 2014 – CAHPS Hospice Survey receives final clearance from OMB to administer the 47-item CAHPS Hospice Survey instrument.
- November 2014 – English and Spanish translations of the survey instrument are made available.
- December 2014 – Traditional Chinese and Simplified Chinese translations of the survey instrument are made available for Mail Only mode of survey administration.

2015
Introduction and Overview

September 2016

- February 2015 – Mode experiment of the CAHPS Hospice Survey begins (patient deaths in February 2015; survey administration beginning in May 2015 and ending in October 2015)
- March 2015 – Dry run of the CAHPS Hospice Survey concludes (patient deaths in March 2015; survey administration beginning in June 2015)
- April 2015 – National implementation of the CAHPS Hospice Survey begins (ongoing monthly participation beginning with patient deaths in April 2015 and survey administration beginning in July 2015)
- May 2015 – The FY 2016 Hospice Payment Rate Update Proposed Rule is published
- August 2015 – The FY 2016 Hospice Payment Rate Update Final Rule is published
- September 2015 – CAHPS Hospice Survey Quality Assurance Guidelines V2.0 manual is released
- September 2015 – Russian and Portuguese translations of the survey instrument are made available for Mail Only mode of survey administration
- September 2015 – The second annual CAHPS Hospice Survey Training session is conducted via Webinar
- October 2015 – Mode experiment of the CAHPS Hospice Survey ends (patient deaths through June 2015)

2016

- February 2016 – CMS submits CAHPS Hospice Survey measures to the National Quality Forum (NQF) for its endorsement
- April 2016 – The FY 2017 Hospice Payment Rate Update Proposed Rule is published
- May 2016 – Vietnamese translation of the survey instrument is made available for Mail Only mode of survey administration
- August 2016 – The FY 2017 Hospice Payment Rate Update Final Rule is published
- September 2016 – CAHPS Hospice Survey Quality Assurance Guidelines V3.0 manual is released
- September 2016 – The third annual CAHPS Hospice Survey Training session is conducted via Webinar
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 for survey administration and data submission outlined in the table below.

<table>
<thead>
<tr>
<th>CAHPS Hospice Survey Administration and Data Submission Schedule</th>
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<tbody>
<tr>
<td><strong>Month of Death</strong></td>
</tr>
<tr>
<td>April 2016</td>
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<td>May 2016</td>
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<td>April 2018</td>
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<tr>
<td>May 2018</td>
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<tr>
<td>June 2018</td>
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</table>
III. Program Requirements

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

Purpose of the CAHPS Hospice Survey Program Requirements
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 members or friends received from the hospice named on the survey

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, and
- to ensure that the caregivers’ responses are unbiased and reflect only the decedents’ and caregivers’ experiences of care

In order to ensure these outcomes:
- The CAHPS Hospice Survey should be the first survey caregivers receive about their family members’ or friends’ experiences of hospice care
- Hospices and survey vendors (and anyone acting on their behalf) must not attempt to influence how caregivers respond to CAHPS Hospice Survey items

Hospice Communication with Patients and/or Their Caregivers
The sections below are intended to provide survey vendors and hospices with guidance when conducting quality improvement activities in conjunction with the CAHPS Hospice Survey.

Communicating with Patients and/or Their Caregivers about the CAHPS Hospice Survey
CAHPS Hospice Survey guidelines allow hospices to communicate about the CAHPS Hospice Survey with patients and/or their caregivers prior to administration of the survey. For example, hospices may inform caregivers during the hospice admission process that they may receive the CAHPS Hospice Survey. If a hospice wants to let caregivers know that they may receive a survey and encourage them to complete it, the hospice must inform all caregivers. Certain types
of communications are not permitted because they may introduce bias in the survey results. For instance, hospices/survey vendors are not allowed to:

- ask any CAHPS Hospice Survey or CAHPS Hospice Survey-like questions of caregivers prior to administration of the survey
- attempt to influence or encourage caregivers to answer CAHPS Hospice Survey questions in a particular way
- imply that the hospice, its personnel or agents will be rewarded or gain benefits for positive feedback from caregivers by asking caregivers to choose certain responses, or indicate that the hospice is hoping for a given response, such as a “10,” “Definitely yes,” or an “Always”
- ask caregivers to explain why a specific response was chosen; for example, it is not acceptable to ask caregivers why they indicated that they would not recommend the hospice to friends and family
- 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
- show or provide the CAHPS Hospice Survey or cover letters to caregivers while they are in the hospice or at any time prior to the administration of the survey
- mail or distribute any pre-notification letters or postcards after patient death to inform caregivers about the CAHPS Hospice Survey

Use of Other Hospice Surveys
In this section, CMS provides guidelines to employ when asking caregivers questions regarding their family members’ or friends’ hospice care. CMS’ intent is to minimize the burden on caregivers, prevent the introduction of bias to CAHPS Hospice Survey responses and not decrease the likelihood that caregivers will complete the CAHPS Hospice Survey.

In general, activities and encounters that are intended to provide or assess clinical care or promote patient/family well-being are permissible. However, activities and encounters that are primarily intended to influence how caregivers, or which caregivers, respond to CAHPS Hospice Survey items must be avoided. If patients or their caregivers are asked questions during their hospice care, we suggest that such questions be worded in a neutral tone and not slanted toward a particular outcome. Questions must not resemble CAHPS Hospice Survey items or their response categories. In addition, references to CMS must not be included on any surveys that are not the official CAHPS Hospice Survey. Hospices should focus on overall quality of care rather than the measures reported to CMS.

Caregivers should not be given any formal, CAHPS Hospice Survey-like, patient experience/satisfaction survey before they receive the official CAHPS Hospice Survey. A formal survey, regardless of the mode employed, is one in which the primary goal is to ask standardized questions of a significant portion of a hospice’s patient/caregiver population.

- When asking non-CAHPS Hospice Survey questions, do not use CAHPS Hospice Survey-like response categories (for instance, “Always,” “Usually,” “Sometimes,” or “Never”)

[Program Requirements] September 2016

Centers for Medicare & Medicaid Services
CAHPS Hospice Survey Quality Assurance Guidelines V3.0
The following are examples of the types of questions that are not permissible:

- “On a scale of 0 to 10, how would you rate your family member’s hospice care?”
- “Is there a way we could always…?”
- “Did the hospice team explain things in a way you could understand?”
- “Overall, how would you rate the care you received from the hospice?”

Note: It is permissible for hospices to ask patients and/or their caregivers questions about their care during their hospice stay or during bereavement calls when this is a normal part of quality improvement activities, as long as the questions and/or response categories do not resemble the CAHPS Hospice Survey.

The CAHPS Hospice Survey should be administered prior to administering any other survey after the patient’s death. As noted above, it is permissible for patients and their caregivers to be asked questions during their hospice stay when the focus is on the clinical care of the individual patient. The hospice or its agents must not seek to influence which caregivers receive the CAHPS Hospice Survey or how caregivers answer CAHPS Hospice Survey items.

Other Communications with Patients and/or Their Caregivers

When communicating with patients and/or their caregivers while in the hospice regarding their healthcare, hospices should take care to avoid introducing bias in the way caregivers may answer questions on the CAHPS Hospice Survey. Many of the guidelines above in the Communicating with Patients and/or Their Caregivers about the CAHPS Hospice Survey and Use of Other Hospice Surveys apply to general communications with patients and their caregivers.

Examples of statements that comply with CAHPS Hospice Survey protocols include:

- “We are looking for ways to improve your family member’s stay. Please share your comments with us.”
- “What can we do to improve your family member’s care?”
- “We want to hear from you, please share your experience with us.”
- “Please let us know if you have any questions about your family member’s treatment plan.”
- “Let us know if your family member’s room is not comfortable.”

Hospices should not:

- wear buttons, stickers, etc. that state “Always” or “10”
- emphasize CAHPS Hospice Survey response options in posters, white boards, rounding questions, in-room televisions, or other media accessible to patients and their caregivers. Examples of statements that do not comply with CAHPS Hospice Survey protocols include:
  - “We expect to be the best hospice possible.”
  - “Our goal is to always address your needs.”
  - “Let us know if we are not listening carefully to you.”
  - “We treat our patients with dignity and respect.”
  - “In order to provide the best possible care, please tell us how we can always…”
  - “Our doctors and nurses always listen carefully to you.”
  - “We want to always explain things to you in a way you can understand.”
  - “We want you to recommend us to family and friends.”
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 support via CAHPS Hospice Survey Information and Technical Assistance and distribute information about survey administration procedures and policy updates on the CAHPS Hospice Survey Web site at www.hospicecahpssurvey.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 exempt from participation for a given APU period. The scenarios under which a Medicare-certified hospice provider can be exempted from participation in the CAHPS Hospice Survey are 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) 2017 data collection period, Medicare-certified hospices that have served fewer than 50 survey-eligible decedents/caregivers in the period from January 1, 2016 through December 31, 2016 can apply for an exemption from CAHPS Hospice Survey CY 2017 data collection and reporting requirements. To qualify for the survey exemption for CY 2017, hospices must submit a Participation Exemption for Size Form online via the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org). For the CY 2017 data collection period, this form must be submitted no later than August 9, 2017. The form must be completed in its entirety. Hospices are not eligible to receive the Participation Exemption for Size if they do not submit a Participation Exemption for Size form for the year. Please see Appendix L for specific information to be submitted on the Participation Exemption for Size Form.
  - Hospices will need to include the total number of decedents for CY 2016, 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, no caregiver of record [a decedent 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, and no publicity decedents/caregivers).
Note: “No publicity” decedents/caregivers are those who initiate or voluntarily request at admission that the hospice: 1) not reveal the patient’s identity; and/or 2) not survey him or her.

Note: For multiple hospice programs sharing one CMS Certification Number (CCN), the survey-eligible decedents/caregivers count is the total from all programs sharing that CCN.

- The Exemption for Newness is based on how recently the hospice received its CCN (formerly known as the Medicare Provider Number). The criterion for this exemption is that the hospice must have received its CCN on or after the first day of the performance year for the CAHPS Hospice Survey. For example, a hospice must receive its CCN on or after January 1, 2016 to be eligible for the Exemption for Newness for CY 2016. CMS will identify hospices eligible for this exemption. There is no form for hospices to submit.

Note: The Exemption for Newness is only applicable for the CY that the hospice is assigned its CCN. Hospices that become eligible to participate in the CAHPS Hospice Survey should begin participating during January of the year after they become eligible.

If a hospice is eligible to participate, it must:
- Contract with an approved CAHPS Hospice Survey vendor to administer the survey on behalf of the hospice
- 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 by submitting a CAHPS Hospice Survey Vendor Authorization Form (refer to Appendix B) 90 days prior to the data submission deadline
  - Once an organization authorizes a survey vendor, it is not necessary to provide additional notification unless the organization chooses to de-authorize its survey vendor
- Complete and submit a CAHPS Hospice Survey Data Warehouse Access Form (refer to Appendix D)
- Work with their approved survey vendor to determine a date each month by when 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

Note: If an organization chooses to de-authorize its survey vendor, it must contact the CAHPS Hospice Survey Project Team immediately to begin the transition process (refer to Appendix C). This change in survey vendor can only take effect at the beginning of a calendar quarter, and the timing of receipt of the request may affect when the change may be made.

- Use a secure method to transmit decedents/caregivers lists to the survey vendor
- Review data submission reports in the CAHPS Hospice Survey Data Warehouse to ensure that the survey vendor has submitted data on time and without data problems
Avoid influencing caregivers in any way about whether to 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.

Note: If a hospice wants to let caregivers know that they may receive a survey and encourage them to complete it, the hospice must inform all caregivers.

Understand the hospices’ responsibilities regarding participation in the HQRP, including key date ranges and deadline dates

Survey Vendor Roles and Responsibilities
CAHPS Hospice Survey vendors are subject to the following requirements:

- Meet all of the CAHPS Hospice Survey Minimum Business Requirements
  - 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.

- 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 process 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 CAHPS Hospice Survey Participation Form for Survey Vendors and request approval to administer the CAHPS Hospice Survey. The CAHPS Hospice Survey Participation Form for Survey Vendors will be available on the CAHPS Hospice Survey Web site prior to the scheduled CAHPS Hospice Survey Training session.

- Participate in and successfully complete all CAHPS Hospice Survey Training sessions
  - The survey vendor’s designated CAHPS Hospice Survey Project Manager must also complete a post-training quiz after participating in CAHPS Hospice Survey Training sessions

- Ensure that all survey vendor staff who work on the CAHPS Hospice Survey are trained and follow the CAHPS Hospice Survey protocols and guidelines

- 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
  - [www.hhs.gov/HIPAA](http://www.hhs.gov/HIPAA)

- Follow the Rules of Participation to administer the CAHPS Hospice Survey

- 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

- Assign and train organizational staff with appropriate back-up responsibilities for coverage of key staff
➢ Work with the client hospice’s staff to create decedents/caregivers lists, including all data elements needed
➢ Designate a date each month by when the hospice must provide the decedents/caregivers lists
➢ Receive and perform checks of the decedents/caregivers lists provided by each hospice to ensure that they include the entire eligible population and all required data elements, including required counts
➢ When updated decedents/caregivers lists are received, the survey vendor must update all decedent/caregiver administrative information available. In addition, the survey vendor must perform quality checks to track and verify changes from the original decedents/caregivers list.
➢ Prepare sample frame
➢ Draw sample of decedents/caregivers according to the sampling protocols contained in the CAHPS Hospice Survey Quality Assurance Guidelines manual
➢ 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 manual
  • Survey vendors administering Telephone Only and Mixed Mode of survey administration must use telephone interviewers who do not know decedents/caregivers either professionally or personally
  • Perform quality checks of all survey administration processes and document the performance of the quality check activities
➢ 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 the 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
➢ Maintain active contract(s) with hospice(s) in order to retain approval status (see CAHPS Hospice Survey Minimum Business Requirements)

Note: If a survey vendor is non-compliant with program requirements for any of their contracted hospices, the non-compliant action may affect that 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.
Customer Support Lines
Survey vendors who administer the CAHPS Hospice Survey must maintain a toll-free customer support telephone line to answer questions about the CAHPS Hospice Survey, offering customer support in all languages in which the survey vendor administers the survey. Survey vendors conducting the Mail Only or Mixed Modes of survey administration must include contact information for their customer support telephone line in the initial and follow-up cover letters. Telephone lines must be staffed during business hours (see guidelines below), and have sufficient capacity to handle incoming calls. Voicemail is acceptable during and after core business hours, but must be regularly monitored and replied to within 1 – 2 business days. The voicemail recording must specify that the caller can leave a message about the CAHPS Hospice Survey. Survey vendors must document questions received and responses provided via a database or tracking log.

In addition to the above requirements, the following guidelines are recommended for customer support lines:

- Staff telephone lines from 9 AM to 9 PM (survey vendor local time), Monday through Friday
- Maintain sufficient capacity so that 90 percent of incoming calls are answered “live” and the average speed of answer is 30 seconds or less
- Establish a “return call” standard of two business days for caller questions that cannot be answered at the time of the initial call

A CAHPS Hospice Survey Frequently Asked Questions (FAQs) document for customer support personnel and project staff is provided in Appendix H. Customer support personnel must use the FAQs as a guide when answering caregivers’ questions about the survey.

Survey Vendor Analysis of CAHPS Hospice Survey Data

- Survey vendors can provide responses linked to a decedent’s/caregiver’s name and other identifying information to the hospice only if the respondent gives his or her consent on the supplemental “Consent to Share Responses” question
- It is acceptable to provide to the hospice de-identified survey responses to Questions 3 – 31 and 35 – 40 of the CAHPS Hospice Survey without the respondent’s consent to share his or her survey responses, provided there are more than 10 responses to each of these questions
  - The term “de-identified” refers to excluding all information that could potentially identify a particular decedent/caregiver
  - The following items are considered to be identifiable; and therefore, cannot be shared with the hospice unless the respondent answers yes to the Consent to Share Responses question:
    - caregiver name, address, telephone number, or email address
    - decedent name, address, sex, race, ethnicity, date of birth, date of death, hospice admission date, payer information, or primary diagnosis
    - caregiver relationship to the decedent
    - responses to open-ended questions that contain text or comments which may infer the identity of the decedent and/or caregiver (e.g., specific languages, physical descriptions)
To ensure that hospices with small sample sizes cannot link survey responses to a specific decedent/caregiver, survey responses to the questions below must only be provided in aggregate form:

- the respondent’s relationship to the decedent (Q1)
- the locations in which the decedent received hospice care (Q2 and Q32 – Q34)
- demographic information regarding the respondent or decedent (Q41 – Q47)

Survey vendors must suppress any report or display of aggregate data that includes counts of 1 – 10 substantive responses (i.e., not missing values) for Questions 1, 2, 32 – 34, and 41 – 47. No information based on 1 – 10 caregivers can be released, meaning no counts of 1 – 10 times can be displayed in any cross tabulations, frequency distributions, tables, Excel files, or other reporting mechanisms.

- For example, if a certain response option is chosen between 1 – 10 times, data for that response option must not be displayed, even if 11 or more responses were received for the question as a whole
- The same guidance applies for any supplemental question that could enable hospices to link survey responses to a specific decedent/caregiver
- No cell counts may be displayed that allow the exact inference of a cell count of 1 – 10
  - For example, if 79 people answer a Yes/No question, with 70 answering yes and 9 answering no, the total number of responses (79) may be displayed, but neither the number of no responses nor the number of yes responses may be displayed, as the latter value of 70 would allow exact inference of the former value of 9.

As with all survey vendor analyses, the survey vendor scores may differ from the official CMS results. When providing hospices with survey data, survey vendors must communicate to hospices that the survey vendor scores are not official CMS scores and should only be used for quality improvement purposes. If hospices or survey vendors choose to use survey vendor provided scores in any way, they must indicate that they are not official CMS scores.

- CMS guidance regarding scoring and analysis (including adjustment for case mix and mode of survey administration) will be released at a later time.

CAHPS Hospice Survey Minimum Business Requirements
A survey vendor 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 at the time the CAHPS Hospice Survey Participation Form is received. In addition, subcontractors and any other organizations that are responsible for 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 at the time the CAHPS Hospice Survey Participation Form is received (a subcontractor’s survey administration experience does not substitute for a survey vendor’s).
The first step is to complete a CAHPS Hospice Survey Participation Form for Survey Vendors and submit it to the CAHPS Hospice Survey Project Team for consideration. Once conditionally approved, the survey vendor must then participate in the CAHPS Hospice Survey Training session. Survey vendors that meet the CAHPS Hospice Survey Minimum Business Requirements will be eligible to receive conditional approval to be a CAHPS Hospice Survey vendor. Survey vendors will be eligible to receive full approval following participation in the CAHPS Hospice Survey Training session and successful completion of the post-training quiz.

Note: In reviewing the CAHPS Hospice Survey Participation Forms submitted by potential CAHPS Hospice Survey vendors, the CAHPS Hospice Survey Project Team will take into consideration the applicant’s prior experience administering other CMS CAHPS Surveys, if any.

Approved CAHPS Hospice Survey vendors must fully comply with the CAHPS Hospice Survey oversight activities

- Participate in CAHPS Hospice Survey oversight activities to confirm 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 of the CAHPS Hospice Survey administration protocols; and thereby substantiate 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 (U.S.). 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.

Note: If a survey vendor is non-compliant with program requirements for any of their contracted hospices, the non-compliant action may affect that 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.
A survey vendor must meet **ALL** of the CAHPS Hospice Survey Minimum Business Requirements at the time the CAHPS Hospice Survey Participation Form is received. In addition, subcontractors and any other organizations that are responsible for 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 at the time the CAHPS Hospice Survey Participation Form is received (a subcontractor’s survey administration experience does not substitute for a survey vendor’s). The CAHPS Hospice Survey Minimum Business Requirements for an organization to become approved to administer the CAHPS Hospice Survey are as follows:

### Management Relationships:

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Survey Vendor</th>
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<tbody>
<tr>
<td><strong>Current/Future Relationships with Hospices</strong></td>
<td>➢ The following types of organizations are not eligible to administer the CAHPS Hospice Survey (as an approved CAHPS Hospice Survey vendor):</td>
</tr>
<tr>
<td></td>
<td>• organizations or divisions within organizations that own or operate a hospice or provide hospice services, even if the division is run as a separate entity to the hospice;</td>
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<td></td>
<td>• organizations that provide telehealth, monitoring of hospice patients, or teleprompting services for the hospice; and</td>
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<td>• organizations that provide staffing to hospices for providing care to hospice patients, whether personal care aides or skilled services staff</td>
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### Relevant Survey Experience:

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Survey Vendor</th>
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</thead>
<tbody>
<tr>
<td><strong>Number of Years in Business</strong></td>
<td>➢ Minimum four years</td>
</tr>
<tr>
<td><strong>Number of Years Conducting Surveys in the Requested Mode</strong></td>
<td>➢ Minimum three years of conducting surveys in the selected mode(s) of administration</td>
</tr>
<tr>
<td><strong>Number of Years Conducting Patient-Specific Surveys</strong></td>
<td>➢ Minimum two years conducting patient-specific surveys as an organization</td>
</tr>
<tr>
<td><strong>Sampling Experience</strong></td>
<td>➢ Two years prior experience selecting a random sample based on specific eligibility criteria:</td>
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<tr>
<td></td>
<td>• Work with contracted client(s) to obtain patient data for sampling via HIPAA-compliant electronic data transfer processes</td>
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<td></td>
<td>• Adequately document sampling process</td>
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<td></td>
<td>• Survey vendors are responsible for conducting the sampling process and must not subcontract this activity</td>
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## Survey Capability and Capacity:

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<tr>
<th>Criteria</th>
<th>Survey Vendor</th>
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<tbody>
<tr>
<td><strong>Personnel</strong></td>
<td>➢ Designated CAHPS Hospice Survey personnel:</td>
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<tr>
<td></td>
<td>• Project Director with minimum two years prior experience conducting patient-specific surveys in the requested mode(s)</td>
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<td>• Staff with minimum one year prior experience in sample frame development and sample selection</td>
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<td></td>
<td>• 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</td>
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<td></td>
<td>• Call Center-Mail Center Supervisor (subcontractor designee, if applicable) with minimum one year prior experience in role</td>
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<td></td>
<td>➢ Have appropriate organizational back-up staff for coverage of key staff</td>
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<td></td>
<td>➢ Volunteers are not permitted to be involved in any aspect of the CAHPS Hospice Survey administration process</td>
</tr>
<tr>
<td><strong>Physical Plant and System Resources</strong></td>
<td>➢ Physical plant resources available to handle the volume of surveys being administered, including computer and technical equipment:</td>
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<tr>
<td></td>
<td>• A secure commercial work environment</td>
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<td></td>
<td>• Home-based or virtual interviewers cannot be used to administer the CAHPS Hospice Survey nor may they conduct any survey administration processes</td>
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<td>• Physical facilities and electronic equipment and software to collect, process and report data securely</td>
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<td></td>
<td>• If offering telephone surveys, must have the equipment, software and facilities to conduct CATI interviews and to monitor interviewers</td>
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<td>➢ Electronic or alternative survey management system to:</td>
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<td></td>
<td>• Track fielded surveys throughout the protocol, avoiding respondent burden and losing respondents</td>
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<tr>
<td></td>
<td>• Assign random, unique, de-identified identification number (Decedent ID) to track each sampled patient/primary informal caregiver (i.e., family member or friend of the hospice patient)</td>
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<tr>
<td></td>
<td>➢ 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.</td>
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<td></td>
<td>➢ All System Resources are subject to oversight activities, including site visits to physical locations</td>
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### Criteria

<table>
<thead>
<tr>
<th>Sample Frame Creation</th>
<th>Survey Vendor</th>
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<tbody>
<tr>
<td></td>
<td>Two years prior experience selecting a random sample based on specific eligibility criteria:</td>
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<tr>
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<td>- Generate the sample frame data file that contains all individuals who meet the eligible population criteria</td>
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<tr>
<td></td>
<td>- Draw random sample of individuals for the survey who meet the eligible population criteria</td>
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<table>
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<tr>
<th>Mail Administration</th>
<th>Survey Vendor</th>
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<tbody>
<tr>
<td>Mail survey administration activities are not to be conducted from a residence, nor from a virtual office</td>
<td></td>
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<tr>
<td>Obtain and update addresses of sampled caregivers of hospice decedents</td>
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<tr>
<td>Produce and print professional quality survey instruments and materials according to guidelines; a sample of all mailing materials must be submitted for review</td>
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<tr>
<td>Merge and print sample names and addresses on personalized mail survey cover letters and print unique Decedent IDs on the survey questionnaire</td>
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<tr>
<td>Mail out survey materials</td>
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<tr>
<td>Receive and process (key-enter or scan) returned questionnaires</td>
<td></td>
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<tr>
<td>Track and identify non-respondents for follow-up mailing</td>
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<tr>
<td>Assign final survey status codes to describe the final result of work on each sampled record</td>
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<tr>
<th>Telephone Administration</th>
<th>Survey Vendor</th>
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<tbody>
<tr>
<td>Telephone interviews are not to be conducted from a residence, nor from a virtual office</td>
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<tr>
<td>Obtain, verify and update telephone numbers</td>
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<tr>
<td>Develop computer programs for electronically administering the survey (CATI)</td>
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<tr>
<td>Collect telephone interview data for the survey using a CATI system; a sample of the telephone script and interviewer screenshots must be submitted for review</td>
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<tr>
<td>Identify non-respondents for follow-up telephone calls</td>
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<tr>
<td>Schedule and conduct call backs to non-respondents at varying times of the day and different days of the week</td>
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<tr>
<td>Assign final survey status codes to reflect the final result of attempts to obtain a completed interview with each sampled record</td>
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<tr>
<th>Mixed Mode Administration (Mail with Telephone Follow-up)</th>
<th>Survey Vendor</th>
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<tbody>
<tr>
<td>Mail survey administration processes and telephone interviews are not to be conducted from a residence, nor from a virtual office</td>
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<tr>
<td>Adhere to all Mail Only and Telephone Only survey administration requirements (described above)</td>
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<tr>
<td>Track cases from mail survey through telephone follow-up activities</td>
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<tr>
<td>Criteria</td>
<td>Survey Vendor</td>
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</table>
| Data Submission | ➢ Survey vendors are responsible for conducting data submission and must not subcontract this process  
|                 | ➢ Survey vendors must have the capacity to do the following actions to submit quarterly data files:  
|                 |   • Register as a user of the CAHPS Hospice Survey Data Warehouse  
|                 |   • Confirm contracted hospices have authorized survey vendors to submit data on behalf of the hospice  
|                 |   • Import scanned or key-entered data from completed mail surveys into a data file, if applicable  
|                 |   • Import data from CATI system into a data file, if applicable  
|                 |   • 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 are exported correctly and 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 issues and data submission problems  
| Data Security   | ➢ Survey vendors must have the capacity to do the following actions to secure electronic data:  
|                 |   • Use a firewall and/or other mechanisms for preventing unauthorized access to electronic files  
|                 |   • Implement access levels and security passwords so that only authorized users have access to sensitive data  
|                 |   • Implement daily data back-up procedures that adequately safeguard system data  
|                 |   • Test back-up files on a quarterly basis, at a minimum, 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  
|                 |   • Develop procedures for identifying and handling breaches of confidential data  
<p>|                 |   • Develop a disaster recovery plan for conducting ongoing business operations in the event of a disaster |</p>
<table>
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<tr>
<th>Criteria</th>
<th>Survey Vendor</th>
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</table>
| Data Retention and Storage     | ➢ Survey vendors must have the capacity to do the following actions to securely store all data related to survey administration:  
  • Store CAHPS Hospice Survey-related data files, including decedents/caregivers lists and de-identified electronic data files, for all applicable survey modes for a minimum of three years. Archived electronic data files must be easily retrievable.  
  • Store de-identified returned mail questionnaires in a secure and environmentally safe location (e.g., locked file cabinet, locked closet or room), if applicable. Paper copies or optically scanned images of the questionnaires must be retained for a minimum of three years and be easily retrievable. |
| Technical Assistance/           | ➢ Two years prior experience providing telephone customer support  
  ➢ Provide toll-free customer support line:  
    • Offering customer support in all languages in which the survey vendor administers the survey  
    • Returning calls within 1 – 2 business days                                                                                                                                  |
### Participation in Quality Control Activities and Documentation Requirements:

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<tr>
<th>Criteria</th>
<th>Survey Vendor</th>
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| **Organizational Confidentiality Requirements** | ➢ Survey vendors must have the capacity to do all of the following actions:  
  - Develop 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. Confidentiality agreements must be reviewed and re-signed periodically, at the discretion of the survey vendor, but not to exceed more than a three-year period.  
  - Execute Business Associate Agreement(s) (BAA) in accordance with HIPAA regulations  
  - Confirm that staff and subcontractors are compliant with HIPAA regulations in regard to decedent/caregiver protected health information (PHI) and personal identifying information (PII)  
  - Establish protocols for secure file transmission. Emailing of PHI or PII via unsecure email is prohibited. |
| **Demonstrated Quality Control Procedures** | ➢ Incorporate well-documented quality control procedures (as applicable) for:  
  - 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:  
  - 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 |
Adhere to all Protocols, Specifications and Agree to Participate in Training Sessions:

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<th>Criteria</th>
<th>Survey Vendor</th>
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<tr>
<td>Survey Training</td>
<td>➢ Attend all CAHPS Hospice Survey Training sessions (subcontractors assigned key roles must attend training)</td>
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</table>
| Administer the Survey according to all Survey Specifications | ➢ Review and follow all procedures described in the *CAHPS Hospice Survey Quality Assurance Guidelines* that are applicable to the selected survey data collection mode(s)  
  ➢ 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 Survey 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 Form:

➢ Submit CAHPS Hospice Survey Participation Form

*Before* attending the CAHPS Hospice Survey Training session, new survey vendors must complete and submit a CAHPS Hospice Survey Participation Form online. The CAHPS Hospice Survey Participation Form for Survey Vendors is available on the CAHPS Hospice Survey Web site at [www.hospicecahpssurvey.org](http://www.hospicecahpssurvey.org) on an annual basis prior to training.

*Note:* Approval of the survey vendor’s 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. Approved survey vendors that are non-compliant with CAHPS Hospice Survey protocols may lose their CAHPS Hospice Survey approval status.
Attend CAHPS Hospice Survey Training Sessions
Survey vendors that intend to administer the CAHPS Hospice Survey must attend all CAHPS Hospice Survey Training sessions sponsored by CMS. At a minimum, the survey vendor’s Project Manager must participate in all CAHPS Hospice Survey Training sessions. Subcontractors and any other organizations that are responsible for major functions of CAHPS Hospice Survey administration (e.g., mail/telephone operations) must attend all CAHPS Hospice Survey Training sessions. Survey vendors must successfully complete a post-training quiz at the conclusion of each CAHPS Hospice Survey Training session.

- 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)

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 Survey Quality Assurance Guidelines. In addition, survey vendors must follow all survey protocols, including those posted on the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org).

- Train Employees to be Compliant with HIPAA Regulations
Survey vendors must conduct trainings on an annual basis, at a minimum, regarding HIPAA regulations for all staff participating in the CAHPS Hospice Survey. In addition, survey vendors must confirm that subcontractor(s), if applicable, have received training on HIPAA regulations.

- Execute Business Associate Agreement(s)
Survey vendors must execute Business Associate Agreement(s) (BAA) in accordance with HIPAA regulations

- Complete an Attestation Document Annually
The survey vendor must review and attest (as determined by CMS) to the accuracy of the organization’s data collection processes and compliance with the CAHPS Hospice Survey Quality Assurance Guidelines

Note: Survey vendors are responsible for sampling and data submission. Therefore, these processes cannot be subcontracted.

Planned variations from survey administration protocols must be pre-approved by CMS through the Exception Request process (see Appendix J). Variations from the survey administration protocols that are not pre-approved by CMS must be reported to CMS immediately upon discovery using a Discrepancy Report (see Appendix K). CMS may determine that data collected in a non-approved manner may not be reported.
Develop 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. The Model QAP document (see Appendix I) 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 survey materials relevant to that year’s CAHPS Hospice Survey administration (as determined by CMS), including mailing materials (e.g., questionnaires, cover letters and outgoing envelopes) and/or telephone scripts (including CATI screenshots 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 conference 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 of 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.
IV. 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 the CAHPS Hospice Survey Project Team:
- via email at hospicecahpssurvey@HCQIS.org
- via telephone at 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 voicemail:
- 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 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

Communicate with CMS Regarding the CAHPS Hospice Survey
To contact CMS regarding the CAHPS Hospice Survey, please email:
- hospicesurvey@cms.hhs.gov
V. Sampling Protocol

Overview
This chapter describes the procedures survey vendors should use to request the decedents/caregivers list from their hospices, identify decedents/caregivers eligible for the survey, construct a sample 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.

Data collection for 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 month of patient death. Submission to the CAHPS Hospice Survey Data Warehouse is on a quarterly basis. Refer to the CAHPS Hospice Survey Data Collection and Submission Timeline in the Introduction and Overview chapter for the data submission timeline.

Hospice Information Submission Requirements
Each hospice must submit the following information to the survey vendor in time for the survey vendor to initiate the survey data collection protocols:

- The decedents/caregivers list
- Total count of all decedents served in the month (this count must include the number of “no publicity” decedents/caregivers, but must not include live discharge patients)
- Total number of hospice offices covered under a single CCN
  - In this context, hospice offices mean separate administrative or practice offices for the CCN, not to be confused with individual facilities or settings in which hospice care is provided (e.g., homes, assisted living facilities, hospitals, hospice facilities, or hospice houses)
- Counts of cases ineligible due to:
  - Live discharge
  - Number of “no publicity” decedents/caregivers ("No publicity" decedents/caregivers are those who initiate or voluntarily request at admission that the hospice: 1) not reveal the patient’s identity; and/or 2) not survey him or her. Hospices must retain documentation of the “no publicity” request for a minimum of three years.)

Counts
As stated above, each hospice must provide the total count of decedents served in the month, and the counts of cases ineligible due to live discharge and request for no contact. Counts should be accurate and add up correctly. Below are several examples of these counts.

Example 1: A hospice has 50 decedents in a month, including 2 decedents/caregivers who voluntarily and expressly requested not to be contacted, and 10 patients discharged alive. For this hospice, the Total Number of Decedents is 50, the Total Number of Live Discharges is 10, the number of “No publicity” decedents/caregivers is 2, and there are 48 decedent/caregiver cases in the decedents/caregivers list.
Example 2: A hospice has 10 decedents in a month, including 1 decedent/caregiver who voluntarily and expressly requested not to be contacted, and 15 patients discharged alive. For this hospice, the Total Number of Decedents is 10, the Total Number of Live Discharges is 15, the number of “No publicity” decedents/caregivers is 1, and there are 9 decedent/caregiver cases in the decedents/caregivers list.

Decedents/Caregivers List
Hospices are required to supply a decedents/caregivers list to their survey vendor containing the data elements below 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). The survey vendor must then apply the eligibility criteria to the decedent/caregiver cases in the decedents/caregivers list provided by the hospice.

- 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 (e.g., 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 (e.g., spouse/partner, child, sibling, other, etc.)

The CAHPS Hospice Survey is designed to be administered to the person who is most knowledgeable about the hospice care received by the decedent (referred to here as the primary informal caregiver). The hospice is responsible for identifying one primary informal caregiver who may be eligible to receive and respond to the CAHPS Hospice Survey for each decedent.

- The caregiver relationship to the decedent should fall into one of the following categories: spouse/partner, parent (or step parent), child (or step child), other family member, friend, or other. A non-familial legal guardian who does not fall into one of these categories cannot be considered a primary informal caregiver for the purposes of the CAHPS Hospice Survey.
- One caregiver category does not automatically have preference over another. Hospices should not prioritize a primary informal caregiver that is a family member over a friend, as a friend may have more knowledge regarding the decedent’s hospice care than a family member. The CAHPS Hospice Survey should be administered to the person most knowledgeable about the care the decedent received at the hospice.
- Staff members or employees of the hospice or the care setting in which the patient received hospice care should not be considered primary informal caregivers.
Hospices should submit only one caregiver per decedent to the survey vendor. Survey vendors should use the following information to determine the primary informal caregiver in instances where the hospice provides multiple caregivers for a given decedent:

- Select the caregiver with the most complete contact information. To determine most complete, first consider caregiver name, then caregiver mailing address (if administering the survey using Mail Only or Mixed Mode) or caregiver telephone number (if administering the survey using Telephone Only mode).
- If multiple caregivers have the same amount of contact information, select the record highest on the list provided by the hospice.
- If two first names are embedded within the caregiver first name field (e.g., “Tom & Jane”), and the remainder of the caregiver information is identical, the survey may be addressed to both caregivers and telephone interviewers may ask to speak with either caregiver.

The information that the hospice provides in the decedents/caregivers list will be used by the survey vendor to identify survey-eligible decedents/caregivers and survey the sampled decedents/caregivers. Survey vendors must develop a process to request missing/inaccurate information to be updated in the decedents/caregivers list. Hospices must resubmit a complete update decedents/caregivers list, rather than providing only the information that was missing or inaccurate. Survey vendors should track and document updates to previously missing information.

*Note: It is not permissible for a hospice to provide an updated primary informal caregiver once the survey vendor has initiated contact.*

**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 occurrence code “42” – Date of Revocation (only) (FL 31-34) and patients who have the following Patient Status Codes (FL17):
    - “01” – Discharge to Home or Self Care (Routine Discharge)
    - “50” – Discharged/Transferred to a Hospice – “Hospice Home” (Routine or Continuous Home Care [CHC])
    - “51” – Discharged/Transferred to a Hospice – “Hospice Medical Facility” (Inpatient Respite or General Inpatient Care [GIP])
- Number of “no publicity” decedents/caregivers (“No publicity” decedents/caregivers are those who initiate or voluntarily request at admission that the hospice: 1) not reveal the patient’s identity; and/or 2) not survey him or her.)
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
  - To determine the 48 hour period, one would establish date of admission plus two calendar days. See the below examples for clarification.
    - **Example 1**: If the patient is admitted to the hospice on January 2 and passes away on January 4; day one is January 3 and day two is January 4. The 48 hours after admission would be met (admission [January 2] plus two days [January 3 and January 4]).
    - **Example 2**: If the patient is admitted to the hospice on January 2 and passes away on January 3; day one is January 3 and there is no day two. The 48 hours after admission would not be met.
- Decedents for whom there is a caregiver of record
- Decedents whose caregiver is someone other than a non-familial legal guardian
  - A familial legal guardian falls into one of the six answer categories available provided in the Sample File Layout of Appendix E (1 = Spouse/partner; 2 = Parent; 3 = Child; 4 = Other family member; 5 = Friend; 7 = Other). The hospice should only indicate the caregiver relationship as 6 = Legal guardian if the caregiver is a non-familial legal guardian.
- Decedents for whom the caregiver has a U.S. or U.S. Territory home address

“No publicity” decedents/caregivers must be excluded from the sample frame. “No publicity” decedents/caregivers are those who initiate or voluntarily request at admission that the hospice: 1) not reveal the patient’s identity; and/or 2) not survey him or her. Patients who are discharged alive will also be excluded.

**Note:** Decedents/caregivers must be included in the CAHPS Hospice Survey sample frame unless the survey vendor has definitive evidence that a decedent/caregiver is ineligible. If information is missing on a variable that affects survey eligibility when the sample frame is constructed, the decedent/caregiver must be included in the sample frame. The only exception to this guideline is the date of death; if any part (i.e., day, month or year) of the decedent’s date of death is missing, the case must not be included in the sample frame, and the case must be included in the count of “Missing Date of Death” submitted by the survey vendor to the CAHPS Hospice Survey Data Warehouse.

**Note:** If a hospice or survey vendor becomes aware that the caregiver is under 18 years old prior to drawing the sample, the caregiver must be excluded from the sample frame.

**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.
De-Duplication for Multiple Hospice Stays
To ensure accurate counts are submitted to CMS, patients with multiple hospice admissions during a given calendar month must be de-duplicated. The de-duplication process should include reviewing decedent names, along with a secondary field, such as date of birth. The admission that controls the handling of the case is dependent on the outcome associated with each admission. The key for inclusion in the CAHPS Hospice Survey is death in the reference month while under hospice care. For example:

- If a patient is admitted on January 15, discharged alive on January 18, readmitted to the hospice on January 22 and dies on January 26, then the patient’s last admission, January 22, controls the handling of the case. The fact that the patient died on January 26 (within the same month) means that decedent/caregiver case will be included in the January decedents/caregivers list. The January 18 live discharge is not counted among the live discharges because the patient was re-admitted and died in January.
- If a patient is admitted on January 15, discharged alive on January 18, readmitted to the hospice on January 22 and passes away on February 3, then the patient will be included in the January count of ineligibles due to live discharge provided to the survey vendor. Additionally, the patient will be included in the February decedents/caregivers list as a decedent.

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 from the decedents/caregivers list received from the hospice. The steps below 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)
  - Survey vendors must implement a de-duplication process to verify a decedent is provided only once in the decedents/caregivers list
- Records with missing or incomplete decedent or caregiver names, addresses and/or telephone numbers must not be removed from the sample frame
  - If this record is drawn into the sample, then every attempt must be made to find the correct name, address and/or telephone number. If the necessary decedent or caregiver contact information is not found, the “Final Survey Status” must be coded as “10 – Non-response: Bad/No Address,” “11 – Non-response: Bad/No Telephone Number,” “12 – Non-response: Incomplete Caregiver Name,” or “13 – Non-response: Incomplete Decedent Name.” (For more information, see the Data Coding and Data File Preparation chapter.)
Survey vendors are required to provide counts of (a) decedents served in the month (a count of all records submitted by the hospice plus the count of “no publicity” decedents/caregivers), (b) number of hospice offices covered by a single CCN (provided by the hospice), (c) patients discharged alive (provided by the hospice), (d) “no publicity” decedents/caregivers (provided by the hospice), (e) total number of decedent/caregivers excluded from the sample frame because any part (i.e., day, month or year) of the decedent’s date of death is missing, and (f) 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 (e.g., number of decedents under the age of 18, number of decedents with no caregiver of record, etc.). This documentation is subject to review.

Note: The total number of ineligible decedents/caregivers should not include cases where the decedent’s date of death is missing as those decedents/caregivers are accounted for in a separate variable.

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

**Sampling Procedure**

Hospices with fewer than 50 survey-eligible decedents/caregivers during the prior calendar year that submit the Participation Exemption for Size Form 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). Hospices with 700 or more survey-eligible decedents/caregivers in the prior year are required to survey a minimum sample of 700 using an equiprobable approach and may conduct a census, if desired. If an organization chooses to survey more than a sample of 700 decedents/caregivers, all data is required to be submitted to the CAHPS Hospice Survey Data Warehouse. 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.

Note: Hospices that share a common CCN 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 may only take place between calendar quarters. 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 four rolling quarters. 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 Hospice 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. The equiprobable approach is used, as every survey-eligible decedent/caregiver for a given month has the same probability of being sampled.

Simple Random Sampling (SRS)
SRS is the most basic sampling technique. 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.

SRS Example 1: End of month percent random sample selection
  ➢ Sampling for Hospice A is conducted only once for a given month at the end of the month
    • Suppose Hospice A has 150 survey-eligible decedents/caregivers for a given month and wishes to use a 50 percent sampling rate
      o Randomly sort all 150 survey-eligible decedents/caregivers prior to sampling
      o Then select 50 percent 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

- Census sampling for Hospice B is required if the hospice served 50 to 699 survey-eligible decedents/caregivers in the prior year
- Census sample is also allowed if Hospice C served more than 700 survey-eligible decedents/caregivers in the prior year and chooses to sample all survey-eligible decedents/caregivers

  - A census sample is considered SRS because each decedent/caregiver has an equal chance (100 percent) of being included in the sample and the decedents/caregivers are not stratified in any manner
  - Suppose Hospice B 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 the CAHPS Hospice Survey Project Team with any questions at hospicecahpssurvey@HCQIS.org or 1-844-472-4621.
VI. Mail Only Survey Administration

Overview
This chapter describes the 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 must send sampled caregivers a first questionnaire with a cover letter within the first seven calendar 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, 6, or 14, as applicable). A Decedent/Caregiver 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 (7, 8, 9, 10, 11, 12, 13, or 15, as applicable).

Survey vendors must include the “Number Survey Attempts – Mail” field in the Decedent/Caregiver Administrative Record. This field is required when “Survey Mode” in the Hospice 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.
<table>
<thead>
<tr>
<th>Activity</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mail initial questionnaire with cover letter to sampled caregivers</td>
<td>Two months after the month of patient death within the first seven calendar days of the field period</td>
</tr>
<tr>
<td>Mail second questionnaire with follow-up cover letter to all sampled caregivers who do not respond to the first survey mailing</td>
<td>Approximately 21 calendar days after the first survey mailing</td>
</tr>
<tr>
<td>Complete data collection</td>
<td>Within six weeks (42 calendar days) of the first survey mailing</td>
</tr>
<tr>
<td>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.</td>
<td>See the quarterly data submission deadlines in the Introduction and Overview chapter</td>
</tr>
</tbody>
</table>

To reiterate, the first mail attempt must occur two months after the month of patient death within the first seven calendar 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 and within the first seven calendar days of the field period)
- 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 calendar 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 calendar days) survey administration time period for this caregiver, then the survey data are not included in the final survey data file (however, a Decedent/Caregiver Administrative 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, Chinese, Russian, Portuguese, and Vietnamese. Survey vendors are provided with the CAHPS Hospice Survey questionnaires in English, Spanish, Chinese, Russian, Portuguese, and Vietnamese, and initial and follow-up cover letters in English, Spanish, Chinese, Russian, Portuguese, and Vietnamese. 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, Chinese, Russian, Portuguese, or Vietnamese 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 that CMS create an official translation of the CAHPS Hospice Survey in those languages.

Each survey vendor must submit a sample of their CAHPS Hospice Survey mailing materials (e.g., questionnaires, cover letters and outgoing envelopes) by the specified due date for review by the CAHPS Hospice Survey Project Team. The due dates for survey vendors to submit samples of their CAHPS Hospice Survey mailing materials will be announced during the CAHPS Hospice Survey Training session and posted on the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org).

Mailings must include a personalized cover letter, a questionnaire and a business reply envelope. The cover letters may be sent in both English and one of the official translations, and may be two-sided, English on one side and one of the official translations 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 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 front of the cover letter or on the front or back of the questionnaire in a font size of 10 point or larger. The OMB language cannot be printed on a separate piece of paper. 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.

**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 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 (Q1 – Q40)
- 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
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 Appendices N, O, P, Q, R, S, and T). Response options that are listed horizontally or in a combined vertical and horizontal format are not allowed. No matrix formats are permitted for question and answer categories.
Dates are not permitted to be included on the questionnaire or the cover letters (e.g., print date, mail date)

Formatting
Wording that is bolded or underlined in the questionnaire provided in the CAHPS Hospice Survey Quality Assurance Guidelines manual 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 bolded and capitalized, including the “SURVEY INSTRUCTIONS” heading
Survey materials must be in a readable font (e.g., Arial) in a font size of 10 point or larger

Other Requirements
All survey content, including headers, instructions, questions, and answer categories, must be printed verbatim and in the same order as shown on the questionnaires provided by CMS
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 N, O, P, Q, R, S, and T
- 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 (see Appendix M for examples of acceptable supplemental questions):

- Hospice-specific supplemental questions can be added immediately after the Core questions (Q1 – Q40) or at the end of all the CAHPS Hospice Survey questions (Q1 – Q47)
  - 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
- 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 details 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 ABC Hospice.”
• “This next set of questions is to provide the hospice additional feedback about your family member’s hospice care.”
  ➢ Hospice-specific supplemental questions must be identical for both mail wave attempts

In addition, one supplemental question must be included in the mail questionnaire if the hospice wishes to view the survey responses linked to the respondent’s 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 survey vendor to provide the hospice with the respondent’s answers linked to the respondent’s name and identifying information. The Consent to Share Responses question is typically placed at the end of the questionnaire as the last question and must be included in the XML file element “supplemental-question-count.” Refer to Appendix M to view the Consent to Share Responses 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 discussed above)

Note: It is not permissible for a supplemental question to request the name and/or contact information of the caregiver.

  ➢ 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
  ➢ request the use of the caregiver comments and/or responses as testimonials or for marketing purposes

Note: A hospice cannot use any comments (anonymous) as testimonials or for marketing purposes.

Cover Letters
Survey vendors are strongly encouraged to use the text in the body of the sample cover letters provided (see Appendices N, O, P, Q, R, S, and T). 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
  ➢ Use of the Spanish, Chinese, Russian, Portuguese, or Vietnamese cover letter is required if the survey vendor is sending a Spanish, Chinese, Russian, Portuguese, or Vietnamese questionnaire to the caregiver
 English must be the default language in the continental U.S. and Spanish must be the default language in Puerto Rico

 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” and “To the caregiver of [Decedent Name]” are not acceptable salutations.)
  • 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.

  • the text “CMS pays for most of the hospice care in the U.S. It is CMS’ responsibility to ensure that hospice patients and their family members and friends get high quality care. One of the ways CMS can fulfill this responsibility is to find out directly from you about the hospice care your family member or friend received.”
  • language indicating that answers may be shared with the hospice for the purposes of quality improvement
  • an explanation that participation in the survey is voluntary
  • the hospice name, in order 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 the survey vendor:
    o Customer support must be offered in all languages in which the survey vendor administers the survey
    o Survey vendors must be ready to support calls from the deaf or the hearing impaired, including, but not limited to TTY

  Note: Survey vendors are permitted to revise the toll-free number statement to include the name of the survey vendor. For example: If you have any questions about the enclosed survey, please call [SURVEY VENDOR NAME] at the toll-free number 1-800-xxx-xxxx.

 The OMB Paperwork Reduction Act language (located in Appendices N, O, P, Q, R, S, and T) 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
Mail Only Survey Administration

- offer caregivers the opportunity to complete the survey over the telephone
- include extraneous titles for caregiver (e.g., Aunt, Uncle)
- include dates (e.g., print date, mail date)

Optional for the Cover Letter

- Cover letters may be double sided (English/Spanish, English/Chinese, English/Russian, English/Portuguese, or English/Vietnamese)
- Information may be added to the cover letters that indicates that the caregiver may request a mail survey in English, Spanish, Chinese, Russian, Portuguese, or Vietnamese
- 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
- A bereavement customer support number (i.e., hospice bereavement contact number) may appear on 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 chapter).

Mailing of Materials

The envelope in which the survey is mailed must be printed with the survey vendor’s address as the return address. The envelope in which the survey is mailed must not be printed with any banners such as “Important Information Enclosed,” Please Reply Immediately” or messages such as “Important Information from the Centers for Medicare & Medicaid Services Enclosed.” The envelope should be printed with the survey vendor logo, the hospice logo, or both. In addition, survey vendors have the following options related to the outgoing envelopes:

- Survey vendors have the option of placing the CMS logo on survey mailing envelopes
- Survey vendors may use window envelopes as a quality measure to ensure that each sampled caregiver’s survey package is mailed to the address of record for that caregiver

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/No 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 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 caregivers with no mailing address. If contacting the hospice to request updated contact information, the survey vendor must ask for updates for all records, not individual decedent/caregiver cases. Attempts to obtain the caregiver’s address must be documented. These decedent/caregiver cases must not be removed or replaced in the sample.

- Self-addressed, stamped business return envelope 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 or distribute any pre-notification letters or postcards after patient death to inform caregivers about the CAHPS Hospice Survey.

Note: In instances where the first wave mail survey is returned with all missing responses (i.e., without any questions answered – blank questionnaires), survey vendors must 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.”

Note: When the first survey is not returned, and the second survey is subsequently mailed and 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 and 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’s survey responses 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 multi-mark questions, if a line is drawn through one response option, then select the choice without the line, as the intent is clear

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.

For CAHPS Hospice Survey multi-mark questions, the following guidelines should be followed:

- 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.
- 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.

Note: 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 Question 47, is up to each individual hospice. Survey vendors must not include responses to open-ended survey items on the data files submitted to the CAHPS Hospice Survey Data Warehouse. However, CMS encourages survey vendors to review the open-ended entries so that they can provide feedback to the CAHPS Hospice Survey Data Coordination Team about adding additional preprinted response options to these survey items, if needed.

Note: If the survey vendor includes the Consent to Share Responses question in the mail survey questionnaire or telephone interview, we recommend that the survey vendor key the response to that question. However, responses to the Consent to Share Responses question must not be included on the data files submitted to the CAHPS Hospice Survey Data Warehouse but must be included in the XML file element “supplemental-question-count.”

**Personnel Training**

Training of personnel on 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), if applicable, responsible for major survey administration functions must participate in all CAHPS Hospice Survey Training sessions sponsored by CMS. Individuals who are involved with and work on any aspect of CAHPS Hospice Survey operations (e.g., account managers, sampling specialists, quality assurance managers, programmers, 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 processes 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 must 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 a balance between keeping PII and PHI confidential and helping a person who needs assistance. For survey research organizations, best interviewing practices recommend having a distressed respondent protocol in place to balance the respondent’s right to confidentiality and privacy with the need to provide assistance if the situation indicates that the respondent’s health and safety are in jeopardy.
- If a respondent requests 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 potential bereavement support is part of the services covered under the Medicare Hospice Benefit.
Training of Mail Data Entry Personnel
Survey vendors must 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), if applicable. Survey vendors must conduct site verification of printing and mailing processes and document the quality check activities conducted during the visit, 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/caregivers in the sample mailing for that month
- include seeded mailings in the survey mail production runs at a minimum of a quarterly basis
  - Seeded mailings are sent to designated CAHPS Hospice Survey vendor 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 vendor project staff
  - Physical and/or scanned copies of seeded mailings must be retained for a minimum of three years
- perform address updates for missing or incorrect information
  - Attempts must be made to update address information to confirm accuracy and correct formatting
  - If contacting a hospice to request updated contact information, the survey vendor must ask for updates for all records, not individual decedent/caregiver cases
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) Coding Accuracy Support System (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 the CAHPS Hospice Survey administration and project staff, including subcontractor(s). Quality check 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; back-up 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 subcontractor(s) are compliant with HIPAA regulations
- monitor the performance of all subcontractor(s)
- provide performance feedback to all project staff and subcontractor(s) through regular assessments, including 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 subcontractor(s), 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 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 a confidentiality agreement which includes language related to HIPAA regulations and the protection of decedent/caregiver information, and obtain signatures from all personnel with access to survey information, including staff and all subcontractor(s) involved in survey administration and data collection
Note: Confidentiality agreements must be signed by all personnel upon employment. Confidentiality agreements must be reviewed and re-signed periodically, at the discretion of the survey vendor, but not to exceed more than a three-year period. The CAHPS Hospice Survey Project Team recommends all personnel involved in the CAHPS Hospice Survey review and re-sign confidentiality agreements on an annual basis.

- Confirm that staff and subcontractor(s), if applicable, are compliant with HIPAA regulations in regard to decedent/caregiver PHI; including BAA requirements
- 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’/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.

**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 back-up procedures that adequately safeguard system data
- Test back-up 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
- Develop a disaster recovery plan for conducting ongoing business operations in the event of a disaster

**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.
VII. Telephone Only Survey Administration

Overview
This chapter describes the 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, 6, or 14, as applicable). A Decedent/Caregiver 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 seven calendar 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 two or three 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 reserve some of the allowable call attempts for the part of the field period for which the caregiver is available. 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 (7, 8, 9, 10, 11, 12, 13, or 15, as applicable).

Survey vendors must include the “Number Survey Attempts – Telephone” field in the Decedent/Caregiver Administrative Record. This field is required when “Survey Mode” in the Hospice 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.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initiate systematic telephone contact with sampled caregivers</td>
<td>Two months after the month of patient death within the first seven calendar days of the field period</td>
</tr>
<tr>
<td>Complete telephone data collection</td>
<td>Within six weeks (42 calendar days) after the first attempt</td>
</tr>
<tr>
<td>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.</td>
<td>See the quarterly data submission deadlines in the Introduction and Overview chapter</td>
</tr>
</tbody>
</table>

To reiterate, the first telephone attempt must occur two months after the month of patient death within the first seven calendar 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:**

- The first telephone attempt is made on July 1 (two months after the month of patient’s death and within the first seven calendar days of the field period)
- Data collection must be closed out by August 12 for this caregiver, which is six weeks (42 calendar days) from the July 1 first telephone attempt date:
  - 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 Data Coding and Data File Preparation chapter.
  - If the survey is **mistakenly** completed **after** August 12 (August 13, for example), which is beyond the six weeks (42 calendar days) survey administration time period for this caregiver, then the survey data are not included in the final survey data file (**however, a Decedent/Caregiver Administrative Record is submitted for this caregiver**) and a “Final Survey Status” code of “9 – Non-response: Non-response after Maximum Attempts” is assigned (Please note, this would also require a Discrepancy Report to be submitted.)

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 at different times until the final data collection protocol is completed.
Telephone Interviewing Systems

Telephone Script

Telephone data collection is permitted in both English and Spanish. English must be the default language in the continental U.S. and Spanish must be the default language in Puerto Rico. Survey vendors are provided standardized telephone scripts in both English and Spanish (Appendices U and V) 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 screenshots (including skip pattern logic) by the specified due date for review by the CAHPS Hospice Survey Project Team. The due dates for survey vendors to submit samples of their CAHPS Hospice Survey telephone materials will be announced during the CAHPS Hospice Survey Training session and posted on the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org).

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 (Q1 – Q40)
- 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 categories for the Core, “About Your Family Member” or “About You” questions
- 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

Note: It is not permissible to substitute capital letters for the text underlined in the telephone script, as text that appears in uppercase letters throughout the CATI script must not be read out loud. Survey vendors are permitted to indicate emphasis of underlined text in a different manner if their CATI system does not permit underlining, such as placing quotes (“”) or asterisks (**) around the text to be emphasized.
All punctuation for the question and answer categories located in Appendices U and V must be programmed

Only one language (English or Spanish) may appear on the electronic interviewing system screen

The survey vendor is responsible for programming the script(s) and specifications into their electronic telephone interviewing system software
- 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
- All probes located throughout the telephone script must be included on the CATI screen

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 (see Appendix M for examples of acceptable supplemental questions):
- Hospice-specific supplemental questions can be added immediately after the Core CAHPS Hospice Survey questions (Q1 – Q40) or at the end of all the CAHPS Hospice Survey questions (Q1 – Q47)
- 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 details 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 the respondent’s 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 survey vendor to provide the hospice with the respondent’s answers linked to the respondent’s name and identifying information. The Consent to Share Responses question is typically placed at the end of the interview as the last question. The number of supplemental questions added to the CAHPS Hospice Survey, including the “Consent to Share Responses,” must be included in the question count for the XML file element “supplemental-question-count.” Refer to Appendix M to view the Consent to Share Responses 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 CAHPS Hospice Survey Core 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 discussed above)

Note: It is not permissible for a supplemental question to request the name and/or contact information of the caregiver.

- 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
- request the use of the caregiver comments and/or responses as testimonials or for marketing purposes

Note: A hospice cannot use any comments (anonymous) as testimonials or for marketing purposes.

Interviewing Systems
Telephone data collection must be computer-assisted telephone interviewing (CATI) using live interviewers. The CATI 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. Paper surveys administered by telephone and the use of touch-tone or speech-enabled interactive voice response (IVR) are not acceptable. 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 from 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 [and/or 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 U and V.

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 not knowledgeable 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 decedent/caregiver case must 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 (seven calendar days). However, the five telephone attempts cannot be made in just one week (seven calendar days). The five call attempts must span more than one week (eight or more days) to account for caregivers who are temporarily unavailable.*

- Confirm the identity of the caregiver using the full name provided in the decedents/caregivers list prior to disclosing any identifiable information (e.g., decedent name).
- 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 a telephone survey already in progress at a later date, 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 accommodate 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 two or three 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 reserve some of the allowable call attempts for the part of the field period for which the caregiver is available.

If the caregiver does not speak the language(s) in which the survey vendor administers the survey, 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 when they have been determined to be missing or incorrect. 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.

Survey vendors must attempt to obtain updated telephone numbers 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
- Survey vendors may contact the hospice to request updated telephone numbers. If contacting the hospice to request updated contact information, the survey vendor must ask for updates for all records, not individual decedent/caregiver cases.

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.

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), if applicable. 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 Appendices G and H 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 a balance between keeping PII and PHI confidential and helping a person who needs assistance. For survey research organizations, best interviewing practices recommend having a distressed respondent protocol in place to balance the respondent’s right to confidentiality and privacy with the need to provide assistance if the situation indicates that the respondent’s health and safety are in jeopardy.
  - If a respondent requests 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 potential bereavement support is part of the services covered under the Medicare Hospice Benefit.

**Note:** *If a survey vendor uses a subcontractor(s) 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(s) 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: In addition to the survey vendor’s monitoring of 10 percent of its subcontractors’ interviews, the CAHPS Hospice Survey Project Team also expects that a survey vendor’s subcontractor(s) will conduct internal monitoring of their telephone interviewers as a matter of good business practice. While it is preferred that each organization continue to monitor 10 percent of CAHPS Hospice Survey interviews (for an overall total of 20 percent), it is permissible for the survey vendor and its subcontractor(s) to conduct a combined total of at least 10 percent monitoring, as long as each organization conducts a portion of the monitoring. Therefore, the survey vendor and its subcontractor(s) can determine the ratio of monitoring that each organization conducts, as long as the combined total meets or exceeds 10 percent. Please note that CAHPS Hospice Survey interviews monitored concurrently by the survey vendor and its subcontractor(s) do not contribute separately to each organization’s monitoring time.

- Interviewers 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 a confidentiality agreement which includes language related to HIPAA regulations and the protection of decedent/caregiver information, and obtain signatures from all personnel with access to survey information, including staff and all subcontractor(s), if applicable, involved in survey administration and data collection

*Note: Confidentiality agreements must be signed by all personnel upon employment. Confidentiality agreements must be reviewed and re-signed periodically, at the discretion of the survey vendor, but not to exceed more than a three-year period. The CAHPS Hospice Survey Project Team recommends all personnel involved in the CAHPS Hospice Survey review and re-sign confidentiality agreements on an annual basis.*

- Confirm that staff and subcontractor(s), if applicable, are compliant with HIPAA regulations in regard to decedent/caregiver PHI; including BAA requirements
- 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.

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 back-up procedures that adequately safeguard system data
- Test back-up 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
- Develop a disaster recovery plan for conducting ongoing business operations in the event of a disaster
VIII. Mixed Mode Survey Administration

Overview
This chapter describes the 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 calendar days of the field period. Survey vendors must send sampled caregivers a questionnaire with a cover letter within the first seven calendar 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.

Note: Reversing the protocol (telephone attempts followed by mail attempt) is not allowed

Note: If the survey vendor learns that a sampled decedent/caregiver is ineligible for the CAHPS Hospice Survey, no further attempts can 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 a “Final Survey Status” code of ineligible (2, 3, 4, 5, 6, or 14, as applicable). A Decedent/Caregiver 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 (7, 8, 9, 10, 11, 12, 13, or 15, as applicable).

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

Survey vendors must include the “Number Survey Attempts – Telephone” field in the Decedent/Caregiver Administrative Record. This field is required when “Survey Mode” in the Hospice 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.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Send mail questionnaire with cover letter to sampled caregiver</td>
<td>Two months after the month of patient death within the first seven calendar days of the field period</td>
</tr>
<tr>
<td>Initiate systematic telephone contact for all non-respondents</td>
<td>Approximately 21 calendar days after mailing of the questionnaire</td>
</tr>
<tr>
<td>Complete data collection activities</td>
<td>Over the next 21 calendar days and within six weeks (42 calendar days) after the initial mailing</td>
</tr>
<tr>
<td>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.</td>
<td>See the quarterly data submission deadlines in the Introduction and Overview chapter</td>
</tr>
</tbody>
</table>

To reiterate, the mail-out of the survey must occur two months after the month of patient death within the first seven calendar 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:**

- 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 calendar days) from the July 1 initial mail-out date:
  - 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 Data Coding and Data File Preparation chapter
  - If the survey is mistakenly completed after August 12 (August 13, for example), which is beyond the six weeks (42 calendar days) survey administration time period for this caregiver, then the survey data are not included in the final survey data file (however, a Decedent/Caregiver Administrative Record is submitted for this caregiver) and a “Final Survey Status” code of “9 – Non-response: Non-response after Maximum Attempts” is assigned (Please note, this would also require a Discrepancy Report to be submitted.)
Mail Protocol
This section describes the 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 N and O). 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.

Each survey vendor must submit a sample of their CAHPS Hospice Survey mailing materials (e.g., questionnaires, cover letters and outgoing envelopes) by the specified due date for review by the CAHPS Hospice Survey Project Team. The due dates for survey vendors to submit samples of their CAHPS Hospice Survey mailing materials will be announced during the CAHPS Hospice Survey Training session and posted on the CAHPS Hospice Survey Web site (www.hospicecahpsurvey.org).

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 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 front of the cover letter or on the front or back of the questionnaire in a font size of 10 point or larger. The OMB language cannot be printed on a separate piece of paper. 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.
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 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 (Q1 – Q40)
- 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
- 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 Appendices N and O). Response options that are listed horizontally or in a combined vertical and horizontal format are not allowed.
- Dates are not permitted to be included on the questionnaire or the cover letters (e.g., print date, mail date)

Formatting

- Wording that is **bolded** or **underlined** in the questionnaire provided in the *CAHPS Hospice Survey Quality Assurance Guidelines* manual 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 bolded and capitalized, including the “SURVEY INSTRUCTIONS” heading
- Survey materials must be in a readable font (e.g., Arial) in a font size of 10 point or larger

Other Requirements

- All survey content, including headers, instructions, questions, and answer categories, must be printed verbatim and in the same order as shown on the questionnaires provided by CMS
- 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 N and O.
- 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 (see Appendix M for examples of acceptable supplemental questions):

- 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 can be added immediately after the Core questions (Q1 – Q40) or at the end of all the CAHPS Hospice Survey questions (Q1 – Q47).
- When supplemental questions are placed in between the Core questions and the “About Your Family Member” questions, the “ABOUT YOUR FAMILY MEMBER” heading must be placed prior to the “About Your Family Member” 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 details 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 the respondent’s 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 in the mail questionnaire for the survey vendor to provide the hospice with the respondent’s answers linked to the respondent’s name and identifying information. The Consent to Share Responses question is typically placed at the end of the questionnaire or interview as the last question and must be included in the XML file element “supplemental-question-count.” Refer to Appendix M to view to view the Consent to Share Responses 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 discussed above)

*Note: It is not permissible for a supplemental question to request the name and/or contact information of the caregiver.*

- 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
- request the use of the caregiver comments and/or responses as testimonials or for marketing purposes.

*Note: A hospice cannot use any comments (anonymous) as testimonials or for marketing purposes.*
Cover Letters
Survey vendors are strongly encouraged to use the text in the body of the sample cover letters (see Appendices N and O). 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.
- Use of the Spanish cover letter is required if the survey vendor is sending a Spanish questionnaire to the caregiver.
- English must be the default language in the continental U.S. and Spanish must be the default language in Puerto Rico.
- 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" and "To the caregiver of [Decedent Name]" are not acceptable salutations.)
  - 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.

- the text “CMS pays for most of the hospice care in the U.S. It is CMS’ responsibility to ensure that hospice patients and their family members and friends get high quality care. One of the ways CMS can fulfill this responsibility is to find out directly from you about the hospice care your family member or friend received.”
- language indicating that answers may be shared with the hospice for the purposes of quality improvement
- an explanation that participation in the survey is voluntary
- the hospice name, in order 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 the survey vendors:
  - Customer support must be offered in all languages in which the survey vendor administers the survey
  - Survey vendors must be ready to support calls from the deaf or the hearing impaired, including but not limited to TTY

  Note: Survey vendors are permitted to revise the toll-free number statement to include the name of the survey vendor. For example: If you have any questions about the enclosed survey, please call [SURVEY VENDOR NAME] at the toll-free number 1-800-xxx-xxxx.

- The OMB Paperwork Reduction Act language (located in Appendices N and O) 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 may 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)
- include dates (e.g., print date, mail date)

Optional for the Cover Letter
- Cover letters may be double sided (English on one side and Spanish on the other)
- 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
- 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
- A bereavement customer support number (i.e., hospice bereavement contact number) may appear on 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 chapter).

Mailing of Materials
The envelope in which the survey is mailed must be printed with the survey vendor’s address as the return address. The envelope in which the survey is mailed must not be printed with any banners such as “Important Information Enclosed,” “Please Reply Immediately” or messages such as “Important Information from the Centers for Medicare & Medicaid Services Enclosed.” The envelope should be printed with the survey vendor logo, the hospice logo, or both. In addition, survey vendors have the following options related to the outgoing envelopes:
- Survey vendors have the option of placing the CMS logo on survey mailing envelopes
- Survey vendors may use windowed envelopes as a quality measure to ensure that each sampled caregiver’s survey package is mailed to the address of record for that caregiver
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/No 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 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 caregivers with no mailing address. If contacting the hospice to request updated contact information, the survey vendor must ask for updates for all records, not individual decedent/caregiver cases. Attempts to obtain the caregiver’s address must be documented. These decedent/caregiver cases must not be removed or replaced in the sample.

- Self-addressed, stamped business return envelope 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, 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 or distribute 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 (ATA) decedents/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 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 completed 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’s survey responses 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 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 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 multi-mark questions, if a line is drawn through one response option, then select the choice without the line, as the intent is clear.
- 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.

- For CAHPS Hospice Survey multi-mark questions, the following guidelines should be followed:
  - 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.
  - 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.

Note: 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 Question 47, is up to each individual hospice. Survey vendors must not include responses to open-ended survey items on the data files submitted to the CAHPS Hospice Survey Data Warehouse. However, CMS encourages survey vendors to review the open-ended entries so that they can provide feedback to the CAHPS Hospice Survey Data Coordination Team about adding additional preprinted response options to these survey items, if needed.

Note: If the survey vendor includes the Consent to Share Responses question in the mail survey questionnaire or telephone interview, we recommend that the survey vendor key the response to that question. However, responses to the Consent to Share Responses question must not be included on the data files submitted to the CAHPS Hospice Survey Data Warehouse but must be included in the XML file element “supplemental-question-count.”
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), if applicable. Survey vendors must conduct site verification of printing and mailing processes and document the quality check activities conducted during the visit, 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 decedents/caregivers in the sample mailing for that month

- include seeded mailings in the survey mail production runs at a minimum of a quarterly basis
  - Seeded mailings are sent to designated CAHPS Hospice Survey vendor 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 vendor project staff
  - Physical and/or scanned copies of seeded mailings must be retained for a minimum of three years

- perform address updates for missing or incorrect information
  - Attempts must be made to update address information to confirm accuracy and correct formatting
  - If contacting the hospice to request updated contact information, the survey vendor must ask for updates for all records, not individual decedent/caregiver cases
  - In addition to working with client hospices to obtain the most current caregiver contact information, survey vendors must employ other options, such as the NCOA and the 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 at different times until the data collection protocol is completed.

Telephone Interviewing Systems
Telephone Script
Telephone data collection is permitted in both English and Spanish. English must be the default language in the continental U.S. and Spanish must be the default language in Puerto Rico. Survey vendors are provided standardized telephone scripts in both English and Spanish (Appendices U and V) 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 screenshots (including skip pattern logic) by the specified due date for review by the CAHPS Hospice Survey Project Team. The due dates for survey vendors to submit samples of their CAHPS Hospice Survey telephone materials will be announced during the CAHPS Hospice Survey Training session and posted on the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org).

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
➢ 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

Note: It is not permissible to substitute capital letters for the text underlined in the telephone script, as text that appears in uppercase letters throughout the CATI script must not be read out loud. Survey vendors are permitted to indicate emphasis of underlined text in a different manner if their CATI system does not permit underlining, such as placing quotes (‘”’) or asterisks (***) around the text to be emphasized.

➢ All punctuation for the question and answer categories located in Appendices U and V must be programmed
➢ Only one language (English or Spanish) may appear on the electronic interviewing system screen
➢ The survey vendor is responsible for programming the script(s) and specifications into their electronic telephone interviewing system software
   • 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
   • All probes located throughout the telephone script must be included on the CATI screen

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 (see Appendix M for examples of acceptable supplemental questions):
➢ 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 can be added immediately after the Core CAHPS Hospice Survey questions (Q1 – Q40) or at the end of all the CAHPS Hospice Survey questions (Q1 – Q47)
➢ 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 details 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 the respondent’s 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 survey vendor to provide the hospice with the respondent’s answers linked to the respondent’s name and identifying information. The Consent to Share Responses question is typically placed at the end of the interview as the last question. The number of supplemental questions added to the CAHPS Hospice Survey, including the “Consent to Share Responses,” must be included in the question count for the XML file element “supplemental-question-count.” Refer to Appendix M to view the Consent to Share Responses 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 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 discussed above)

Note: It is not permissible for a supplemental question to request the name and/or contact information of the caregiver.

- 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 (CATI) using live interviewers. The CATI 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. Paper surveys administered by telephone and the use of Touch-tone or Speech-enabled IVR are not acceptable. 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 from 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 FTC and 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 [and/or 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 U and V.

**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 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 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 must 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 caregiver.

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

- Confirm the identity of the caregiver using the full name provided in the decedents/caregivers list prior to disclosing any identifiable information (e.g., decedent name).
- 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.

  \textit{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 two or three 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 reserve some of the allowable calls for the part of the field period for which the caregiver is available.

If the caregiver does not speak the language(s) in which the survey vendor administers the survey, 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 when they have been determined to be missing or incorrect. 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.

Survey vendors should attempt to obtain updated telephone numbers 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
- Survey vendors may contact the hospice to request updated telephone numbers. If contacting the hospice to request updated contact information, the survey vendor must ask for updates for all records, not individual decedent/caregiver cases.

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 ATA decedents/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 for more information)
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.

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), if applicable. 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 Appendices G and H 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 a balance between keeping PII and PHI confidential and helping a person who needs assistance. For survey research organizations, best interviewing practices recommend having a distressed respondent protocol in place to balance the respondent’s right to confidentiality and privacy with the need to provide assistance if the situation indicates that the respondent’s health and safety are in jeopardy.

- If a respondent requests 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 potential bereavement support is part of the services covered under the Medicare Hospice Benefit.

Note: If the survey vendor uses a subcontractor(s) 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(s) 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: In addition to the survey vendor’s monitoring of 10 percent of its subcontractors’ interviews, the CAHPS Hospice Survey Project Team also expects that a survey vendor’s subcontractor(s) will conduct internal monitoring of their telephone interviewers as a matter of good business practice. While it is preferred that each organization continue to monitor 10 percent of CAHPS Hospice Survey interviews (for an overall total of 20 percent), it is permissible for the survey vendor and its subcontractor(s) to conduct a combined total of at least 10 percent monitoring, as long as each organization conducts a portion of the monitoring. Therefore, the survey vendor and its subcontractor(s) can determine the ratio of monitoring that each organization conducts, as long as the combined total meets or exceeds 10 percent. Please note that CAHPS Hospice Survey interviews monitored concurrently by the survey vendor and its subcontractor(s) do not contribute separately to each organization’s monitoring time.

- Interviewers 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 a confidentiality agreement which includes language related to HIPAA regulations and the protection of decedent/caregiver information, and obtain signatures from all personnel with access to survey information, including staff and all subcontractor(s), if applicable, involved in survey administration and data collection

Note: Confidentiality agreements must be signed by all personnel upon employment. Confidentiality agreements must be reviewed and re-signed periodically, at the discretion of the survey vendor, but not to exceed more than a three-year period. The CAHPS Hospice Survey Project Team recommends all personnel involved in the CAHPS Hospice Survey review and re-sign confidentiality agreements on an annual basis.
- Confirm that staff and subcontractor(s), if applicable, are compliant with HIPAA regulations in regard to decedent/caregiver PHI; including BAA requirements
- 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 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.

**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 back-up procedures that adequately safeguard system data
- Test back-up 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
- Develop a disaster recovery plan for conducting ongoing business operations in the event of a disaster
IX. 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, identification 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 decedents/caregivers list is randomized prior to the assignment of the Decedent ID.

File Specifications
The survey vendor must submit their data files to the CAHPS Hospice Survey Data Warehouse before the quarterly submission deadline listed in the “CAHPS Hospice Survey Administration and Data Submission Schedule” table (see Introduction and Overview chapter). 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 Vendor Record and Hospice Record for that month.

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 the decedents/caregivers list 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
CAHPS Hospice Survey data are to be submitted using an XML file format. Survey vendors are permitted to submit multiple XML files as long as all three months of data for given CCNs are in their own XML files. Survey vendors may also submit one XML file containing all months of data for all CCNs. If, for example, a survey vendor has 10 client hospices, the survey vendor may submit anywhere between 1 and 10 XML files for the quarter, but months of data for one CCN may not be split among multiple files. A separate file for each month of data is not permitted.

If a hospice’s data file contains a decedent/caregiver case 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 CAHPS Hospice Survey 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 F.

Each XML file consists of four parts:
1. Vendor Record
2. Hospice Record
3. Decedent/Caregiver Administrative Record
4. Survey Results Record

1. Vendor Record
Each quarterly data file submitted by a survey vendor begins with the Vendor Record. The Vendor Record contains information on the date and number of submissions, and is applicable to every record in the file.

2. Hospice Record
The second part of the data submission file is the Hospice Record. There are three Hospice Records per CCN contained within the file, one for each month of the quarter. The Hospice Record contains identification and sampling information that is applicable to every survey record in that month for the given hospice. The Hospice Record includes such variables as: hospice name; CCN; National Provider Identifier (NPI); survey mode; the total number of decedent cases received from the hospice in the month; the number of live discharge patients reported by the hospice in the month; the number of cases excluded from the sample frame because the decedent’s date of death is missing; the number of “no publicity” decedents/caregivers reported by the hospice in the month; the number of decedents/caregivers determined by the survey vendor to be ineligible (pre-sample and post-sample); and the sample size for the month.
For example:

- The “Available Sample” field should equal the total number of decedents from the CCN in the month, minus the number of “no publicity” decedents/caregivers (<no-publicity>), the number of decedents missing date of death (<missing-dod>), and the number of decedents/caregivers found ineligible prior to sampling (<ineligible-presample>)

“Available Sample” should be calculated as:

Available Sample = Total Decedents – (No Publicity + Missing DOD + Ineligible Presample)

- The “Sampled Cases” field should equal the total number of decedents/caregivers drawn into the sample for the month. For CCNs using census sampling, the “Sampled Cases” field should equal the “Available Sample” field (<available-sample>) because all cases available for sampling are drawn into the sample.

“Sampled Cases” should be calculated as:

Sampled Cases = Available Sample – Any cases not drawn into the sample

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<th>Missing Date of Death</th>
<th>Ineligible Pre-sample</th>
<th>Available Sample</th>
<th>Sampled Cases</th>
<th>Ineligible Post-sample</th>
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</tr>
</tbody>
</table>

A critical component in the Hospice Sub-Record is the “Type of Sampling” used. See the Sampling Protocol chapter for information on sampling options.
3. Decedent/Caregiver Administrative Record
The third part of the data submission file is the Decedent/Caregiver Administrative Record. This contains information on each sampled decedent/caregiver in the file including the Decedent ID; final survey status; survey completion mode, 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 Administrative Record also includes:

- The “Number Survey Attempts – Telephone” is required when “Survey Mode” in the Hospice Record is “2 – Telephone Only.” It is also required when “Survey Mode” in the Hospice 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 Hospice 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 “88 – Not Applicable” if appropriate.

4. Survey Results Record
The fourth part of the 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 “1 – Completed Survey,” “6 – Ineligible: Never Involved in Decedent Care,” 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.

Note: The Survey Results Record is not required for “Final Survey Status” of anything other than “1 – Completed Survey,” “6 – Ineligible: Never Involved in Decedent Care,” 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 decision rules and coding guidelines included in the survey administration chapters to ensure valid and consistent coding of these situations.
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.

- 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 telephone 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, 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.

Vendor Record
- The Vendor Record must appear once per file, and the year, month, and day of the submission must correspond to the date on which the file is submitted to the CAHPS Hospice Survey Data Warehouse
- The file submission number is an ordinal variable that represents the number of submissions for the given date. This number will usually be 1.

Hospice Record
- In calculating the “Sample Size” 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
• If a decedent/caregiver is selected for the survey sample and is later determined to be ineligible (i.e., “Final Survey Status” codes of “2 – Ineligible: Deceased,” “3 – Ineligible: Not in Eligible Population,” “4 – Ineligible: Language Barrier,” “5 – Ineligible: Mental/Physical Incapacity, “6 – Ineligible: Never Involved in Decedent Care,” or “14 – Ineligible: Institutionalized”), then the decedent/caregiver must be subtracted from the number of survey-eligible decedents/caregivers in the month and must be included in the “Ineligible Post-sample” field

➢ When hospices sample 100 percent of the survey-eligible decedents/caregivers (i.e., a census), the “Type of Sampling” must be coded as “2 – Census Sample”

Note: A CAHPS Hospice Survey Hospice Record must still be submitted for hospices with zero survey-eligible decedents/caregivers (zero cases) in a month.

Decedent/Caregiver Administrative Record

➢ All fields in the Decedent/Caregiver Administrative Record must have a valid value. Use code “M – Missing/Don’t Know” for all missing fields, with the following exception:
• The “language” field must be completed with the appropriate valid value indicating the survey language in which the survey was administered (English, Spanish, Chinese, Russian, Portuguese, or Vietnamese), 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 or excluded prior to survey administration

➢ The “Survey Completion Mode” field must be submitted if the “Survey Mode” in the Hospice Record is “3 – Mixed Mode” and the “Final Survey Status” is “1 – Completed Survey,” “6 – Ineligible: Never Involved in Decedent Care,” or “7 – Non-response: Break-off”

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 Hospice Record is “2 – Telephone Only”
• the “Survey Mode” in the Hospice 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 Hospice 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 Survey 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 (e.g., date of receipt of mail survey and/or comment from caregiver indicating the appropriate “Final Survey Status” code)
- All surveys (i.e., “Final Survey Status” codes of 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 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 calendar days) of initial contact (first mailing of the mail survey or first telephone attempt).

**Note:** If the code 33 is used for interim data submissions, calculation of lag time is not required.

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 notification date indicating 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 notification date indicating 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 notification date indicating 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 notification date indicating 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 notification date indicating 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 notification date that 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 notification date that 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/No 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 Telephone 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

• **Non-response: Incomplete Caregiver Name** (code 12): Lag time is the number of days between the decedent’s date of death and the date it is determined that the caregiver’s complete name is not available

• **Non-response: Incomplete Decedent Name** (code 13): Lag time is the number of days between the decedent’s date of death and the date it is determined that the decedent’s complete name is not available

• **Ineligible: Institutionalized** (code 14): Lag time is the number of days between the decedent’s date of death and the notification date indicating that the caregiver is institutionalized

• **Non-Response: Hospice Disavowal** (code 15): Lag time is the number of days between the decedent’s date of death and the notification date indicating that the decedent did not receive care from any hospice or the named hospice
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

<table>
<thead>
<tr>
<th>Mode of Survey Administration</th>
<th>Mail Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decedent Date of Death</td>
<td>March 16</td>
</tr>
<tr>
<td>Date of First Mail Attempt</td>
<td>June 1 (75 days after death)</td>
</tr>
<tr>
<td>Date of Follow-up Mail Attempt</td>
<td>June 22 (21 days after first mail attempt)</td>
</tr>
<tr>
<td>Date Data Collection Activities Ended for this Decedent/Caregiver</td>
<td>July 13 (42 calendar days after first mail attempt) Caregiver never returned the CAHPS Hospice Survey</td>
</tr>
<tr>
<td>CAHPS Hospice Survey Final Status</td>
<td>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</td>
</tr>
<tr>
<td>Lag Time</td>
<td>Calculated as 119 days (number of days between the patient’s death [March 16] to the date data collection activities ended [July 13])</td>
</tr>
</tbody>
</table>

### Example B: Lag Time Calculation – Telephone

<table>
<thead>
<tr>
<th>Mode of Survey Administration</th>
<th>Telephone Only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decedent Date of Death</td>
<td>March 16</td>
</tr>
<tr>
<td>Date of First Attempt</td>
<td>June 1 (75 days after decedent death)</td>
</tr>
<tr>
<td>Date Data Collection Activities Ended for this</td>
<td>July 13 (42 calendar days after the first telephone attempt)</td>
</tr>
<tr>
<td>CAHPS Hospice Survey Final Status</td>
<td>Code as “9 – Non-response: Non-response after Maximum Attempts” because the data collection protocol of 42 calendar days had ended and the caregiver had not been reached although five attempts were made</td>
</tr>
<tr>
<td>Lag Time</td>
<td>Calculated as 119 days (number of days between the decedent’s death [March 16] to the date data collection activities ended [July 13])</td>
</tr>
</tbody>
</table>
To illustrate the calculation of lag time when a caregiver responds and completes the survey, one example is provided:

<table>
<thead>
<tr>
<th>Example C: Lag Time Calculation – Mail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mode of Survey Administration</td>
</tr>
<tr>
<td>Decedent Date of Death</td>
</tr>
<tr>
<td>Date of First Mail Attempt</td>
</tr>
<tr>
<td>Date of Response</td>
</tr>
<tr>
<td>CAHPS Hospice Survey Final Status</td>
</tr>
<tr>
<td>Lag Time</td>
</tr>
</tbody>
</table>

- The “Supplemental Questions Count” field must be submitted when the “Final Survey Status” is “1 – Completed Survey,” “6 – Ineligible: Never Involved in Decedent Care,” or “7 – Non-response: Break-off.” 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). This count must include the Consent to Share Responses supplemental question if included in 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 after 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,” “6 – Ineligible: Never Involved in Decedent Care,” 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. 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.”
• Telephone Survey
  o 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 must use 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.

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

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 ATA 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

In addition, should it be determined that a patient is still living or that his or her last admission to the hospice resulted in a live discharge, then survey vendors should assign “Final Survey Status” code of “3 – Ineligible: Not in Eligible Population.”

Note: Cases ineligible due to live discharge or “no publicity” should not be included in sample files received from hospices. Survey vendors should work closely with hospices that have not removed these patients prior to submitting the decedents/caregivers list to ensure that subsequent file submissions do not include such patients. In addition, a Discrepancy Report must be filed for cases that are included in the decedents/caregivers list and drawn into the sample that are later determined to be a live discharge or “no publicity.”

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/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 ATA 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 a blank survey with no completed questions with a note stating they do not wish to participate, or when a caregiver verbally refuses to complete the survey. Surveys completed by a respondent outside of the sampled caregiver household are coded as “8 – Non-response: Refusal.”

Note: If a caregiver returns a survey with a note stating they do not wish to participate or if a caregiver verbally refuses to complete the survey, but the caregiver has already answered at least one survey question, the case should be coded as “1 – Completed Survey” or “7 – Non-response: Break-off,” as appropriate.

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 survey 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 calendar days from initial contact), or
- if the survey is returned by mail or completed by telephone more than 42 calendar days from initial contact

10 Non-response: Bad/No Address
This disposition code applies only to the Mail Only mode. Survey vendors assign a “Final Survey Status” code of “10 – Non-response: Bad/No 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 Telephone 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 Telephone Number” is used when there is evidence that a caregiver’s address and telephone number are both bad.

12 **Non-response: Incomplete Caregiver Name**
Survey vendors assign a “Final Survey Status” code of “12 – Non-response: Incomplete Caregiver Name” when there is evidence that the full caregiver name is unavailable (e.g., survey vendor re-contacted the hospice client to inquire about an update for missing or partial name information).

13 **Non-response: Incomplete Decedent Name**
Survey vendors assign a “Final Survey Status” code of “13 – Non-response: Incomplete Decedent Name” when there is evidence that the full decedent name is unavailable (e.g., survey vendor re-contacted the hospice client to inquire about an update for missing or partial name information).

14 **Ineligible: Institutionalized**
Survey vendors assign a “Final Survey Status” code of “14 – Ineligible: Institutionalized” to a decedent/caregiver case when the caregiver is unable to complete the survey because he/she is identified to be institutionalized. This includes caregivers who are in a psychiatric facility, nursing home or correctional institution.

15 **Non-response: Hospice Disavowal**
Survey vendors assign a “Final Survey Status” code of “15 – Non-response: Hospice Disavowal” when a caregiver indicates that a decedent did not receive care from any hospice or the named hospice. This may occur when a mail survey is returned with a note from the caregiver, through a call to the project toll-free number or during telephone interviewing.
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/No Address,” and “11 – Non-response: Bad/No Telephone 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 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 decedents/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. These decedent/caregiver cases must not be removed or replaced in the sample. All materials relevant to survey administration are subject to review by CMS.

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

- the hospice does not provide an address in the decedents/caregivers 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 non-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 non-viability of caregiver’s telephone number includes:

- the hospice does not provide a telephone number in the decedents/caregivers 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 non-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/No Address,” and “11 – Non-response: Bad/No Telephone 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.

<table>
<thead>
<tr>
<th>Mail Only Methodology</th>
<th>Assigning Final Survey Status/Disposition Codes 9, 10 and 11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Final Survey Status Code</td>
<td>Viable Address and No Response After Maximum Attempts</td>
</tr>
<tr>
<td></td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Telephone Only Methodology</th>
<th>Assigning Final Survey Status/Disposition Codes 9, 10 and 11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Final Survey Status Code</td>
<td>Viable Telephone Number and No Response After Maximum Attempts</td>
</tr>
<tr>
<td></td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mixed Mode Methodology</th>
<th>Assigning Final Survey Status/Disposition Codes 9, 10 and 11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Final Survey Status Code</td>
<td>Viable Address and/or Telephone Number and No Response After Maximum Attempts</td>
</tr>
<tr>
<td></td>
<td>9</td>
</tr>
</tbody>
</table>
Assigning Missing or Incomplete Caregiver Name Disposition Codes
Dependent upon the completeness of the caregiver name, the “Final Survey Status” codes of “3 – Ineligible: Not in Eligible Population” and “12 – Non-response: Incomplete Caregiver Name” are assigned. Respondents with no caregiver name or an incomplete caregiver name are not removed from the sample frame. If there is no caregiver name or the first or last name of the caregiver is missing or incomplete, survey vendors must make every reasonable attempt to obtain the caregiver’s full name, including re-contacting the hospice client to inquire about an update for decedents/caregivers with missing or partial name information. If all of the caregiver name is missing after every reasonable attempt has been made to obtain the caregiver’s full name and the decedent/caregiver case has been selected for the sample, the decedent/caregiver case must be considered “Decedent has no caregiver of record” and coded with a “Final Survey Status” of “3 – Ineligible: Not in Eligible Population.”

Note: If the caregiver name information is incomplete after every reasonable attempt has been made to obtain the caregiver’s full name and the decedent/caregiver case has been selected for the sample, hospices/survey vendors have flexibility in not administering surveys to caregivers with incomplete caregiver name information. It is not permissible to address the CAHPS Hospice Survey cover letters with “To the caregiver of [decedent name]:”

If caregivers with incomplete name information are not surveyed, the decedent/caregiver case must be coded with a “Final Survey Status” of “12 – Non-response: Incomplete Caregiver Name.” This non-response disposition code must not be removed from the denominator of the response rate calculation.

Assigning Missing or Incomplete Decedent Name Disposition Code
Survey vendors must assign the code “13 – Non-response: Incomplete Decedent Name” when there is evidence that the full decedent name is unavailable. Decedent/Caregiver cases with no decedent name or an incomplete decedent name are not removed from the sample frame. If there is no decedent name or the first or last name of the decedent is missing or incomplete, survey vendors must make every reasonable attempt to obtain the decedent’s full name, including re-contacting the hospice client to inquire about an update for decedents/caregivers with missing or partial name information.

Caregivers of decedents with incomplete name information must not be administered the survey. This non-response disposition code must not be removed from the denominator of the response rate calculation.

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 “Final Survey Status” code of “1 – Completed Survey” to decedent/caregiver cases when at least 50 percent of the questions ATA 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 ATA decedents/caregivers

\[ R = \text{total number of questions answered} \]

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

\[ \text{Percentage Complete} = \left( \frac{R}{34} \right) \times 100 \]

**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, 12, 13, 14, 15, and M
- **Total Number of Ineligible Surveys** is the total number of surveys with a “Final Survey Status” code of 2, 3, 4, 5, 6, and 14

It is important to emphasize that the remaining non-response disposition codes (i.e., “7 – Non-response: Break-off,” “8 – Non-response: Refusal,” “9 – Non-response: Non-response after Maximum Attempts,” “10 – Non-response: Bad/No Address,” “11 – Non-response: Bad/No Telephone Number,” “12 – Non-response: Incomplete Caregiver Name,” “13 – Non-response: Incomplete Decedent Name,” and “15 – Non-response: Hospice Disavowal”) are not removed from the denominator of the response rate calculation.
X. Data Submission

Overview
The CAHPS Hospice Survey uses 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. Submission to the CAHPS Hospice Survey Data Warehouse is on a quarterly basis. Refer to the CAHPS Hospice Survey Data Collection and Submission Timeline in the Introduction and Overview chapter for the data submission timeline.

Data Submission Process
The CAHPS Hospice Survey Data Coordination Team has developed a secure data warehouse hosted by the RAND Corporation. This data warehouse operates 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 Symantec File Share Encryption software (formerly PGP) for file encryption. The interface for the data warehouse is user friendly and requires 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 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, fully correct data file(s) must be submitted by 11:59 PM Eastern Time on the required submission date. The data file(s) with the latest timestamp for each CCN will be retained.

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 the RAND Corporation. 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.

If a survey vendor attempts to submit the hospice’s survey data without authorization, the data will be rejected by the CAHPS Hospice Survey Data Warehouse. The survey vendor will need to contact the hospice about the authorization, and re-submit the data once authorization is obtained.
Switching Survey Vendors
Hospices that choose to switch from one survey vendor to another can only do so at the beginning of a calendar quarter. In order to switch from one survey vendor to another, the Hospice Administrator must complete and submit a CAHPS Hospice Survey Authorization Form for Changing Survey Vendors (see Appendix C) 90 days prior to the data submission deadline. Contact the CAHPS Hospice Survey Project Team for assistance with the process for switching survey vendors. The following items must be completed on the CAHPS Hospice Survey Authorization Form for Changing Survey Vendors before a new survey vendor can be successfully authorized:

1. The Last Quarter of Survey Administration for the Current CAHPS Hospice Survey Vendor should be the last month of the quarter based on the death of the patient for which the current survey vendor will be collecting CAHPS Hospice Survey data on behalf of the hospice.

   Note: If the survey vendor is authorized to administer the survey through Quarter 1 CY 2017 (deaths in January, February or March, 2017), the survey vendor must have a survey administration end date after March 2017.

2. The Survey Administration Start Date for the New CAHPS Hospice Survey Vendor should be the first month of the quarter based on the death of the patient for which the new survey vendor will be collecting CAHPS Hospice Survey data on behalf of the hospice.

   Note: If the current survey vendor is authorized to administer the survey through Quarter 1 CY 2017 (deaths in January, February or March, 2017), the new survey vendor must have a survey administration start date beginning Quarter 2 CY 2017 (deaths in April, May or June, 2017). This should be the date immediately following the administration date selected in number 1 above.

Preparation for Data Submission
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 by submitting a new CAHPS Hospice Survey Data Warehouse Form. 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 survey vendors and review of data submission reports by both hospices and survey 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 by submitting a new CAHPS Hospice Survey Data Warehouse Form. 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 the CAHPS Hospice Survey Data Warehouse 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 clients to submit data on their behalf, a folder will be created on the CAHPS Hospice Survey Data Warehouse site for each survey vendor and hospice designee. Each person authorized to use the CAHPS Hospice Survey Data Warehouse will receive an automated email containing a link that will direct them to the CAHPS Hospice Survey Data Warehouse login screen where they will be able to choose a password, login to the CAHPS Hospice Survey Data Warehouse and access their secure folder.

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 or data submission.

**Survey File Submission Naming Convention**

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

```
vendorname.mmddyy.submission#.xml.pgp
```

Where

- `vendorname` = name of survey vendor
- `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
- `submission#` = submission number for each date

Example: `XYZResearch.060115.1.xml.pgp`

Note: 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 survey vendor has not yet completed the survey must be coded with the 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 receive an email directing them to the CAHPS Hospice Survey Data Warehouse, where they can login using their email address as the login ID. On their first login, all users will be prompted to choose a new 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
Survey vendors will upload data files to a secure CAHPS Hospice Survey Data Warehouse hosted by 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 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 survey 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 Symantec File Share Encryption (formerly PGP and still widely known as and referred to in this document as PGP) prior to submitting files to the CAHPS Hospice Survey Data Warehouse. This software 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 license if they do not already use Symantec File Share Encryption. The software is available from http://www.symantec.com/file-share-encryption?fid=encryption. Prior versions of PGP software may also be used for encryption.

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 survey vendor’s 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 Back-up 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 D 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 must be followed for each authorized user of the CAHPS Hospice Survey Data Warehouse. Hospice Data Administrators can only view and download reports. They may not submit files to the CAHPS Hospice Survey Data Warehouse.

Data Auditing, Validation Checks and Data Submission Reports

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 File Preparation in this manual. Survey vendors and hospices are responsible for accessing and reviewing the CAHPS Hospice Survey Data Submission Reports.

Data Audit and Validation

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. After a file has been submitted to the CAHPS Hospice Survey Data Warehouse, the survey vendor and hospice will receive an automated email confirming the file submission.

Once submitted, an automated program will check 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 a new report is available. The report will state 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, a corrected file will need to be resubmitted prior to the deadline. If the file has been sent with the correct “.pgp” extension, the survey vendor will not receive this email. Both the confirmation email and the incorrect encryption email will be sent within two hours of the file upload.
Successfully submitted files will be put through a series of edits check such as:

- 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 (Data Administrator and Back-up Data Administrator) will receive a second email indicating that the CAHPS Hospice Survey Data Submission Reports comprised from these edit checks are available for viewing in their respective folders on the CAHPS Hospice Survey Data Warehouse. Reports will be posted by 5 PM Eastern Time on the next business day after upload. CAHPS Hospice Survey 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:** Each set of CAHPS Hospice Survey Data Submission Reports will correspond to only the data included in that XML file. If a survey vendor chooses to submit each CCN in a different XML file, the survey vendor will be responsible for reviewing the CAHPS Hospice Survey Data Submission Reports for each separate XML file.

**Note:** Survey vendors must retain all received emails indicating a successful upload of data to the CAHPS Hospice Survey Data Warehouse, and be prepared to provide copies of these emails upon request.

Survey vendors are responsible for uploading a corrected file by the submission deadline. If the data file uploaded passes the edit checks described above, no additional action is required. If the uploaded data file fails any of the edit checks, it will be noted in the report uploaded to the survey vendor’s and hospice’s Data Warehouse folder. Survey vendors and hospices will need to review their CAHPS Hospice Survey Data Submission Reports to determine what errors were found in the files, and survey vendors will be required to resubmit a corrected survey data file. Hospices will receive updated reports after new data are submitted for their hospice, until their dataset has passed all edit checks. Survey vendors will receive reports for each data submission.

**Data Submission Reports**

Four 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:

- **Data Submission Detail Report (Part I):** This report indicates whether or not the data submitted by the survey vendor was accepted and processed. If the uploaded file fails to conform to the correct XML specifications, the file will not be processed and the remainder of the reports will not be generated. A corrected file will need to be resubmitted prior to the data submission deadline.
Data Submission Detail Report (Part II): This report indicates if the submitted data passed data quality checks. If any values are out of range, “Data Value Checks Status” will show as “Rejected” and survey vendors must submit a new file. If all data values pass the data quality checks, “Data Value Checks Status” will show as “Accepted,” and no further action is needed.

Survey Status Summary Report: This report lists the number of records and number of completed surveys for each hospice contained within the file. These are listed separately by month of death, and overall. The column “# Decedent-Level Data Records” is the number of decedent records within the file, and the column “# Completed Surveys” is the number of completed surveys.

Review and Correction Report: For hospices, this report lists the number of valid and invalid responses to each variable in the file. For survey vendors, this report lists the frequency of values for each variable in the file.

Note: All hospices should review the Data Submission Reports after they are uploaded to their CAHPS Hospice Survey Data Warehouse folder.
XI. 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 for Survey Vendors 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 activities. 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 QAP
  The CAHPS Hospice Survey 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 subcontractor(s), if applicable. The CAHPS Hospice Survey Project Team reviews 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., questionnaires, cover letters and outgoing envelopes) and/or telephone scripts and interviewer CATI screenshots 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, follow-up will occur with the survey vendor.

- Site Visits/Conference Calls
  All survey vendors (and their subcontractor(s), if 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.
Oversight Activities

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- Additional Activities
  Additional activities as specified by CMS may be conducted.

**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 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 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
  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 CAHPS Hospice Survey operations.
- ensure high quality data collection and continuity in survey processes

The QAP must provide sufficient detail so that the CAHPS Hospice Survey Project Team can determine the survey vendor’s adherence to survey administration guidelines and that rigorous quality checks and 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.
A Model QAP can be found in Appendix I. 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 manual, as well as the deadline dates 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 subcontractor(s), if applicable. Survey vendors must make their subcontractor(s) 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 PHI. The site review includes a review of sampling procedures. The survey vendor must retain CAHPS Hospice Survey-related data files, including decedents/caregivers lists and electronic data files (e.g., CAHPS Hospice Survey sampling frame) for a minimum of three years. The CAHPS Hospice Survey Project Team will review specific data records and trace the documentation of activities from the receipt of the decedents/caregivers 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 subcontractor(s), 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. Be aware that a survey vendor that loses approved status cannot submit data to the CAHPS Hospice Survey Data Warehouse; and therefore, cannot help the hospice in meeting CMS compliance requirements.*
XII. 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). The hospice CCN(s) 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 manual.

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

Overview
The Discrepancy Report 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 hospice(s)
- 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.hospicecahpssurvey.org). This report informs 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. The hospice CCN(s) 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. Please note, CMS requires survey vendors to complete and submit Discrepancy Reports. CMS will not revoke a survey vendor’s approval status due to submission of a Discrepancy Report, unless corrective actions are not successfully implemented. CMS will, however, consider revoking a survey vendor’s approval if the survey vendor is found to have repeated unreported discrepancies.
XIV. 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 must 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 the sample size for the given month
• Check that Hospice 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

Minimum Business Requirements
CAHPS Hospice Survey

Minimum Business Requirements

A survey vendor must meet ALL of the Survey Vendor Minimum Business Requirements at the time the CAHPS Hospice Survey Participation Form is received. In addition, subcontractors and any other organizations that are responsible for 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:

Management Relationships:

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Survey Vendor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current/Future Relationships with Hospices</td>
<td>The following types of organizations are not eligible to administer the CAHPS Hospice Survey (as an approved CAHPS Hospice Survey vendor):</td>
</tr>
<tr>
<td></td>
<td>• organizations or divisions within organizations that own or operate a hospice or provide hospice services, even if the division is run as a separate entity to the hospice;</td>
</tr>
<tr>
<td></td>
<td>• organizations that provide telehealth, monitoring of hospice patients, or teleprompting services for the hospice; and</td>
</tr>
<tr>
<td></td>
<td>• organizations that provide staffing to hospices for providing care to hospice patients, whether personal care aides or skilled services staff.</td>
</tr>
</tbody>
</table>

Relevant Survey Experience:

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Survey Vendor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Years in Business</td>
<td>Minimum four years</td>
</tr>
<tr>
<td>Number of Years Conducting Surveys in the Requested Mode</td>
<td>Minimum three years in conducting surveys in the selected mode(s) of administration</td>
</tr>
<tr>
<td>Number of Years Conducting Patient-Specific Surveys</td>
<td>Minimum two years conducting patient-specific surveys as an organization</td>
</tr>
<tr>
<td>Sampling Experience</td>
<td>Two years prior experience selecting a random sample based on specific eligibility criteria:</td>
</tr>
<tr>
<td></td>
<td>• Work with contracted client(s) to obtain patient data for sampling via HIPAA-compliant electronic data transfer processes</td>
</tr>
<tr>
<td></td>
<td>• Adequately document sampling process</td>
</tr>
<tr>
<td></td>
<td>• Survey vendors are responsible for conducting the sampling process and must not subcontract this activity</td>
</tr>
</tbody>
</table>
### Survey Capability and Capacity:

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Survey Vendor</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Personnel</strong></td>
<td></td>
</tr>
<tr>
<td>➢ Designated CAHPS Hospice Survey personnel:</td>
<td></td>
</tr>
<tr>
<td>➢ Project Director with minimum two years prior experience conducting patient-specific surveys in the requested mode(s)</td>
<td></td>
</tr>
<tr>
<td>➢ Staff with minimum one year prior experience in sample frame development and sample selection</td>
<td></td>
</tr>
<tr>
<td>➢ 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</td>
<td></td>
</tr>
<tr>
<td>➢ Call Center-Mail Center Supervisor (subcontractor designee, if applicable) with minimum one year prior experience in role</td>
<td></td>
</tr>
<tr>
<td>➢ Have appropriate organizational back-up staff for coverage of key staff</td>
<td></td>
</tr>
<tr>
<td>➢ Volunteers are not permitted to be involved in any aspect of the CAHPS Hospice Survey administration process</td>
<td></td>
</tr>
<tr>
<td><strong>Physical Plant and System Resources</strong></td>
<td></td>
</tr>
<tr>
<td>➢ Physical plant resources available to handle the volume of surveys being administered, including computer and technical equipment:</td>
<td></td>
</tr>
<tr>
<td>➢ A secure commercial work environment</td>
<td></td>
</tr>
<tr>
<td>➢ Home-based or virtual interviewers cannot be used to administer the CAHPS Hospice Survey nor may they conduct any survey administration processes</td>
<td></td>
</tr>
<tr>
<td>➢ Physical facilities and electronic equipment and software to collect, process and report data securely</td>
<td></td>
</tr>
<tr>
<td>➢ If offering telephone surveys, must have the equipment, software and facilities to conduct CATI interviews and to monitor interviewers</td>
<td></td>
</tr>
<tr>
<td>➢ Electronic or alternative survey management system to:</td>
<td></td>
</tr>
<tr>
<td>➢ Track fielded surveys throughout the protocol, avoiding respondent burden and losing respondents</td>
<td></td>
</tr>
<tr>
<td>➢ 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)</td>
<td></td>
</tr>
<tr>
<td>➢ 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.</td>
<td></td>
</tr>
<tr>
<td>➢ All System Resources are subject to oversight activities, including site visits to physical locations</td>
<td></td>
</tr>
<tr>
<td>Criteria</td>
<td>Survey Vendor</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Sample Frame</td>
<td>Two years prior experience selecting a random sample based on specific eligibility criteria:</td>
</tr>
<tr>
<td>Creation</td>
<td>- Generate the sample frame data file that contains all individuals who meet the eligible population criteria</td>
</tr>
<tr>
<td></td>
<td>- Draw random sample of individuals for the survey who meet the eligible population criteria</td>
</tr>
<tr>
<td>Mail Administration</td>
<td>Mail survey administration activities are not to be conducted from a residence, nor from a virtual office</td>
</tr>
<tr>
<td></td>
<td>- Obtain and update addresses of sampled caregivers of hospice decedents</td>
</tr>
<tr>
<td></td>
<td>- Produce and print professional quality survey instruments and materials according to guidelines; a sample of all mailing materials must be submitted for review</td>
</tr>
<tr>
<td></td>
<td>- Merge and print sample name and address on personalized mail survey cover letters and print unique Tracking ID on the survey questionnaire</td>
</tr>
<tr>
<td></td>
<td>- Mail out survey materials</td>
</tr>
<tr>
<td></td>
<td>- Receive and process (key-enter or scan) completed questionnaires</td>
</tr>
<tr>
<td></td>
<td>- Track and identify non-respondents for follow-up mailing</td>
</tr>
<tr>
<td></td>
<td>- Assign final survey status codes to describe the final result of work on each sampled record</td>
</tr>
<tr>
<td>Telephone Administration</td>
<td>Telephone interviews are not to be conducted from a residence, nor from a virtual office</td>
</tr>
<tr>
<td></td>
<td>- Obtain, verify and update telephone numbers</td>
</tr>
<tr>
<td></td>
<td>- Develop computer program for electronically administering the survey (CATI)</td>
</tr>
<tr>
<td></td>
<td>- Collect telephone interview data for the survey using CATI system; a sample of the telephone script and interviewer screenshots must be submitted for review</td>
</tr>
<tr>
<td></td>
<td>- Identify non-respondents for follow-up telephone calls</td>
</tr>
<tr>
<td></td>
<td>- Schedule and conduct callbacks to non-respondents at varying times of the day and different days of the week</td>
</tr>
<tr>
<td></td>
<td>- Assign final survey status codes to reflect the final result of attempts to obtain a completed interview with each sampled record</td>
</tr>
<tr>
<td>Mixed Mode Administration (Mail with Telephone Follow-up)</td>
<td>Mail survey administration and telephone interviews are not to be conducted from a residence, nor from a virtual office</td>
</tr>
<tr>
<td></td>
<td>- Adhere to all Mail Only and Telephone Only survey administration requirements (described above)</td>
</tr>
<tr>
<td></td>
<td>- Track cases from mail survey through telephone follow-up activities</td>
</tr>
<tr>
<td>Criteria</td>
<td>Survey Vendor</td>
</tr>
<tr>
<td>-------------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Data Submission | - Survey vendors are responsible for conducting data submission and must not subcontract this process  
|              | - Survey vendors must have the capacity to do the following actions to submit quarterly data files:  
|              |   - Register as a user of the CAHPS Hospice Survey Data Warehouse  
|              |   - Confirm contracted hospices have authorized survey vendor to submit data on behalf of the hospice  
|              |   - Import scanned or key-entered data from completed mail surveys into a data file, if applicable  
|              |   - Import (as necessary) data from CATI system into a data file, if applicable  
|              |   - 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 are exported correctly and 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  
| Data Security | - Survey vendors must have the capacity to do the following actions to secure electronic data:  
|              |   - Use a firewall and/or other mechanisms for preventing unauthorized access to electronic files  
|              |   - Implement access levels and security passwords so that only authorized users have access to sensitive data  
|              |   - Implement daily data back-up procedures that adequately safeguard system data  
|              |   - Test back-up files on a quarterly basis, at a minimum, 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  
|              |   - Develop procedures for identifying and handling breaches of confidential data  
<p>|              |   - Develop a disaster recovery plan for conducting ongoing business operations in the event of a disaster |</p>
<table>
<thead>
<tr>
<th>Criteria</th>
<th>Survey Vendor</th>
</tr>
</thead>
</table>
| **Data Retention and Storage** | ➢ Survey vendors must have the capacity to do the following actions to securely store all data related to survey administration:  
  • Store CAHPS Hospice Survey-related data files, including decedents/caregivers lists and de-identified electronic data files, for all applicable survey modes for a minimum of three years. Archived electronic data files must be easily retrievable.  
  • Store de-identified returned mail questionnaires in a secure and environmentally safe location (e.g., locked file cabinet, locked closet or room), if applicable. Paper copies or optically scanned images of the questionnaires must be retained for a minimum of three years and be easily retrievable. |
| **Technical Assistance/ Customer Support** | ➢ Two years prior experience providing telephone customer support  
  ➢ Provide toll-free customer support line:  
  • Offering customer support in all languages that the survey vendor administers the survey in  
  • Returning calls within 24-48 hours |
| **Organizational Confidentiality Requirements** | ➢ Survey vendors must have the capacity to do all of the following actions:  
  • Develop 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. Confidentiality agreements must be reviewed and re-signed periodically, at the discretion of the survey vendor, but not to exceed more than a three-year period.  
  • Execute Business Associate Agreement(s) (BAA) in accordance with HIPAA regulations  
  • Confirm that staff and subcontractors are compliant with HIPAA regulations in regard to decedent/caregiver protected health information (PHI) and personal identifying information (PII)  
  • Establish protocols for secure file transmission. Emailing of PHI or PII via unsecure email is prohibited. |
## Participation in Quality Control Activities and Documentation Requirements:

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Survey Vendor</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demonstrated Quality Control Procedures</strong></td>
<td>➢ Incorporate well-documented quality control procedures (as applicable) for:</td>
</tr>
<tr>
<td></td>
<td>• In-house training of staff and subcontractors involved in survey operations</td>
</tr>
<tr>
<td></td>
<td>• Printing, mailing and recording receipt of survey questionnaires, if applicable</td>
</tr>
<tr>
<td></td>
<td>• Telephone administration of survey, if applicable</td>
</tr>
<tr>
<td></td>
<td>• Coding and verifying of survey data and survey-related materials</td>
</tr>
<tr>
<td></td>
<td>• Scanning or keying-in survey data</td>
</tr>
<tr>
<td></td>
<td>• Preparation of final person-level data files for submission</td>
</tr>
<tr>
<td></td>
<td>• All other functions and processes that affect the administration of the CAHPS Hospice Survey</td>
</tr>
<tr>
<td></td>
<td>➢ Participate in any conference calls and site visits as part of overall quality monitoring activities:</td>
</tr>
<tr>
<td></td>
<td>• 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</td>
</tr>
<tr>
<td><strong>Documentation Requirements</strong></td>
<td>➢ Keep electronic or hard copy files of staff training and training dates</td>
</tr>
<tr>
<td></td>
<td>➢ Maintain electronic documentation of telephone monitoring, if applicable</td>
</tr>
<tr>
<td></td>
<td>➢ Maintain documentation of mail production quality checks, if applicable</td>
</tr>
<tr>
<td></td>
<td>➢ Maintain documentation of all survey administration activities and related quality checks for review during site visits</td>
</tr>
</tbody>
</table>
### Adhere to all Protocols, Specifications and Agree to Participate in Training Sessions:

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Survey Vendor</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Survey Training</strong></td>
<td>łuże. Attend the Introduction to CAHPS Hospice Survey Training session and all CAHPS Hospice Survey Update Training sessions (subcontractors assigned key roles must attend training)</td>
</tr>
</tbody>
</table>
| **Administer the Survey according to all Survey Specifications** | łuże. Review and follow all procedures described in the *CAHPS Hospice Survey Quality Assurance Guidelines* that are applicable to the selected survey data collection mode(s)  
łeś. Fully comply with the CAHPS Hospice Survey oversight activities  
łeś. 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 Survey 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. |
Appendix B

Survey Vendor Authorization Form
CAHPS Hospice Survey

Survey Vendor Authorization Form

Hospice agencies must authorize an approved CAHPS Hospice Survey vendor to submit data on their behalf for the 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 one calendar quarter (90 days) prior to the first time data will be submitted to the CAHPS Hospice Survey Data Warehouse. 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 survey vendor.

If your hospice is switching from one survey vendor to another, complete the Authorization Form for Changing Survey Vendors available on the project website, not this form.

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 the CAHPS Hospice Survey Vendor Authorization Form pertaining to multiple hospice agencies, it is appropriate to attach a list to the form (signed and dated by the CAHPS Hospice Survey Administrator) of all the hospices (hospice names and CMS Certification Numbers [CCNs]). Please check the box on the form indicating that a separate document is attached and indicate the number of hospice names or CCNs listed on the separate sheet.

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 5599

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

I, ____________________________ (print CAHPS Hospice Survey Administrator’s name), acknowledge and accept the role and all of the responsibilities of the CAHPS Hospice Survey Administrator for ____________________________ (print name of hospice), ____________ (CMS Certification Number [CCN] or 

☐ CCN List is attached (indicate number of hospices on list _____)

Start Date for Survey Administration: ____________________________

In this role I will be responsible for:

1) Authorizing a survey vendor to collect data for ____________________________ (print name of hospice or “See attached document”) as part of the CAHPS Hospice Survey and to submit data to CMS on behalf of the hospice.

2) Notifying CMS and the RAND Corporation immediately if the hospice de-authorizes a survey vendor by completing an Authorization Form for Changing Survey Vendors.

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 survey 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 CAHPS Hospice Survey vendor name) to collect data for the hospice I represent as part of the CAHPS Hospice Survey and to submit data to CMS on behalf of the hospice.

Hospice Administrator First and Last Name: __________________________________________

Hospice Administrator Signature: ____________________________ Date: __________

Title: __________________________________________

Phone Number: (____)________________________ Email: ____________________________

Hospice Mailing Address: __________________________________________

City: ____________________________ State: ___________ Zip Code: ___________________

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

First and Last Name: ____________________________

Phone Number: (____)________________________ Email: ____________________________

Name of Survey Vendor Authorizing: ____________________________________________

Notary Public Signature: ____________________________________________

Stamp: ____________________________

Notary Public Date: ____________________________
Appendix C

Authorization Form for Switching Survey Vendors
CAHPS Hospice Survey

Authorization Form for Changing Survey Vendors

Hospice agencies must authorize an approved CAHPS Hospice Survey vendor to submit data on their behalf for the administration of the CAHPS Hospice Survey. If a hospice wishes to change CAHPS Hospice Survey vendors, it may do so ONLY at the beginning of a calendar quarter.

Note: A quarter is based on the calendar year (CY) and will correspond to the month of patient death. For example, Quarter 1 2017 begins with January 2017 patient deaths (caregivers to be surveyed April 2017).

In order to change a survey vendor, the hospice’s CAHPS Hospice Survey Administrator must complete the Authorization Form for Changing Survey Vendors and submit it to the RAND Corporation one calendar quarter (90 days) prior to the first time data will be submitted to the CAHPS Hospice Survey Data Warehouse by the new survey vendor.

➢ The CAHPS Hospice Survey Administrator for the hospice should complete and submit this form
➢ This form must be signed and dated in the presence of a notary public, notarized and sent to the RAND Corporation
➢ When completing the Authorization Form for Changing Survey Vendors pertaining to multiple hospice agencies, it is appropriate to attach a list to the form of all the hospices (hospice names and CMS Certification Numbers [CCNs]). Please check the box on the form indicating that a separate document is attached and indicate the number of hospice names or CCNs listed on the separate sheet. The list must be signed and dated by the CAHPS Hospice Survey Administrator.

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 5599

Note: After submission of the Authorization Form for Changing Survey Vendors, no further action is required by the hospice to notify CMS of their change in survey vendor selection. The RAND Corporation communicates to CMS which hospice agencies have authorized a survey vendor to administer the CAHPS Hospice Survey on their behalf.
**CAHPS Hospice Survey**  
**Authorization Form for Changing Survey Vendors**

I. ____________________________ (print CAHPS Hospice Survey Administrator’s name), authorize the following change in CAHPS Hospice Survey vendor for:

- Hospice Name (please print): ________________________________________________
- Hospice CCN(s): __________________________________________________________

OR Check box if list is attached:
- ☐ Document attached listing (print number) _______ hospice names and CCNs.

**A. Survey Vendor Information**

- Name of Current Survey Vendor (De-authorizing): ____________________________
- Name of New Survey Vendor (Authorizing): ________________________________

**B. Last Quarter of Survey Administration for the Current CAHPS Hospice Survey Vendor and First Quarter of Survey Administration for the New CAHPS Hospice Survey Vendor**

Please check the box that corresponds to the quarters in which the change will occur.

<table>
<thead>
<tr>
<th>Check One</th>
<th>Last Quarter of Survey Administration for the Current CAHPS Hospice Survey Vendor (De-authorizing)</th>
<th>First Quarter of Survey Administration for the New CAHPS Hospice Survey Vendor</th>
</tr>
</thead>
</table>
| ☐         | **Quarter 2 CY 2016**  
Deaths in April, May and June, 2016  
Survey administration July, August and September, 2016  
Data submission November 9, 2016 | **Quarter 3 CY 2016**  
Deaths in July, August and September, 2016  
Survey administration October, November and December, 2016  
Data submission February 8, 2017 |
| ☐         | **Quarter 3 CY 2016**  
Deaths in July, August and September, 2016  
Survey administration October, November and December, 2016  
Data submission February 8, 2017 | **Quarter 4 CY 2016**  
Deaths in October, November and December, 2016  
Survey administration January, February and March, 2017  
Data submission May 10, 2017 |
| ☐         | **Quarter 4 CY 2016**  
Deaths in October, November and December, 2016  
Survey administration January, February and March, 2017  
Data submission May 10, 2017 | **Quarter 1 CY 2017**  
Deaths in January, February and March, 2017  
Survey administration April, May and June, 2017  
Data submission August 9, 2017 |
| ☐         | **Quarter 1 CY 2017**  
Deaths in January, February and March, 2017  
Survey administration April, May and June, 2017  
Data submission August 9, 2017 | **Quarter 2 CY 2017**  
Deaths in April, May and June, 2017  
Survey administration July, August and September, 2017  
Data submission November 8, 2017 |
| ☐         | **Quarter 2 CY 2017**  
Deaths in April, May and June, 2017  
Survey administration July, August and September, 2017  
Data submission November 8, 2017 | **Quarter 3 CY 2017**  
Deaths in July, August and September, 2017  
Survey administration October, November and December, 2017  
Data submission February 14, 2018 |
Hospice Administrator First and Last Name: ________________________________
Hospice Administrator Signature: _______________________________________
Title: __________________________________________________________________
Phone Number: _______________ Email: ________________________________
Hospice Mailing Address: ________________________________
City: __________________________ State: _____________ Zip Code: ____________

Notary Public Signature: ________________________________________________

Stamp: __________________________________________________________________
Notary Public Date: _____________________________________________________
Appendix D

Data Warehouse Access Form
The CAHPS Hospice Survey Data Warehouse is maintained by the RAND Corporation. All survey vendors contracting with hospices to implement the CAHPS Hospice Survey must have a user account on the CAHPS Hospice Survey Data Warehouse. In addition, all hospices must have user account information and be granted access to the CAHPS Hospice Survey Data Warehouse in order to monitor data submission activities. Complete this form and submit it as an email attachment to cahpshospicetechsupport@rand.org or by fax to the CAHPS Hospice Survey Data Coordination Team at (703) 413-8111. Your form must be received one calendar quarter (90 days) prior to the first time data will be submitted to the CAHPS Hospice Survey Data Warehouse.

Provide contact information below for your organization’s Data Administrator and Back-up Data Administrator. Complete contact information is required to authorize a user account for the CAHPS Hospice Survey Data Warehouse. By submitting a new form, your hospice CCN is indicating a change to its data administrator and/or back-up administrator. Administrators listed on prior Data Warehouse Access Forms submitted by your hospice will no longer have access to the Data Warehouse.

Date form submitted: __________
Your Organization’s Name: ____________________________________________
Your Organization’s CCN(s): ____________________________________________

☐ CCN List is attached (Indicate number of hospices on list _____)

**Data Administrator**
First and Last Name: ____________________________________________
Phone Number: (_____) ____________________________________________
Data Administrator Email: __________________________________________

**Back-up Data Administrator**
First and Last Name: ____________________________________________
Phone Number: (_____) ____________________________________________
Back-up Data Administrator Email: __________________________________

**Additional Data Administrator (Optional)**
First and Last Name: ____________________________________________
Phone Number: (_____) ____________________________________________
Email: __________________________________________________________
Appendix E

Sample File Layout
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 used to facilitate the standardized administration of the CAHPS Hospice Survey and includes the data elements necessary for data submission, sampling and proper record keeping. The decedent/caregiver identifying information and other italicized Data Element fields will not be submitted to the CAHPS Hospice Survey Data Warehouse.

2. CMS strongly recommends that survey vendors collect all data elements whether or not they are required for data submission.

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Length</th>
<th>Value Labels and Use</th>
<th>Required for Data Submission</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider Name</td>
<td>100</td>
<td>Name of the hospice</td>
<td>Yes</td>
</tr>
<tr>
<td>Provider ID</td>
<td>10</td>
<td>CMS Certification Number (CCN) [formerly known as Medicare Provider Number]</td>
<td>Yes</td>
</tr>
<tr>
<td>NPI</td>
<td>10</td>
<td>National Provider Identifier (NPI)</td>
<td>No</td>
</tr>
<tr>
<td>Facility Name¹</td>
<td>100</td>
<td>Name of hospice, inpatient or nursing home facility, if applicable</td>
<td>No</td>
</tr>
<tr>
<td>Number of Hospice Offices</td>
<td>10</td>
<td>The total number of hospice offices operating within this CCN. These are separate administrative or practice offices for the CCN, not to be confused with individual facilities or settings in which hospice care is provided.</td>
<td>Yes</td>
</tr>
<tr>
<td>Total Number of Live Discharges</td>
<td>10</td>
<td>Number of patients who were discharged alive during the month</td>
<td>Yes</td>
</tr>
<tr>
<td>Total Number of Decedents</td>
<td>10</td>
<td>Number of decedents during the month (calculated as the number of records provided by hospice plus the number of “no publicity” cases)</td>
<td>Yes</td>
</tr>
</tbody>
</table>

¹ A caregiver may associate their family member’s care with the facility where hospice care was received, rather than the actual name of the hospice organization. Therefore, "Facility Name" refers to the name of the facility (e.g., name of the assisted living facility, nursing home, hospital, or hospice house) where care was received. For example, if the decedent received care from Hospice ABC while in Facility XYZ, Facility XYZ is the "Facility Name."
### Sample File Layout

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Length</th>
<th>Value Labels and Use</th>
<th>Required for Data Submission</th>
</tr>
</thead>
<tbody>
<tr>
<td>“No-Publicity” Decedents/Caregivers</td>
<td>10</td>
<td>Number of “no publicity” decedents/caregivers during the month who initiated or voluntarily requested at admission that they not be revealed as a patient and/or whose caregiver requests that they not be surveyed, and were excluded from the file</td>
<td>Yes</td>
</tr>
<tr>
<td>Hospice Decedent/Caregiver ID</td>
<td>16</td>
<td>Hospice-generated ID submitted to survey vendor</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver First Name</td>
<td>30</td>
<td>Name information used to personalize materials to caregiver</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver Middle Initial</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Last Name</td>
<td>30</td>
<td>Name information used to personalize materials to caregiver</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver Prefix Name</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Suffix Name</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decedent First Name</td>
<td>30</td>
<td>Name information used to personalize materials to caregiver</td>
<td>No</td>
</tr>
<tr>
<td>Decedent Middle Initial</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decedent Last Name</td>
<td>30</td>
<td>Name information used to personalize materials to caregiver</td>
<td>No</td>
</tr>
<tr>
<td>Decedent Prefix Name</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decedent Suffix Name</td>
<td>10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Decedent Sex                         | 1      | 1 = Male  
2 = Female  
M = Missing                                                                                                                                                                                          | Yes                          |
| Decedent Hispanic                    | 1      | 1 = Hispanic  
2 = Non-Hispanic  
M = 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 = Missing                                                                                                                                   | Yes                          |
<table>
<thead>
<tr>
<th>Data Element</th>
<th>Length</th>
<th>Value Labels and Use</th>
<th>Required for Data Submission</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decedent Date of Birth</td>
<td>8</td>
<td>MMDDYYYY Used by survey vendor to calculate decedent age to confirm decedent meets eligibility criteria.</td>
<td>Yes</td>
</tr>
<tr>
<td>Decedent Date of Death</td>
<td>8</td>
<td>MMDDYYYY Used by survey vendor to calculate decedent age to confirm decedent meets eligibility criteria.</td>
<td>Yes</td>
</tr>
<tr>
<td>Decedent Hospice Admission Date</td>
<td>8</td>
<td>MMDDYYYY Decedent admission date for his/her final episode of hospice care. Used by survey vendor to confirm decedent meets eligibility criteria.</td>
<td>Yes</td>
</tr>
</tbody>
</table>
| 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 = Missing  
*The Valid Values are derived from the Healthcare Common Procedure Coding System (HCPCS) Codes: Q Codes for Hospices.* | 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 = Missing | Yes                           |
## Sample File Layout

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Length</th>
<th>Value Labels and Use</th>
<th>Required for Data Submission</th>
</tr>
</thead>
</table>
| 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 = 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 = Missing                          | Yes                           |
| Decedent Primary Diagnosis       | 8      | ICD-10 codes must be 3-8 characters. All codes use an alphabetic lead character.  
Most codes use numeric characters for the second and third characters, though some codes have an alphabetic third character.  
Do not submit descriptions of diagnoses that are not in the ICD-10 format, and do not submit Z-level codes, which represent reasons for encounters, not diagnoses.  
Examples of ICD-10 codes in the correct format are:  
G20 – Parkinson’s disease  
G30.9 – Alzheimer’s disease, unspecified  
I50.22 – Chronic systolic (congestive) heart failure  
C7A.024 – Malignant carcinoid tumor of the descending colon  
V00.818A – Other accident with wheelchair (powered): Initial encounter  
MMMMMMMMM = Missing | Yes                           |
| Decedent Primary Diagnosis Code Format | 1      | 1 = ICD-9  
2 = ICD-10  
M = Missing                          | Yes                           |
<table>
<thead>
<tr>
<th>Data Element</th>
<th>Length</th>
<th>Value Labels and Use</th>
<th>Required for Data Submission</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Mailing Address 1</td>
<td>50</td>
<td>Street address or post office box (address information used in protocols that have a mail mode of survey administration)</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver Mailing Address 2</td>
<td>50</td>
<td>Mailing address 2nd line (if needed)</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver Mailing City</td>
<td>50</td>
<td>Mailing city</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver Mailing State</td>
<td>2</td>
<td>Two-character state abbreviation</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver Mailing Zip Code</td>
<td>9</td>
<td>Nine-digit zip code; no hyphen, separators or de-limiters (i.e., 5-digit zip code followed by 4 digit extension)</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver Telephone Number 1</td>
<td>10</td>
<td>Three-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)</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver Telephone Number 2</td>
<td>10</td>
<td>Three-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)</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver Telephone Number 3</td>
<td>10</td>
<td>Three-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)</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver Email Address</td>
<td>30</td>
<td>Email address of caregiver</td>
<td>No</td>
</tr>
<tr>
<td>Caregiver Relationship to the Decedent</td>
<td>1</td>
<td>1 = Spouse/Partner</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 = Parent</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 = Child</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 = Other family member</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>5 = Friend</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 = Legal guardian (non-familial)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>7 = Other</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>8 = No caregiver of record</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>M = Missing</td>
<td></td>
</tr>
</tbody>
</table>
Appendix F

XML File Specification
Version 3.0
This XML File Specification (Version 3.0) applies to **Q1 2017 decedents/caregivers and forward.**

Each file submission can include all months in the quarter for all hospices (per CCN).

A CAHPS Hospice Survey XML file is made up of 4 parts: 1) **Vendor Record**, 2) **Hospice (Provider) Record**, 3) **Decedent/Caregiver Administrative Record**, and 4) **Survey Results Record**.

There should be only one Vendor Record for each CAHPS Hospice Survey XML file. Each decedent within the CAHPS Hospice Survey XML file should have a Decedent/Caregiver Administrative Record; and if survey results are being submitted for the decedent, they should have a Survey Results Record.

Each field (except several conditional items – see Data Element Required field for more details) of the Vendor Record, Hospice Record, and Decedent/Caregiver Administrative Record 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 fields must have an entry. Survey Results Records are required if the final <survey-status> is “1 – Completed Survey,” “6 – Ineligible: Never Involved in Decedent Care” or “7 – Non-response: Break-off.”
<table>
<thead>
<tr>
<th>XML Element</th>
<th>Attributes</th>
<th>Description</th>
<th>Valid Values</th>
<th>Data Type</th>
<th>Max Field Size</th>
<th>Data Element Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>The following section defines the format of the Vendor Record.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><code>&lt;vendordata&gt;</code></td>
<td>None</td>
<td>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 <code>&lt;&gt;</code></td>
<td>N/A</td>
<td>NA</td>
<td>N/A</td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of vendordata</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><code>&lt;vendor-name&gt;</code></td>
<td>None</td>
<td>The name of the survey vendor.</td>
<td>Must be vendor's business name up to 100 alphanumeric characters.</td>
<td>Alphanumeric</td>
<td>100</td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of vendordata</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| `<file-submission-yr>` | None       | The year in which the file is submitted.              | YYYY
YY = (2017 or greater)
(cannot be 9999) | Numeric      | 4              | Yes                   |
| Sub-element of vendordata |          |                                                       |                                                                               |              |                 |                       |
| `<file-submission-month>` | None     | The month in which the file is submitted.             | MM
MM = (1 - 12)
(cannot be 00, 13 - 99) | Numeric      | 2              | Yes                   |
| Sub-element of vendordata |          |                                                       |                                                                               |              |                 |                       |
| `<file-submission-day>` | None       | The day in which the file is submitted.               | DD
DD = (1 - 31)
(cannot be 00, 32 - 99) | Numeric      | 2              | Yes                   |
<table>
<thead>
<tr>
<th>XML Element</th>
<th>Attributes</th>
<th>Description</th>
<th>Valid Values</th>
<th>Data Type</th>
<th>Max Field Size</th>
<th>Data Element Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;file-submission-number&gt;</td>
<td>None</td>
<td>Ordinal number of the submission for the day. The submission count re-starts with every new day of the file submission.</td>
<td>1 - 99</td>
<td>Numeric</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>&lt;hospicedata&gt;</td>
<td>None</td>
<td>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This hospicedata element should only occur once per file.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;reference-yr&gt;</td>
<td>None</td>
<td>The year for which decedent counts were collected. YYYY = (2017 or greater) (cannot be 9999)</td>
<td></td>
<td>Numeric</td>
<td>4</td>
<td>Yes</td>
</tr>
<tr>
<td>&lt;reference-month&gt;</td>
<td>None</td>
<td>The month for which decedents counts were collected. MM = (1 - 12) (cannot be 00, 13 - 99)</td>
<td></td>
<td>Numeric</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
<td>-------------</td>
<td>--------------</td>
<td>-----------</td>
<td>----------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>&lt;provider-name&gt;</td>
<td>None</td>
<td>The name of the hospice represented by the survey.</td>
<td>N/A</td>
<td>Alphanumeric Character</td>
<td>100</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This hospicedata element should only occur once for each hospicedata record in the file. There should be one hospicedata record for each month of the survey. Example: <code>&lt;provider-name&gt;Sample Hospice&lt;/provider-name&gt;</code></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;provider-id&gt;</td>
<td>None</td>
<td>The ID number (CCN) of the hospice represented by the survey.</td>
<td>Valid 6-digit CMS Certification Number (formerly known as Medicare Provider Number)</td>
<td>Alphanumeric Character</td>
<td>10</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This hospicedata element should only occur once for each hospicedata record in the file. There should be one hospicedata record for each month of the survey. Example: <code>&lt;provider-id&gt;123456&lt;/provider-id&gt;</code></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;npi&gt;</td>
<td>None</td>
<td>The National Provider Identifier (NPI) of the hospice represented by the survey.</td>
<td>Valid 10 digit National Provider Identifier M = Missing</td>
<td>Alphanumeric Character</td>
<td>10</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This hospicedata element should only occur once for each hospicedata record in the file. There should be one hospicedata record for each month of the survey. Example: <code>&lt;npi&gt;1234567890&lt;/npi&gt;</code></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| <survey-mode> | None       | The mode of survey administration. The survey mode must be the same for all three months within a quarter. | 1 - Mail Only
2 - Telephone Only
3 - Mixed Mode
8 - Not Applicable (no decedents in the sampled month) | Alphanumeric Character | 1               | Yes                   |
<p>|               |            | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This hospicedata element should only occur once for each hospicedata record in the file. There should be one hospicedata record for each month of the survey. Example: <code>&lt;survey-mode&gt;1&lt;/survey-mode&gt;</code> |</p>
<table>
<thead>
<tr>
<th>XML Element</th>
<th>Attributes</th>
<th>Description</th>
<th>Valid Values</th>
<th>Data Type</th>
<th>Max Field Size</th>
<th>Data Element Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;total-decedents&gt;</td>
<td></td>
<td>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This hospicedata element should occur three times, once for each month of data collection, for each provider in the file. Example: <code>&lt;total-decedents&gt;150&lt;/total-decedents&gt;</code></td>
<td>None</td>
<td>The total number of decedents in the hospice in the month including “no-publicity” decedents/caregivers.</td>
<td>M = Missing</td>
<td>Alphanumeric Character</td>
</tr>
<tr>
<td>&lt;live-discharges&gt;</td>
<td></td>
<td>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This hospicedata element should occur three times, once for each month of data collection, for each provider in the file. Example: <code>&lt;live-discharges&gt;5&lt;/live-discharges&gt;</code></td>
<td>None</td>
<td>The number of patients who were discharged alive during the month.</td>
<td>M = Missing</td>
<td>Alphanumeric Character</td>
</tr>
<tr>
<td>&lt;no-publicity&gt;</td>
<td></td>
<td>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This hospicedata element should occur three times, once for each month of data collection, for each provider in the file. Example: <code>&lt;no-publicity&gt;1&lt;/no-publicity&gt;</code></td>
<td>None</td>
<td>The number of “no publicity” decedents/caregivers during the month who initiated or voluntarily requested at admission that they not be revealed as a patient and/or whose caregiver requests that they not be surveyed, and were excluded from the file.</td>
<td>M = Missing</td>
<td>Alphanumeric Character</td>
</tr>
<tr>
<td>&lt;missing-dod&gt;</td>
<td></td>
<td>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This hospicedata element should occur three times, once for each month of data collection, for each provider in the file. Example: <code>&lt;missing-dod&gt;5&lt;/missing-dod&gt;</code></td>
<td>None</td>
<td>The number of decedents/caregivers not included in the sample frame for the month because any part (i.e., day, month, or year) of the decedent's date of death is missing.</td>
<td>N/A</td>
<td>Numeric</td>
</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
</tr>
<tr>
<td>--------------------------</td>
<td>------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------</td>
<td>-----------</td>
<td>-----------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td><code>&lt;ineligible-presample&gt;</code></td>
<td>None</td>
<td>The number of decedents/caregivers determined to be ineligible for the month prior to sampling, for any of the following reasons: 1. Decedent was under the age of 18 2. Decedent’s death was less than 48 hours following last admission to hospice care 3. Decedent has no caregiver of record 4. Decedent’s caregiver is a non-familial legal guardian 5. Decedent’s caregiver has an address outside the U.S. or U.S. Territories This count should NOT include cases that are ineligible because of missing date of death.</td>
<td>N/A</td>
<td>Numeric</td>
<td>10</td>
<td>Yes</td>
</tr>
<tr>
<td><code>&lt;available-sample&gt;</code></td>
<td>None</td>
<td>The total number of decedents from the CCN in the month, minus the number of “no publicity” decedents/caregivers (&lt;no-publicity&gt;), the number of decedents missing date of death (&lt;missing-dod&gt;) and the number of decedents/caregivers found ineligible prior to sampling (&lt;ineligible-p…</td>
<td>N/A</td>
<td>Numeric</td>
<td>10</td>
<td>Yes</td>
</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
</tr>
<tr>
<td>------------------------</td>
<td>------------</td>
<td>------------------------------------------------------------------------------</td>
<td>--------------</td>
<td>-----------</td>
<td>----------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td><code>&lt;sampled-cases&gt;</code></td>
<td>None</td>
<td>The total number of decedents/caregivers drawn into the sample for the month. For CCNs using census sampling, the “Sampled Cases” field should equal the “Available Sample” field (&lt;available-sample&gt;) because all cases available for sampling are drawn into the sample.</td>
<td>N/A</td>
<td>Numeric</td>
<td>10</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Example: <code>&lt;sampled-cases&gt;139&lt;/sampled-cases&gt;</code></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><code>&lt;sample-size&gt;</code></td>
<td>None</td>
<td>Each element must have a closing tag that is the same as the opening tag but with a forward slash. This hospicedata element should occur three times, once for each month of data collection, for each provider in the file.</td>
<td>N/A</td>
<td>Numeric</td>
<td>10</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Example: <code>&lt;sample-size&gt;136&lt;/sample-size&gt;</code></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><code>&lt;ineligible-postsample&gt;</code></td>
<td>None</td>
<td>The number of eligible decedents/caregivers drawn into the sample for the month, not including ineligible pre-sample (&lt;ineligible-presample&gt;) or ineligible post-sample (&lt;ineligible-postsample&gt;) cases.</td>
<td>N/A</td>
<td>Numeric</td>
<td>10</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Example: <code>&lt;ineligible-postsample&gt;3&lt;/ineligible-postsample&gt;</code></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
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</tr>
<tr>
<td><code>&lt;sample-type&gt;</code></td>
<td>None</td>
<td>The type of sampling used for the month.</td>
<td>1 - Simple Random Sample</td>
<td>Numeric</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of hospicedata</td>
<td>None</td>
<td></td>
<td>2 - Census Sample</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>8 - Not applicable (no decedents in the sampled month)</td>
<td></td>
<td></td>
<td></td>
</tr>
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<td></td>
<td>Example:</td>
<td></td>
<td><code>&lt;sample-type&gt;1&lt;/sample-type&gt;</code></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><code>&lt;number-offices&gt;</code></td>
<td>None</td>
<td>The total number of hospice offices operating within this CCN. These are separate administrative or practice offices for the CCN, not to be confused with individual facilities or settings in which hospice care is provided.</td>
<td>N/A</td>
<td>Numeric</td>
<td>10</td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of hospicedata</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Example:</td>
<td></td>
<td><code>&lt;number-offices&gt;3&lt;/number-offices&gt;</code></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><code>&lt;hospicedata&gt;</code></td>
<td>None</td>
<td>Note: This closing element for the hospice record is required in the XML document, however, it contains no data. This hospicedata element should only occur once for each hospicedata record in the file. There should be one hospicedata record for each month of the survey.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Closing tag for hospicedata</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
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<td>-----------------------</td>
</tr>
<tr>
<td>The following section defines the format of the Decedent/Caregiver Administrative Record.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;decedent-level-data&gt;</td>
<td></td>
<td>This is the opening element of the decedent/caregiver level data record. <strong>Note:</strong> The &lt;decedent-level-data&gt; section includes the opening and closing &lt;decedent-level-data&gt; tags and all the tags between these two tags. The &lt;decedent-level-data&gt; section is required in the XML file, if at least one decedent/caregiver is being submitted. If the &lt;sample-size&gt; is 0, and no decedent/caregiver data is being submitted, the &lt;decedent-level-data&gt; section should not be included in the XML file. This decedent/caregiver level data element should only occur once per decedent/caregiver.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;provider-id&gt;</td>
<td>None</td>
<td>The ID number (CCN) of the hospice represented by the survey.</td>
<td>Valid 6-digit CMS Certification Number (formerly known as Medicare Provider Number)</td>
<td>Alphanumeric Character</td>
<td>10</td>
<td>Yes</td>
</tr>
<tr>
<td>&lt;decedent-id&gt;</td>
<td>None</td>
<td>The unique de-identified decedent/caregiver ID assigned by the survey vendor to uniquely identify the survey.</td>
<td>N/A</td>
<td>Alphanumeric Character</td>
<td>16</td>
<td>Yes</td>
</tr>
<tr>
<td>&lt;birth-yr&gt;</td>
<td>None</td>
<td>The year the decedent was born as provided by the hospice.</td>
<td>YYYY (cannot be 9999) Use 8888 only if unable to obtain information by the data submission due date.</td>
<td>Numeric</td>
<td>4</td>
<td>Yes</td>
</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
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<td>------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
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<td>-----------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>&lt;birth-month&gt;</td>
<td>None</td>
<td>The month the decedent was born as provided by the hospice.</td>
<td>MM</td>
<td>Numeric</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>MM = (1 - 12)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(cannot be 00, 13 - 99)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Use 88 only if unable to obtain information by the data submission due date.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sub-element of decedentleveldata</td>
<td>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.</td>
<td>Example: <code>&lt;birth-month&gt;1&lt;/birth-month&gt;</code></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;birth-day&gt;</td>
<td>None</td>
<td>The day the decedent was born as provided by the hospice.</td>
<td>DD</td>
<td>Numeric</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>DD = (1 - 31)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(cannot be 00, 32 - 99)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Use 88 only if unable to obtain information by the data submission due date.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Sub-element of decedentleveldata</td>
<td>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.</td>
<td>Example: <code>&lt;birth-day&gt;1&lt;/birth-day&gt;</code></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;death-yr&gt;</td>
<td>None</td>
<td>The year the decedent died as provided by the hospice.</td>
<td>YYYY</td>
<td>Numeric</td>
<td>4</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>YYYY = (2017 or greater)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(cannot be 9999)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sub-element of decedentleveldata</td>
<td>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.</td>
<td>Example: <code>&lt;death-yr&gt;2017&lt;/death-yr&gt;</code></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;death-month&gt;</td>
<td>None</td>
<td>The month the decedent died as provided by the hospice.</td>
<td>MM</td>
<td>Numeric</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>MM = (1 - 12)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(cannot be 00, 13 - 99)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sub-element of decedentleveldata</td>
<td>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.</td>
<td>Example: <code>&lt;death-month&gt;1&lt;/death-month&gt;</code></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
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<td>------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
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<td>-----------------------</td>
</tr>
<tr>
<td><code>&lt;death-day&gt;</code></td>
<td></td>
<td>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. <strong>Example: <code>&lt;death-day&gt;1&lt;/death-day&gt;</code></strong></td>
<td>The day the decedent died as provided by the hospice. DD DD = (1 - 31) (cannot be 00, 32 - 99)</td>
<td>Numeric</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td><code>&lt;admission-yr&gt;</code></td>
<td></td>
<td>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. <strong>Example: <code>&lt;admission-yr&gt;2016&lt;/admission-yr&gt;</code></strong></td>
<td>The year the decedent was admitted for final episode of hospice care as provided by the hospice. YYYY YYYY = (2009 or later) (cannot be 9999) Use 8888 only if unable to obtain information by the data submission due date.</td>
<td>Numeric</td>
<td>4</td>
<td>Yes</td>
</tr>
<tr>
<td><code>&lt;admission-month&gt;</code></td>
<td></td>
<td>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. <strong>Example: <code>&lt;admission-month&gt;1&lt;/admission-month&gt;</code></strong></td>
<td>The month the decedent was admitted for final episode of hospice care as provided by the hospice. MM MM = (1 - 12) (cannot be 00, 13 - 99) Use 88 only if unable to obtain information by the data submission due date.</td>
<td>Numeric</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
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</tr>
<tr>
<td>&lt;admission-day&gt;</td>
<td></td>
<td>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.</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>decedent-level-data</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Example: &lt;admission-day&gt;1&lt;/admission-day&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>The day the decedent was admitted for final episode of hospice care as provided by the hospice.</td>
<td>DD</td>
<td>Numeric</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DD = (1 - 31)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(cannot be 00, 32 - 99)</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Use 88 only if unable to obtain information by the data submission due date.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>&lt;sex&gt;</td>
<td></td>
<td>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.</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of</td>
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<td></td>
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<tr>
<td>decedent-level-data</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Example: &lt;sex&gt;1&lt;/sex&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>The decedent's sex as provided by the hospice.</td>
<td>1 - Male</td>
<td>Alphanumeric</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 - Female</td>
<td></td>
<td>Character</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>M - Missing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;decedent-hispanic&gt;</td>
<td></td>
<td>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.</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>decedent-level-data</td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Example: &lt;decedent-hispanic&gt;2&lt;/decedent-hispanic&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>The indication whether on not decedent was Hispanic as provided by the hospice.</td>
<td>1 - Hispanic</td>
<td>Alphanumeric</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 - Non-Hispanic</td>
<td></td>
<td>Character</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>M - Missing</td>
<td></td>
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<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
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<td>-----------------------</td>
</tr>
<tr>
<td><code>&lt;decedent-race&gt;</code></td>
<td>Sub-element of decedentleveldata</td>
<td>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: <code>&lt;decedent-race&gt;1&lt;/decedent-race&gt;</code></td>
<td>The decedent's race as provided by the hospice.</td>
<td>1 - White</td>
<td>Alphanumeric Character</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 - Black or African American</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 - Asian</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>4 - Native Hawaiian or Pacific Islander</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5 - American Indian or Alaska Native</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>6 - More than one race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>7 - Other</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>M - Missing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><code>&lt;caregiver-relationship&gt;</code></td>
<td>Sub-element of decedentleveldata</td>
<td>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: <code>&lt;caregiver-relationship&gt;1&lt;/caregiver-relationship&gt;</code></td>
<td>The caregiver relationship to the decedent as provided by the hospice.</td>
<td>1 - Spouse/partner</td>
<td>Alphanumeric Character</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 - Parent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 - Child</td>
<td></td>
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<td></td>
<td>4 - Other family member</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>5 - Friend</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>6 - Legal guardian</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td>7 - Other</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>M - Missing</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
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</tr>
</tbody>
</table>
| `<decedent-payer-primary>` | None       | The decedent's primary payer for healthcare services as 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>` | None       | The decedent's secondary payer for healthcare services as 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 |
<table>
<thead>
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<th>XML Element</th>
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<th>Valid Values</th>
<th>Data Type</th>
<th>Max Field Size</th>
<th>Data Element Required</th>
</tr>
</thead>
<tbody>
<tr>
<td><code>&lt;decedent-payer-other&gt;</code></td>
<td></td>
<td>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.</td>
<td>The decedent's other payer for healthcare services as provided by the hospice.</td>
<td>Alphanumeric Character</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td></td>
<td>1 - Medicare, 2 - Medicaid, 3 - Private, 4 - Uninsured/no payer, 5 - Program for All Inclusive Care for the Elderly (PACE), 6 - Other, M - Missing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><code>&lt;last-location&gt;</code></td>
<td></td>
<td>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.</td>
<td>The decedent's last location/setting of hospice care as provided by the hospice.</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td></td>
<td>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</td>
<td></td>
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<tr>
<td>XML Element</td>
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<td>Description</td>
<td>Valid Values</td>
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<tr>
<td>&lt;facility-name&gt;</td>
<td>None</td>
<td>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.</td>
<td>Facility name up to 100 alphanumeric characters. N/A = Missing/Not Applicable</td>
<td>Alphanumeric Character</td>
<td>100</td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of decedentleveldata</td>
<td></td>
<td>Example: <code>&lt;facility-name&gt;Facility&lt;/facility-name&gt;</code></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;decedent-primary-diagnosis&gt;</td>
<td>None</td>
<td>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.</td>
<td>ICD-10 code for the primary diagnosis of the decedent. (ICD-9 codes accepted for decedents prior to October 1, 2015) MMMMMMMMM=Missing</td>
<td>Alphanumeric Character</td>
<td>8</td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of decedentleveldata</td>
<td></td>
<td>Example: <code>&lt;decedent-primary-diagnosis&gt;G30.9&lt;/decedent-primary-diagnosis&gt;</code></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
| <diagnosis-code-format>     | None       | 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. | 1 - ICD-9  
2 - ICD-10  
M- Missing | Alphanumeric Character | 1                | Yes                   |
<p>| Sub-element of decedentleveldata |            | Example: <code>&lt;diagnosis-code-format&gt;1&lt;/diagnosis-code-format&gt;</code>                                                                                           |                                                                              |                 |                  |                       |</p>
<table>
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<th>Data Element Required</th>
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</thead>
<tbody>
<tr>
<td>&lt;survey-status&gt;</td>
<td>None</td>
<td>The disposition of the survey.</td>
<td>1 - Completed Survey&lt;br&gt;2 - Ineligible: Deceased&lt;br&gt;3 - Ineligible: Not in Eligible Population&lt;br&gt;4 - Ineligible: Language Barrier&lt;br&gt;5 - Ineligible: Mental/Physical Incapacity&lt;br&gt;6 - Ineligible: Never Involved in Decedent Care&lt;br&gt;7 - Non-response: Break-off&lt;br&gt;8 - Non-response: Refusal&lt;br&gt;9 - Non-response: Non-response after Maximum Attempts&lt;br&gt;10 - Non-response: Bad/No Address&lt;br&gt;11 - Non-response: Bad/No Telephone Number&lt;br&gt;12 - Non-response: Incomplete Caregiver Name&lt;br&gt;13 - Non-response: Incomplete Decedent Name&lt;br&gt;14 - Ineligible: Institutionalized&lt;br&gt;15 - Non-response: Hospice Disavowal&lt;br&gt;33 - No response collected (used only for interim data file submission)&lt;br&gt;M - Missing</td>
<td>Alphanumeric</td>
<td>Character</td>
<td>2</td>
</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
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<tr>
<td>&lt;survey-completion-mode&gt;</td>
<td>None</td>
<td>The survey mode used to complete a survey administered via the Mixed Mode.</td>
<td>1 - Mixed Mode-mail</td>
<td>Numeric</td>
<td>2</td>
<td>No, required only if survey mode is Mixed and Survey Status is “1 – Completed Survey,” “6 – Ineligible: Never Involved in Decedent Care” or “7 – Non-response: Break-off.”</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>2 - Mixed Mode-phone</td>
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<td></td>
<td>88 - Not Applicable</td>
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<tr>
<td>&lt;number-survey-attempts-telephone&gt;</td>
<td>None</td>
<td>The number of telephone contact attempts per survey with a survey mode of Telephone Only or Mixed Mode.</td>
<td>1 - First Telephone Attempt</td>
<td>Numeric</td>
<td>2</td>
<td>No, conditionally required only if the survey mode is Telephone Only Mode or Mixed Mode with survey completion mode: “2 – Mixed Mode-phone.”</td>
</tr>
<tr>
<td></td>
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<td>2 - Second Telephone Attempt</td>
<td></td>
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<td>3 - Third Telephone Attempt</td>
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<td>4 - Fourth Telephone Attempt</td>
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<td>5 - Fifth Telephone Attempt</td>
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<td>88 - Not Applicable</td>
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<td>XML Element</td>
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<td>Description</td>
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<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
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</tr>
<tr>
<td><code>&lt;number-survey-attempts-mail&gt;</code></td>
<td>None</td>
<td>The mail wave for which “Final Survey Status” code is determined per survey with a survey mode of Mail Only.</td>
<td>1 - First Wave Mailing</td>
<td>Numeric</td>
<td>2</td>
<td>No, conditionally required only if the survey mode is Mail Only.</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>2 - Second Wave Mailing</td>
<td></td>
<td></td>
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<td></td>
<td>88 - Not Applicable</td>
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</tr>
<tr>
<td><code>&lt;language&gt;</code></td>
<td>None</td>
<td>The survey language in which the survey was administered (English, Spanish, Chinese).</td>
<td>1 - English</td>
<td>Numeric</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>2 - Spanish</td>
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<td>3 - Chinese</td>
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<td>4 - Russian</td>
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<td>5 - Portuguese</td>
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<td>6 - Vietnamese</td>
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<td></td>
<td></td>
<td></td>
<td>88 - Not Applicable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><code>&lt;lag-time&gt;</code></td>
<td>None</td>
<td>The number of days between decedent date of death and the date that data collection activities ended for the decedent/caregiver.</td>
<td>0 - 365</td>
<td>Numeric</td>
<td>3</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>888 - Not Applicable (use only for interim data file submission)</td>
<td></td>
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</tbody>
</table>
### The following section defines the format of the Survey Results Record (caregiver response).

Note: Survey Results Records (caregiver response) are not required for a valid data submission; however, if survey results are included then all fields must have an entry. Survey Results Record (caregiver response) is required if the final `<survey-status>` is "1 - Completed survey," "6 - Ineligible: Never Involved in Decedent Care," or "7 - Non-response: Break-off."

<table>
<thead>
<tr>
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<th>Data Type</th>
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</thead>
<tbody>
<tr>
<td><code>&lt;supplemental-question-count&gt;</code></td>
<td>None</td>
<td>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. <strong>Example:</strong> <code>&lt;supplemental-question-count&gt;4&lt;/supplemental-question-count&gt;</code></td>
<td>0 - 15</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>No. Required only if “Final Survey Status” is “1 – Completed Survey,” “6 – Ineligible: Never Involved in Decedent Care” or “7 – Non-response: Break-off.”</td>
</tr>
<tr>
<td><code>&lt;caregiverresponse&gt;</code></td>
<td>None</td>
<td>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. <strong>Note:</strong> There will be one <code>&lt;caregiverresponse&gt;</code> section for each caregiver if survey results are being submitted for the caregiver. The <code>&lt;caregiverresponse&gt;</code> section includes the opening and closing <code>&lt;caregiverresponse&gt;</code> tags and all the tags between these two tags. This <code>&lt;caregiverresponse&gt;</code> 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 <code>&lt;caregiverresponse&gt;</code> section should not be submitted. This caregiver response element should only occur once per decedent.</td>
<td>N/A</td>
<td>N/A</td>
<td>NA</td>
<td>Yes</td>
</tr>
<tr>
<td><code>&lt;provider-id&gt;</code></td>
<td>None</td>
<td>The ID number (CCN) of the hospice represented by the survey. <strong>Example:</strong> <code>&lt;provider-id&gt;123456&lt;/provider-id&gt;</code></td>
<td>Valid 6-digit CMS Certification Number (formerly known as Medicare Provider Number).</td>
<td>Alphanumeric Character</td>
<td>10</td>
<td>Yes</td>
</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
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<tr>
<td>&lt;decedent-id&gt;</td>
<td></td>
<td>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 decedentleveldata record.</td>
<td></td>
<td>Alphanumeric Character</td>
<td>16</td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of caregiverresponse</td>
<td></td>
<td>Example: &lt;decedent-id&gt;12345&lt;/decedent-id&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>The unique de-identified decedent/caregiver ID assigned by the hospice to uniquely identify the survey.</td>
<td>N/A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;related&gt;</td>
<td></td>
<td>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.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Sub-element of caregiverresponse</td>
<td></td>
<td>Example: &lt;related&gt;1&lt;/related&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>Question 1: Related.</td>
<td>1 - My spouse or partner</td>
<td>Alphanumeric Character</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 - My parent</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>3 - My mother-in-law or father-in-law</td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td>4 - My grandparent</td>
<td></td>
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<td>5 - My aunt or uncle</td>
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<td>6 - My sister or brother</td>
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<td>7 - My child</td>
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<td>8 - My friend</td>
<td></td>
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<td></td>
<td></td>
<td>9 - Other</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td>M - Missing/Don't Know</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;location-home&gt;</td>
<td></td>
<td>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 location 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.</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Sub-element of caregiverresponse</td>
<td></td>
<td>Example: &lt;location-home&gt;1&lt;/location-home&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>Question 2: Location: at home.</td>
<td>1 - Home</td>
<td>Alphanumeric Character</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0 - Not home</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td>M - Missing/Don't Know</td>
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</tbody>
</table>
| `<location-assisted>`     | None       | Question 2: Location: assisted living facility.                              | 1 - Assisted living facility  
0 - Not assisted living facility  
M - Missing/Don't Know | Alphanumeric Character | 1 | Yes                  |
| Sub-element of            |            |                                                                               |                                                                               |                   |                 |                      |
| caregiverresponse         |            |                                                                               |                                                                               |                   |                 |                      |
| `<location-nursinghome>`  | None       | Question 2: Location: nursing home.                                          | 1 - Nursing home  
0 - Not nursing home  
M - Missing/Don't Know | Alphanumeric Character | 1 | Yes                  |
| Sub-element of            |            |                                                                               |                                                                               |                   |                 |                      |
| caregiverresponse         |            |                                                                               |                                                                               |                   |                 |                      |
| `<location-hospital>`     | None       | Question 2: Location: hospital.                                              | 1 - Hospital  
0 - Not hospital  
M - Missing/Don't Know | Alphanumeric Character | 1 | Yes                  |
<p>| Sub-element of            |            |                                                                               |                                                                               |                   |                 |                      |
| caregiverresponse         |            |                                                                               |                                                                               |                   |                 |                      |</p>
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</table>
| <location-hospice-facility> |            | 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 location 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> | 1 - Hospice facility/hospice house  
0 - Not hospice facility/hospice house  
M - Missing/Don't Know | Alphanumeric Character | 1 | Yes |
| <location-other>           |            | 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 location 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> | 1 - Other  
0 - Not other  
M - Missing/Don't Know | Alphanumeric Character | 1 | Yes |
| <oversee>                  |            | 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> | 1 - Never  
2 - Sometimes  
3 - Usually  
4 - Always  
M - Missing/Don't Know | Alphanumeric Character | 1 | Yes |
<table>
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<th>Description</th>
<th>Valid Values</th>
<th>Data Type</th>
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</table>
| `<needhelp>` | None       | Question 4: Need help. | 1 - Yes  
2 - No  
88 - Not Applicable  
M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| 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>` | | | | |
| `<gethelp>` | None       | Question 5: Get help. | 1 - Never  
2 - Sometimes  
3 - Usually  
4 - Always  
88 - Not Applicable  
M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| 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>` | | | | |
| `<h_informtime>` | None       | Question 6: Hospice inform. | 1 - Never  
2 - Sometimes  
3 - Usually  
4 - Always  
88 - Not Applicable  
M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
<p>| 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. <strong>Example:</strong> <code>&lt;h_informtime&gt;4&lt;/h_informtime&gt;</code> | | | | |</p>
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<tr>
<td>&lt;helpasan&gt;</td>
<td>None</td>
<td>Question 7: Help as soon as need.</td>
<td>1 - Never&lt;br&gt;2 - Sometimes&lt;br&gt;3 - Usually&lt;br&gt;4 - Always&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<td>&lt;h_explain&gt;</td>
<td>None</td>
<td>Question 8: Hospice explain.</td>
<td>1 - Never&lt;br&gt;2 - Sometimes&lt;br&gt;3 - Usually&lt;br&gt;4 - Always&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
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<tr>
<td>&lt;h_inform&gt;</td>
<td>None</td>
<td>Question 9: Hospice inform.</td>
<td>1 - Never&lt;br&gt;2 - Sometimes&lt;br&gt;3 - Usually&lt;br&gt;4 - Always&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
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</table>
| <h_confuse>       |            | 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>` | $\begin{align*} 
1 - & \text{Never} \\
2 - & \text{Sometimes} \\
3 - & \text{Usually} \\
4 - & \text{Always} \\
88 - & \text{Not Applicable} \\
M - & \text{Missing/Don't Know} 
\end{align*}$ | Alphanumeric Character | 2               | Yes                   |
| <h_dignity>       |            | 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>` | $\begin{align*} 
1 - & \text{Never} \\
2 - & \text{Sometimes} \\
3 - & \text{Usually} \\
4 - & \text{Always} \\
88 - & \text{Not Applicable} \\
M - & \text{Missing/Don't Know} 
\end{align*}$ | Alphanumeric Character | 2               | Yes                   |
| <h_cared>         |            | 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>` | $\begin{align*} 
1 - & \text{Never} \\
2 - & \text{Sometimes} \\
3 - & \text{Usually} \\
4 - & \text{Always} \\
88 - & \text{Not Applicable} \\
M - & \text{Missing/Don't Know} 
\end{align*}$ | Alphanumeric Character | 2               | Yes                   |
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<th>Description</th>
<th>Valid Values</th>
<th>Data Type</th>
<th>Max Field Size</th>
<th>Data Element Required</th>
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</thead>
</table>
| <h_talk>            | None       | 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. | 1 - Yes  
2 - No  
88 - Not Applicable  
M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
|                     |            | **Example:** `<h_talk>1</h_talk>`                 |                                        |                    |                 |                       |
| <h_talklisten>      | None       | 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. | 1 - Never  
2 - Sometimes  
3 - Usually  
4 - Always  
88 - Not Applicable  
M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
|                     |            | **Example:** `<h_talklisten>4</h_talklisten>`    |                                        |                    |                 |                       |
| <pain>              | None       | 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. | 1 - Yes  
2 - No  
88 - Not Applicable  
M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
<p>|                     |            | <strong>Example:</strong> <code>&lt;pain&gt;1&lt;/pain&gt;</code>                    |                                        |                    |                 |                       |</p>
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<tr>
<th>XML Element</th>
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<th>Description</th>
<th>Valid Values</th>
<th>Data Type</th>
<th>Max Field Size</th>
<th>Data Element Required</th>
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</thead>
</table>
| <painhlp>            |            | 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
2 - Yes, somewhat
3 - No
88 - Not Applicable
M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| <painrx>             |            | 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
2 - No
88 - Not Applicable
M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| <painrxside>         |            | 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
2 - Yes, somewhat
3 - No
88 - Not Applicable
M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| <painrxwatch>        |            | 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
2 - Yes, somewhat
3 - No
88 - Not Applicable
M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
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<th>Data Type</th>
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<tr>
<td>&lt;painrxtrain&gt;</td>
<td>None</td>
<td>Question 20: Pain medicine train.</td>
<td>1 - Yes, definitely&lt;br&gt;2 - Yes, somewhat&lt;br&gt;3 - No&lt;br&gt;4 - I did not need to give pain medicine to my family member&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<tr>
<td>&lt;breath&gt;</td>
<td>None</td>
<td>Question 21: Breath.</td>
<td>1 - Yes&lt;br&gt;2 - No&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<tr>
<td>&lt;breathhlp&gt;</td>
<td>None</td>
<td>Question 22: Breath help.</td>
<td>1 - Never&lt;br&gt;2 - Sometimes&lt;br&gt;3 - Usually&lt;br&gt;4 - Always&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<tr>
<td>&lt;breathtrain&gt;</td>
<td>None</td>
<td>Question 23: Breath train.</td>
<td>1 - Yes, definitely 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</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of caregiverresponse</td>
<td>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: &lt;breathtrain&gt;4&lt;/breathtrain&gt;</td>
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</tbody>
</table>

| constip> | None | Question 24: Constipation. | 1 - Yes 2 - No 88 - Not Applicable M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| 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> |

<p>| constiphelp&gt; | None | Question 25: Constipation help. | 1 - Never 2 - Sometimes 3 - Usually 4 - Always 88 - Not Applicable M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| 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: &lt;constiphelp&gt;4&lt;/constiphelp&gt; |</p>
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<th>Data Type</th>
<th>Max Field Size</th>
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<td>&lt;sad&gt;</td>
<td>None</td>
<td>Question 26: Sad.</td>
<td>1 - Yes, 2 - No, 88 - Not Applicable, M - Missing/Don’t Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<tr>
<td>&lt;sadethlp&gt;</td>
<td>None</td>
<td>Question 27: Sad get help.</td>
<td>1 - Never, 2 - Sometimes, 3 - Usually, 4 - Always, 88 - Not Applicable, M - Missing/Don’t Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<td>Sub-element of caregiverresponse</td>
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<tr>
<td>&lt;restless&gt;</td>
<td>None</td>
<td>Question 28: Restless.</td>
<td>1 - Yes, 2 - No, 88 - Not Applicable, M - Missing/Don’t Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<tr>
<td>&lt;restlesstrain&gt;</td>
<td>None</td>
<td>Question 29: Restless train.</td>
<td>1 - Yes, definitely, 2 - Yes, somewhat, 3 - No, 88 - Not Applicable, M - Missing/Don’t Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<tr>
<td>&lt;movetrain&gt;</td>
<td>None</td>
<td>Question 30: Move train.</td>
<td>1 - Yes, definitely&lt;br&gt;2 - Yes, somewhat&lt;br&gt;3 - No&lt;br&gt;4 - I did not need to move my family member&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<tr>
<td>Sub-element of caregiverresponse</td>
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<td>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: <code>&lt;movetrain&gt;4&lt;/movetrain&gt;</code></td>
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<tr>
<td>&lt;expectinfo&gt;</td>
<td>None</td>
<td>Question 31: Expect info.</td>
<td>1 - Yes, definitely&lt;br&gt;2 - Yes, somewhat&lt;br&gt;3 - No&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<tr>
<td>Sub-element of caregiverresponse</td>
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<td>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: <code>&lt;expectinfo&gt;1&lt;/expectinfo&gt;</code></td>
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<tr>
<td>&lt;receivednh&gt;</td>
<td>None</td>
<td>Question 32: Received nursing home.</td>
<td>1 - Yes&lt;br&gt;2 - No&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
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<td>Yes</td>
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<tr>
<td>Sub-element of caregiverresponse</td>
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<td>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: <code>&lt;receivednh&gt;1&lt;/receivednh&gt;</code></td>
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<tr>
<td>&lt;cooperatehnh&gt;</td>
<td>None</td>
<td>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. <strong>Example: &lt;cooperatehnh&gt;4&lt;/cooperatehnh&gt;</strong></td>
<td>1 - Never&lt;br&gt;2 - Sometimes&lt;br&gt;3 - Usually&lt;br&gt;4 - Always&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<tr>
<td>&lt;differhnh&gt;</td>
<td>None</td>
<td>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. <strong>Example: &lt;differhnh&gt;4&lt;/differhnh&gt;</strong></td>
<td>1 - Never&lt;br&gt;2 - Sometimes&lt;br&gt;3 - Usually&lt;br&gt;4 - Always&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<td>&lt;h_clisten&gt;</td>
<td>None</td>
<td>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. <strong>Example: &lt;h_clisten&gt;4&lt;/h_clisten&gt;</strong></td>
<td>1 - Never&lt;br&gt;2 - Sometimes&lt;br&gt;3 - Usually&lt;br&gt;4 - Always&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
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<td>XML Element</td>
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<tr>
<td>&lt;beliefrespect&gt;</td>
<td></td>
<td>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.</td>
<td>1 - Too little&lt;br&gt;2 - Right amount&lt;br&gt;3 - Too much&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
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<tr>
<td></td>
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<td><strong>Example:</strong> <code>&lt;beliefrespect&gt;1&lt;/beliefrespect&gt;</code></td>
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<td>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.</td>
<td>1 - Too little&lt;br&gt;2 - Right amount&lt;br&gt;3 - Too much&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
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<td><strong>Example:</strong> <code>&lt;emotion&gt;1&lt;/emotion&gt;</code></td>
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<td>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.</td>
<td>1 - Too little&lt;br&gt;2 - Right amount&lt;br&gt;3 - Too much&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
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<td>Yes</td>
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<td><strong>Example:</strong> <code>&lt;emotionafter&gt;1&lt;/emotionafter&gt;</code></td>
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<td><code>&lt;ratehospice&gt;</code></td>
<td></td>
<td>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. <strong>Example:</strong> <code>&lt;ratehospice&gt;8&lt;/ratehospice&gt;</code></td>
<td>0 - Worst hospice care possible&lt;br&gt;1&lt;br&gt;2&lt;br&gt;3&lt;br&gt;4&lt;br&gt;5&lt;br&gt;6&lt;br&gt;7&lt;br&gt;8&lt;br&gt;9&lt;br&gt;10 - Best hospice care possible&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td><code>&lt;h_recommend&gt;</code></td>
<td></td>
<td>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. <strong>Example:</strong> <code>&lt;h_recommend&gt;4&lt;/h_recommend&gt;</code></td>
<td>1 - Definitely no&lt;br&gt;2 - Probably no&lt;br&gt;3 - Probably yes&lt;br&gt;4 - Definitely yes&lt;br&gt;88 - Not Applicable&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
</tr>
<tr>
<td>-------------</td>
<td>------------</td>
<td>-------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>-----------------------</td>
<td>-----------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>&lt;pEdu&gt;</td>
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<td></td>
<td>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.</td>
<td></td>
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<td>Yes</td>
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<td></td>
<td><strong>Example:</strong> <code>&lt;pEdu&gt;4&lt;/pEdu&gt;</code></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>None</td>
<td>Question 41: Decedent education.</td>
<td>1 - 8th grade or less</td>
<td>Alphanumeric Character</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 - Some high school but did not graduate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 - High school graduate or GED</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4 - Some college or 2-year degree</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5 - 4-year college graduate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>6 - More than 4-year college degree</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>7 - Don't Know</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>M - Missing/Don't Know</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| <pLatino>   |            |             | 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. |                       |                 | Yes                   |
|             |            | None        | Question 42: Decedent 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                                                          |                       |                 |                       |

Note: 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.
<table>
<thead>
<tr>
<th>XML Element</th>
<th>Attributes</th>
<th>Description</th>
<th>Valid Values</th>
<th>Data Type</th>
<th>Max Field Size</th>
<th>Data Element Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;race-white&gt;</td>
<td>None</td>
<td>Question 43: Race, White.</td>
<td>1 - White</td>
<td>Alphanumeric Character</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0 - Not White</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>M - Missing/Don't Know</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;race-african-amer&gt;</td>
<td>None</td>
<td>Question 43: Race, African-American.</td>
<td>1 - Black or African-American</td>
<td>Alphanumeric Character</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0 - Not Black or African-American</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>M - Missing/Don't Know</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;race-asian&gt;</td>
<td>None</td>
<td>Question 43: Race, Asian.</td>
<td>1 - Asian</td>
<td>Alphanumeric Character</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0 - Not Asian</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>M - Missing/Don't Know</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>XML Element</td>
<td>Attributes</td>
<td>Description</td>
<td>Valid Values</td>
<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
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<td>-----------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>&lt;race-hi-pacific-islander&gt;</td>
<td>None</td>
<td>Question 43: Race, Pacific Islander.</td>
<td>1 - Native Hawaiian or other Pacific Islander&lt;br&gt;0 - Not Native Hawaiian or other Pacific Islander&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>caregiverresponse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;race-amer-indian-ak&gt;</td>
<td>None</td>
<td>Question 43: Race, American Indian/Alaska Native.</td>
<td>1 - American Indian or Alaska native&lt;br&gt;0 - Not American Indian or Alaska native&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td>Sub-element of</td>
<td></td>
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<td>Data Type</td>
<td>Max Field Size</td>
<td>Data Element Required</td>
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<td>-------------</td>
<td>--------------</td>
<td>-----------</td>
<td>-----------------</td>
<td>-----------------------</td>
</tr>
</tbody>
</table>
| <cAge>      | None       | Question 44: Caregiver, 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  
M - Missing/Don't Know | Alphanumeric Character | 1 | Yes |
| <cSex>      | None       | Question 45: Caregiver, sex. | 1 - Male  
2 - Female  
M - Missing/Don't Know | Alphanumeric Character | 1 | Yes |
| <cEdu>      | None       | Question 46: Caregiver, education. | 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  
M - Missing/Don't Know | Alphanumeric Character | 1 | Yes |
<table>
<thead>
<tr>
<th>XML Element</th>
<th>Attributes</th>
<th>Description</th>
<th>Valid Values</th>
<th>Data Type</th>
<th>Max Field Size</th>
<th>Data Element Required</th>
</tr>
</thead>
<tbody>
<tr>
<td><code>&lt;HomeLang&gt;</code></td>
<td>None</td>
<td>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. <strong>Example:</strong> <code>&lt;HomeLang&gt;4&lt;/HomeLang&gt;</code></td>
<td>1 - English&lt;br&gt;2 - Spanish&lt;br&gt;3 - Chinese&lt;br&gt;4 - Russian&lt;br&gt;5 - Portuguese&lt;br&gt;6 - Vietnamese&lt;br&gt;7 - Some other language&lt;br&gt;M - Missing/Don't Know</td>
<td>Alphanumeric Character</td>
<td>1</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Note:** This tag is required in the XML file, however, it contains no data. This caregiverresponse element should only occur once per caregiver.

| `/caregiverresponse` | None       | **Note:** This tag is required in the XML file, however, it contains no data. This caregiverresponse element should only occur once per caregiver. |                                                                                           |               |                 |                      |

| `/decedentleveldata` | None       | **Note:** This tag is required in the XML file, however, it contains no data. This decedentleveldata element should only occur once per decedent/caregiver. |                                                                                           |               |                 |                      |

| `/vendordata`        | None       | **Note:** This tag is required in the XML file, however, it contains no data. This vendordata element should only occur once per file. |                                                                                           |               |                 |                      |

Closing tag for<br>caregiverresponse  
Closing tag for<br>decedentleveldata  
Closing tag for<br>vendordata
CAHPS Hospice Survey
Sample XML File Layout Version 3.0

<?xml version="3.0"?>
<!-- CAHPS Hospice Survey XML File Specification Version 3.0 -->
<vendordata>
  <vendor-name>Vendor Business Name</vendor-name>
  <file-submission-yr>2017</file-submission-yr>
  <file-submission-month>1</file-submission-month>
  <file-submission-day>31</file-submission-day>
  <file-submission-number>1</file-submission-number>
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    <reference-month>1</reference-month>
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    <npi>1234567890</npi>
    <survey-mode>1</survey-mode>
    <total-decedents>150</total-decedents>
    <live-discharges>5</live-discharges>
    <no-publicity>1</no-publicity>
    <missing-dod>5</missing-dod>
    <ineligible-presample>5</ineligible-presample>
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    <sample-size>136</sample-size>
    <ineligible-postsample>3</ineligible-postsample>
    <sample-type>1</sample-type>
    <number-offices>3</number-offices>
  </hospicedata>
  - <decedentleveldata>
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    <decedent-id>12345</decedent-id>
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    <death-month>1</death-month>
    <death-day>1</death-day>
    <admission-yr>2016</admission-yr>
    <admission-month>1</admission-month>
    <admission-day>1</admission-day>
    <sex>1</sex>
  </decedentleveldata>
</vendordata>
<decedent-hispanic>2</decedent-hispanic>
<decedent-race>1</decedent-race>
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<decedent-payer-secondary>2</decedent-payer-secondary>
<decedent-payer-other>3</decedent-payer-other>
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<facility-name>Facility</facility-name>
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<number-survey-attempts-mail>1</number-survey-attempts-mail>
<language>1</language>
<lag-time>106</lag-time>
<supplemental-question-count>4</supplemental-question-count>
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    <decedent-id>12345</decedent-id>
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    <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_info>4</h_info>
CAHPS Hospice Survey
Sample XML File Layout Version 3.0

<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>
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<painrx>1</painrx>
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<breathtrain>4</breathtrain>
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<pEdu>4</pEdu>
<pLatino>1</pLatino>
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<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>
CAHPS Hospice Survey
Sample XML File Layout Version 3.0

<?xml version="1.0"?>
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  <cEdu>4</cEdu>
  <cHomeLang>4</cHomeLang>
</caregiverresponse>
</decedentleveldata>

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  <decedent-id>1234567</decedent-id>
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  <birth-month>1</birth-month>
  <birth-day>1</birth-day>
  <death-yr>2017</death-yr>
  <death-month>1</death-month>
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  <admission-yr>2016</admission-yr>
  <admission-month>2</admission-month>
  <admission-day>1</admission-day>
  <sex>1</sex>
  <decedent-hispanic>2</decedent-hispanic>
  <decedent-race>1</decedent-race>
  <caregiver-relationship>1</caregiver-relationship>
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  <decedent-payer-other>3</decedent-payer-other>
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  <facility-name>Facility</facility-name>
  <decedent-primary-diagnosis>310.11</decedent-primary-diagnosis>
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  <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>
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  <h_dignity>4</h_dignity>
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<pEdu>4</pEdu>
<pLatino>1</pLatino>
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<cSex>1</cSex>
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</decedentleveldata>

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  <npi>4567890123</npi>
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  <missing-dod>0</missing-dod>
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  <available-sample>133</available-sample>
  <sampled-cases>133</sampled-cases>
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    <death-day>1</death-day>
    <admission-yr>2016</admission-yr>
    <admission-month>1</admission-month>
    <admission-day>1</admission-day>
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    <decedent-race>1</decedent-race>
    <caregiver-relationship>1</caregiver-relationship>
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    <decedent-payer-secondary>2</decedent-payer-secondary>
    <decedent-payer-other>3</decedent-payer-other>
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CAHPS Hospice Survey
Sample XML File Layout Version 3.0

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Appendix G

Interviewing Guidelines for Telephone Surveys
CAHPS Hospice Survey

Interviewing Guidelines for Telephone Surveys

Overview
These guidelines address expectations for interviewers conducting the CAHPS 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 caregivers and you are the person who assures the caregivers that their participation is important.

Due to the nature of this survey, you may encounter caregivers who express grief or other emotions; therefore, it will be necessary for you to familiarize yourself with your organization’s 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 caregivers are answering the same question. Questions that are re-worded can bias the caregiver’s response and the overall survey results.
- not attempt to increase the likelihood of the caregiver providing one answer over another answer
- read all transitional statements
- never skip over a question because you think the caregiver has answered it already
- speak in a courteous tone
- maintain a professional and neutral relationship with the caregiver at all times
- not provide personal information or opinions about the survey
- listen carefully to any caregiver questions and offer concise responses. You may not provide extra information or lengthy explanations.
- tell the caregiver that there are no more questions and thank the caregiver for his or her time at the end of the survey
- not administer the CAHPS Hospice Survey to any caregiver whom you know personally

Introduction and Refusal Avoidance
For optimal response rates, it is important that telephone interviewers attempt to avoid telephone refusals from the caregiver. The introduction and initial moments of the interview are critical to gaining cooperation from the caregiver.
Interviewers must:
- read the telephone script introductions verbatim, unless the caregiver interrupts to ask a question or voices a concern
- speak clearly and politely to establish a rapport with the caregiver
- 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; if the caregiver refuses, the interviewer should politely end the call. The interviewer should not argue with or antagonize the caregiver.

**Answering Questions and Probing**

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

- Interviewer probes must be neutral and must not increase the likelihood of the caregiver providing one answer over another answer. Probes should stimulate the caregiver to give answers that meet the question’s 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 answers for the caregiver

**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 caregiver 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 caregiver 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 caregiver 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, and 20, and go to Question 21. Questions 18, 19, and 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 (English or Spanish) that appears on the electronic telephone interviewing system screen
Appendix H

Frequently Asked Questions
For Customer Support
CAHPS Hospice Survey

Frequently Asked Questions for Customer Support

Overview
This document provides customer support guidance on responding to frequently asked questions (FAQs) from caregivers answering the CAHPS 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 for more information on communicating with caregivers.

I. General Questions About the Survey

- Who is conducting this survey? Who is sponsoring this survey?
  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 (HHS) 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.
How can I verify this survey is legitimate?
You can contact [HOSPICE NAME] at [TELEPHONE NUMBER] for information about the survey.

NOTE: SURVEY VENDORS MUST 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 (CMS), a federal agency within the Department of Health and Human Services (HHS) 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. Your responses, linked to your name, will not be shared with the hospice without your permission.

How long will this take?
The survey takes about 11 minutes [OR SURVEY VENDOR SPECIFY].

NOTE: THE NUMBER OF MINUTES WILL DEPEND ON WHETHER THE 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 while 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 also 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 11 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 session.

[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 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 SPECIFIED TIME].

[IF “NO,” SET FUTURE DATE/TIME FOR CALL BACK.]

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 THE 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 caregivers have
returned a completed questionnaire.
Appendix I

Model Quality Assurance Plan
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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 a Quality Assurance Plan (QAP). The QAP is a comprehensive working document that 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 CAHPS Hospice Survey Project Team, the survey vendor will be provided with feedback that indicates whether the QAP has been accepted, conditionally accepted (pending completion of required follow-up 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 CAHPS Hospice Survey Project Team can determine a survey vendor’s adherence to survey administration guidelines and that rigorous quality checks and/or controls have been put in place. All survey materials (mail materials and screenshots of the telephone script) in English 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 or other organization, 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/back-up) 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 back-up systems, etc.

5. Describe the background and qualifications of all key personnel (e.g., Project Director, Project Manager, Sampling Manager, Programmer, Call Center/Mail Center Supervisor) involved in the CAHPS Hospice Survey, including a description of the capabilities of all subcontractors and any other organizations that are responsible for major functions of CAHPS Hospice Survey administration 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 Training session 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 and other organizations, if subcontractors and other organizations are used during the CAHPS Hospice Survey process. Survey vendors must 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(s) of survey administration, including a timeline of key survey administration events.**
   
   A. Mail Only – describe the process for updating addresses, producing mailing materials, including seeded mailings, and the process for mailing out the surveys (*Mail Only Survey Administration* chapter)
   
   B. Telephone Only – 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
      2. Describe how interviewers redirect the call when the respondent is personally known by the initial interviewer
   
   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 decedents/caregivers 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 is 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 Exception Requests for which the survey vendor has received approval and describe how these approved Exception Requests are incorporated into the CAHPS Hospice Survey processes.**
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 decedents/caregivers list received from the hospice)
   B. Describe the process for converting data into XML files and uploading the data to the CAHPS Hospice Survey Data Warehouse
   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 voicemail message that specifies the caller can leave a message about the survey
   D. Include the hours of live/voicemail operations for the customer support line and the time frame for returning voicemail messages
   E. Describe how survey vendor will provide customer support in all languages that the survey vendor administers the survey in
   F. Describe how the survey vendor will be ready to support calls from the deaf or the hearing impaired, including, but not limited to TTY, if applicable
   G. Describe how survey vendor will handle respondents who request or are in need of bereavement services
   H. Describe how customer support calls, including the resolution of the inquiry, are documented
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 decedents/caregivers 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 16 – 21, please 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’ or other organizations’ work to ensure high quality results. Include monitoring of telephone interviewers, if applicable, and checks of printed mailing materials, if applicable.

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 percent census sample)

18. Describe the quality control process to validate the accuracy of manual data entry and/or electronic scanning procedures, if applicable. Include the quality control process to verify the accuracy of the application of CAHPS Hospice Survey decision rules for processing mail surveys.

19. Describe the quality control checks of telephone (CATI) procedures, if applicable, to confirm that programming is accurate and in accordance with CAHPS Hospice Survey protocols, and that data integrity is maintained.

20. Describe the quality control process to validate the accuracy of data submission, including the review of the CAHPS Hospice Survey Data Submission Reports.

21. Describe the process for electronic back-up, including the quality control checks that are in place to ensure the back-up files are retrievable.

22. Describe the disaster recovery plan for conducting ongoing business operations in the event of a disaster.
Confidentiality, Privacy and Security Procedures

23. Provide a copy of the blank confidentiality agreements that are signed by staff and subcontractors or other organizations involved in any aspect of survey administration. In addition, describe the process that all staff and subcontractors follow in reviewing and signing confidentiality agreements, including the timeframe for re-signing.

24. 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

25. 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

26. 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 J

Exception Request Form
CAHPS Hospice Survey

Exception Request Form

To complete and submit the Exception Request Form online, visit the CAHPS Hospice Survey Web site at [www.hospecahpsurvey.org](http://www.hospecahpsurvey.org). Survey vendors must submit an Exception Request Form on behalf of their client hospice(s). 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

<table>
<thead>
<tr>
<th>Submission Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Survey Vendor Submitting the Exception Request: *</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>First Name, Last Name: *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title: *</td>
</tr>
<tr>
<td>Mailing Address: *</td>
</tr>
<tr>
<td>Mailing Address 2:</td>
</tr>
<tr>
<td>City: *</td>
</tr>
<tr>
<td>(Area Code) Telephone Number: *</td>
</tr>
<tr>
<td>Contact Email: *</td>
</tr>
</tbody>
</table>

III. Exception Request - Please complete items 1, 2, and 3 below for each requested exception.

1. Exception Request for (please select one): *
   1a. ○ New Exception
   1b. Exception (specify): *

2. List of hospices applicable to this Exception Request
   2a. Total number of Affected Hospices: *
   2b. Add the information for the affected hospices by populating the following 2 fields.
      Name of Hospice: * | CCN: * |
      [Add Above Affected Hospice Information]

<table>
<thead>
<tr>
<th>Number Affected</th>
<th>Hospice Name</th>
<th>CCN</th>
</tr>
</thead>
</table>
3. Description of Exception Request

3a. Purpose of proposed Exception Requested (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: *

36 + 5 = ?
Captcha

Submit

The Exception Request Form must be completed and submitted online via the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org).
Appendix K

Discrepancy Report Form
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CAHPS Hospice Survey

Discrepancy Report Form

To complete and submit the Discrepancy Report Form online, visit the CAHPS Hospice Survey Web site at www.hospicecahpssurvey.org. Survey vendors must submit a Discrepancy Report Form on behalf of their client hospice(s) immediately upon discovering any discrepancies in following CAHPS Hospice Survey protocols. 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

#### 1. Survey Vendor Organization Information

<table>
<thead>
<tr>
<th>Date Submitted:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indicate whether this report is an Initial Discrepancy Report or an Updated Discrepancy Report. *</td>
</tr>
<tr>
<td>○ Initial Report</td>
</tr>
<tr>
<td>Organization Name: *</td>
</tr>
</tbody>
</table>

#### 2. Date Discrepancy Was Discovered

| Date: * |

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

<table>
<thead>
<tr>
<th>First Name, Last Name: *</th>
<th>Title: *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mailing Address: *</td>
<td></td>
</tr>
<tr>
<td>Mailing Address 2:</td>
<td></td>
</tr>
<tr>
<td>City: *</td>
<td>State: *</td>
</tr>
<tr>
<td>(Area Code) Telephone Number: *</td>
<td>(Area Code) Fax Number:</td>
</tr>
<tr>
<td>Email Address: *</td>
<td></td>
</tr>
</tbody>
</table>
II. Discrepancy Information

Please complete items 1 through 4 below in detail.

1. Description of Discrepancy: *

2. Description of How the Discrepancy was Identified: *

3. Description of the Corrective Action to Fix the Discrepancy, Including Estimated Time for Implementation: *

4. Additional Information that would be Helpful that has not been Included Above: *

III. List of Hospice(s) Applicable to this Discrepancy

A hospice may be added more than once if there are multiple time frames for the hospice. It is important that the effects of the Discrepancy Report are quantified; however, "unknown" will be accepted as a valid response.

Name of Hospice: *

CCN: *

Hospice Contact Person: *

Hospice Contact Email: *

Eligible Decedents/Caregivers Affected: * Average Eligible Decedents/Caregivers per Month: *

Sampled Decedents/Caregivers Affected: * Average Number of Surveys Administered per Month: *

Timeframe - Begin Date: * Timeframe - End Date: *

Add Above Affected Hospice Information

<table>
<thead>
<tr>
<th>Hospice Name</th>
<th>CCN</th>
<th>Hospice Contact Name</th>
<th>Hospice Contact Email</th>
<th>Eligible Decedents/Caregivers</th>
<th>Avg. Eligible Decedents/Caregivers per Month</th>
<th>Sampled Decedents/Caregivers</th>
<th>Avg. Surveys per Month</th>
<th>Begin Date</th>
<th>End Date</th>
</tr>
</thead>
</table>

36 + 5 = ?

Captcha

Submit

The Discrepancy Report Form must be completed and submitted online via the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org).
Appendix L

Participation Exemption for Size Form
CAHPS Hospice Survey

Participation Exemption for Size Form

To complete and submit the Participation Exemption for Size Form online, visit the CAHPS Hospice Survey Web site at [www.hospicecahpssurvey.org](http://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

<table>
<thead>
<tr>
<th>CCN Number:*</th>
<th>Submission Date:</th>
<th>Name of Hospice:*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>[Auto Populated]</td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>2a. First Name:*</th>
<th>2b. Middle Initial:</th>
<th>2c. Last Name:*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2d. Title:*</th>
<th>2e. Mailing Address 1:*</th>
<th>2f. Mailing Address 2:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2g. City:*</th>
<th>2h. State:*</th>
<th>2i. Zip Code:*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2j. Telephone:* (xxx-xxx-xxxx)</th>
<th>Ext:</th>
<th>2k. Fax Number:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2l. Email Address:*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

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, 2016 and December 31, 2016 (CY 2016)*

2. Enter the total number of patients during CY 2016 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*
   b. Enter the number of decedents:
      i. who were under the age of 18*
      ii. who died within 48 hours of admission to hospice care*
      iii. for whom there is no caregiver of record*
      iv. for whom the caregiver is a non-familial legal guardian*
      v. for whom the caregiver has a foreign (non-U.S. or U.S. Territory) home address*
      vi. who initiate or voluntarily request at admission that the hospice 1) not reveal the patient’s identity; and/or 2) whose caregiver requests that they not be surveyed (“no publicity” decedents/caregivers)*

Print Participation Exemption for Size Form  Submit Form

The Participation Exemption for Size Form must be completed and submitted online via the CAHPS Hospice Survey Web site ([www.hospicecahpssurvey.org](http://www.hospicecahpssurvey.org)).
Appendix M

Examples of Additional Supplemental Questions for Survey Vendor Use
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 Equipment

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 S6

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

1 □ Yes  
2 □ No

---

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

1 □ Yes
2 □ No

**Personal Care Needs**

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 ➔ If No, please go to the End

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

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

---

2 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.
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. Below are translations of the Consent to Share Responses question in English, Spanish, Traditional Chinese, Simplified Chinese, Russian, and Portuguese.

**English**
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.

**Spanish**
El hospicio que le brindó el cuidado a su familiar tal vez quiera revisar sus respuestas de modo que ellos puedan decidir cómo abordar cualquier preocupación que usted tenga. No compartiremos sus respuestas a esta encuesta junto a su nombre a menos que usted dé su permiso para que esta información sea compartida con el hospicio.

¿Da usted su permiso de proporcionar sus respuestas a esta encuesta junto a su nombre al hospicio?

- [ ] Sí, yo doy mi permiso para que compartan mi nombre con mis respuestas a la encuesta con el hospicio.
- [ ] No, yo no doy mi permiso para que compartan mi nombre con mis respuestas a la encuesta con el hospicio.
向您的家屬提供護理的臨終關懷醫院可能想要瞭解您的答案，以便確定如何解決您的顧慮。但是除非得到您的同意，否則我們不會將您對此調查問卷的回答與您的姓名聯繫起來，並向臨終關懷醫院分享此資訊。

您是否同意將您對此調查問卷的回答與您的姓名聯繫起來，並向臨終關懷醫院提供此資訊？

☐ 是，我同意將我的姓名及我對此調查問卷的回答分享給臨終關懷醫院。
☐ 否，我不同意將我的姓名及我對此調查問卷的回答分享給臨終關懷醫院。

向您的家屬提供護理的臨終關懷醫院可能想要了解您的答案，以便确定如何解决您的顾虑。但是除非得到您的同意，否则我们不会将您对此调查问卷的回答与您的姓名联系起来，并向临终关怀医院分享此信息。

您是否同意将您对此调查问卷的回答与您的姓名联系起来，并向临终关怀医院提供此信息？

☐ 是，我同意将我的姓名及我对此调查问卷的回答分享给临终关怀医院。
☐ 否，我不同意将我的姓名及我对此调查问卷的回答分享给临终关怀医院。

Хоспис, который обеспечил уход за членом Вашей семьи, может захотеть изучить Ваши ответы, чтобы решить, как устранить отмеченные Вами недостатки. Мы не покажем представителям хосписа ответы на вопросы этой анкеты, связанной с Вашим именем, если Вы не дадите разрешение на передачу этой информации хоспису.

Даете ли Вы разрешение на передачу хоспису ответов на вопросы этой анкеты, связанной с Вашим именем?

☐ Да, я разрешаю сообщать мое имя хоспису и передавать ему мои ответы на вопросы этой анкеты.
☐ Нет, я не разрешаю сообщать мое имя хоспису и передавать ему мои ответы на вопросы этой анкеты.
Centers for Medicare & Medicaid Services
CAHPS Hospice Survey Quality Assurance Guidelines V3.0

Portuguese
O centro de cuidados paliativos que prestou cuidados ao seu familiar pode desejar rever as suas respostas para poder decidir como proceder relativamente às preocupações que apresenta. Não partilharemos as suas respostas a este inquérito associadas ao seu nome a não ser que dê permissão para que estas informações sejam partilhadas com o centro de cuidados paliativos.

Autoriza que as suas respostas a este inquérito sejam fornecidas associadas ao seu nome ao centro de cuidados paliativos?

☐ Sim, autorizo que o meu nome e as minhas respostas ao inquérito sejam partilhadas com o centro de cuidados paliativos.
☐ Não, não autorizo que o meu nome e as minhas respostas ao inquérito sejam partilhadas com o centro de cuidados paliativos.

Vietnamese
Hospice đã cung cấp dịch vụ chăm sóc cho thành viên gia đình bạn có thể muốn xem xét câu trả lời của bạn để họ có thể quyết định làm thế nào để giải quyết bất kỳ vấn đề nào mà bạn quan tâm. Chúng tôi sẽ không chia sẻ công khai những câu trả lời kèm với tên của bạn trừ khi bạn cho phép thông tin này sẽ được chia sẻ với Hospice.

Bạn có cho phép Chúng tôi cung cấp câu trả lời cho cuộc điều tra này liên quan đến tên của bạn vào nhà bạn hay hospice?

☐ Vâng, tôi cho phép chia sẻ tên và phản hồi kháo sát với Hospice.
☐ Không, tôi không cho phép chia sẻ tên và phản hồi kháo sát với Hospice.
Appendix N

Mail Survey Materials (English)
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#0938-1257
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

♦ 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?
   1 □ Never ➔ If Never, go to Question 41
   2 □ Sometimes
   3 □ Usually
   4 □ 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?
   1 □ Yes 
   2 □ 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?
   1 □ Never
   2 □ Sometimes
   3 □ Usually
   4 □ 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?
   1 □ Never
   2 □ Sometimes
   3 □ Usually
   4 □ 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?
   1 □ Never
   2 □ Sometimes
   3 □ Usually
   4 □ 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?
   1 □ Never
   2 □ Sometimes
   3 □ Usually
   4 □ 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?
   1 □ Never
   2 □ Sometimes
   3 □ Usually
   4 □ 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?

1. Yes
2. 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?

1. Yes, definitely
2. Yes, somewhat
3. 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?

1. Yes, definitely
2. Yes, somewhat
3. No
4. 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?

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

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?

1. Yes
2. 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?

1. Never
2. Sometimes
3. Usually
4. 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?

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

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 1  Definitely no
2 2  Probably no
3 3  Probably yes
4 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
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 □ Russian
   5 □ Portuguese
   6 □ Vietnamese
   7 □ 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#0938-1257
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.

♦ Answer all the questions by completely filling in the circle to the left of your answer.

  ● Yes
  ● No

♦ 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?

   0 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.

   0 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?
   - 0 Never
   - 2 Sometimes
   - 3 Usually
   - 4 Always

   If Never, go to Question 41

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?
   - 1 Yes
   - 0 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?
   - 1 Never
   - 2 Sometimes
   - 3 Usually
   - 4 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?
   - 1 Never
   - 2 Sometimes
   - 3 Usually
   - 4 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?
   - 1 Never
   - 2 Sometimes
   - 3 Usually
   - 4 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?
   - 1 Never
   - 2 Sometimes
   - 3 Usually
   - 4 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?

- 0 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?

- 0 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?

- 0 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?

- 0 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?

- 0 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?

- 0 Never
- 20 Sometimes
- 30 Usually
- 40 Always

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

- 0 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?

- 0 Yes, definitely
- 20 Yes, somewhat
- 30 No

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

- 0 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?

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
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27. How often did your family member get the help he or she needed from the hospice team for feelings of anxiety or sadness?

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3. Usually
4. Always

28. While your family member was in hospice care, did he or she ever become restless or agitated?

1. Yes
2. 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?

1. Yes, definitely
2. Yes, somewhat
3. 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?

1. Yes, definitely
2. Yes, somewhat
3. No
4. 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?

1. Yes, definitely
2. Yes, somewhat
3. 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?

1. Yes
2. 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?

1. Never
2. Sometimes
3. Usually
4. 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?

1. Never
2. Sometimes
3. Usually
4. Always
<table>
<thead>
<tr>
<th>YOUR OWN EXPERIENCE WITH HOSPICE</th>
<th>OVERALL RATING OF HOSPICE CARE</th>
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<td>35. While your family member was in hospice care, how often did the hospice team listen carefully to you?</td>
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<tr>
<td>0 Never</td>
<td>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?</td>
</tr>
<tr>
<td>2 Sometimes</td>
<td>0 0 Worst hospice care possible</td>
</tr>
<tr>
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</tr>
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</tr>
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<td>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?</td>
<td>3 3</td>
</tr>
<tr>
<td>0 Too little</td>
<td>4 4</td>
</tr>
<tr>
<td>2 Right amount</td>
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</tr>
<tr>
<td>3 Too much</td>
<td>6 6</td>
</tr>
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</tr>
<tr>
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<td>8 8</td>
</tr>
<tr>
<td>2 Right amount</td>
<td>9 9</td>
</tr>
<tr>
<td>3 Too much</td>
<td>10 10 Best hospice care possible</td>
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<td>38. In the weeks after your family member died, how much emotional support did you get from the hospice team?</td>
<td>40. Would you recommend this hospice to your friends and family?</td>
</tr>
<tr>
<td>0 Too little</td>
<td>0 Definitely no</td>
</tr>
<tr>
<td>2 Right amount</td>
<td>2 Probably no</td>
</tr>
<tr>
<td>3 Too much</td>
<td>3 Probably yes</td>
</tr>
<tr>
<td>4</td>
<td>4 Definitely yes</td>
</tr>
</tbody>
</table>
### 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

### ABOUT YOU

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

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?

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<tbody>
<tr>
<td>1</td>
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</tr>
<tr>
<td>2</td>
<td>Some high school but did not graduate</td>
</tr>
<tr>
<td>3</td>
<td>High school graduate or GED</td>
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<td>Some college or 2-year degree</td>
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<td>4-year college graduate</td>
</tr>
<tr>
<td>6</td>
<td>More than 4-year college degree</td>
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47. What language do you mainly speak at home?

<table>
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<th>Language</th>
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<tbody>
<tr>
<td>English</td>
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<td>3</td>
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<td>Russian</td>
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</tr>
<tr>
<td>Portuguese</td>
<td>5</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>6</td>
</tr>
<tr>
<td>Some other language (please print):</td>
<td>7</td>
</tr>
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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#0938-1257
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.

♦ Answer all the questions by completely filling in the circle to the left of your answer.
  
    ☐ Yes
    ☐ No

♦ 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?
   1️⃣ Never ➔ If Never, go to Question 41
   2️⃣ Sometimes
   3️⃣ Usually
   4️⃣ 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?
   1️⃣ Yes
   2️⃣ 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?
   1️⃣ Never
   2️⃣ Sometimes
   3️⃣ Usually
   4️⃣ 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?
   1️⃣ Never
   2️⃣ Sometimes
   3️⃣ Usually
   4️⃣ 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?
   1️⃣ Never
   2️⃣ Sometimes
   3️⃣ Usually
   4️⃣ 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?
   1️⃣ Never
   2️⃣ Sometimes
   3️⃣ Usually
   4️⃣ 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?
   1. Never
   2. Sometimes
   3. Usually
   4. 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
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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 medication?
    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 O Yes, definitely
   2 O Yes, somewhat
   3 O No

19. Did the hospice team give you the training you needed about what side effects to watch for from pain medicine?
   1 O Yes, definitely
   2 O Yes, somewhat
   3 O 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 O Yes, definitely
   2 O Yes, somewhat
   3 O No
   4 O 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 O Yes
   2 O 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 O Never
   2 O Sometimes
   3 O Usually
   4 O 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 O Yes, definitely
   2 O Yes, somewhat
   3 O No
   4 O 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 O Yes
   2 O 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 O Never
   2 O Sometimes
   3 O Usually
   4 O Always

26. While your family member was in hospice care, did he or she show any feelings of anxiety or sadness?
   1 O Yes
   2 O No ➔ If No, go to Question 28

Centers for Medicare & Medicaid Services
CAHPS Hospice Survey Quality Assurance Guidelines V3.0
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 O Never
2 O Sometimes
3 O Usually
4 O Always

28. While your family member was in hospice care, did he or she ever become restless or agitated?

1 O Yes
2 O No \(\Rightarrow\) 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?

1 O Yes, definitely
2 O Yes, somewhat
3 O 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?

1 O Yes, definitely
2 O Yes, somewhat
3 O No
4 O 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?

1 O Yes, definitely
2 O Yes, somewhat
3 O 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?

1 O Yes
2 O No \(\Rightarrow\) 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?

1 O Never
2 O Sometimes
3 O Usually
4 O 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?

1 O Never
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### YOUR OWN EXPERIENCE WITH HOSPICE

35. While your family member was in hospice care, how often did the hospice team listen carefully to you?

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</tbody>
</table>

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?

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Too little</td>
</tr>
<tr>
<td>2</td>
<td>Right amount</td>
</tr>
<tr>
<td>3</td>
<td>Too much</td>
</tr>
</tbody>
</table>

37. While your family member was in hospice care, how much emotional support did you get from the hospice team?

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<tr>
<th>Option</th>
<th>Description</th>
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<tbody>
<tr>
<td>1</td>
<td>Too little</td>
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<tr>
<td>2</td>
<td>Right amount</td>
</tr>
<tr>
<td>3</td>
<td>Too much</td>
</tr>
</tbody>
</table>

38. In the weeks after your family member died, how much emotional support did you get from the hospice team?

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<tr>
<th>Option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Too little</td>
</tr>
<tr>
<td>2</td>
<td>Right amount</td>
</tr>
<tr>
<td>3</td>
<td>Too much</td>
</tr>
</tbody>
</table>

### 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?

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<thead>
<tr>
<th>Option</th>
<th>Description</th>
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<tbody>
<tr>
<td>0</td>
<td>0 Worst hospice care possible</td>
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<td>1</td>
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<td>9</td>
<td>9</td>
</tr>
<tr>
<td>10</td>
<td>10 Best hospice care possible</td>
</tr>
</tbody>
</table>

40. Would you recommend this hospice to your friends and family?

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<thead>
<tr>
<th>Option</th>
<th>Description</th>
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<tbody>
<tr>
<td>1</td>
<td>Definitely no</td>
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<tr>
<td>2</td>
<td>Probably no</td>
</tr>
<tr>
<td>3</td>
<td>Probably yes</td>
</tr>
<tr>
<td>4</td>
<td>Definitely yes</td>
</tr>
</tbody>
</table>
ABOUT YOUR FAMILY MEMBER

41. What is the highest grade or level of school that your family member completed?

1 O 8th grade or less
2 O Some high school but did not graduate
3 O High school graduate or GED
4 O Some college or 2-year degree
5 O 4-year college graduate
6 O More than 4-year college degree
7 O Don’t know

42. Was your family member of Hispanic, Latino, or Spanish origin or descent?

1 O No, not Spanish/Hispanic/Latino
2 O Yes, Puerto Rican
3 O Yes, Mexican, Mexican American, Chicano/a
4 O Yes, Cuban
5 O Yes, Other Spanish/Hispanic/ Latino

43. What was your family member’s race? Please choose one or more.

1 O White
2 O Black or African American
3 O Asian
4 O Native Hawaiian or other Pacific Islander
5 O American Indian or Alaska Native

ABOUT YOU

44. What is your age?

1 O 18 to 24
2 O 25 to 34
3 O 35 to 44
4 O 45 to 54
5 O 55 to 64
6 O 65 to 74
7 O 75 to 84
8 O 85 or older

45. Are you male or female?

1 O Male
2 O 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. Russian
5. Portuguese
6. Vietnamese
7. 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 ]

[ 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 [ DECEDEENT 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 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]

[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 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]
OMB Paperwork Reduction Act Language

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. The following is the language that must be used:

English Version

“According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-1257. The time required to complete this information collection is estimated to average 11 minutes for questions 1 – 40, the “About Your Family Member” questions and the “About You” questions on the survey, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have any comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: Centers for Medicare & Medicaid Services, 7500 Security Boulevard, C1-25-05, Baltimore, MD 21244-1850.”
Appendix O

Mail Survey Materials (Spanish)
CAHPS® Encuesta de Hospicio

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, llame a [TOLL FREE NUMBER]. Todas las llamadas son gratis.

OMB#0938-1257
**INSTRUCCIONES PARA LA ENCUESTA**

- Por favor entregue 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 cuadrito para indicar su respuesta. Vea el siguiente ejemplo:
  
  - Si
  - No

- 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:

  - Si → *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?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Es mi esposo/a o pareja</td>
</tr>
<tr>
<td>2</td>
<td>Es mi padre/madre</td>
</tr>
<tr>
<td>3</td>
<td>Es mi suegro/a</td>
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<td>4</td>
<td>Es mi abuelo/a</td>
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<td>5</td>
<td>Es mi tío/a</td>
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<td>6</td>
<td>Es mi hermano/a</td>
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<td>7</td>
<td>Es mi hijo/a</td>
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<tr>
<td>8</td>
<td>Es un/a amigo/a</td>
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<tr>
<td>9</td>
<td>Otro (por favor imprima):</td>
</tr>
</tbody>
</table>

#### 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.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>En su casa</td>
</tr>
<tr>
<td>2</td>
<td>En un hogar de asistencia parcial</td>
</tr>
<tr>
<td>3</td>
<td>En una casa de ancianos y convalecencia</td>
</tr>
<tr>
<td>4</td>
<td>En un hospital</td>
</tr>
<tr>
<td>5</td>
<td>En un centro u hogar de hospicio</td>
</tr>
<tr>
<td>6</td>
<td>Otro (Por favor imprima):</td>
</tr>
</tbody>
</table>
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 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?

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<thead>
<tr>
<th></th>
<th>Nunca</th>
<th>A veces</th>
<th>La mayoría de las veces</th>
<th>Siempre</th>
</tr>
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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?

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<th></th>
<th>Nunca</th>
<th>A veces</th>
<th>La mayoría de las veces</th>
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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?

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<tr>
<th></th>
<th>Nunca</th>
<th>A veces</th>
<th>La mayoría de las veces</th>
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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?

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<thead>
<tr>
<th></th>
<th>Nunca</th>
<th>A veces</th>
<th>La mayoría de las veces</th>
<th>Siempre</th>
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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?

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<th></th>
<th>Nunca</th>
<th>A veces</th>
<th>La mayoría de las veces</th>
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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?

<table>
<thead>
<tr>
<th></th>
<th>Sí</th>
<th>No</th>
<th>Si contestó No, pase a la Pregunta 15</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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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?

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<th></th>
<th>Nunca</th>
<th>A veces</th>
<th>La mayoría de las veces</th>
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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

4 □ No tuve necesidad de dar medicamento para el dolor a mi familiar

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 oagitado?

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?

☐ Sí, definitivamente  
☐ Sí, más o menos  
☐ No

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?

☐ Sí  
☐ 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?

☐ Nunca  
☐ A veces  
☐ La mayoría de las veces  
☐ 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?

☐ Nunca  
☐ A veces  
☐ La mayoría de las veces  
☐ Siempre

35. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿con qué frecuencia el equipo del hospicio le escuchó a usted con atención?

☐ Nunca  
☐ A veces  
☐ La mayoría de las veces  
☐ 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?

☐ Demasiado poco  
☐ Justo el necesario  
☐ 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 □ 0 Los peores cuidados posibles de un hospicio

1 □ 1
2 □ 2
3 □ 3
4 □ 4
5 □ 5
6 □ 6
7 □ 7
8 □ 8
9 □ 9
10 □ 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
   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 84 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

47. ¿En qué idioma habla usted principalmente en casa?

1. ☐ Inglés
2. ☐ Español
3. ☐ Chino
4. ☐ Ruso
5. ☐ Portugués
6. ☐ Vietnamita
7. ☐ 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]

[RETURN ADDRESS OF SURVEY VENDOR]
CAHPS® Encuesta de Hospicio

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, llame a [TOLL FREE NUMBER]. Todas las llamadas son gratis.

OMB#0938-1257
CAHPS® Encuesta de Hospicio

INSTRUCCIONES PARA LA ENCUESTA

♦ Por favor entregue 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.

♦ Conteste todas las preguntas y llene completamente el círculo que aparece a la izquierda de la respuesta que usted seleccione.

0 Sí
0 No

♦ 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

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.

10 En su casa
20 En un hogar de asistencia parcial
30 En una casa de ancianos y convalecencia
40 En un hospital
50 En un centro u hogar de hospicio
60 Otro (Por favor imprima):

El PACIENTE DEL HOSPICIO

1. ¿Qué relación tiene con usted la persona cuyo nombre aparece en la carta de presentación de esta encuesta?

0 Es mi esposo/a o pareja
20 Es mi padre/madre
30 Es mi suegro/a
40 Es mi abuelo/a
50 Es mi tío/a
60 Es mi hermano/a
70 Es mi hijo/a
80 Es un/a amigo/a
90 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 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. Nunca

2. A veces

3. La mayoría de las veces

4. Siempre

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 0 Sí
2 0 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 0 Nunca
2 0 A veces
3 0 La mayoría de las veces
4 0 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 0 Sí, definitivamente
2 0 Sí, más o menos
3 0 No
4 0 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 0 Sí
2 0 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 0 Nunca
2 0 A veces
3 0 La mayoría de las veces
4 0 Siempre

26. Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento él/ella sintió ansiedad o tristeza?

1 0 Sí
2 0 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 0 Nunca
2 0 A veces
3 0 La mayoría de las veces
4 0 Siempre

28. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿en algún momento se puso su familiar inquieto o agitado?

1 0 Sí
2 0 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

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. 1
2. 2
3. 3
4. 4
5. 5
6. 6
7. 7
8. 8
9. 9
10. 10 Los mejores cuidados posibles de un hospicio
<table>
<thead>
<tr>
<th></th>
<th>¿Le recomendaría este hospicio a sus amigos y familiares?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Definitivamente no</td>
</tr>
<tr>
<td>2</td>
<td>Probablemente no</td>
</tr>
<tr>
<td>3</td>
<td>Probablemente sí</td>
</tr>
<tr>
<td>4</td>
<td>Definitivamente sí</td>
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<tr>
<td>40.</td>
<td>¿Cuál es el grado o nivel escolar más alto que ha completado su familiar?</td>
</tr>
<tr>
<td>1</td>
<td>8 años de escuela o menos</td>
</tr>
<tr>
<td>2</td>
<td>Estudios de escuela secundaria, pero sin graduarse</td>
</tr>
<tr>
<td>3</td>
<td>Graduado de escuela de secundaria, o diploma de la secundaria, o su equivalente (o GED)</td>
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<td>4</td>
<td>Algunos cursos universitarios o un título universitario de un programa de 2 años</td>
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<tr>
<td>5</td>
<td>Título universitario de 4 años</td>
</tr>
<tr>
<td>6</td>
<td>Título universitario de más de 4 años</td>
</tr>
<tr>
<td>7</td>
<td>No sé</td>
</tr>
</tbody>
</table>

| 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                 |

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<tr>
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<td>de 25 a 34 años</td>
</tr>
<tr>
<td>3</td>
<td>de 35 a 44 años</td>
</tr>
<tr>
<td>4</td>
<td>de 45 a 54 años</td>
</tr>
<tr>
<td>5</td>
<td>de 55 a 64 años</td>
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<tr>
<td>6</td>
<td>de 65 a 74 años</td>
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<tr>
<td>7</td>
<td>de 75 a 84 años</td>
</tr>
<tr>
<td>8</td>
<td>85 años o más</td>
</tr>
</tbody>
</table>

| 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

47. ¿En qué idioma habla usted principalmente en casa?

1. 0 Inglés
2. 0 Español
3. 0 Chino
4. 0 Ruso
5. 0 Portugués
6. 0 Vietnamita
7. 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]

[RETURN ADDRESS OF SURVEY VENDOR]
CAHPS® Encuesta de Hospicio

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, llame a [TOLL FREE NUMBER]. Todas las llamadas son gratis.

OMB#0938-1257
CAHPS® Encuesta de Hospicio

INSTRUCCIONES PARA LA ENCUESTA

♦ Por favor entregue 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.

♦ Conteste todas las preguntas y llene completamente el círculo que aparece a la izquierda de la respuesta que usted seleccione.

   O Sí
   ● No

♦ 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
   O 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 O Es mi esposo/a o pareja
   2 O Es mi padre/madre
   3 O Es mi suegro/a
   4 O Es mi abuelo/a
   5 O Es mi tío/a
   6 O Es mi hermano/a
   7 O Es mi hijo/a
   8 O Es un/a amigo/a
   9 O 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 O En su casa
   2 O En un hogar de asistencia parcial
   3 O En una casa de ancianos y convalecencia
   4 O En un hospital
   5 O En un centro u hogar de hospicio
   6 O 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 O Nunca ➔ Si contestó Nunca, pase a la Pregunta 41
   2 O A veces
   3 O La mayoría de las veces
   4 O 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 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 O Sí
   2 O 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 O Nunca
   2 O A veces
   3 O La mayoría de las veces
   4 O 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 O Nunca
   2 O A veces
   3 O La mayoría de las veces
   4 O 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 O Nunca
   2 O A veces
   3 O La mayoría de las veces
   4 O 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 O Nunca
   2 O A veces
   3 O La mayoría de las veces
   4 O 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 O Nunca  
2 O A veces  
3 O La mayoría de las veces  
4 O 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 O Nunca  
2 O A veces  
3 O La mayoría de las veces  
4 O 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 O Nunca  
2 O A veces  
3 O La mayoría de las veces  
4 O 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 O Nunca  
2 O A veces  
3 O La mayoría de las veces  
4 O 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 O Sí  
2 O 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 O Nunca  
2 O A veces  
3 O La mayoría de las veces  
4 O Siempre

15. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿tuvo él/ella algún tipo de dolor?

1 O Sí  
2 O No → Si contestó No, pase a la Pregunta 17

16. ¿Recibió su familiar toda la ayuda que necesitaba contra el dolor?

1 O Sí, definitivamente  
2 O Sí, más o menos  
3 O No

17. Mientras su familiar estaba bajo los cuidados del hospicio, ¿le dieron a él o a ella algún medicamento contra el dolor?

1 O Sí  
2 O 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 O Nunca  
2 O A veces  
3 O La mayoría de las veces  
4 O Siempre

26. Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento él/ella sintió ansiedad o tristeza?

1 O Sí  
2 O 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 O Nunca  
2 O A veces  
3 O La mayoría de las veces  
4 O Siempre

28. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿en algún momento se puso su familiar inquieto o agitado?

1 O Sí  
2 O 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 O Sí, definitivamente  
2 O Sí, más o menos  
3 O 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 O Sí, definitivamente  
2 O Sí, más o menos  
3 O No  
4 O 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 O Sí, definitivamente  
2 O Sí, más o menos  
3 O 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?

<table>
<thead>
<tr>
<th>Opción</th>
<th>Respuesta</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sí</td>
</tr>
<tr>
<td>2</td>
<td>No</td>
</tr>
</tbody>
</table>

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 acoplan bien para proporcionarle los cuidados a su familiar?

<table>
<thead>
<tr>
<th>Opción</th>
<th>Respuesta</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Nunca</td>
</tr>
<tr>
<td>2</td>
<td>A veces</td>
</tr>
<tr>
<td>3</td>
<td>La mayoría de las veces</td>
</tr>
<tr>
<td>4</td>
<td>Siempre</td>
</tr>
</tbody>
</table>

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?

<table>
<thead>
<tr>
<th>Opción</th>
<th>Respuesta</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Nunca</td>
</tr>
<tr>
<td>2</td>
<td>A veces</td>
</tr>
<tr>
<td>3</td>
<td>La mayoría de las veces</td>
</tr>
<tr>
<td>4</td>
<td>Siempre</td>
</tr>
</tbody>
</table>

### 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?

<table>
<thead>
<tr>
<th>Opción</th>
<th>Respuesta</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Nunca</td>
</tr>
<tr>
<td>2</td>
<td>A veces</td>
</tr>
<tr>
<td>3</td>
<td>La mayoría de las veces</td>
</tr>
<tr>
<td>4</td>
<td>Siempre</td>
</tr>
</tbody>
</table>

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?

<table>
<thead>
<tr>
<th>Opción</th>
<th>Respuesta</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Demasiado poco</td>
</tr>
<tr>
<td>2</td>
<td>Justo el necesario</td>
</tr>
<tr>
<td>3</td>
<td>Demasiado</td>
</tr>
</tbody>
</table>

37. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿cuánto apoyo emocional recibió usted del equipo del hospicio?

<table>
<thead>
<tr>
<th>Opción</th>
<th>Respuesta</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Demasiado poco</td>
</tr>
<tr>
<td>2</td>
<td>Justo el necesario</td>
</tr>
<tr>
<td>3</td>
<td>Demasiado</td>
</tr>
</tbody>
</table>
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 O Demasiado poco
2 O Justo el necesario
3 O Demasiado

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 usaria para calificar los cuidados que recibió su familiar por parte de este hospicio?
0 O 0 Los peores cuidados posibles de un hospicio
1 O 1
2 O 2
3 O 3
4 O 4
5 O 5
6 O 6
7 O 7
8 O 8
9 O 9
10 O 10 Los mejores cuidados posibles de un hospicio

40. ¿Le recomendaría este hospicio a sus amigos y familiares?
1 O Definitivamente no
2 O Probablemente no
3 O Probablemente sí
4 O Definitivamente sí

41. ¿Cuál es el grado o nivel escolar más alto que ha completado su familiar?
1 O 8 años de escuela o menos
2 O Estudios de escuela secundaria, pero sin graduarse
3 O Graduado de escuela de secundaria, o diploma de la secundaria), o su equivalente (o GED)
4 O Algunos cursos universitarios o un título universitario de un programa de 2 años
5 O Título universitario de 4 años
6 O Título universitario de más de 4 años
7 O No sé

42. ¿Su familiar es de origen hispano, latino o español?
1 O No, ni hispano, ni latino, ni español
2 O Sí, puertorriqueño
3 O Sí, mexicano, mexicano-americano, chicano
4 O Sí, cubano
5 O Sí, de otro origen hispano, latino o español
43. ¿A qué raza pertenece su familiar? Marque una o más.

- [ ] Blanca
- [ ] Negra o afroamericana
- [ ] Asiática
- [ ] Nativa de Hawái u otras Islas del Pacífico
- [ ] Indígena americana o nativa de Alaska

**SOBRE USTED**

44. ¿Qué edad tiene usted?

- [ ] de 18 a 24 años
- [ ] de 25 a 34 años
- [ ] de 35 a 44 años
- [ ] de 45 a 54 años
- [ ] de 55 a 64 años
- [ ] de 65 a 74 años
- [ ] de 75 a 84 años
- [ ] 85 años o más

45. ¿Es usted hombre o mujer?

- [ ] Hombre
- [ ] Mujer

46. ¿Cuál es el grado o nivel escolar más alto que ha completado?

- [ ] 8 años de escuela o menos
- [ ] Estudios de escuela secundaria, pero sin graduarse
- [ ] Graduado de escuela de secundaria o diploma de la secundaria, o su equivalente (o GED)
- [ ] Algunos cursos universitarios o un título universitario de un programa de 2 años
- [ ] Título universitario de 4 años
- [ ] Título universitario de más de 4 años

47. ¿En qué idioma habla usted principalmente en casa?

- [ ] Inglés
- [ ] Español
- [ ] Chino
- [ ] Ruso
- [ ] Portugués
- [ ] Vietnamita
- [ ] 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]

[RETURN ADDRESS OF SURVEY VENDOR]
Sample Initial Cover Letter for the CAHPS Hospice Survey

[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 envíe en el sobre con el porte o franqueo pagado. Sus respuestas 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]
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 toma 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 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]
OMB Paperwork Reduction Act Language

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. The following is the language that must be used:

Spanish Version
“Según la Ley de Reducción de Trámites (Paperwork Reduction Act) de 1995, no se exige que una persona responda a la recopilación de información a menos que la solicitud de recopilación tenga un número válido de control de la OMB. El número válido de control de la OMB para esta recopilación de información es el 0938-1257. Se calcula que el tiempo que se necesita para llenar esta recopilación de información es, en promedio, de 11 minutos para las preguntas 1 – 40, al igual que las preguntas Sobre Sue Familia y Sobre Usted de la encuesta. En este cálculo se incluye el tiempo que la persona tarda en leer las instrucciones, buscar en los recursos existentes de datos, reunir los datos necesarios y llenar y repasar la recopilación de información. Si usted tiene comentarios relacionados con la exactitud del cálculo de tiempo o si tiene sugerencias para mejorar este formulario, escriba a: Centers for Medicare & Medicaid Services, 7500 Security Boulevard, C1- 25-05, Baltimore, MD 21244-1850.”
Appendix P

Mail Survey Materials (Traditional Chinese)
CAHPS® 臨終關懷醫院調查

請根據患者從以下臨終關懷醫院所得到的服務回答調查問題：

[NAME OF HOSPICE]

本調查中提出的全部問題都與該臨終關懷醫院帶來的經歷有關。

如果想知道有關此調查的更多資訊，請致電[TOLL FREE NUMBER]. 致電此號碼完全免費。

OMB# 0938-1257
請將此問卷交給您家庭中最瞭解患者所接受的臨終關懷服務的人，患者名字已在調查問卷附件中列出。

問卷填寫指南

◆ 此問卷需用深色的筆填寫。
◆ 請用正楷填寫問題答案。
◆ 請直接在選項前面的方框內畫“X”作為回答，如下所示：
  ☒ 是
  ☐ 否
◆ 調查中有些地方會提示您跳過一些問題。在這種情況下，您會看到一個箭頭，旁邊的提示資訊會告訴您接下來要回答哪個問題，如下所示：
  ☒ 是 ➔ 如果選擇“是”，請跳至問題 1
  ☐ 否

臨終關懷患者

1. 您與調查問卷附件中所列的患者是什麼關係？
   1 ☐ 我的配偶或伴侶
   2 ☐ 我的父母
   3 ☐ 我的岳母（婆婆）或岳父（公公）
   4 ☐ 我的（外）祖父/母
   5 ☐ 我的姑姑（姨媽）或叔叔（舅舅）
   6 ☐ 我的姐妹或兄弟
   7 ☐ 我的孩子
   8 ☐ 我的朋友
   9 ☐ 其他（請用正楷填寫）：

2. 在此次調查中，詞語“家屬”是指調查問卷附件中所列之人。您的家屬在什麼地點接受了該醫院的臨終關懷服務？請選擇一項或多項。
   1 ☐ 家
   2 ☐ 補助生活機構
   3 ☐ 療養院
   4 ☐ 醫院
   5 ☐ 臨終關懷機構/安養院
   6 ☐ 其他（請用正楷填寫）：

__________________________
6. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常會通知您他們何時到達來照料您的家屬？

1. ☐ 從未
2. ☐ 有時
3. ☐ 經常
4. ☐ 總是

7. 在您的家屬接受臨終關懷期間，當您或者您的家屬向臨終關懷小組求助的時候，多經常能立即得到說明？

1. ☐ 從未
2. ☐ 有時
3. ☐ 經常
4. ☐ 總是

8. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常能用清晰易懂的方式向您解釋事情？

1. ☐ 從未
2. ☐ 有時
3. ☐ 經常
4. ☐ 總是

9. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常會通知您讓您瞭解您家屬的情況？

1. ☐ 從未
2. ☐ 有時
3. ☐ 經常
4. ☐ 總是
10. 在您的家屬接受臨終關懷期間，臨終關懷小組中的任何成員多經常會給出關於您家屬的狀況或護理情況的令您困惑或相互矛盾的資訊？

1. ☐ 從未
2. ☐ 有時
3. ☐ 經常
4. ☐ 總是

11. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常以尊敬和尊重的態度對待您的家屬？

1. ☐ 從未
2. ☐ 有時
3. ☐ 經常
4. ☐ 總是

12. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常讓您感覺到他們是真的關心您的家屬？

1. ☐ 從未
2. ☐ 有時
3. ☐ 經常
4. ☐ 總是

13. 在您的家屬接受臨終關懷期間，您是否有跟臨終關懷小組討論過家屬在臨終關懷中遇到的問題？

1. ☐ 是
2. ☐ 否 ➔ 如果選擇“否”，請跳至問題 15

14. 在您與臨終關懷小組討論家屬的臨終關懷中出現的問題時，他們多經常會認真傾聽？

1. ☐ 從未
2. ☐ 有時
3. ☐ 經常
4. ☐ 總是

15. 在您的家屬接受臨終關懷期間，他或她是否有任何疼痛？

1. ☐ 是
2. ☐ 否 ➔ 如果選擇“否”，請跳至問題 17

16. 在您的家屬有需要時，醫院是否盡可能地提供幫助來緩解他或她的痛苦？

1. ☐ 是的，當然是
2. ☐ 是的，某種程度上是
3. ☐ 否

17. 在您的家屬接受臨終關懷期間，他或她是否服用了任何止痛的藥物？

1. ☐ 是
2. ☐ 否 ➔ 如果選擇“否”，請跳至問題 21

18. 止痛藥物有副作用，當中包括嗜睡。臨終關懷小組成員是否曾與您或者您的家屬討論過止痛藥物的副作用？

1. ☐ 是的，當然是
2. ☐ 是的，某種程度上是
3. ☐ 否
19. 關於使用止痛藥物時需要注意哪些副作用，臨終關懷小組是否對您進行了您所需的培訓？
   1 ☐ 是的，當然是
   2 ☐ 是的，某種程度上是
   3 ☐ 否

20. 關於是否以及何時要給您的家屬服用更多劑量的止痛藥物，臨終關懷小組是否對您進行了您所需的培訓？
   1 ☐ 是的，當然是
   2 ☐ 是的，某種程度上是
   3 ☐ 否
   4 ☐ 我不需要給我的家屬服用任何止痛藥物

21. 在您的家屬接受臨終關懷期間，您的家屬是否曾有過呼吸困難或者接受過呼吸困難的治療？
   1 ☐ 是
   2 ☐ 否 ➔ 如果選擇“否”，請跳至問題 24

22. 您的家屬多經常能在呼吸困難的時候得到了他或她所需的幫助？
   1 ☐ 從未
   2 ☐ 有時
   3 ☐ 經常
   4 ☐ 總是

23. 關於如何在家屬呼吸困難時向他或她提供幫助，臨終關懷小組是否對您進行了您所需的培訓？
   1 ☐ 是的，當然是
   2 ☐ 是的，某種程度上是
   3 ☐ 否
   4 ☐ 我不需要幫助我的家屬解決呼吸困難問題

24. 在您的家屬接受臨終關懷期間，您的家屬是否曾有便秘問題？
   1 ☐ 是
   2 ☐ 否 ➔ 如果選擇“否”，請跳至問題 26

25. 您的家屬多經常能在遭遇便秘問題的時候得到他或她所需的說明？
   1 ☐ 從未
   2 ☐ 有時
   3 ☐ 經常
   4 ☐ 總是

26. 在您的家屬接受臨終關懷期間，他或她是否曾表現出焦慮或悲傷的跡象？
   1 ☐ 是
   2 ☐ 否 ➔ 如果選擇“否”，請跳至問題 28
27. 在您的家屬感到焦慮或悲傷時，他或她多經常能從臨終關懷小組處得到所需說明？

1 ☐ 从未
2 ☐ 有时
3 ☐ 经常
4 ☐ 总是

28. 在您的家屬接受臨終關懷期間，他或她是否曾變得不安或激動？

1 ☐ 是
2 ☐ 否 ➔ 如果選擇“否”，請跳至問題 30

29. 關於在家屬變得不安或激動時應該如何處理，臨終關懷小組是否對您進行了您所需的培訓？

1 ☐ 是的，當然是
2 ☐ 是的，某種程度上是
3 ☐ 否

30. 移動您的家屬包括幫助他或她在床上翻身，或者上下床和上下輪椅等等。關於怎樣安全移動您的家屬，臨終關懷小組是否對您進行了您所需的培訓？

1 ☐ 是的，當然是
2 ☐ 是的，某種程度上是
3 ☐ 否
4 ☐ 我不需要移動我的家屬

31. 關於家屬瀕臨死亡時您應該知道的事，臨終關懷小組是否向您提供了你所想要的盡可能多的相關資訊？

1 ☐ 是的，當然是
2 ☐ 是的，某種程度上是
3 ☐ 否

32. 有些人是在療養院中接受臨終關懷服務的。您的家屬是否在他或她於療養院居住期間從該臨終關懷醫院接受臨終關懷服務？

1 ☐ 是
2 ☐ 否 ➔ 如果選擇“否”，請跳至問題 30

33. 在您的家屬接受臨終關懷期間，療養院工作人員和臨終關懷小組多經常能協調一致來關懷您的家屬？

1 ☐ 從未
2 ☐ 有時
3 ☐ 經常
4 ☐ 總是

34. 在您的家屬接受臨終關懷期間，療養院工作人員給您的資訊與臨終關懷小組給您的資訊不一樣的情況多經常發生？

1 ☐ 從未
2 ☐ 有時
3 ☐ 經常
4 ☐ 總是
您自己的與臨終關懷有關的經歷

35. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常認真聽您說話？
   1 ☐ 從未
   2 ☐ 有時
   3 ☐ 經常
   4 ☐ 總是

36. 支持宗教信仰或精神信仰指包括談話、禱告、靈修或其他滿足宗教需要或精神需要的表達方式。在您的家屬接受臨終關懷期間，您從臨終關懷小組得到了多少在宗教信仰和精神信仰方面的支持？
   1 ☐ 太少
   2 ☐ 適中
   3 ☐ 太多

37. 在您的家屬接受臨終關懷期間，您從臨終關懷小組得到了多少的情感支持？
   1 ☐ 太少
   2 ☐ 適中
   3 ☐ 太多

38. 在您的家屬去世後的幾周，您從臨終關懷小組得到了多少情感支持？
   1 ☐ 太少
   2 ☐ 適中
   3 ☐ 太多

臨終關懷整體評分

39. 根據您的家屬從問卷首頁所示的臨終關懷醫院得到的關懷服務，回答以下問題。在回答時請不要將其他關懷醫院的關懷考慮在內。

請用數字 0 到 10 表示，0 代表最差的臨終關懷，10 則代表最好的臨終關懷。您會用哪個數字評價您家屬的臨終關懷？

   0 ☐ 0 最差的臨終關懷
   1 ☐ 1
   2 ☐ 2
   3 ☐ 3
   4 ☐ 4
   5 ☐ 5
   6 ☐ 6
   7 ☐ 7
   8 ☐ 8
   9 ☐ 9
   10 ☐ 10 最好的臨終關懷

40. 您會向您的朋友和家人推薦該臨終關懷醫院嗎？

   1 ☐ 當然不會
   2 ☐ 可能不會
   3 ☐ 可能會
   4 ☐ 當然會
### 關於您的家屬

41. 您的家屬已完成的最高學校年級或最高學歷是？
- [ ] 八年級或以下
- [ ] 上過高中，但是沒有畢業
- [ ] 高中畢業或高中同等學歷
- [ ] 上過大學或兩年制大學學位
- [ ] 四年制大學畢業
- [ ] 四年以上大學學位
- [ ] 不知道

42. 您的家屬是否是西班牙裔、拉丁裔、西班牙後裔或有西班牙血統？
- [ ] 否，不是西班牙人/西班牙裔/拉丁裔
- [ ] 是，是波多黎各人
- [ ] 是，是墨西哥人、墨西哥裔美國人或奇卡諾人
- [ ] 是，是古巴人
- [ ] 是，是其他西班牙人/西班牙裔/拉丁裔

43. 您的家屬的種族是？請選擇一項或多項。
- [ ] 白人
- [ ] 黑人或非裔美國人
- [ ] 亞洲人
- [ ] 夏威夷島原住民或其他太平洋島民
- [ ] 印第安人或阿拉斯加原住民

### 關於您自己

44. 您的年齡是？
- [ ] 18 至 24
- [ ] 25 至 34
- [ ] 35 至 44
- [ ] 45 至 54
- [ ] 55 至 64
- [ ] 65 至 74
- [ ] 75 至 84
- [ ] 85 及以上

45. 您的性別是？
- [ ] 男
- [ ] 女
46. 您已完成的最高學校年級或最高學歷是？
1 ☐ 八年級或以下
2 ☐ 上過高中，但是沒有畢業
3 ☐ 高中畢業或高中同等學歷
4 ☐ 上過大學或兩年制大學學位
5 ☐ 四年制大學畢業
6 ☐ 四年以上大學學位

47. 您在家裏主要講哪種語言？
1 ☐ 英語
2 ☐ 西班牙語
3 ☐ 中文
4 ☐ 俄語
5 ☐ 葡萄牙語
6 ☐ 越南語
7 ☐ 其他語言（請用正楷填寫）：

謝謝。
請完成填寫此問卷後將其放入已付郵費的信封中寄回。

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
CAHPS® 臨終關懷醫院調查

請根據患者從以下臨終關懷醫院所得到的服務回答調查問題：

[NAME OF HOSPICE]

本調查中提出的全部問題都與該臨終關懷醫院帶來的經歷有關。

如果想知道有關此調查的更多資訊，請致電[TOLL FREE NUMBER]. 致電此號碼完全免費。

OMB# 0938-1257
請將此問卷交給您家庭中最瞭解患者所接受的臨終關懷服務的人，患者名字已在調查問卷附件中列出。

問卷填寫指南

◆ 此問卷需用深色的筆填寫。

◆ 請用正楷填寫問題答案。

◆ 請直接在選項前面的橢圓內畫“X”作為回答，如下所示：

  ❑ 是
  ❑ 否

◆ 調查中有些地方會提示您跳過一些問題。在這種情況下，您會看到一個箭頭，旁邊的提示資訊會告訴您接下來要回答哪個問題，如下所示：

  ❑ 是 ➔ 如果選擇“是”，請跳至問題 1
  ❑ 否

臨終關懷患者

1. 您與調查問卷附件中所列的患者是什麼關係？

   1.0 我的配偶或伴侶
   2.0 我的父母
   3.0 我的岳母（婆婆）或岳父（公公）
   4.0 我的（外）祖父/母
   5.0 我的姑姑（姨媽）或叔叔（舅舅）
   6.0 我的姐妹或兄弟
   7.0 我的孩子
   8.0 我的朋友
   9.0 其他（請用正楷填寫）：


2. 在此次調查中，詞語“家屬”是指調查問卷附件中所列之人。您的家屬在哪裡接受了該醫院的臨終關懷服務？請選擇一枚或多枚。

   1.0 家
   2.0 輔助生活機構
   3.0 療養院
   4.0 醫院
   5.0 臨終關懷機構/安養院
   6.0 其他（請用正楷填寫）：

   ____________________________

   ____________________________
您的角色

3. 在您的家屬接受臨終關懷期間，您多
經常參與或監督他或她所接受的臨終
關懷？

1 0 從未 ➔ 如果選擇“從未”，請跳至
問題 41
2 0 有時
3 0 經常
4 0 總是

您的家屬的臨終關懷

在回答調查中所有剩餘問題的時候，請只
考慮您的家屬在本調查問卷附件中所列臨
終關懷醫院的經歷。

4. 在此問卷中，臨終關懷小組包括所有
護士、醫生、社會福利工作者、牧師
以及其他曾經向您的家屬提供臨終關
懷的人。在您的家屬接受臨終關懷期間，
您是否需要在夜間、週末或節假日裏
聯絡臨終關懷小組，對家屬的護理提
出問題或者尋求幫助呢？

1 0 是
2 0 否 ➔ 如果選擇“否”，請跳至問題 6

5. 您多經常能在夜間、週末或節假日裏
從臨終關懷小組那裏得到所需幫助？

1 0 從未
2 0 有時
3 0 經常
4 0 總是

6. 在您的家屬接受臨終關懷期間，臨終
關懷小組多經常會通知您他們何時到
達來照料您的家屬？

1 0 從未
2 0 有時
3 0 經常
4 0 總是

7. 在您的家屬接受臨終關懷期間，當您
或者您的家屬向臨終關懷小組求助的
時候，多經常能立即得到說明？

1 0 從未
2 0 有時
3 0 經常
4 0 總是

8. 在您的家屬接受臨終關懷期間，臨終
關懷小組多經常能用清晰易懂的方式
向您解釋事情？

1 0 從未
2 0 有時
3 0 經常
4 0 總是

9. 在您的家屬接受臨終關懷期間，臨終
關懷小組多經常會通知您讓您瞭解您
家屬的情況？

1 0 從未
2 0 有時
3 0 經常
4 0 總是
10. 在您的家屬接受臨終關懷期間，臨終關懷小組中的任何成員多經常會給出關於您家屬的狀況或護理情況的令您困惑或相互矛盾的資訊？
   1 0 從未
   2 0 有時
   3 0 經常
   4 0 總是

11. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常以尊敬和尊重的態度對待您的家屬？
   1 0 從未
   2 0 有時
   3 0 經常
   4 0 總是

12. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常讓您感覺到他們是真的關心您的家屬？
   1 0 從未
   2 0 有時
   3 0 經常
   4 0 總是

14. 在您與臨終關懷小組討論家屬的臨終關懷中出現的問題時，他們多經常會認真傾聽？
   1 0 從未
   2 0 有時
   3 0 經常
   4 0 總是

15. 在您的家屬接受臨終關懷期間，他或她是否有任何痛苦？
   1 0 是
   2 0 否 ➔ 如果選擇“否”，請跳至問題 17

16. 在您的家屬有需要時，醫院是否盡可能地提供幫助來緩解他或她的痛苦？
   1 0 是的，當然是
   2 0 是的，某種程度上是
   3 0 否

17. 在您的家屬接受臨終關懷期間，他或她是否服用了任何止痛的藥物？
   1 0 是
   2 0 否 ➔ 如果選擇“否”，請跳至問題 21

18. 止痛藥物有副作用，當中包括嗜睡。臨終關懷小組成員是否曾與您或者您的家屬討論過止痛藥物的副作用？
   1 0 是的，當然是
   2 0 是的，某種程度上是
   3 0 否
19. 關於使用止痛藥物時需要注意哪些副作用，臨終關懷小組是否對您進行了您所需的培訓？
   1.0 是的，當然是  
   2.0 是的，某種程度上是  
   3.0 否  

20. 關於是否以及何時要給您的家屬服用更多劑量的止痛藥物，臨終關懷小組是否對您進行了您所需的培訓？
   1.0 是的，當然是  
   2.0 是的，某種程度上是  
   3.0 否  
   4.0 我不需要給我的家屬服用任何止痛藥物  

21. 在您的家屬接受臨終關懷期間，您的家屬是否曾有過呼吸困難或者接受過呼吸困難的治療？
   1.0 是  
   2.0 否 ➔ 如果選擇“否”，請跳至問題 24  

22. 您的家屬多經常能在呼吸困難的時候得到了他或她所需的幫助？
   1.0 從未  
   2.0 有時  
   3.0 經常  
   4.0 總是  

23. 關於如何在家屬呼吸困難時向他或她提供幫助，臨終關懷小組是否對您進行了您所需的培訓？
   1.0 是的，當然是  
   2.0 是的，某種程度上是  
   3.0 否  
   4.0 我不需要幫助我的家屬解決呼吸困難問題  

24. 在您的家屬接受臨終關懷期間，您的家屬是否曾有便秘問題？
   1.0 是  
   2.0 否 ➔ 如果選擇“否”，請跳至問題 26  

25. 您的家屬多經常能在遭遇便秘問題的時候得到他或她所需的說明？
   1.0 從未  
   2.0 有時  
   3.0 經常  
   4.0 總是  

26. 在您的家屬接受臨終關懷期間，他或她是否曾表現出焦慮或悲傷的跡象？
   1.0 是  
   2.0 否 ➔ 如果選擇“否”，請跳至問題 28  

27. 關於……
27. 在您的家屬感到焦慮或悲傷時，他或她多經常能從臨終關懷小組處得到所需說明？
  1.0 從未
  2.0 有時
  3.0 經常
  4.0 總是

28. 在您的家屬接受臨終關懷期間，他或她是否曾變得不安或激動？
  1.0 是
  2.0 否 ➔ 如果選擇“否”，請跳至問題 30

29. 關於在家屬變得不安或激動時應該如何處理，臨終關懷小組是否對您進行了您所需的培訓？
  1.0 是的，當然是
  2.0 是的，某種程度上是
  3.0 否

30. 移動您的家屬包括幫助他或她在床上翻身，或者上下床和上下輪椅等等。關於怎樣安全移動您的家屬，臨終關懷小組是否對您進行了您所需的培訓？
  1.0 是的，當然是
  2.0 是的，某種程度上是
  3.0 否
  4.0 我不需要移動我的家屬

31. 關於家屬瀕臨死亡時您應該知道的事，臨終關懷小組是否向您提供了您所想要的盡可能多的相關資訊？
  1.0 是的，當然是
  2.0 是的，某種程度上是
  3.0 否

32. 有些人是在療養院中接受臨終關懷服務的。您的家屬是否在其他療養院居住期間從該臨終關懷醫院接受臨終關懷服務？
  1.0 是
  2.0 否 ➔ 如果選擇“否”，請跳至問題 35

33. 在您的家屬接受臨終關懷期間，療養院工作人員和臨終關懷小組多經常能協調一致來關懷您的家屬？
  1.0 從未
  2.0 有時
  3.0 經常
  4.0 總是

34. 在您的家屬接受臨終關懷期間，療養院工作人員給您的資訊與臨終關懷小組給您的資訊不一樣的情況多經常發生？
  1.0 從未
  2.0 有時
  3.0 經常
  4.0 總是
您自己的與臨終關懷有關的經歷

35. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常認真聽您說話？
   1.0 從未
   2.0 有時
   3.0 經常
   4.0 總是

36. 支持宗教信仰或精神信仰指包括談話、禱告、靈修或其他滿足宗教需要或精神需要的表達方式。在您的家屬接受臨終關懷期間，您從臨終關懷小組得到了多少宗教信仰和精神信仰方面的支持？
   1.0 太少
   2.0 適中
   3.0 太多

37. 在您的家屬接受臨終關懷期間，您從臨終關懷小組得到了多少的情感支持？
   1.0 太少
   2.0 適中
   3.0 太多

38. 在您的家屬去世後的幾周，您從臨終關懷小組得到了多少情感支持？
   1.0 太少
   2.0 適中
   3.0 太多

臨終關懷整體評分

39. 根據您的家屬從問卷首頁所示的臨終關懷醫院得到的關懷服務，回答以下問題。在回答時請不要將其他關懷醫院的關懷考慮在內。
   請用數字 0 到 10 表示，0 代表最差的臨終關懷，10 則代表最好的臨終關懷。您會用哪個數字評價您家屬的臨終關懷？
   0 0 0 最差的臨終關懷
   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 最好的臨終關懷

40. 您會向您的朋友和家人推薦該臨終關懷醫院嗎？
   1.0 當然不會
   2.0 可能不會
   3.0 可能會
   4.0 當然會
關於您的家屬

41. 您的家屬已完成的最高學校年級或最高學歷是？
   1 0 八年級或以下
   2 0 上過高中，但是沒有畢業
   3 0 高中畢業或高中同等學歷
   4 0 上過大學或兩年制大學學位
   5 0 四年制大學畢業
   6 0 四年以上大學學位
   7 0 不知道

42. 您的家屬是否是西班牙裔、拉丁裔、西班牙後裔或有西班牙血統？
   1 0 否，不是西班牙人/西班牙裔/拉丁裔
   2 0 是，是波多黎各人
   3 0 是，是墨西哥人、墨西哥裔美國人或奇卡諾人
   4 0 是，是古巴人
   5 0 是，是其他西班牙人/西班牙裔/拉丁裔

43. 您的家屬的種族是？請選擇一項或多項。
   1 0 白人
   2 0 黑人或非裔美國人
   3 0 亞洲人
   4 0 夏威夷島原住民或其他太平洋島民
   5 0 印第安人或阿拉斯加原住民

關於您自己

44. 您的年齡是？
   1 0 18 至 24
   2 0 25 至 34
   3 0 35 至 44
   4 0 45 至 54
   5 0 55 至 64
   6 0 65 至 74
   7 0 75 至 84
   8 0 85 及以上

45. 您的性別是？
   1 0 男
   2 0 女
46. 您已完成的最高學校年級或最高學歷是？

1. 0 八年級或以下
2. 0 上過高中，但是沒有畢業
3. 0 高中畢業或高中同等學歷
4. 0 上過大學或兩年制大學學位
5. 0 四年制大學畢業
6. 0 四年以上大學學位

47. 您在家裡主要講哪種語言？

1. 0 英語
2. 0 西班牙語
3. 0 中文
4. 0 俄語
5. 0 葡萄牙語
6. 0 越南語
7. 0 其他語言（請用正楷填寫）：

___________________________

謝謝。

請完成填寫此問卷後將其放入已付郵費的信封中寄回。

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
CAHPS® 臨終關懷醫院調查

請根據患者從以下臨終關懷醫院所得到的服務回答調查問題:

(NAME OF HOSPICE)

本調查中提出的全部問題都與該臨終關懷醫院帶來的經歷有關。

如果想知道有關此調查的更多資訊，請致電[TOLL FREE NUMBER]. 致電此號碼完全免費。

OMB# 0938-1257
請將此問卷交給您家庭中最瞭解患者所接受的臨終關懷服務的人，患者名字已在調查問卷附件中列出。

問卷填寫指南

◆ 此問卷需用深色的筆填寫。
◆ 請用正楷填寫問題答案。
◆ 請直接在選項前面的圓圈內畫"X"作為回答，如下所示:

● 是  
○ 否

◆ 調查中有些地方會提示您跳過一些問題。在這種情況下，您會看到一個箭頭，旁邊的提示資訊會告訴您接下來要回答哪個問題，如下所示:

● 是 ➔ 如果選擇“是”，請跳至問題 1  
○ 否

臨終關懷患者

1. 您與調查問卷附件中所列的患者是什麼關係？

   1 O 我的配偶或伴侶  
   2 O 我的父母  
   3 O 我的岳母（婆婆）或岳父（公公）  
   4 O 我的（外）祖父/母  
   5 O 我的姑姑（姨媽）或叔叔（舅舅）  
   6 O 我的姐妹或兄弟  
   7 O 我的孩子  
   8 O 我的朋友  
   9 O 其他（請用正楷填寫）：

   __________________________________________

2. 在此次調查中，詞語“家屬”是指調查問卷附件中所列之人。您的家屬在什麼地點接受了該醫院的臨終關懷服務？請選擇一項或多項。

   1 O 家  
   2 O 輔助生活機構  
   3 O 療養院  
   4 O 醫院  
   5 O 臨終關懷機構/安養院  
   6 O 其他（請用正楷填寫）：

   __________________________________________
您的角色

3. 在您的家屬接受臨終關懷期間，您多
經常參與或監督他或她所接受的臨終
關懷？

1 □ 從未 ➔ 如果選擇“從未”，請跳
至問題 41

2 □ 有時

3 □ 經常

4 □ 總是

您的家屬的臨終關懷

在回答調查中所有剩餘問題的時候，請
只考慮您的家屬在本調查問卷附件中所
列臨終關懷醫院的經歷。

4. 在此問卷中，臨終關懷小組包括所有
護士、醫生、社會福利工作者、牧師
以及其他曾經向您的家屬提供臨終關
懷的人。在您的家屬接受臨終關懷期
間，您是否需要在夜間、週末或節假
日裏聯絡臨終關懷小組，對家屬的護
理提出問題或者尋求幫助呢？

1 □ 是

2 □ 否 ➔ 如果選擇“否”，請跳至問題

6

5. 您多經常能在夜間、週末或節假日裏
從臨終關懷小組那裏得到所需幫助？

1 □ 從未

2 □ 有時

3 □ 經常

4 □ 總是

6. 在您的家屬接受臨終關懷期間，臨終
關懷小組多經常會通知您他們何時到
達來照料您的家屬？

1 □ 從未

2 □ 有時

3 □ 經常

4 □ 總是

7. 在您的家屬接受臨終關懷期間，當您
或者您的家屬向臨終關懷小組求助的
時候，多經常能立即得到說明？

1 □ 從未

2 □ 有時

3 □ 經常

4 □ 總是

8. 在您的家屬接受臨終關懷期間，臨終
關懷小組多經常能用清晰易懂的方式
向您解釋事情？

1 □ 從未

2 □ 有時

3 □ 經常

4 □ 總是

9. 在您的家屬接受臨終關懷期間，臨終
關懷小組多經常會通知您讓您瞭解您
家屬的情況？

1 □ 從未

2 □ 有時

3 □ 經常

4 □ 總是
10. 在您的家屬接受臨終關懷期間，臨終關懷小組中的任何成員多經常會給出關於您家屬的狀況或護理情況的令您困惑或相互矛盾的資訊？

   1. 从未
   2. 有時
   3. 經常
   4. 總是

11. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常以尊敬和尊重的態度對待您的家屬？

   1. 从未
   2. 有時
   3. 經常
   4. 總是

12. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常讓您感覺到他們是真的關心您的家屬？

   1. 从未
   2. 有時
   3. 經常
   4. 總是

13. 在您的家屬接受臨終關懷期間，您是否有跟臨終關懷小組討論過家屬在臨終關懷中遇到的問題？

   1. 是
   2. 否 ➔ 如果選擇“否”，請跳至問題 15

14. 在您與臨終關懷小組討論家屬的臨終關懷中出現的問題時，他們多經常會認真傾聽？

   1. 从未
   2. 有時
   3. 經常
   4. 總是

15. 在您的家屬接受臨終關懷期間，他或她是否有任何痛苦？

   1. 是
   2. 否 ➔ 如果選擇“否”，請跳至問題 17

16. 在您的家屬有需要時，醫院是否盡可能地提供幫助來緩解他或她的痛苦？

   1. 是的，當然是
   2. 是的，某種程度上是
   3. 否

17. 在您的家屬接受臨終關懷期間，他或她是否服用了任何止痛的藥物？

   1. 是
   2. 否 ➔ 如果選擇“否”，請跳至問題 21

18. 止痛藥物有副作用，當中包括嗜睡。臨終關懷小組成員是否曾與您或者您的家屬討論過止痛藥物的副作用？

   1. 是的，當然是
   2. 是的，某種程度上是
   3. 否
19. 關於使用止痛藥物時需要注意哪些副作用，臨終關懷小組是否對您進行了您所需的培訓？
   1. 是的，當然是
   2. 是的，某種程度上是
   3. 否

20. 關於是否以及何時要給您的家屬服用更多劑量的止痛藥物，臨終關懷小組是否對您進行了您所需的培訓？
   1. 是的，當然是
   2. 是的，某種程度上是
   3. 否
   4. 我不需要給我的家屬服用任何止痛藥物

21. 在您的家屬接受臨終關懷期間，您的家屬是否曾有過呼吸困難或者接受過呼吸困難的治療？
   1. 是
   2. 否 ➔ 如果選擇“否”，請跳至問題 24

22. 在您的家屬接受臨終關懷期間，他或她是否曾表現出焦慮或悲傷的跡象？
   1. 是
   2. 否 ➔ 如果選擇“否”，請跳至問題 28
27. 在您的家屬感到焦慮或悲傷時，他或她多經常能從臨終關懷小組處得到所需說明？
1. O 從未
2. O 有時
3. O 經常
4. O 總是

28. 在您的家屬接受臨終關懷期間，他或她是否曾變得不安或激動？
1. O 是
2. O 否 ➔ 如果選擇“否”，請跳至問題 30

29. 關於在家屬變得不安或激動時應該如何處理，臨終關懷小組是否對您進行了您所需的培訓？
1. O 是的，當然是
2. O 是的，某種程度上是
3. O 否

30. 移動您的家屬包括幫助他或她在床上翻身，或者上下床和上下輪椅等等.關於怎樣安全移動您的家屬，臨終關懷小組是否對您進行了您所需的培訓？
1. O 是的，當然是
2. O 是的，某種程度上是
3. O 否
4. O 我不需要移動我的家屬

31. 關於家屬瀕臨死亡時您應該知道的事，臨終關懷小組是否向您提供了你所想要的盡可能多的相關資訊？
1. O 是的，當然是
2. O 是的，某種程度上是
3. O 否

32. 有些人是在療養院中接受臨終關懷服務的.您的家屬是否在他或她於療養院居住期間從該臨終關懷醫院接受臨終關懷服務？
1. O 是
2. O 否 ➔ 如果選擇“否”，請跳至問題 35

33. 在您的家屬接受臨終關懷期間，療養院工作人員和臨終關懷小組多經常能協調一致來關懷您的家屬？
1. O 從未
2. O 有時
3. O 經常
4. O 總是

34. 在您的家屬接受臨終關懷期間，療養院工作人員給您的資訊與臨終關懷小組給您的資訊不一樣的情況多經常發生？
1. O 從未
2. O 有時
3. O 經常
4. O 總是

35. 在療養院中得到的臨終關懷
35. 在您的家屬接受臨終關懷期間，臨終關懷小組多經常認真聽您說話？
   1. O從未
   2. O有時
   3. O經常
   4. O總是

36. 支持宗教信仰或精神信仰指包括談話、禱告、靈修或其他滿足宗教需要或精神需要的表達方式。在您的家屬接受臨終關懷期間，您從臨終關懷小組得到了多少在宗教信仰和精神信仰方面的支持？
   1. O太少
   2. O適中
   3. O太多

37. 在您的家屬接受臨終關懷期間，您從臨終關懷小組得到了多少的情感支持？
   1. O太少
   2. O適中
   3. O太多

38. 在您的家屬去世後的幾周，您從臨終關懷小組得到了多少的情感支持？
   1. O太少
   2. O適中
   3. O太多

39. 根據您的家屬從問卷首頁所示的臨終關懷醫院得到的關懷服務，回答以下問題。在回答時請不要將其他關懷醫院的關懷考慮在內。
   請用數字 0 到 10 表示，0 代表最差的臨終關懷，10 則代表最好的臨終關懷。您會用哪個數字評價您家屬的臨終關懷？
   0 O 0 最差的臨終關懷
   1 O 1
   2 O 2
   3 O 3
   4 O 4
   5 O 5
   6 O 6
   7 O 7
   8 O 8
   9 O 9
   10 O 10 最好的臨終關懷

40. 您會向您的朋友和家人推薦該臨終關懷醫院嗎？
   1. O當然不會
   2. O可能不會
   3. O可能會
   4. O當然會
### 關於您的家屬

41. **您的家屬已完成的最高學校年級或最高學歷是？**

<table>
<thead>
<tr>
<th>選項</th>
<th>描述</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>八年級或以下</td>
</tr>
<tr>
<td>2</td>
<td>上過高中，但是沒有畢業</td>
</tr>
<tr>
<td>3</td>
<td>高中畢業或高中同等學歷</td>
</tr>
<tr>
<td>4</td>
<td>上過大學或兩年制大學學位</td>
</tr>
<tr>
<td>5</td>
<td>四年制大學畢業</td>
</tr>
<tr>
<td>6</td>
<td>四年以上大學學位</td>
</tr>
<tr>
<td>7</td>
<td>不知道</td>
</tr>
</tbody>
</table>

42. **您的家屬是否是西班牙裔、拉丁裔、西班牙後裔或有西班牙血統？**

<table>
<thead>
<tr>
<th>選項</th>
<th>描述</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>否，不是西班牙人/西班牙裔/拉丁裔</td>
</tr>
<tr>
<td>2</td>
<td>是，是波多黎各人</td>
</tr>
<tr>
<td>3</td>
<td>是，是墨西哥人、墨西哥裔美國人或奇卡諾人</td>
</tr>
<tr>
<td>4</td>
<td>是，是古巴人</td>
</tr>
<tr>
<td>5</td>
<td>是，是其他西班牙人/西班牙裔/拉丁裔人</td>
</tr>
</tbody>
</table>

43. **您的家屬的種族是？請選擇一項或多項。**

<table>
<thead>
<tr>
<th>選項</th>
<th>描述</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>白人</td>
</tr>
<tr>
<td>2</td>
<td>黑人或非裔美國人</td>
</tr>
<tr>
<td>3</td>
<td>亞洲人</td>
</tr>
<tr>
<td>4</td>
<td>夏威夷島原住民或其他太平洋島民</td>
</tr>
<tr>
<td>5</td>
<td>印第安人或阿拉斯加原住民</td>
</tr>
</tbody>
</table>

### 關於您自己

44. **您的年齡是？**

<table>
<thead>
<tr>
<th>選項</th>
<th>年齡範圍</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>18 至 24</td>
</tr>
<tr>
<td>2</td>
<td>25 至 34</td>
</tr>
<tr>
<td>3</td>
<td>35 至 44</td>
</tr>
<tr>
<td>4</td>
<td>45 至 54</td>
</tr>
<tr>
<td>5</td>
<td>55 至 64</td>
</tr>
<tr>
<td>6</td>
<td>65 至 74</td>
</tr>
<tr>
<td>7</td>
<td>75 至 84</td>
</tr>
<tr>
<td>8</td>
<td>85 及以上</td>
</tr>
</tbody>
</table>

45. **您的性別是？**

<table>
<thead>
<tr>
<th>選項</th>
<th>性別</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>男</td>
</tr>
<tr>
<td>2</td>
<td>女</td>
</tr>
</tbody>
</table>
46. 您已完成的最高學校年級或最高學歷是？
1. ○ 八年級或以下
2. ○ 上過高中，但是沒有畢業
3. ○ 高中畢業或高中同等學歷
4. ○ 上過大學或兩年制大學學位
5. ○ 四年制大學畢業
6. ○ 四年以上大學學位

47. 您在家裏主要講哪種語言？
1. ○ 英語
2. ○ 西班牙語
3. ○ 中文
4. ○ 俄語
5. ○ 葡萄牙語
6. ○ 越南語
7. ○ 其他語言（請用正楷填寫）：

___________________________

謝謝。

請完成填寫此問卷後將其放入已付郵費的信封中寄回。

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
Sample Initial Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]
[ADDRESS]
[CITY, STATE ZIP]

親愛的[SAMPLED CAREGIVER NAME]:

[HOSPICE NAME]正在對患者及其家屬接受的臨終關懷服務進行調查。您被抽中參加此次調查，是因為您曾是[DECEDEDNT NAME]的護理員。我們知道您現在心裡可能很難受，但是我們希望您能幫助我們瞭解臨終關懷機構為您和您的家人或者朋友提供的護理品質情況。

所附的調查問題[NOTE THE QUESTION NUMBERS]是美國衛生及公共服務部（HHS）為了衡量臨終關懷機構的護理品質所倡議的一項全國調查的一部分。這項調查由HHS的下屬機構聯邦醫療保險及各州醫療補助服務中心（CMS）開辦，目的是為了改善寧養護理品質。美國大部分寧養護理都由CMS支付費用，CMS有責任確保臨終關懷患者及其家屬和朋友能得到優質護理服務。要履行這個責任，其中一個方法就是直接向您瞭解您的家屬或朋友得到的臨終關懷護理情況。你的參與純屬自願，您的健康護理或福利不受任何影響。

我們希望您能花些時間填寫這項調查。填寫完後，請用郵資預付的信封將它寄回給我們。您的答案可能會與臨終關懷機構分享，以便改進品質。[OPTIONAL：您可能會注意到調查問卷上有個編號。這個編號是用來告訴我們您是否寄回了調查問卷，這樣我們就無需向您發送提醒。]

如果您對所附的調查有任何疑問，請撥打我們的免費電話1-800-xxx-xxxx。感謝您為改善所有消費者的臨終關懷護理所提供的幫助。

敬啟
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]
Sample Follow-up Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]
[ADDRESS]
[CITY, STATE ZIP]

親愛的[SAMPLED CAREGIVER NAME]:

我們的記錄顯示您最近在[HOSPICE NAME]為[DECEDEDNT NAME]提供了護理．大約三周前，我們給您發送了一份有關您和您的家人或朋友在這件臨終關懷機構所接受的護理的調查．如果您已經將調查寄回給我們，請接受我們的謝意，並忽略此信．但是如果您還沒有寄出，如果您能花些時間完成這份重要的調查問卷，我們將不勝感激．

我們希望您能借此機會幫助我們瞭解您的家人或朋友所受到的護理品質情況．這份調查的結果將用來幫助確保所有美國人都能受到最高品質的寧養護理服務．

所附的調查問題[NOTE THE QUESTION NUMBERS]是美國衛生及公共服務部（HHS）為了衡量臨終關懷機構的護理品質所倡議的一項全國調查的一部分．你的參與純屬自願，您的健康護理或福利不受任何影響．

請花幾分鐘的時間填寫所附的調查．填寫完後，請用郵資預付的信封將它寄回給我們．您的答案可能會與臨終關懷機構分享，以便改進品質．[OPTIONAL：您可能會注意到調查問卷上有個編號．這個編號是用來告訴我們您是否寄回了調查問卷，這樣我們就無需向您發送提醒．]

如果您對所附的調查有任何疑問，請撥打我們的免費電話1-800-xxx-xxxx．感謝您為改善所有消費者的臨終關懷護理所提供的幫助．

敬啟
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]
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. The following is the language that must be used:

Traditional Chinese Version
Appendix Q

Mail Survey Materials (Simplified Chinese)
THIS PAGE
INTENTIONALLY
LEFT BLANK
请根据患者从以下临终关怀医院所得到的服务回答调查问题:

[NAME OF HOSPICE]

本调查中提出的全部问题都与该临终关怀医院带来的经历有关。

如果想知道有关此调查的更多信息，请致电[TOLL FREE NUMBER].致电此号码完全免费。

OMB# 0938-1257
请将此问卷交给您家庭中最了解患者所接受的临终关怀服务的人，患者名字已在调查问卷附件中列出。

问卷填写指南

◆ 此问卷需用深色的笔填写。
◆ 请用正楷填写问题答案。
◆ 请直接在选项前面的方框内画“X”作为回答，如下所示：
  □ 是
  □ 否

◆ 调查中有些地方会提示您跳过一些问题.在这种情况下，您会看到一个箭头，旁边的提示信息会告诉您接下来要回答哪个问题，如下所示：
  □ 是 ➔ 如果选择“是”，请跳至问题
  □ 否

临终关怀患者

1. 您与调查问卷附件中所列的患者是什么关系？
   1. □ 我的配偶或伴侣
   2. □ 我的父母
   3. □ 我的岳父（婆）或岳母（公）
   4. □ 我的（外）祖父/母
   5. □ 我的姑姑（姨妈）或叔叔（舅舅）
   6. □ 我的姐妹或兄弟
   7. □ 我的孩子
   8. □ 我的朋友
   9. □ 其他（请用正楷填写）：

2. 在此次调查中，词语“家属”是指调查问卷附件中所列之人.您的家属在什么地点接受了该医院的临终关怀服务？请选择一项或多项。
   1. □ 家
   2. □ 辅助生活机构
   3. □ 疗养院
   4. □ 医院
   5. □ 临终关怀/安养院
   6. □ 其他（请用正楷填写）：

___________________________________________
您的角色

3. 在您的家属接受临终关怀期间，您多经常参与或监督他或她所接受的临终关怀？
   1 ☐ 从未 ➔ 如果选择 “从未”，请跳至问题 41
   2 ☐ 有时
   3 ☐ 经常
   4 ☐ 总是

您的家属的临终关怀

在回答调查中所有剩余问题的时候，请只考虑您的家属在本调查问卷附件中所列临终关怀医院的经历。

4. 在此问卷中，临终关怀小组包括所有护士、医生、社会福利工作者、牧师以及其他曾经向您的家属提供临终关怀的人。在您的家属接受临终关怀期间，您是否需要在夜间、周末或节假日里联络临终关怀小组，对家属的护理提出问题或者寻求帮助呢？
   1 ☐ 是
   2 ☐ 否 ➔ 如果选择 “否”，请跳至问题 6

5. 您多经常能在夜间、周末或节假日里从临终关怀小组那里得到所需帮助？
   1 ☐ 从未
   2 ☐ 有时
   3 ☐ 经常
   4 ☐ 总是

6. 在您的家属接受临终关怀期间，临终关怀小组多经常会通知您他们何时到达来照料您的家属？
   1 ☐ 从未
   2 ☐ 有时
   3 ☐ 经常
   4 ☐ 总是

7. 在您的家属接受临终关怀期间，当您或者您的家属向临终关怀小组求助的时候，多经常能立即得到帮助？
   1 ☐ 从未
   2 ☐ 有时
   3 ☐ 经常
   4 ☐ 总是

8. 在您的家属接受临终关怀期间，临终关怀小组多经常能用清晰易懂的方式向您解释事情？
   1 ☐ 从未
   2 ☐ 有时
   3 ☐ 经常
   4 ☐ 总是

9. 在您的家属接受临终关怀期间，临终关怀小组多经常会通知您让您了解您家属的情况？
   1 ☐ 从未
   2 ☐ 有时
   3 ☐ 经常
   4 ☐ 总是
10. 在您的家属接受临终关怀期间，临终关怀小组中的任何成员多经常会给出关于您家属的状况或护理情况的令您困惑或相互矛盾的信息？
1 □ 从未
2 □ 有时
3 □ 经常
4 □ 总是

11. 在您的家属接受临终关怀期间，临终关怀小组多经常以尊敬和尊重的态度对待您的家属？
1 □ 从未
2 □ 有时
3 □ 经常
4 □ 总是

12. 在您的家属接受临终关怀期间，临终关怀小组多经常让您感觉到他们是真的关心您的家属？
1 □ 从未
2 □ 有时
3 □ 经常
4 □ 总是

13. 在您的家属接受临终关怀期间，您是否有跟临终关怀小组讨论过家属在临终关怀中遇到的问题？
1 □ 是
2 □ 否 → 如果选择“否”，请跳至问题 15

14. 在您与临终关怀小组讨论家属的临终关怀中出现的问题时，他们多经常会认真倾听？
1 □ 从未
2 □ 有时
3 □ 经常
4 □ 总是

15. 在您的家属接受临终关怀期间，他或她是否有任何痛苦？
1 □ 是
2 □ 否 → 如果选择“否”，请跳至问题 17

16. 在您的家属有需要时，医院是否尽可能地提供帮助来缓解他或她的痛苦？
1 □ 是的，当然是
2 □ 是的，某种程度上是
3 □ 否

17. 在您的家属接受临终关怀期间，他或她是否服用了任何止痛的药物？
1 □ 是
2 □ 否 → 如果选择“否”，请跳至问题 21

18. 止痛药物有副作用，当中包括嗜睡。临终关怀小组成员是否曾与您或者您的家属讨论过止痛药物的副作用？
1 □ 是的，当然是
2 □ 是的，某种程度上是
3 □ 否
19. 关于使用止痛药物时需要注意哪些副作用，临终关怀小组是否对您进行了您所需的培训？

☐ 是的，当然是
☐ 是的，某种程度上是
☐ 否

20. 关于是否以及何时要给您的家属服用更多剂量的止痛药物，临终关怀小组是否对您进行了您所需的培训？

☐ 是的，当然是
☐ 是的，某种程度上是
☐ 否
☐ 我不需要给我的家属服用任何止痛药物

21. 在您的家属接受临终关怀期间，您的家属曾有过呼吸困难或者接受过呼吸困难的治疗？

☐ 是
☐ 否 ➔ 如果选择“否”，请跳至问题 24

22. 您的家属多经常能在呼吸困难的时候得到了他或她所需的帮助？

☐ 从未
☐ 有时
☐ 经常
☐ 总是

23. 关于如何在家属呼吸困难时向他或她提供帮助，临终关怀小组是否对您进行了您所需的培训？

☐ 是的，当然是
☐ 是的，某种程度上是
☐ 否
☐ 我不需要帮助我的家属解决呼吸困难问题

24. 在您的家属接受临终关怀期间，您的家属是否曾有便秘问题？

☐ 是
☐ 否 ➔ 请跳至问题 26

25. 您的家属多经常能在遭遇便秘问题的时候得到他或她所需的帮助？

☐ 从未
☐ 有时
☐ 经常
☐ 总是

26. 在您的家属接受临终关怀期间，他或她是否曾表现出焦虑或悲伤的迹象？

☐ 是
☐ 否 ➔ 如果选择“否”，请跳至问题 28
27. 当您的家属感到焦虑或悲伤时，他或她多长时间能从临终关怀小组得到所需帮助？

1. ☐ 从未
2. ☐ 有时
3. ☐ 经常
4. ☐ 总是

28. 当您的家属在临终关怀期间，他或她是否曾变得不安或激动？

1. ☐ 是
2. ☐ 否 ➔ 如果选择“否”，请跳至问题 30

29. 关于当家属变得不安或激动时应该如何处理，临终关怀小组是否对您进行了所需的培训？

1. ☐ 是的，当然是
2. ☐ 是的，某种程度上是
3. ☐ 否

30. 移动您的家属包括帮助他或她在床上翻身，或者上下床和上下轮椅等等。关于怎样安全移动您的家属，临终关怀小组是否对您进行了所需的培训？

1. ☐ 是的，当然是
2. ☐ 是的，某种程度上是
3. ☐ 否

31. 关于家属临终死亡时应该知道的事，临终关怀小组是否将您想要的尽可能多的有关信息提供给了您？

1. ☐ 是的，当然是
2. ☐ 是的，某种程度上是
3. ☐ 否

在疗养院中得到的临终关怀

32. 有些人是在疗养院中接受临终关怀服务的。您的家属是否在他或她于疗养院居住期间从该临终关怀机构接受了临终关怀服务？

1. ☐ 是
2. ☐ 否 ➔ 如果选择“否”，请跳至问题 35

33. 在您的家属在临终关怀期间，疗养院工作人员和临终关怀小组多长时间能协调一致来关怀您的家属？

1. ☐ 从未
2. ☐ 有时
3. ☐ 经常
4. ☐ 总是

34. 在您的家属接受临终关怀期间，疗养院工作人员给您的信息与临终关怀小组给您的信息不一样的情况多经常发生？

1. ☐ 从未
2. ☐ 有时
3. ☐ 经常
4. ☐ 总是
您自己的与临终关怀有关的经历

35. 在您的家属接受临终关怀期间，临终关怀小组多经常认真听您说话？
   1. ☐ 从未
   2. ☐ 有时
   3. ☐ 经常
   4. ☐ 总是

36. 支持宗教信仰或精神信仰指包括谈话、祷告、灵修或其他满足宗教需要或精神需要的表达方式。在您的家属接受临终关怀期间，您从临终关怀小组得到了多少在宗教信仰和精神信仰方面的支持？
   1. ☐ 太少
   2. ☐ 适中
   3. ☐ 太多

37. 在您的家属接受临终关怀期间，您从临终关怀小组得到了多少的情感支持？
   1. ☐ 太少
   2. ☐ 适中
   3. ☐ 太多

38. 在您的家属去世后的几周，您从临终关怀小组得到了多少情感支持？
   1. ☐ 太少
   2. ☐ 适中
   3. ☐ 太多

临终关怀整体评分

39. 根据您的家属从问卷首页所示的临终关怀医院得到的关怀服务，回答以下问题。在回答时请不要将其他关怀医院的关怀考虑在内。

请用数字 0 到 10 表示，0 代表最差的临终关怀，10 则代表最好的临终关怀。您会用哪个数字评价您家属的临终关怀？

   0  ☐ 0 最差的临终关怀
   1  ☐ 1
   2  ☐ 2
   3  ☐ 3
   4  ☐ 4
   5  ☐ 5
   6  ☐ 6
   7  ☐ 7
   8  ☐ 8
   9  ☐ 9
  10  ☐ 10 最好的临终关怀

40. 您会向您的朋友和家人推荐该临终关怀医院吗？
   1. ☐ 当然不会
   2. ☐ 可能不会
   3. ☐ 可能会
   4. ☐ 当然会
关于您的家属

41. 您的家属已完成的最高学校年级或最高学历是？
   1. ☐ 八年级或以下
   2. ☐ 上过高中，但是没有毕业
   3. ☐ 高中毕业或高中同等学历
   4. ☐ 上过大学或两年制大学学位
   5. ☐ 四年制大学毕业
   6. ☐ 四年以上大学学位
   7. ☐ 不知道

42. 您的家属是否是西班牙裔、拉丁裔、西班牙裔后裔或有西班牙血统？
   1. ☐ 否，不是西班牙人/西班牙裔/拉丁裔
   2. ☐ 是，是波多黎各人
   3. ☐ 是，是墨西哥人、墨西哥裔美国人或奇卡诺人
   4. ☐ 是，是古巴人
   5. ☐ 是，是其他西班牙人/西班牙裔/拉丁裔

43. 您的家属的种族是？请选择一项或多项。
   1. ☐ 白人
   2. ☐ 黑人或非裔美国人
   3. ☐ 亚洲人
   4. ☐ 夏威夷岛原住民或其他太平洋岛民
   5. ☐ 印第安人或阿拉斯加原住民

关于您自己

44. 您的年龄是？
   1. ☐ 18 至 24
   2. ☐ 25 至 34
   3. ☐ 35 至 44
   4. ☐ 45 至 54
   5. ☐ 55 至 64
   6. ☐ 65 至 74
   7. ☐ 75 至 84
   8. ☐ 85 及以上

45. 您的性别是？
   1. ☐ 男
   2. ☐ 女
46. 您已完成的最高学校年级或最高学历是？
1 ☐ 八年级或以下
2 ☐ 上过高中，但是没有毕业
3 ☐ 高中毕业或高中同等学历
4 ☐ 上过大学或两年制大学学位
5 ☐ 四年制大学毕业
6 ☐ 四年以上大学学位

47. 你家里主要讲哪种语言？
1 ☐ 英语
2 ☐ 西班牙语
3 ☐ 中文
4 ☐ 俄语
5 ☐ 葡萄牙语
6 ☐ 越南语
7 ☐ 其他语言（请用正楷填写）：

谢谢。
请完成填写此问卷后将其放入已付邮费的信封中寄回。

(NAME OF SURVEY VENDOR)

(RETURN ADDRESS OF SURVEY VENDOR)
请根据患者从以下临终关怀医院所得到的服务回答调查问题:

[NAME OF HOSPICE]

本调查中提出的全部问题都与该临终关怀医院带来的经历有关。

如果想知道有关此调查的更多信息，请致电[TOLL FREE NUMBER].致电此号码完全免费。

OMB# 0938-1257
请将此问卷交给您家庭中最了解患者所接受的临终关怀服务的人，患者名字已在调查问卷附件中列出。

问卷填写指南

◆ 此问卷需用深色的笔填写。
◆ 请用正楷填写问题答案。
◆ 请直接在选项前面的椭圆内画“X”作为回答，如下所示：

0 是
0 否

◆ 调查中有些地方会提示您跳过一些问题。在这种情况下，您会看到一个箭头，旁边的提示信息会告诉您接下来要回答哪个问题，如下所示：
0 是→ 如果选择“是”，请跳至问题 1
0 否

临终关怀患者

1. 您与调查问卷附件中所列的患者是什么关系？

0 我的配偶或伴侣
1 我的父母
2 我的岳母（婆婆）或岳父（公公）
3 我的（外）祖父/母
4 我的姑姑（姨妈）或叔叔（舅舅）
5 我的姐妹或兄弟
6 我的孩子
7 我的朋友
8 其他（请用正楷填写）：

2. 在此次调查中，词语“家属”是指调查问卷附件中所列之人。您的家属在什么地点接受了该医院的临终关怀服务？请选择一项或多项。

0 家
1 辅助生活机构
2 疗养院
3 医院
4 临终关怀机构/安养院
5 其他（请用正楷填写）：

______________________________
### 您的角色

3. 在您的家属接受临终关怀期间，您多常参与或监督他或她所接受的临终关怀？

<table>
<thead>
<tr>
<th>选项</th>
<th>描述</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>从未</td>
</tr>
<tr>
<td>2</td>
<td>有时</td>
</tr>
<tr>
<td>3</td>
<td>经常</td>
</tr>
<tr>
<td>4</td>
<td>总是</td>
</tr>
</tbody>
</table>

如果选择“从未”，请跳至问题41

### 您的家属的临终关怀

在回答调查中所有剩余问题的时候，请只考虑您的家属在本调查问卷附件中所列临终关怀医院的经历。

4. 在此问卷中，临终关怀小组包括所有护士、医生、社会福利工作者、牧师以及其他曾经向您的家属提供临终关怀的人。在您的家属接受临终关怀期间，您是否需要在夜间、周末或节假日里联络临终关怀小组，对家属的护理提出问题或者寻求帮助呢？

<table>
<thead>
<tr>
<th>选项</th>
<th>描述</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>是</td>
</tr>
<tr>
<td>2</td>
<td>否</td>
</tr>
</tbody>
</table>

如果选择“否”，请跳至问题6

5. 您多常能在夜间、周末或节假日里从临终关怀小组那里得到所需帮助？

<table>
<thead>
<tr>
<th>选项</th>
<th>描述</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>3</td>
<td>经常</td>
</tr>
<tr>
<td>4</td>
<td>总是</td>
</tr>
</tbody>
</table>

6. 在您的家属接受临终关怀期间，临终关怀小组多常会通知您他们何时到达照料您的家属？

<table>
<thead>
<tr>
<th>选项</th>
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</thead>
<tbody>
<tr>
<td>1</td>
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<tr>
<td>3</td>
<td>经常</td>
</tr>
<tr>
<td>4</td>
<td>总是</td>
</tr>
</tbody>
</table>

7. 在您的家属接受临终关怀期间，当您或者您的家属向临终关怀小组求助的时候，多常能立即得到帮助？

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<tr>
<td>3</td>
<td>经常</td>
</tr>
<tr>
<td>4</td>
<td>总是</td>
</tr>
</tbody>
</table>

8. 在您的家属接受临终关怀期间，临终关怀小组多常能用清晰易懂的方式向您解释事情？

<table>
<thead>
<tr>
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<th>描述</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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</tr>
<tr>
<td>3</td>
<td>经常</td>
</tr>
<tr>
<td>4</td>
<td>总是</td>
</tr>
</tbody>
</table>

9. 在您的家属接受临终关怀期间，临终关怀小组多常会通知您让您了解您家属的情况？

<table>
<thead>
<tr>
<th>选项</th>
<th>描述</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>3</td>
<td>经常</td>
</tr>
<tr>
<td>4</td>
<td>总是</td>
</tr>
</tbody>
</table>

10. 在您的家属接受临终关怀期间，临终关怀小组中的任何成员多常会给出关于您家属的状况或护理情况的令您困惑或相互矛盾的信息？

<table>
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<tr>
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<tr>
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<td>3</td>
<td>经常</td>
</tr>
<tr>
<td>4</td>
<td>总是</td>
</tr>
</tbody>
</table>
11. 在您的家属接受临终关怀期间，临终关怀小组多经常以尊敬和尊重的态度对待您的家属？

| 0 | 从未       |
| 1 |                |
| 2 | 有时       |
| 3 | 经常       |
| 4 | 总是       |

12. 在您的家属接受临终关怀期间，临终关怀小组多经常让您感觉到他们是真的关心您的家属？

| 0 | 从未       |
| 1 |                |
| 2 | 有时       |
| 3 | 经常       |
| 4 | 总是       |

13. 在您的家属接受临终关怀期间，您是否有跟临终关怀小组讨论过家属在临终关怀中遇到的问题？

| 0 | 是       |
| 1 |                |
| 2 | 否 ➔ 如果选择“否”，请跳至问题 15 |

14. 在您与临终关怀小组讨论家属的临终关怀中出现的问题时，他们多经常会认真倾听？

| 0 | 从未       |
| 1 |                |
| 2 | 有时       |
| 3 | 经常       |
| 4 | 总是       |

15. 在您的家属接受临终关怀期间，他或她是否有任何痛苦？

| 0 | 是       |
| 1 |                |
| 2 | 否 ➔ 如果选择“否”，请跳至问题 17 |

16. 在您的家属有需要时，医院是否尽可能地提供帮助来缓解他或她的痛苦？

| 0 | 是的，当然是       |
| 1 |                |
| 2 | 是的，某种程度上是       |
| 3 | 否       |

17. 在您的家属接受临终关怀期间，他或她是否服用了任何止痛的药物？

| 0 | 是       |
| 1 |                |
| 2 | 否 ➔ 如果选择“否”，请跳至问题 21 |

18. 止痛药物有副作用，当中包括嗜睡。临终关怀小组成员是否曾与您或者您的家属讨论过止痛药物的副作用？

| 0 | 是的，当然是       |
| 1 |                |
| 2 | 是的，某种程度上是       |
| 3 | 否       |

19. 关于使用止痛药物时需要注意哪些副作用，临终关怀小组是否对您进行了您所需的培训？

| 0 | 是的，当然是       |
| 1 |                |
| 2 | 是的，某种程度上是       |
| 3 | 否       |

20. 关于是否以及何时要给您的家属服用更多剂量的止痛药物，临终关怀小组是否对您进行了您所需的培训？

| 0 | 是的，当然是       |
| 1 |                |
| 2 | 是的，某种程度上是       |
| 3 | 否       |

| 4 | 我不需要给我的家属服用任何止痛药物       |
21. 在您的家属接受临终关怀期间，您的家属是否曾有过呼吸困难或者接受过呼吸困难的治疗？
   1️⃣ 是
   2️⃣ 否 ➔ 如果选择“否”，请跳至问题 24

22. 您的家属多经常能在呼吸困难的时候得到了他或她所需的帮助？
   1️⃣ 从未
   2️⃣ 有时
   3️⃣ 经常
   4️⃣ 总是

23. 关于如何在家属呼吸困难时向他或她提供帮助，临终关怀小组是否对您进行了您所需的培训？
   1️⃣ 是的，当然是
   2️⃣ 是的，某种程度上是
   3️⃣ 否
   4️⃣ 我不需要帮助我的家属解决呼吸困难问题

24. 在您的家属接受临终关怀期间，您的家属是否曾有便秘问题？
   1️⃣ 是
   2️⃣ 否 ➔ 如果选择“否”，请跳至问题 26

25. 您的家属多经常能在遭遇便秘问题的时候得到他或她所需的帮助？
   1️⃣ 从未
   2️⃣ 有时
   3️⃣ 经常
   4️⃣ 总是

26. 在您的家属接受临终关怀期间，他或她是否曾表现出焦虑或悲伤的迹象？
   1️⃣ 是
   2️⃣ 否 ➔ 如果选择“否”，请跳至问题 28

27. 在您的家属感到焦虑或悲伤时，他或她多经常能从临终关怀小组处得到所需帮助？
   1️⃣ 从未
   2️⃣ 有时
   3️⃣ 经常
   4️⃣ 总是

28. 在您的家属接受临终关怀期间，他或她在感到焦虑或悲伤时是否曾变得不安或激动？
   1️⃣ 是
   2️⃣ 否 ➔ 如果选择“否”，请跳至问题 30

29. 关于在家属变得不安或激动时应该如何处理，临终关怀小组是否对您进行了您所需的培训？
   1️⃣ 是的，当然是
   2️⃣ 是的，某种程度上是
   3️⃣ 否

30. 移动您的家属包括帮助他或她在床上翻身，或者上下床和上下轮椅等。关于怎样安全移动您的家属，临终关怀小组是否对您进行了您所需的培训？
   1️⃣ 是的，当然是
   2️⃣ 是的，某种程度上是
   3️⃣ 否
   4️⃣ 我不需要移动我的家属
31. 关于家属濒临死亡时您应该知道的事，临终关怀小组是否向您提供了您所想要的尽可能多的相关信息？
1. 是的，当然是
2. 是的，某种程度上是
3. 否

在疗养院中得到的临终关怀

32. 有些人是在疗养院中接受临终关怀服务的。您的家属是否在他或她于疗养院居住期间从该临终关怀医院接受临终关怀服务？
1. 是
2. 否 ➔ 如果选择“否”，请跳至问题 35

33. 在您的家属接受临终关怀期间，疗养院工作人和临终关怀小组多经常能协调一致来关怀您的家属？
1. 从未
2. 有时
3. 经常
4. 总是

34. 在您的家属接受临终关怀期间，疗养院工作人员给您的信息与临终关怀小组给您的信息不一样的情况多经常发生？
1. 从未
2. 有时
3. 经常
4. 总是

您自己的与临终关怀有关的经历

35. 在您的家属接受临终关怀期间，临终关怀小组多经常认真听您说话？
1. 从未
2. 有时
3. 经常
4. 总是

36. 支持宗教信仰或精神信仰指包括谈话、祷告、灵修或其他满足宗教需要或精神需要的表达方式。在您的家属接受临终关怀期间，您从临终关怀小组得到了多少在宗教信仰和精神信仰方面的支持？
1. 太少
2. 适中
3. 太多

37. 在您的家属接受临终关怀期间，您从临终关怀小组得到了多少的情感支持？
1. 太少
2. 适中
3. 太多

38. 在您的家属去世后的几周，您从临终关怀小组得到了多少情感支持？
1. 太少
2. 适中
3. 太多
临终关怀整体评分

39. 根据您的家属从问卷首页所示的临终关怀医院得到的关怀服务，回答以下问题。在回答时请不要将其他关怀医院的关怀考虑在内。

请用数字 0 到 10 表示，0 代表最差的临终关怀，10 则代表最好的临终关怀。您会用哪个数字评价您家属的临终关怀？

0 0 最差的临终关怀
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 最好的临终关怀

关于您的家属

41. 您的家属已完成的最高学校年级或最高学历是？

1 0 八年级或以下
2 0 上过高中，但是没有毕业
3 0 高中毕业或高中同等学历
4 0 过大学或两年制大学学位
5 0 四年制大学毕业
6 0 四年以上大学学位
7 0 不知道

42. 您的家属是否是西班牙裔、拉丁裔、西班牙后裔或有西班牙血统？

1 0 否，不是西班牙人/西班牙裔/拉丁裔
2 0 是，是波多黎各人
3 0 是，是墨西哥人、墨西哥裔美国人或奇卡诺人
4 0 是，是古巴人
5 0 是，是其他西班牙人/西班牙裔/拉丁裔

43. 您的家属的种族是？请选择一项或多项。

1 0 白人
2 0 黑人或非裔美国人
3 0 亚洲人
4 0 夏威夷岛原住民或其他太平洋岛民
5 0 印第安人或阿拉斯加原住民
关于您自己

44. 您的年龄是？
   10 18 至 24
   20 25 至 34
   30 35 至 44
   40 45 至 54
   50 55 至 64
   60 65 至 74
   70 75 至 84
   80 85 及以上

45. 您的性别是？
   10 男
   20 女

46. 您已完成的最高学校年级或最高学历是？
   10 八年级或以下
   20 上过高中，但是没有毕业
   30 高中毕业或高中同等学历
   40 上过大学或两年制大学学位
   50 四年制大学毕业
   60 四年以上大学学位

47. 您在家里主要讲哪种语言？
   10 英语
   20 西班牙语
   30 中文
   40 俄语
   50 葡萄牙语
   60 越南语
   70 其他语言（请用正楷填写）：

谢谢。

请完成填写此问卷后将其放入已付邮资的信封中寄回。

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
CAHPS® 临终关怀医院调查

请根据患者从以下临终关怀医院所得到的服务回答调查问题：

[NAME OF HOSPICE]

本调查中提出的全部问题都与该临终关怀医院带来的经历有关。

如果想知道有关此调查的更多信息，请致电[TOLL FREE NUMBER]. 致电此号码完全免费。

OMB# 0938-1257
请将此问卷交给您家庭中最了解患者所接受的临终关怀服务的人，患者名字已在调查问卷附件中列出。

问卷填写指南

◆ 此问卷需用深色的笔填写。
◆ 请用正楷填写问题答案。
◆ 请直接在选项前面的圆圈内画“X”作为回答，如下所示：
  ● 是
  ○ 否

◆ 调查中有些地方会提示您跳过一些问题。在这种情况下，您会看到一个箭头，旁边的提示信息会告诉您接下来要回答哪个问题，如下所示：
  ● 是 ➔ 如果选择“是”，请跳至问题 1
  ○ 否

临终关怀患者

1. 您与调查问卷附件中所列的患者是什么关系？
   1. O 我的配偶或伴侣
   2. O 我的父母
   3. O 我的岳母（婆婆）或岳父（公公）
   4. O 我的（外）祖父/母
   5. O 我的姑姑（姨妈）或叔叔（舅舅）
   6. O 我的姐妹或兄弟
   7. O 我的孩子
   8. O 我的朋友
   9. O 其他（请用正楷填写）：

2. 在此次调查中，词语“家属”是指调查问卷附件中所列之人。您的家属在什么地点接受了该医院的临终关怀服务？请选择一项或多选。
   1. O 家
   2. O 辅助生活机构
   3. O 疗养院
   4. O 医院
   5. O 临终关怀机构/安养院
   6. O 其他（请用正楷填写）：

_________________________________________
您的角色

3. 在您的家属接受临终关怀期间，您多经常参与或监督他或她所接受的临终关怀？

   1. 从未 ➔ 如果选择“从未”，请跳至问题 41
   2. 有时
   3. 经常
   4. 总是

您的家属的临终关怀

在回答调查中所有剩余问题的时候，请只考虑您的家属在本调查问卷附件中所列临终关怀医院的经历。

4. 在此问卷中，临终关怀小组包括所有护士、医生、社会福利工作者、牧师以及其他曾经向您的家属提供临终关怀的人。在您的家属接受临终关怀期间，您是否需要在夜间、周末或节假日里联络临终关怀小组，对家属的护理提出问题或者寻求帮助呢？

   1. 是
   2. 否 ➔ 如果选择“否”，请跳至问题 6

5. 您多经常能在夜间、周末或节假日里从临终关怀小组那里得到所需帮助？

   1. 从未
   2. 有时
   3. 经常
   4. 总是

6. 在您的家属接受临终关怀期间，临终关怀小组多经常会通知您他们何时到达来照料您的家属？

   1. 从未
   2. 有时
   3. 经常
   4. 总是

7. 在您的家属接受临终关怀期间，当您或者您的家属向临终关怀小组求助的时候，多经常能立即得到帮助？

   1. 从未
   2. 有时
   3. 经常
   4. 总是

8. 在您的家属接受临终关怀期间，临终关怀小组多经常能用清晰易懂的方式向您解释事情？

   1. 从未
   2. 有时
   3. 经常
   4. 总是

9. 在您的家属接受临终关怀期间，临终关怀小组多经常会通知您让您了解您家属的情况？

   1. 从未
   2. 有时
   3. 经常
   4. 总是
10. 在您的家属接受临终关怀期间，临终关怀小组中的任何成员多经常会给出关于您家属的状况或护理情况的令您困惑或相互矛盾的信息？
   1 O 从未
   2 O 有时
   3 O 经常
   4 O 总是

11. 在您的家属接受临终关怀期间，临终关怀小组多经常以尊敬和尊重的态度对待您的家属？
   1 O 从未
   2 O 有时
   3 O 经常
   4 O 总是

12. 在您的家属接受临终关怀期间，临终关怀小组多经常让您感觉到他们是真的关心您的家属？
   1 O 从未
   2 O 有时
   3 O 经常
   4 O 总是

13. 在您的家属接受临终关怀期间，您是否有跟临终关怀小组讨论过家属在临终关怀中遇到的问题？
   1 O 是
   2 O 否 ➔ 如果选择“否”，请跳至问题 15

14. 在您与临终关怀小组讨论家属的临终关怀中出现的问题时，他们多经常会认真倾听？
   1 O 从未
   2 O 有时
   3 O 经常
   4 O 总是

15. 在您的家属接受临终关怀期间，他或她是否有任何痛苦？
   1 O 是
   2 O 否 ➔ 如果选择“否”，请跳至问题 17

16. 在您的家属有需要时，医院是否尽可能地提供帮助来缓解他或她的痛苦？
   1 O 是的，当然是
   2 O 是的，某种程度上是
   3 O 否

17. 在您的家属接受临终关怀期间，他或她是否服用了任何止痛的药物？
   1 O 是
   2 O 否 ➔ 如果选择“否”，请跳至问题 21

18. 止痛药物有副作用，当中包括嗜睡。临终关怀小组成员是否曾与您或者您的家属讨论过止痛药物的副作用？
   1 O 是的，当然是
   2 O 是的，某种程度上是
   3 O 否

19. 关于使用止痛药物时需要注意哪些副作用，临终关怀小组是否对您进行了您所需的培训？
   1 O 是的，当然是
   2 O 是的，某种程度上是
   3 O 否
20. 关于是否以及何时要给您的家属服用更多剂量的止痛药物，临终关怀小组是否对您进行了您所需的培训?
   1) 是的，当然是
   2) 是的，某种程度上是
   3) 否
   4) 我不需要给我的家属服用任何止痛药物

21. 在您的家属接受临终关怀期间，您的家属是否曾有过呼吸困难或者接受过呼吸困难的治疗?
   1) 是
   2) 否 ➔ 如果选择“否”，请跳至问题 24

22. 您的家属多经常能在呼吸困难的时候得到了他或她所需的帮助?
   1) 从未
   2) 有时
   3) 经常
   4) 总是

23. 关于如何在家属呼吸困难时向他或她提供帮助，临终关怀小组是否对您进行了您所需的培训?
   1) 是的，当然是
   2) 是的，某种程度上是
   3) 否
   4) 我不需要帮助我的家属解决呼吸困难问题

24. 在您的家属接受临终关怀期间，您的家属是否曾有便秘问题?
   1) 是
   2) 否 ➔ 如果选择“否”，请跳至问题 26

25. 您的家属多经常能在遭遇便秘问题的时候得到他或她所需的帮助?
   1) 从未
   2) 有时
   3) 经常
   4) 总是

26. 在您的家属接受临终关怀期间，他或她是否曾表现出焦虑或悲伤的迹象?
   1) 是
   2) 否 ➔ 如果选择“否”，请跳至问 28

27. 在您的家属感到焦虑或悲伤时，他或她多经常能从临终关怀小组处得到所需帮助?
   1) 从未
   2) 有时
   3) 经常
   4) 总是

28. 在您的家属接受临终关怀期间，他或她是否曾变得不安或激动?
   1) 是
   2) 否 ➔ 如果选择“否”，请跳至问 30

29. 关于在家属变得不安或激动时应该如何处理，临终关怀小组是否对您进行了您所需的培训?
   1) 是的，当然是
   2) 是的，某种程度上是
   3) 否
30. 移动您的家属包括帮助他或她在床上翻身，或者上下床和上下轮椅等等。关于怎样安全移动您的家属，临终关怀小组是否对您进行了您所需的培训？
   1. 是的，当然是
   2. 是的，某种程度上是
   3. 否
   4. 我不需要移动我的家属

31. 关于家属濒临死亡时您应该知道的事，临终关怀小组是否向您提供了您所想要的尽可能多的相关信息？
   1. 是的，当然是
   2. 是的，某种程度上是
   3. 否

32. 有些人是在疗养院中接受临终关怀服务的。您的家属是否在他或她于疗养院居住期间从该临终关怀医院接受临终关怀服务？
   1. 是
   2. 否→如果选择“否”，请跳至问题35

33. 在您的家属接受临终关怀期间，疗养院工作人员和临终关怀小组多经常能协调一致来关怀您的家属？
   1. 从未
   2. 有时
   3. 经常
   4. 总是

34. 在您的家属接受临终关怀期间，疗养院工作人员给您的信息与临终关怀小组给您的信息不一样的情况多经常发生？
   1. 从未
   2. 有时
   3. 经常
   4. 总是

35. 在您的家属接受临终关怀期间，临终关怀小组多经常认真听您说话？
   1. 从未
   2. 有时
   3. 经常
   4. 总是

36. 支持宗教信仰或精神信仰指包括谈话、祷告、灵修或其他满足宗教需要或精神需要的表达方式。在您的家属接受临终关怀期间，您从临终关怀小组得到了多少在宗教信仰和精神信仰方面的支持？
   1. 太少
   2. 适中
   3. 太多

37. 在您的家属接受临终关怀期间，您从临终关怀小组得到了多少的情感支持？
   1. 太少
   2. 适中
   3. 太多

38. 在您的家属去世后的几周，您从临终关怀小组得到了多少情感支持？
   1. 太少
   2. 适中
   3. 太多
39. 根据您的家属从问卷首页所示的临终关怀医院得到的关怀服务，回答以下问题。在回答时请不要将其他关怀医院的关怀考虑在内。

请用数字 0 到 10 表示，0 代表最差的临终关怀，10 则代表最好的临终关怀。您会用哪个数字评价您家属的临终关怀？

- 0 0 最差的临终关怀
- 1 1
- 2 2
- 3 3
- 4 4
- 5 5
- 6 6
- 7 7
- 8 8
- 9 9
- 10 10 最好的临终关怀

40. 您会向您的朋友和家人推荐该临终关怀医院吗？

- 1 当然不会
- 2 可能不会
- 3 可能会
- 4 当然会

41. 您的家属已完成的最高学校年级或最高学历是？

- 1 八年级或以下
- 2 上过高中，但是没有毕业
- 3 高中毕业或高中同等学历
- 4 上过大学或两年制大学学位
- 5 四年制大学毕业
- 6 四年以上大学学位
- 7 不知道

42. 您的家属是否是西班牙裔、拉丁裔、西班牙后裔或有西班牙血统？

- 1 否，不是西班牙人/西班牙裔/拉丁裔
- 2 是，是波多黎各人
- 3 是，是墨西哥人、墨西哥裔美国人或奇卡诺人
- 4 是，是古巴人
- 5 是，是其他西班牙人/西班牙裔/拉丁裔人

43. 您的家属的种族是？请选择一项或多项。

- 1 白人
- 2 黑人或非裔美国人
- 3 亚洲人
- 4 夏威夷岛原住民或其他太平洋岛民
- 5 印第安人或阿拉斯加原住民
关于您自己

44. 您的年龄是?
   1 ○ 18 至 24
   2 ○ 25 至 34
   3 ○ 35 至 44
   4 ○ 45 至 54
   5 ○ 55 至 64
   6 ○ 65 至 74
   7 ○ 75 至 84
   8 ○ 85 及以上

45. 您的性别是?
   1 ○ 男
   2 ○ 女

46. 您已完成的最高学校年级或最高学历是?
   1 ○ 八年级或以下
   2 ○ 上过高中，但是没有毕业
   3 ○ 高中毕业或高中同等学历
   4 ○ 上过大学或两年制大学学位
   5 ○ 四年制大学毕业
   6 ○ 四年以上大学学位

47. 您在家里主要讲哪种语言?
   1 ○ 英语
   2 ○ 西班牙语
   3 ○ 中文
   4 ○ 俄语
   5 ○ 葡萄牙语
   6 ○ 越南语
   7 ○ 其他语言（请用正楷填写）：

谢谢。

请完成填写此问卷后将其放入已付邮费的信封中寄回。

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
Sample Initial Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]
[ADDRESS]
[CITY, STATE ZIP]

亲爱的[SAMPLED CAREGIVER NAME]:

[HOSPICE NAME]正在对患者及其家属接受的临终关怀服务进行调查。您被抽中参加此次调查，是因为您曾是[DECEDENT NAME]的护理员。我们知道您现在心里可能很难受，但是我们希望您能帮助我们了解临终关怀机构为您和您的家人或者朋友提供的护理质量情况。

所附的调查问题[NOTE THE QUESTION NUMBERS]是美国卫生及公共服务部（HHS）为了衡量临终关怀机构的护理质量所倡议的一项全国调查的一部分。这项调查由HHS的下属机构联邦医疗保险及各州医疗补助服务中心（CMS）开展，目的是为了改善临终关怀护理质量。美国大部分临终关怀护理都由CMS支付费用，CMS有责任确保临终关怀患者及其家属和朋友能得到优质护理服务。要履行这个责任，其中一个方法就是直接向您了解您的家属或朋友得到的临终关怀护理情况。您的参与纯属自愿，您的健康护理或福利不受任何影响。

我们希望您能花些时间填写这项调查。填写完后，请用邮资预付的信封将它寄回给我们。您的答案可能会与临终关怀机构分享，以便改进质量。[OPTIONAL：您可能会注意到调查问卷上有个编号。这个编号是用来告诉我们您是否寄回了调查问卷，这样我们就无需向您发送提醒。]

如果您对所附的调查有任何疑问，请拨打我们的免费电话1-800-xxx-xxxx。感谢您为改善所有消费者的临终关怀护理所提供的帮助。

敬启
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]
Sample Follow-up Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]  
[ADDRESS]  
[CITY, STATE ZIP]

亲爱的[SAMPLED CAREGIVER NAME]:


我们希望您能借此机会帮助我们了解您的家人或朋友所受到的护理质量情况.这份调查的结果将用来帮助确保所有美国人都能受到最高质量的临终关怀护理服务.

所附的调查问题[NOTE THE QUESTION NUMBERS]是美国卫生及公共事务部（HHS）为了衡量临终关怀机构的护理质量所倡议的一项全国调查的一部分.你的参与纯属自愿，您的健康护理或福利不受任何影响.

请花几分钟的时间填写所附的调查.填写完后，请用邮资预付的信封将它寄回给我们.您的答案可能会与临终关怀机构分享，以便改进质量.[OPTIONAL：您可能会注意到调查问卷上有个编号.这个编号是用来告诉我们您是否寄回了调查问卷，这样我们就无需向您发送提醒.]

如果您对所附的调查有任何疑问，请拨打我们的免费电话1-800-xxx-xxxx.感谢您为改善所有消费者的临终关怀护理所提供的帮助.

敬启  
[HOSPICE ADMINISTRATOR]  
[HOSPICE NAME]
OMB Paperwork Reduction Act Language

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. The following is the language that must be used:

Simplified Chinese Version
Appendix R

Mail Survey Materials (Russian)
Ответьте, пожалуйста, на вопросы относительно ухода за пациентом в этом хосписе:

[NAME OF HOSPICE]

Все вопросы данной анкеты связаны с работой данного хосписа.

Если Вы желаете получить более подробную информацию о данной анкете, позвоните, пожалуйста, по тел. [TOLL FREE NUMBER]. Все звонки на данный номер являются бесплатными.

OMB# 0938-1257
Дайте заполнить эту анкету члену семьи, наиболее осведомленному об уходе, который получил в хосписе человек, указанный в сопроводительном письме.

**ИНСТРУКЦИИ К АНКЕТЕ**

♦ Для заполнения анкеты используйте чернила темного цвета.
♦ Пишите ответы печатными буквами, пожалуйста.
♦ Поставьте X непосредственно внутри квадратика возле ответа, как показано в примере ниже.
  ✖ Да
  ☐ Нет
♦ Иногда Вам будет предложено пропустить несколько вопросов анкеты. В таком случае Вы увидите стрелку с указанием перехода к следующему вопросу, на который Вам необходимо ответить, как здесь:
  ✖ Да → Если ответ «Да», перейдите к Вопросу 1
  ☐ Нет

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**ПАЦИЕНТ ХОСПИСА**

1. Какова Ваша степень родства с пациентом, указанным в сопроводительном письме к данной анкете?

   1 ☐ Мой/моя супруг/а или партнер/ша
   2 ☐ Мой родитель
   3 ☐ Моя/мой теща/свекровь или тёсть/свекр
   4 ☐ Мой/моя дедушка/бабушка
   5 ☐ Моя/мой тетя или дядя
   6 ☐ Моя/мой сестра или брат
   7 ☐ Мой ребенок
   8 ☐ Мой друг
   9 ☐ Другое (впишите, пожалуйста, печатными буквами):

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2. В данной анкете фраза «член семьи» относится к человеку, указанному в сопроводительном письме. Где именно (в каких местах) член Вашей семьи получал помощь хосписа? Выберите один или несколько вариантов ответа.

   1 ☐ Дома
   2 ☐ В доме престарелых
   3 ☐ В центре сестринского ухода
   4 ☐ В больнице
   5 ☐ В хосписе
   6 ☐ Другое (впишите печатными буквами, пожалуйста):

______________________________
ВАША РОЛЬ

3. Пока член Вашей семьи получал хосписную помощь, как часто Вы принимали в ней участие либо наблюдаете?

1 ☐ Ни разу ➔ Если ответ «ни разу», перейдите к вопросу 41
2 ☐ Иногда
3 ☐ Как правило
4 ☐ Постоянно

ХОСПИСНАЯ ПОМОЩЬ ЧЛЕНУ ВАШЕЙ СЕМЬИ

Что касается ответов на все остальные вопросы в данной анкете, просим Вас учитывать исключительно опыт члена Вашей семьи с хосписом, указанном в сопроводительном письме.

4. Для данной анкеты хосписная команда включает весь средний медицинский персонал, докторов, социальных работников, священников и других людей, обеспечивающих хосписный уход за членом Вашей семьи. Когда член Вашей семьи получал хосписный уход, приходилось ли Вам обращаться к хосписной команде с вопросами или за помощью по поводу ухода за ним по вечерам, в выходные или праздничные дни?

1 ☐ Да
2 ☐ Нет ➔ Если ответ «Нет», перейдите к Вопросу 6

5. Как часто Вы получали необходимую Вам помощь хосписной команды по вечерам, в выходные или праздничные дни?

1 ☐ Ни разу
2 ☐ Иногда
3 ☐ Как правило
4 ☐ Всегда

6. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда информировала Вас о времени своего прибытия для оказания ему помощи?

1 ☐ Ни разу
2 ☐ Иногда
3 ☐ Как правило
4 ☐ Всегда

7. Когда член Вашей семьи получал хосписный уход, и он или Вы обращались к хосписной команде за помощью, как часто вы получали ее своевременно?

1 ☐ Ни разу
2 ☐ Иногда
3 ☐ Как правило
4 ☐ Всегда
8. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда предоставляла объяснения в простой и доступной форме?

☐ Ни разу
☐ Иногда
☐ Как правило
☐ Всегда

9. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда информировала Вас о его состоянии?

☐ Ни разу
☐ Иногда
☐ Как правило
☐ Всегда

10. Когда член Вашей семьи получал хосписный уход, как часто кто-либо из хосписной команды предоставлял Вам нечеткую либо противоречивую информацию о состоянии здоровья или уходе за членом Вашей семьи?

☐ Ни разу
☐ Иногда
☐ Как правило
☐ Всегда

11. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда относилась к нему с достоинством и уважением?

☐ Ни разу
☐ Иногда
☐ Как правило
☐ Всегда

12. Когда член Вашей семьи получал хосписный уход, как часто Вы испытывали ощущение, что хосписная команда действительно заботится о нем?

☐ Ни разу
☐ Иногда
☐ Как правило
☐ Всегда

13. Когда член Вашей семьи получал хосписный уход, обсуждали ли Вы с хосписной командой проблемы, которые возникали у Вас во время ухода за ним?

☐ Да
☐ Нет ➔ Если ответ «Нет», перейдите к Вопросу 15

14. Как часто хосписная команда внимательно Вас выслушивала, когда Вы рассказывали о проблемах, возникающих во время ухода за членом Вашей семьи?

☐ Ни разу
☐ Иногда
☐ Как правило
☐ Всегда
15. Когда член Вашей семьи получал хосписный уход, испытывал ли он боль?

| 1 | Да |
| 2 | Нет ➤ Если ответ «Нет», перейдите к Вопросу 17 |

16. Получал член Вашей семьи всю возможную необходимую ему помощь, когда испытывал боль?

| 1 | Да, несомненно |
| 2 | Да, можно так сказать |
| 3 | Нет |

17. Когда член Вашей семьи получал хосписный уход, получал ли он какие-то обезболивающие препараты?

| 1 | Да |
| 2 | Нет ➤ Если ответ «Нет», перейдите к Вопросу 21 |

18. Побочные эффекты обезболивающих препаратов включают, например, сонливость. Обсуждал ли кто-либо из хосписной команды с Вами или членом Вашей семьи побочные эффекты обезболивающих препаратов?

| 1 | Да, несомненно |
| 2 | Да, можно так сказать |
| 3 | Нет |
| 4 | У меня не было необходимости давать обезболивающие препараты члену моей семьи |

19. Проводила ли с Вами хосписная команда необходимое обучение на тему побочных эффектов, за которыми необходимо следить при приеме обезболивающих препаратов?

| 1 | Да, несомненно |
| 2 | Да, можно так сказать |
| 3 | Нет |

20. Проводила ли с Вами хосписная команда необходимое обучение относительно того, в каких случаях и когда необходимо увеличивать дозу обезболивающего препарата члену Вашей семьи?

| 1 | Да, несомненно |
| 2 | Да, можно так сказать |
| 3 | Нет |

21. Когда член Вашей семьи получал хосписный уход, были ли у него проблемы с дыханием или получал ли он лечение в связи с затруднением дыхания?

| 1 | Да |
| 2 | Нет ➤ Если ответ «Нет», перейдите к Вопросу 24 |
22. Как часто член Вашей семьи получал всю необходимую помощь вследствие затрудненного дыхания?

1 ☐ Ни разу
2 ☐ Иногда
3 ☐ Как правило
4 ☐ Всегда

23. Проводила ли с Вами хосписная команда обучение по предоставлению помощи члену Вашей семьи, когда он испытывает проблемы с дыханием?

1 ☐ Да, несомненно
2 ☐ Да, можно так сказать
3 ☐ Нет
4 ☐ У меня не было необходимости оказывать помощь члену моей семьи по поводу проблем с дыханием

24. Когда член Вашей семьи получал хосписный уход, были ли у него запоры?

1 ☐ Да
2 ☐ Нет ➞ Если ответ «Нет», перейдите к Вопросу 26

25. Как часто член Вашей семьи получал необходимую помощь вследствие запоров?

1 ☐ Ни разу
2 ☐ Иногда
3 ☐ Как правило
4 ☐ Всегда

26. Когда член Вашей семьи получал хосписный уход, испытывал ли он чувства тревоги или грусти?

1 ☐ Да
2 ☐ Нет ➞ Если ответ «Нет», перейдите к Вопросу 28

27. Как часто член Вашей семьи получал необходимую помощь хосписной команды по поводу чувств тревоги или грусти?

1 ☐ Ни разу
2 ☐ Иногда
3 ☐ Как правило
4 ☐ Всегда

28. Когда член Вашей семьи получал хосписный уход, испытывал ли он ощущение беспокойства или возбуждения?

1 ☐ Да
2 ☐ Нет ➞ Если ответ «Нет», перейдите к Вопросу 30

29. Проводила ли с Вами хосписная команда обучение на тему того, что делать в случае, если член Вашей семьи испытывает ощущение беспокойства или возбуждения?

1 ☐ Да, несомненно
2 ☐ Да, можно так сказать
3 ☐ Нет
30. Передвигать члена Вашей семьи означает помочь ему перевернуться в кровати, подняться/лечь в кровать или пересесть в инвалидную коляску. Проводила ли с Вами хосписная команда необходимое обучение на тему того, каким образом Вы можете безопасно передвигать члена Вашей семьи?

1 □ Да, несомненно
2 □ Да, можно так сказать
3 □ Нет
4 □ У меня не было необходимости передвигать члена моей семьи

31. Предоставляла ли Вам хосписная команда всю необходимую информацию относительно того, что ожидать, когда умирал член Вашей семьи?

1 □ Да, несомненно
2 □ Да, можно так сказать
3 □ Нет

32. Некоторые люди получают хосписный уход, проживая в центре сестринского ухода. Получал ли член Вашей семьи уход от данного хосписа, проживая в центре сестринского ухода?

1 □ Да
2 □ Нет ➔ Если ответ «Нет», перейдите к Вопросу 35

33. Пока член Вашей семьи получал хосписный уход, как часто сотрудники центра сестринского ухода эффективно сотрудничали с хосписной командой, чтобы вместе заботиться о члене Вашей семьи?

1 □ Ни разу
2 □ Иногда
3 □ Как правило
4 □ Всегда

34. Пока член Вашей семьи получал хосписный уход, как часто информация о члене Вашей семьи, которую Вы получали от сотрудников центра сестринского ухода, отличалась от данных, предоставленных хосписной командой?

1 □ Ни разу
2 □ Иногда
3 □ Как правило
4 □ Всегда

Ваш Опыт с Хосписом

35. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда внимательно выслушивала Вас?

1 □ Ни разу
2 □ Иногда
3 □ Как правило
4 □ Всегда
36. Поддержка религиозных или духовных убеждений подразумевает беседы, молитвы, уединение или другие способы удовлетворения религиозных или духовных потребностей. Когда член Вашей семьи получал хосписный уход, насколько велика была поддержка Ваших религиозных или духовных убеждений со стороны хосписной команды?

☐ Слишком мала
☐ Достаточная
☐ Чрезмерная

37. Когда член Вашей семьи получал хосписный уход, насколько велика была эмоциональная поддержка со стороны хосписной команды?

☐ Слишком мала
☐ Достаточная
☐ Чрезмерная

38. В ближайшие недели после смерти члена Вашей семьи, насколько велика была эмоциональная поддержка со стороны хосписной команды?

☐ Слишком мала
☐ Достаточная
☐ Чрезмерная

39. Ответьте, пожалуйста, на следующие вопросы относительно ухода за членом Вашей семьи хосписом, указанным в сопроводительном письме к данной анкете. Просим в своих ответах не упоминать об уходе, полученном в других хосписах.

Используя шкалу от 1 до 10, где 0 означает наихудшее качество, а 10 — наилучшее качество хосписного ухода, которое только можно представить, оцените хосписный уход за членом Вашей семьи?

☐ 0 0 Найхудшее качество хосписного ухода, которое только можно представить
☐ 1
☐ 2
☐ 3
☐ 4
☐ 5
☐ 6
☐ 7
☐ 8
☐ 9
☐ 10 10 Наилучшее качество хосписного ухода, которое только можно представить
40. Порекомендовали ли бы Вы данный хоспис своим друзьям и семье?

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1</td>
<td>□ Точно нет</td>
</tr>
<tr>
<td>2</td>
<td>□ Скорее всего, нет</td>
</tr>
<tr>
<td>3</td>
<td>□ Скорее всего, да</td>
</tr>
<tr>
<td>4</td>
<td>□ Да, несомненно</td>
</tr>
</tbody>
</table>

**Информация о члене Вашей семьи**

41. Какое образование получил член Вашей семьи?

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1</td>
<td>□ 8 классов и меньше</td>
</tr>
<tr>
<td>2</td>
<td>□ Учился в старших классах, но не окончил школу</td>
</tr>
<tr>
<td>3</td>
<td>□ Окончил среднюю школу</td>
</tr>
<tr>
<td>4</td>
<td>□ Колледж или диплом о двухгодичном обучении</td>
</tr>
<tr>
<td>5</td>
<td>□ Четырехгодичное законченное высшее образование</td>
</tr>
<tr>
<td>6</td>
<td>□ Обучение свыше четырех лет высшего образования</td>
</tr>
<tr>
<td>7</td>
<td>□ Не знаю</td>
</tr>
</tbody>
</table>

42. Был ли член Вашей семьи испанского либо латино-американского происхождения?

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1</td>
<td>□ Нет, он не испанского/латино-американского происхождения</td>
</tr>
<tr>
<td>2</td>
<td>□ Да, он пуэрториканец</td>
</tr>
<tr>
<td>3</td>
<td>□ Да, он мексиканец, мексикано-американец, американец мексиканского происхождения</td>
</tr>
<tr>
<td>4</td>
<td>□ Да, он кубинец</td>
</tr>
<tr>
<td>5</td>
<td>□ Да, другого испанского/латино-американского происхождения</td>
</tr>
</tbody>
</table>

43. К какой расовой группе принадлежал член Вашей семьи? Выберите, пожалуйста, один или несколько вариантов ответа.

<p>| | |</p>
<table>
<thead>
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<th></th>
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<tbody>
<tr>
<td>1</td>
<td>□ Белая раса</td>
</tr>
<tr>
<td>2</td>
<td>□ Черная раса или афро-американец</td>
</tr>
<tr>
<td>3</td>
<td>□ Азиат</td>
</tr>
<tr>
<td>4</td>
<td>□ Коренной гаваец или уроженец других островов Тихого океана</td>
</tr>
<tr>
<td>5</td>
<td>□ Американский индеец или уроженец Аляски</td>
</tr>
</tbody>
</table>
### ИНФОРМАЦИЯ О ВАС

44. Сколько Вам лет?
- [ ] ☐ От 18 до 24 лет
- [ ] ☐ От 25 до 34 лет
- [ ] ☐ От 35 до 44 лет
- [ ] ☐ От 45 до 54 лет
- [ ] ☐ От 55 до 64 лет
- [ ] ☐ От 65 до 74 лет
- [ ] ☐ От 75 до 84 лет
- [ ] ☐ 85 лет или старше

45. Ваш пол?
- [ ] ☐ Мужской
- [ ] ☐ Женский

46. Какое образование Вы получили?
- [ ] ☐ 8 классов и меньше
- [ ] ☐ Учился в старших классах, но не окончил школу
- [ ] ☐ Окончил среднюю школу
- [ ] ☐ Колледж или диплом о двухгодичном обучении
- [ ] ☐ Четырехгодичное законченное высшее образование
- [ ] ☐ Обучение свыше четырех лет высшего образования

47. На каком языке Вы в основном общаетесь дома?
- [ ] ☐ Английский
- [ ] ☐ Испанский
- [ ] ☐ Китайский
- [ ] ☐ Русский
- [ ] ☐ Португальский
- [ ] ☐ Вьетнамский
- [ ] ☐ Другой язык (укажите печатными буквами):

---

Спасибо

Отправьте, пожалуйста, заполненную анкету в конверте с предварительно оплаченным почтовым сбором.

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
Анкетирование на тему хосписной помощи CAHPS®

Ответьте, пожалуйста, на вопросы относительно ухода за пациентом в этом хосписе:

[NAME OF HOSPICE]

Все вопросы данной анкеты связаны с работой данного хосписа.

Если Вы желаете получить более подробную информацию о данной анкете, позвоните, пожалуйста, по тел. [TOLL FREE NUMBER]. Все звонки на данный номер являются бесплатными.

OMB# 0938-1257
Дайте заполнить эту анкету члену семьи, наиболее осведомленному об уходе, который получил в хосписе человек, указанный в сопроводительном письме.

**Инструкции к анкете**

♦ Для заполнения анкеты используйте чернила темного цвета.

♦ Пишите ответы печатными буквами, пожалуйста.

♦ Поставьте X непосредственно внутри овала возле ответа, как показано в примере ниже.

  0 Да
  0 Нет

♦ Иногда Вам будет предложено пропустить несколько вопросов анкеты. В таком случае Вы увидите стрелку с указанием перехода к следующему вопросу, на который Вам необходимо ответить, как здесь:

  0 Да ➔ Если ответ «Да», перейдите к Вопросу 1
  0 Нет

---

**Пациент хосписа**

1. Какова Ваша степень родства с пациентом, указанным в сопроводительном письме к данной анкете?

  1 0 Мой/моя супруг/а или партнер/ша
  2 0 Мой родитель
  3 0 Моя/мой теща/свекровь или тещь/свекр
  4 0 Мой/моя дедушка/бабушка
  5 0 Моя/мой тетя или дядя
  6 0 Моя/мой сестра или брат
  7 0 Мой ребенок
  8 0 Мой друг
  9 0 Другое (впишите, пожалуйста, печатными буквами):

2. В данной анкете фраза «член семьи» относится к человеку, указанному в сопроводительном письме. Где именно (в каких местах) член Вашей семьи получил помощь хосписа? Выберите один или несколько вариантов ответа.

  1 0 Дома
  2 0 В доме престарелых
  3 0 В центре сестринского ухода
  4 0 В больнице
  5 0 В хосписе
  6 0 Другое (впишите печатными буквами, пожалуйста):

______________________________
### ВАША РОЛЬ

3. Пока член Вашей семьи получал хосписную помощь, как часто Вы принимали в ней участие либо наблюдали?

<table>
<thead>
<tr>
<th>Опция</th>
<th>Описание</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 0</td>
<td>Ни разу → Если ответ «ни разу», перейдите к вопросу 41</td>
</tr>
<tr>
<td>2 0</td>
<td>Иногда</td>
</tr>
<tr>
<td>3 0</td>
<td>Как правило</td>
</tr>
<tr>
<td>4 0</td>
<td>Постоянно</td>
</tr>
</tbody>
</table>

### ХОСПИСНАЯ ПОМОЩЬ ЧЛЕНУ ВАШЕЙ СЕМЬИ

Что касается ответов на все остальные вопросы в данной анкете, просим Вас учитывать исключительно опыт члена Вашей семьи с хосписом, указанном в сопроводительном письме.

4. Для данной анкеты хосписная команда включает весь средний медицинский персонал, докторов, социальных работников, священников и других людей, обеспечивающих хосписный уход за членом Вашей семьи. Когда член Вашей семьи получал хосписный уход, приходилось ли Вам обращаться к хосписной команде с вопросами или за помощью по поводу ухода за ним по вечерам, в выходные или праздничные дни?

<table>
<thead>
<tr>
<th>Опция</th>
<th>Описание</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 0</td>
<td>Да</td>
</tr>
<tr>
<td>2 0</td>
<td>Нет → Если ответ «Нет», перейдите к Вопросу 6</td>
</tr>
</tbody>
</table>

5. Как часто Вы получали необходимую Вам помощь хосписной команды по вечерам, в выходные или праздничные дни?

<table>
<thead>
<tr>
<th>Опция</th>
<th>Описание</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 0</td>
<td>Ни разу</td>
</tr>
<tr>
<td>2 0</td>
<td>Иногда</td>
</tr>
<tr>
<td>3 0</td>
<td>Как правило</td>
</tr>
<tr>
<td>4 0</td>
<td>Всегда</td>
</tr>
</tbody>
</table>

6. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда информировала Вас о времени своего прибытия для оказания ему помощи?

<table>
<thead>
<tr>
<th>Опция</th>
<th>Описание</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 0</td>
<td>Ни разу</td>
</tr>
<tr>
<td>2 0</td>
<td>Иногда</td>
</tr>
<tr>
<td>3 0</td>
<td>Как правило</td>
</tr>
<tr>
<td>4 0</td>
<td>Всегда</td>
</tr>
</tbody>
</table>

7. Когда член Вашей семьи получал хосписный уход, и он или Вы обращались к хосписной команде за помощью, как часто вы получали ее своевременно?

<table>
<thead>
<tr>
<th>Опция</th>
<th>Описание</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 0</td>
<td>Ни разу</td>
</tr>
<tr>
<td>2 0</td>
<td>Иногда</td>
</tr>
<tr>
<td>3 0</td>
<td>Как правило</td>
</tr>
<tr>
<td>4 0</td>
<td>Всегда</td>
</tr>
</tbody>
</table>

8. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда предоставляла объяснения в простой и доступной форме?

<table>
<thead>
<tr>
<th>Опция</th>
<th>Описание</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 0</td>
<td>Ни разу</td>
</tr>
<tr>
<td>2 0</td>
<td>Иногда</td>
</tr>
<tr>
<td>3 0</td>
<td>Как правило</td>
</tr>
<tr>
<td>4 0</td>
<td>Всегда</td>
</tr>
</tbody>
</table>
9. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда информировала Вас о его состоянии?

1 0 Ни разу  
2 0 Иногда  
3 0 Как правило  
4 0 Всегда

10. Когда член Вашей семьи получал хосписный уход, как часто кто-либо из хосписной команды предоставлял Вам нечеткую либо противоречивую информацию о состоянии здоровья или уходе за членом Вашей семьи?

1 0 Ни разу  
2 0 Иногда  
3 0 Как правило  
4 0 Всегда

11. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда относилась к нему с достоинством и уважением?

1 0 Ни разу  
2 0 Иногда  
3 0 Как правило  
4 0 Всегда

12. Когда член Вашей семьи получал хосписный уход, как часто Вы испытывали ощущение, что хосписная команда действительно заботится о нем?

1 0 Ни разу  
2 0 Иногда  
3 0 Как правило  
4 0 Всегда

13. Когда член Вашей семьи получал хосписный уход, обсуждали ли Вы с хосписной командой проблемы, которые возникали у Вас во время ухода за ним?

1 0 Да  
2 0 Нет ➔ Если ответ «Нет», перейдите к Вопросу 15

14. Как часто хосписная команда внимательно Вас выслушивала, когда Вы рассказывали о проблемах, возникающих во время ухода за членом Вашей семьи?

1 0 Ни разу  
2 0 Иногда  
3 0 Как правило  
4 0 Всегда

15. Когда член Вашей семьи получал хосписный уход, испытывал ли он боль?

1 0 Да  
2 0 Нет ➔ Если ответ «Нет», перейдите к Вопросу 17

16. Получал член Вашей семьи всю возможную необходимую ему помощь, когда испытывал боль?

1 0 Да, несомненно  
2 0 Да, можно так сказать  
3 0 Нет

17. Когда член Вашей семьи получал хосписный уход, получил ли он какие-то обезболивающие препараты?

1 0 Да  
2 0 Нет ➔ Если ответ «Нет», перейдите к Вопросу 21
18. Побочные эффекты обезболивающих препаратов включают, например, сонливость. Обсуждал ли кто-либо из хосписной команды с Вами или членом Вашей семьи побочные эффекты обезболивающих препаратов?

1 Да, несомненно
2 Да, можно так сказать
3 Нет

19. Проводила ли с Вами хосписная команда необходимое обучение на тему побочных эффектов, за которыми необходимо следить при приеме обезболивающих препаратов?

1 Да, несомненно
2 Да, можно так сказать
3 Нет

20. Проводила ли с Вами хосписная команда необходимое обучение относительно того, в каких случаях и когда необходимо увеличивать дозу обезболивающего препарата члену Вашей семьи?

1 Да, несомненно
2 Да, можно так сказать
3 Нет
4 У меня не было необходимости давать обезболивающие препараты члену моей семьи

21. Когда член Вашей семьи получал хосписный уход, были ли у него проблемы с дыханием или получал ли он лечение в связи с затруднением дыхания?

1 Да
2 Нет ➔ Если ответ «Нет», перейдите к Вопросу 24

22. Как часто член Вашей семьи получал всю необходимую помощь вследствие затрудненного дыхания?

1 Ни разу
2 Иногда
3 Как правило
4 Всегда

23. Проводила ли с Вами хосписная команда обучение по предоставлению помощи члену Вашей семьи, когда он испытывает проблемы с дыханием?

1 Да, несомненно
2 Да, можно так сказать
3 Нет
4 У меня не было необходимости оказывать помощь члену моей семьи по поводу проблем с дыханием

24. Когда член Вашей семьи получал хосписный уход, были ли у него запоры?

1 Да
2 Нет ➔ Если ответ «Нет», перейдите к Вопросу 26

25. Как часто член Вашей семьи получал необходимую помощь вследствие запоров?

1 Ни разу
2 Иногда
3 Как правило
4 Всегда
26. Когда член Вашей семьи получал хосписный уход, испытывал ли он чувства тревоги или грусти?

1 0 Да
2 0 Нет ➔ Если ответ «Нет», перейдите к Вопросу 28

27. Как часто член Вашей семьи получал необходимую помощь хосписной команды по поводу чувств тревоги или грусти?

1 0 Ни разу
2 0 Иногда
3 0 Как правило
4 0 Всегда

28. Когда член Вашей семьи получал хосписный уход, испытывал ли он ощущение беспокойства или возбуждения?

1 0 Да
2 0 Нет ➔ Если ответ «Нет», перейдите к Вопросу 30

29. Проводила ли с Вами хосписная команда обучение на тему того, что делать в случае, если член Вашей семьи испытывает ощущение беспокойства или возбуждения?

1 0 Да, несомненно
2 0 Да, можно так сказать
3 0 Нет
4 0 У меня не было необходимости передвигать члена моей семьи

30. Передвигать члена Вашей семьи означает помощь ему перевернуться в кровати, подняться/лечь в кровать или пересесть в инвалидную коляску. Проводила ли с Вами хосписная команда необходимое обучение на тему того, каким образом Вы можете безопасно передвигать члена Вашей семьи?

1 0 Да, несомненно
2 0 Да, можно так сказать
3 0 Нет
4 0 У меня не было необходимости передвигать члена моей семьи

31. Предоставляла ли Вам хосписная команда всю необходимую информацию относительно того, чего ожидать, когда умирал член Вашей семьи?

1 0 Да, несомненно
2 0 Да, можно так сказать
3 0 Нет

32. Некоторые люди получают хосписный уход, проживая в центре сестринского ухода. Получал ли член Вашей семьи уход от данного хоспина, проживая в центре сестринского ухода?

1 0 Да
2 0 Нет ➔ Если ответ «Нет», перейдите к Вопросу 35
33. Пока член Вашей семьи получал хосписный уход, как часто сотрудники центра сестринского ухода эффективно сотрудничали с хосписной командой, чтобы вместе заботиться о члене Вашей семьи?

1. 0 Ни разу
2. 0 Иногда
3. 0 Как правило
4. 0 Всегда

34. Пока член Вашей семьи получал хосписный уход, как часто информация о члене Вашей семьи, которую Вы получали от сотрудников центра сестринского ухода, отличалась от данных, предоставляемых хосписной командой?

1. 0 Ни разу
2. 0 Иногда
3. 0 Как правило
4. 0 Всегда

35. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда внимательно выслушивала Вас?

1. 0 Ни разу
2. 0 Иногда
3. 0 Как правило
4. 0 Всегда

36. Поддержка религиозных или духовных убеждений подразумевает беседы, молитвы, уединение или другие способы удовлетворения религиозных или духовных потребностей. Когда член Вашей семьи получал хосписный уход, насколько велика была поддержка Ваших религиозных или духовных убеждений со стороны хосписной команды?

1. 0 Слишком мала
2. 0 Достаточная
3. 0 Чрезмерная

37. Когда член Вашей семьи получал хосписный уход, насколько велика была эмоциональная поддержка со стороны хосписной команды?

1. 0 Слишком мала
2. 0 Достаточная
3. 0 Чрезмерная

38. В ближайшие недели после смерти члена Вашей семьи, насколько велика была эмоциональная поддержка со стороны хосписной команды?

1. 0 Слишком мала
2. 0 Достаточная
3. 0 Чрезмерная
39. Ответьте, пожалуйста, на следующие вопросы относительно ухода за членом Вашей семьи хосписом, указанным в сопроводительном письме к данной анкете. Просим в своих ответах не упоминать об уходе, полученном в других хосписах.
Используя шкалу от 1 до 10, где 0 означает наихудшее качество, а 10 — наилучшее качество хосписного ухода, которое только можно представить, оцените хосписный уход за членом Вашей семьи?

<table>
<thead>
<tr>
<th>Оценка</th>
<th>Описание</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 0 0</td>
<td>Наихудшее качество хосписного ухода, которое только можно представить</td>
</tr>
<tr>
<td>1 0 1</td>
<td></td>
</tr>
<tr>
<td>2 0 2</td>
<td></td>
</tr>
<tr>
<td>3 0 3</td>
<td></td>
</tr>
<tr>
<td>4 0 4</td>
<td></td>
</tr>
<tr>
<td>5 0 5</td>
<td></td>
</tr>
<tr>
<td>6 0 6</td>
<td></td>
</tr>
<tr>
<td>7 0 7</td>
<td></td>
</tr>
<tr>
<td>8 0 8</td>
<td></td>
</tr>
<tr>
<td>9 0 9</td>
<td></td>
</tr>
<tr>
<td>10 0 10</td>
<td>Наилучшее качество хосписного ухода, которое только можно представить</td>
</tr>
</tbody>
</table>

40. Порекомендовали ли бы Вы данный хоспис своим друзьям и семье?

<table>
<thead>
<tr>
<th>Оценка</th>
<th>Описание</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 0</td>
<td>Точно нет</td>
</tr>
<tr>
<td>2 0</td>
<td>Скорее всего, нет</td>
</tr>
<tr>
<td>3 0</td>
<td>Скорее всего, да</td>
</tr>
<tr>
<td>4 0</td>
<td>Да, несомненно</td>
</tr>
</tbody>
</table>

41. Какое образование получили член Вашей семьи?

<table>
<thead>
<tr>
<th>Оценка</th>
<th>Описание</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 0</td>
<td>8 классов и меньше</td>
</tr>
<tr>
<td>2 0</td>
<td>Учился в старших классах, но не окончил школу</td>
</tr>
<tr>
<td>3 0</td>
<td>Окончил среднюю школу</td>
</tr>
<tr>
<td>4 0</td>
<td>Колледж или диплом о двухгодичном обучении</td>
</tr>
<tr>
<td>5 0</td>
<td>Четырехгодичное законченное высшее образование</td>
</tr>
<tr>
<td>6 0</td>
<td>Обучение свыше четырех лет высшего образования</td>
</tr>
<tr>
<td>7 0</td>
<td>Не знаю</td>
</tr>
</tbody>
</table>

42. Был ли член Вашей семьи испанского либо латино-американского происхождения?

<table>
<thead>
<tr>
<th>Оценка</th>
<th>Описание</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 0</td>
<td>Нет, он не испанского/латино-американского происхождения</td>
</tr>
<tr>
<td>2 0</td>
<td>Да, он пуэрториканец</td>
</tr>
<tr>
<td>3 0</td>
<td>Да, он мексиканец, мексикано-американец, американец мексиканского происхождения</td>
</tr>
<tr>
<td>4 0</td>
<td>Да, он кубинец</td>
</tr>
<tr>
<td>5 0</td>
<td>Да, другого испанского/латино-американского происхождения</td>
</tr>
</tbody>
</table>

43. К какой расовой группе принадлежал член Вашей семьи? Выберите, пожалуйста, один или несколько вариантов ответа.

<table>
<thead>
<tr>
<th>Оценка</th>
<th>Описание</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 0</td>
<td>Белая раса</td>
</tr>
<tr>
<td>2 0</td>
<td>Черная раса или афро-американец</td>
</tr>
<tr>
<td>3 0</td>
<td>Азиат</td>
</tr>
<tr>
<td>4 0</td>
<td>Коренной гаваец или уроженец других островов Тихого океана</td>
</tr>
<tr>
<td>5 0</td>
<td>Американский индеец или уроженец Аляски</td>
</tr>
</tbody>
</table>
Информация о Вас

44. Сколько Вам лет?

1 0 От 18 до 24 лет
2 0 От 25 до 34 лет
3 0 От 35 до 44 лет
4 0 От 45 до 54 лет
5 0 От 55 до 64 лет
6 0 От 65 до 74 лет
7 0 От 75 до 84 лет
8 0 85 лет или старше

45. Ваш пол?

1 0 Мужской
2 0 Женский

46. Какое образование Вы получили?

1 0 8 классов и меньше
2 0 Учился в старших классах, но не окончил школу
3 0 Окончил среднюю школу
4 0 Колледж или диплом о двухгодичном обучении
5 0 Четырехгодичное законченное высшее образование
6 0 Обучение свыше четырех лет высшего образования

47. На каком языке Вы в основном общаетесь дома?

1 0 Английский
2 0 Испанский
3 0 Китайский
4 0 Русский
5 0 Португальский
6 0 Вьетнамский
7 0 Другой язык (укажите печатными буквами):
________________________

Спасибо

Отправьте, пожалуйста, заполненную анкету в конверте с предварительно оплаченным почтовым сбором.

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
Ответьте, пожалуйста, на вопросы относительно ухода за пациентом в этом хосписе:

[NAME OF HOSPICE]

Все вопросы данной анкеты связаны с работой данного хосписа.

Если Вы желаете получить более подробную информацию о данной анкете, позвоните, пожалуйста, по тел. [TOLL FREE NUMBER]. Все звонки на данный номер являются бесплатными.

OMB# 0938-1257
Дайте заполнить эту анкету члену семьи, наиболее осведомленному об уходе, который получил в хосписе человек, указанный в сопроводительном письме.

**ИНСТРУКЦИИ К АНКЕТЕ**

♦ Для заполнения анкеты используйте чернила темного цвета.
♦ Пишите ответы печатными буквами, пожалуйста.
♦ Поставьте X непосредственно внутри кружка возле ответа, как показано в примере ниже.
  ● Да
  ○ Нет
♦ Иногда Вам будет предложено пропустить несколько вопросов анкеты. В таком случае Вы увидите стрелку с указанием перехода к следующему вопросу, на который Вам необходимо ответить, как здесь:
  ● Да ➔ Если ответ «Да», перейдите к Вопросу 1
  ○ Нет

### ПАЦИЕНТ ХОСПИСА

1. Какова Ваша степень родства с пациентом, указанным в сопроводительном письме к данной анкете?
   1 ○ Мой/моя супруг/а или партнер/ша
   2 ○ Мой родитель
   3 ○ Моя/мой теща/свекровь или тесть/свекр
   4 ○ Мой/моя дедушка/бабушка
   5 ○ Моя/мой тетя или дядя
   6 ○ Моя/мой сестра или брат
   7 ○ Мой ребенок
   8 ○ Мой друг
   9 ○ Другое (впишите, пожалуйста, печатными буквами):

2. В данной анкете фраза «член семьи» относится к человеку, указанному в сопроводительном письме. Где именно (в каких местах) член Вашей семьи получал помощь хосписа? Выберите один или несколько вариантов ответа.
   1 ○ Дома
   2 ○ В доме престарелых
   3 ○ В центре сестринского ухода
   4 ○ В больнице
   5 ○ В хосписе
   6 ○ Другое (впишите печатными буквами, пожалуйста):

____________________________
ВАША РОЛЬ

3. Пока член Вашей семьи получал хосписную помощь, как часто Вы принимали в ней участие либо наблюдали?

1. О Ни разу ➞ Если ответ «ни разу», перейдите к вопросу 41
2. О Иногда
3. О Как правило
4. О Постоянно

ХОСПИНАЯ ПОМОЩЬ ЧЛЕНУ
ВАШЕЙ СЕМЬИ

Что касается ответов на все остальные вопросы в данной анкете, просим Вас учитывать исключительно опыт члена Вашей семьи с хосписом, указанном в сопроводительном письме.

4. Для данной анкеты хосписная команда включает весь средний медицинский персонал, докторов, социальных работников, священников и других людей, обеспечивающих хосписный уход за членом Вашей семьи. Когда член Вашей семьи получал хосписный уход, приходилось ли Вам обращаться к хосписной команде с вопросами или за помощью по поводу ухода за ним по вечерам, в выходные или праздничные дни?

1. О Да
2. О Нет ➞ Если ответ «Нет», перейдите к Вопросу 6

5. Как часто Вы получали необходимую Вам помощь хосписной команды по вечерам, в выходные или праздничные дни?

1. О Ни разу
2. О Иногда
3. О Как правило
4. О Всегда

6. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда информировала Вас о времени своего прибытия для оказания ему помощи?

1. О Ни разу
2. О Иногда
3. О Как правило
4. О Всегда

7. Когда член Вашей семьи получал хосписный уход, он или Вы обращались к хосписной команде за помощью, как часто вы получали ее своевременно?

1. О Ни разу
2. О Иногда
3. О Как правило
4. О Всегда

8. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда предоставляла объяснения в простой и доступной форме?

1. О Ни разу
2. О Иногда
3. О Как правило
4. О Всегда
9. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда информировала Вас о его состоянии?

1. Ни разу
2. Иногда
3. Как правило
4. Всегда

10. Когда член Вашей семьи получал хосписный уход, как часто кто-либо из хосписной команды предоставлял Вам нечеткую либо противоречивую информацию о состоянии здоровья или уходе за членом Вашей семьи?

1. Ни разу
2. Иногда
3. Как правило
4. Всегда

11. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда относилась к нему с достоинством и уважением?

1. Ни разу
2. Иногда
3. Как правило
4. Всегда

12. Когда член Вашей семьи получал хосписный уход, как часто Вы испытывали ощущение, что хосписная команда действительно заботится о нем?

1. Ни разу
2. Иногда
3. Как правило
4. Всегда

13. Когда член Вашей семьи получал хосписный уход, обсуждали ли Вы с хосписной командой проблемы, которые возникали у Вас во время ухода за ним?

1. Да
2. Нет ➔ Если ответ «Нет», перейдите к Вопросу 15

14. Как часто хосписная команда внимательно Вас выслушивала, когда Вы рассказывали о проблемах, возникающих во время ухода за членом Вашей семьи?

1. Ни разу
2. Иногда
3. Как правило
4. Всегда

15. Когда член Вашей семьи получал хосписный уход, испытывал ли он боль?

1. Да
2. Нет ➔ Если ответ «Нет», перейдите к Вопросу 17

16. Получал член Вашей семьи всю возможную необходимую ему помощь, когда испытывал боль?

1. Да, несомненно
2. Да, можно так сказать
3. Нет

17. Когда член Вашей семьи получал хосписный уход, получал ли он какие-то обезболивающие препараты?

1. Да
2. Нет ➔ Если ответ «Нет», перейдите к Вопросу 21
18. Побочные эффекты обезболивающих препаратов включают, например, сонливость. Обсуждал ли кто-либо из хосписной команды с Вами или членом Вашей семьи побочные эффекты обезболивающих препаратов?

1 ○ Да, несомненно
2 ○ Да, можно так сказать
3 ○ Нет

19. Проводила ли с Вами хосписная команда необходимое обучение на тему побочных эффектов, за которыми необходимо следить при приеме обезболивающих препаратов?

1 ○ Да, несомненно
2 ○ Да, можно так сказать
3 ○ Нет

20. Проводила ли с Вами хосписная команда необходимое обучение относительно того, в каких случаях и когда необходимо увеличивать дозу обезболивающего препарата члену Вашей семьи?

1 ○ Да, несомненно
2 ○ Да, можно так сказать
3 ○ Нет
4 ○ У меня не было необходимости давать обезболивающие препараты члену моей семьи

21. Когда член Вашей семьи получал хосписный уход, были ли у него проблемы с дыханием или получал ли он лечение в связи с затруднением дыхания?

1 ○ Да
2 ○ Нет ➔ Если ответ «Нет», перейдите к Вопросу 24

22. Как часто член Вашей семьи получал всю необходимую помощь вследствие затрудненного дыхания?

1 ○ Ни разу
2 ○ Иногда
3 ○ Как правило
4 ○ Всегда

23. Проводила ли с Вами хосписная команда обучение по предоставлению помощи члену Вашей семьи, когда он испытывает проблемы с дыханием?

1 ○ Да, несомненно
2 ○ Да, можно так сказать
3 ○ Нет
4 ○ У меня не было необходимости оказывать помощь члену моей семьи по поводу проблем с дыханием

24. Когда член Вашей семьи получал хосписный уход, были ли у него запоры?

1 ○ Да
2 ○ Нет ➔ Если ответ «Нет», перейдите к Вопросу 26

25. Как часто член Вашей семьи получал необходимую помощь вследствие запоров?

1 ○ Ни разу
2 ○ Иногда
3 ○ Как правило
4 ○ Всегда
26. Когда член Вашей семьи получал хосписный уход, испытывал ли он чувства тревоги или грусти?

1 О Да
2 О Нет ➔ Если ответ «Нет», перейдите к Вопросу 28

27. Как часто член Вашей семьи получал необходимую помощь хосписной команды по поводу чувств тревоги или грусти?

1 О Ни разу
2 О Иногда
3 О Как правило
4 О Всегда

28. Когда член Вашей семьи получал хосписный уход, испытывал ли он ощущение беспокойства или возбуждения?

1 О Да
2 О Нет ➔ Если ответ «Нет», перейдите к Вопросу 30

29. Проводила ли с Вами хосписная команда обучение на тему того, что делать в случае, если член Вашей семьи испытывает ощущение беспокойства или возбуждения?

1 О Да, несомненно
2 О Да, можно так сказать
3 О Нет
4 О У меня не было необходимости передвигать члена моей семьи

30. Передвигать члена Вашей семьи означает помощь ему перевернуться в кровати, подняться/лечь в кровать или пересесть в инвалидную коляску. Проводила ли с Вами хосписная команда необходимое обучение на тему того, каким образом Вы можете безопасно передвигать члена Вашей семьи?

1 О Да, несомненно
2 О Да, можно так сказать
3 О Нет
4 О У меня не было необходимости передвигать члена моей семьи

31. Предоставляла ли Вам хосписная команда всю необходимую информацию относительно того, чего ожидать, когда умирал член Вашей семьи?

1 О Да, несомненно
2 О Да, можно так сказать
3 О Нет

32. Некоторые люди получают хосписный уход, проживая в центре сестринского ухода. Получал ли член Вашей семьи уход от данного хосписа, проживая в центре сестринского ухода?

1 О Да
2 О Нет ➔ Если ответ «Нет», перейдите к Вопросу 35
33. Пока член Вашей семьи получал хосписный уход, как часто сотрудники центра сестринского ухода эффективно сотрудничали с хосписной командой, чтобы вместе заботиться о члене Вашей семьи?

1 О НИ РАЗУ
2 О Иногда
3 О Как правило
4 О Всегда

34. Пока член Вашей семьи получал хосписный уход, как часто информация о члене Вашей семьи, которую Вы получали от сотрудников центра сестринского ухода, отличалась от данных, предоставленных хосписной командой?

1 О НИ РАЗУ
2 О Иногда
3 О Как правило
4 О Всегда

35. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда внимательно выслушивала Вас?

1 О НИ РАЗУ
2 О Иногда
3 О Как правило
4 О Всегда

36. Поддержка религиозных или духовных убеждений подразумевает беседы, молитвы, уединение или другие способы удовлетворения религиозных или духовных потребностей. Когда член Вашей семьи получал хосписный уход, насколько велика была поддержка Ваших религиозных или духовных убеждений со стороны хосписной команды?

1 О СЛИШКОМ МАЛА
2 О ДОСТАТОЧНАЯ
3 О ЧРЕЗМЕРНАЯ

37. Когда член Вашей семьи получал хосписный уход, насколько велика была эмоциональная поддержка со стороны хосписной команды?

1 О СЛИШКОМ МАЛА
2 О ДОСТАТОЧНАЯ
3 О ЧРЕЗМЕРНАЯ

38. В ближайшие недели после смерти члена Вашей семьи, насколько велика была эмоциональная поддержка со стороны хосписной команды?

1 О СЛИШКОМ МАЛА
2 О ДОСТАТОЧНАЯ
3 О ЧРЕЗМЕРНАЯ
### Общая оценка хосписного ухода

39. Ответьте, пожалуйста, на следующие вопросы относительно ухода за членом Вашей семьи хосписом, указанным в сопроводительном письме к данной анкете. Просим в своих ответах не упоминать об уходе, полученном в других хосписах.

Используя шкалу от 1 до 10, где 0 означает наихудшее качество, а 10 — наилучшее качество хосписного ухода, которое только можно представить, оцените хосписный уход за членом Вашей семьи?

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<td>0 Наихудшее качество хосписного ухода, которое только можно представить</td>
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<td>10</td>
<td>10 Наилучшее качество хосписного ухода, которое только можно представить</td>
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### Информация о члене Вашей семьи

40. Порекомендовали ли бы Вы данный хоспис своим друзьям и семье?

1. Четко нет
2. Скорее всего, нет
3. Скорее всего, да
4. Да, несомненно

### Информация о члене Вашей семьи

41. Какое образование получил член Вашей семьи?

1. 8 классов и меньше
2. Учился в старших классах, но не окончил школу
3. Окончил среднюю школу
4. Колледж или диплом о двухгодичном обучении
5. Четырехгодичное законченное высшее образование
6. Обучение свыше четырех лет высшего образования
7. Не знаю

42. Был ли член Вашей семьи испанского либо латиноамериканского происхождения?

1. Нет, он не испанского/латиноамериканского происхождения
2. Да, он пуэрториканец
3. Да, он мексиканец, мексикано-американец, американец мексиканского происхождения
4. Да, он кубинец
5. Да, другого испанского/латиноамериканского происхождения
43. К какой расовой группе принадлежал член Вашей семьи? Выберите, пожалуйста, один или несколько вариантов ответа.

1 О Белая раса
2 О Черная раса или афро-американец
3 О Азиат
4 О Коренной гаваец или уроженец других островов Тихого океана
5 О Американский индеец или уроженец Аляски

44. Сколько Вам лет?

1 О От 18 до 24 лет
2 О От 25 до 34 лет
3 О От 35 до 44 лет
4 О От 45 до 54 лет
5 О От 55 до 64 лет
6 О От 65 до 74 лет
7 О От 75 до 84 лет
8 О 85 лет или старше

45. Ваш пол?

1 О Мужской
2 О Женский

46. Какое образование Вы получили?

1 О 8 классов и меньше
2 О Учился в старших классах, но не окончил школу
3 О Окончил среднюю школу
4 О Колледж или диплом о двухгодичном обучении
5 О Четырехгодичное законченное высшее образование
6 О Обучение свыше четырех лет высшего образования

47. На каком языке Вы в основном общаетесь дома?

1 О Английский
2 О Испанский
3 О Китайский
4 О Русский
5 О Португальский
6 О Вьетнамский
7 О Другой язык (укажите печатными буквами):

____________________________________________________________________

Спасибо

Отправьте, пожалуйста, заполненную анкету в конверте с предварительно оплаченным почтовым сбором.

[[NAME OF SURVEY VENDOR]]

[RETURN ADDRESS OF SURVEY VENDOR]
Sample Initial Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]
[ADDRESS]
[CITY, STATE ZIP]

Уважаемый/ая [SAMPLED CAREGIVER NAME]

[HOSPICE NAME] проводит исследование на тему хосписных услуг, оказываемых пациентам и членам их семей. Вас отобрали для участия в данном опросе, потому что Вы были указаны как опекун [DECEDEDENT NAME]. Мы понимаем, что это тяжелое для Вас время, но все же мы надеемся на то, что Вы сможете нам узнать о качестве ухода, предоставленного хосписом Вам, члену Вашей семьи или другу.

Вопросы [NOTE THE QUESTION NUMBERS] в приложенной анкете являются частью национальной инициативы оценки качества хосписного ухода, финансируемой Департаментом здравоохранения и социального обеспечения США. Центры обеспечения услуг по программам «Медикэйр» и «Медикэйд» (Centers for Medicare & Medicaid Services — CMS), которые являются частью Департамента здравоохранения и социального обеспечения, проводят данное исследование с целью улучшения качества хосписного ухода. CMS оплачивает большинство хосписных услуг в США, поэтому несет ответственность за то, чтобы пациенты хосписа, члены их семей и друзья получали высококачественное обслуживание. Один из способов выполнения такого обязательства — получить непосредственно от Вас информацию о хосписном уходе, предоставленном члену Вашей семьи либо другу. Ваше участие является добровольным и никоим образом не повлияет на получаемое Вами медицинское обслуживание или льготы.

Мы надеемся, что Вы найдете время на заполнение данной анкеты. После того как Вы заполните анкету, отправьте ее, пожалуйста, в конверте с предварительно оплаченным почтовым сбором. Ваши ответы будут объединены с ответами других респондентов и могут быть предоставлены хоспису с целью повышения качества. [OPTIONAL: На анкете указан номер. Данный номер поможет нам определить, вернули ли Вы нам анкету, чтобы нам не пришлось отправлять Вам напоминания.]

Если у Вас возникли какие-либо вопросы по поводу прилагаемой анкеты, позвоните нам по бесплатному номеру 1-800-xxx-xxxx. Благодарим Вас за помощь! Ваше участие позволит улучшить хосписный уход для всех клиентов.

С уважением,
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]
Sample Follow-up Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]
[ADDRESS]
[CITY, STATE ZIP]

Уважаемый/ая [SAMPLED CAREGIVER NAME],

Согласно имеющейся у нас информации, Вы являлись опекуном [HOSPICE NAME] в [DECEDENT NAME]. Приблизительно три недели назад мы отправили Вам анкету, касающуюся ухода, предоставленного хосписом Вам и члену Вашей семьи или Вашему другу. Если Вы уже отправили анкету обратно, примите, пожалуйста, нашу благодарность и не обращайте внимания на данное письмо. Если же Вы еще не отправили анкету, мы будем очень благодарны, если Вы уделите время и все же заполните этот важнейший опросник.

Мы надеемся, что Вы поможете нам узнать о качестве ухода, предоставленного члену Вашей семьи или другу. Результаты данного исследования будут использованы для того, чтобы гарантировать каждому американцу наивысшее качество хосписного ухода.

Вопросы [NOTE THE QUESTION NUMBERS] в прилагаемой анкете являются частью национальной инициативы оценки качества хосписного ухода, финансируемой Департаментом здравоохранения и социального обеспечения США. Ваше участие является добровольным и никоим образом не повлияет на получаемое Вами медицинское обеспечение или льготы.

Уделите, пожалуйста, несколько минут, чтобы заполнить прилагаемую анкету. После того как Вы заполните анкету, отправьте ее, пожалуйста, в конверте с предварительно оплаченным почтовым сбором. Ваши ответы могут быть предоставлены хоспису с целью повышения качества. [OPTIONAL: На анкете указан номер. Данный номер поможет нам определить, вернули ли Вы нам анкету, чтобы нам не пришлось отправлять Вам напоминания.]

Если у Вас возникли какие-либо вопросы по поводу прилагаемой анкеты, позвоните нам по бесплатному номеру 1-800-xxx-xxxx. Благодарим Вас за помощь! Ваше участие позволит улучшить хосписный уход для всех клиентов.

С уважением,
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]
OMB Paperwork Reduction Act Language

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. The following is the language that must be used:

Russian Version

Appendix S

Mail Survey Materials (Portuguese)
Inquérito CAHPS® Sobre Centros de Cuidados Paliativos

Responda às questões do inquérito sobre os cuidados que o doente recebeu neste centro de cuidados paliativos:

[TNAME OF HOSPICE]

Todas as questões deste inquérito irão cobrir as experiências neste centro de cuidados paliativos.

Se desejar obter mais informações sobre este inquérito, ligue para [TOLL FREE NUMBER]. Todas as chamadas para este número são grátis.

OMB# 0938-1257
Dê este inquérito à pessoa no seu agregado familiar que melhor conhece os cuidados paliativos recebidos pela pessoa indicada na carta de apresentação do inquérito.

**INSTRUÇÕES DO INQUÉRITO**

♦ Utilize uma caneta de cor escura para preencher o inquérito.
♦ Escreva as suas respostas às perguntas de resposta longa em letra de imprensa.
♦ Coloque um X diretamente dentro do quadrado indicando a resposta, como no exemplo a seguir.
  ✗ Sim
  ☐ Não
♦ Por vezes, ser-lhe-á pedido que salte algumas questões neste inquérito. Quando tal acontecer, verá uma seta com uma nota indicando que questão deve responder a seguir, como se mostra a seguir:
  ✗ Sim ➔ Se Sim, passe para a Questão 1
  ☐ Não

---

**O DOENTE DO CENTRO DE CUIDADOS PALIATIVOS**

1. Qual a sua relação com a pessoa indicada na carta de apresentação do inquérito?

   1 ☐ Meu cônjuge ou parceiro
   2 ☐ Meu pai ou mãe
   3 ☐ Meu sogro ou sogra
   4 ☐ Meu avô ou avó
   5 ☐ Meu tio ou tia
   6 ☐ Meu irmão ou irmã
   7 ☐ Meu filho ou filha
   8 ☐ Meu amigo ou amiga
   9 ☐ Outro (escrever em letras de imprensa):

---

2. Neste inquérito, "familiar" refere-se à pessoa indicada na carta de apresentação do inquérito. Em que locais o seu familiar recebeu cuidados neste centro? Selecione um ou mais.

   1 ☐ Casa
   2 ☐ Unidades de residência assistida
   3 ☐ Casa de repouso
   4 ☐ Hospital
   5 ☐ Unidades de cuidados paliativos
   6 ☐ Outro (escrever em letras de imprensa):

   ________________________________
3. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência participou ou supervisionou os cuidados prestados?

1 ☐ Nunca → Se Nunca, passe para a Questão 41
2 ☐ Por vezes
3 ☐ Frequentemente
4 ☐ Sempre

5. Com que frequência obteve a assistência de que necessitou da parte da equipa do centro de cuidados paliativos durante a noite, fins de semana ou feriados?

1 ☐ Nunca
2 ☐ Por vezes
3 ☐ Frequentemente
4 ☐ Sempre

6. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos o manteve informado sobre quando iria chegar para prestar cuidados ao seu familiar?

1 ☐ Nunca
2 ☐ Por vezes
3 ☐ Frequentemente
4 ☐ Sempre

7. Enquanto o seu familiar esteve no centro de cuidados paliativos, quando pediu ou quando o seu familiar pediu assistência da parte da equipa do centro de cuidados paliativos, com que frequência a obteve assim que precisou dela?

1 ☐ Nunca
2 ☐ Por vezes
3 ☐ Frequentemente
4 ☐ Sempre
8. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos explicou as coisas de uma forma fácil de compreender?

1. Nunca
2. Por vezes
3. Frequentemente
4. Sempre

9. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos mantve informado sobre a condição do seu familiar?

1. Nunca
2. Por vezes
3. Frequentemente
4. Sempre

10. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência um membro da equipa do centro de cuidados paliativos lhe deu informação confusa ou contraditória sobre a condição ou cuidados do seu familiar?

1. Nunca
2. Por vezes
3. Frequentemente
4. Sempre

11. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos tratou o seu familiar com dignidade e respeito?

1. Nunca
2. Por vezes
3. Frequentemente
4. Sempre

12. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência sentiu que a equipa do centro de cuidados paliativos realmente se importava com o seu familiar?

1. Nunca
2. Por vezes
3. Frequentemente
4. Sempre

13. Enquanto o seu familiar esteve no centro de cuidados paliativos, falou com a equipa do centro de cuidados paliativos sobre quaisquer problemas com os cuidados paliativos prestados ao seu familiar?

1. Sim
2. Não ➔ Se Não, passe para a Questão 15
14. Com que frequência a equipa do centro de cuidados paliativos o escutou atentamente quando lhe falou sobre problemas com os cuidados paliativos prestados ao seu familiar?

☐ 1. Nunca
☐ 2. Por vezes
☐ 3. Frequentemente
☐ 4. Sempre

15. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) sentiu qualquer dor?

☐ 1. Sim
☐ 2. Não ➔ Se Não, passe para a Questão 17

16. O seu familiar recebeu a assistência para as dores que necessitava?

☐ 1. Sim, sem dúvida
☐ 2. Sim, de certa forma
☐ 3. Não

17. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) tomou algum medicamento para as dores?

☐ 1. Sim
☐ 2. Não ➔ Se Não, passe para a Questão 21

18. Os efeitos secundários dos medicamentos para as dores incluem efeitos secundários, como sonolência. Algum membro da equipa do centro de cuidados paliativos discutiu consigo, ou com o seu familiar, os efeitos secundários dos medicamentos para as dores?

☐ 1. Sim, sem dúvida
☐ 2. Sim, de certa forma
☐ 3. Não

19. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre que efeitos secundários dos medicamentos para as dores deveria vigiar?

☐ 1. Sim, sem dúvida
☐ 2. Sim, de certa forma
☐ 3. Não

20. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre se e quando deveria dar mais medicamentos para as dores ao seu familiar?

☐ 1. Sim, sem dúvida
☐ 2. Sim, de certa forma
☐ 3. Não
☐ 4. Não tive de dar medicamento para as dores ao meu familiar
21. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) teve problemas a respirar ou recebeu tratamento para a dificuldade em respirar?

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<table>
<thead>
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<tbody>
<tr>
<td>1</td>
<td>Sim</td>
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<tr>
<td>2</td>
<td>Não ➔ Se Não, passe para a Questão 24</td>
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</tbody>
</table>

22. Com que frequência o seu familiar obteve a assistência necessária para a dificuldade em respirar?

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<tbody>
<tr>
<td>1</td>
<td>Nunca</td>
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<tr>
<td>2</td>
<td>Por vezes</td>
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<tr>
<td>3</td>
<td>Frequentemente</td>
</tr>
<tr>
<td>4</td>
<td>Sempre</td>
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23. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre como ajudar o seu familiar caso ele(a) tivesse problemas a respirar?

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<tbody>
<tr>
<td>1</td>
<td>Sim, sem dúvida</td>
</tr>
<tr>
<td>2</td>
<td>Sim, de certa forma</td>
</tr>
<tr>
<td>3</td>
<td>Não</td>
</tr>
<tr>
<td>4</td>
<td>Não precisei de dar assistência ao meu familiar para a dificuldade em respirar</td>
</tr>
</tbody>
</table>

24. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) teve problemas de prisão de ventre?

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<tbody>
<tr>
<td>1</td>
<td>Sim</td>
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<tr>
<td>2</td>
<td>Não ➔ Se Não, passe para a Questão 26</td>
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</tbody>
</table>

25. Com que frequência o seu familiar obteve a assistência necessária para problemas de prisão de ventre?

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<tbody>
<tr>
<td>1</td>
<td>Nunca</td>
</tr>
<tr>
<td>2</td>
<td>Por vezes</td>
</tr>
<tr>
<td>3</td>
<td>Frequentemente</td>
</tr>
<tr>
<td>4</td>
<td>Sempre</td>
</tr>
</tbody>
</table>

26. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) mostrou sentimentos de ansiedade ou tristeza?

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<tbody>
<tr>
<td>1</td>
<td>Sim</td>
</tr>
<tr>
<td>2</td>
<td>Não ➔ Se Não, passe para a Questão 28</td>
</tr>
</tbody>
</table>

27. Com que frequência o seu familiar obteve a assistência necessária por parte da equipa do centro de cuidados paliativos para sentimentos de ansiedade ou tristeza?

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<tbody>
<tr>
<td>1</td>
<td>Nunca</td>
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<tr>
<td>2</td>
<td>Por vezes</td>
</tr>
<tr>
<td>3</td>
<td>Frequentemente</td>
</tr>
<tr>
<td>4</td>
<td>Sempre</td>
</tr>
</tbody>
</table>

28. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) alguma vez ficou inquieto(a) ou agitado(a)?

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<tr>
<td>1</td>
<td>Sim</td>
</tr>
<tr>
<td>2</td>
<td>Não ➔ Se Não, passe para a Questão 30</td>
</tr>
</tbody>
</table>
29. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre o que fazer se o seu familiar ficasse inquieto ou agitado?

1 ☐ Sim, sem dúvida
2 ☐ Sim, de certa forma
3 ☐ Não

30. Mover o seu familiar inclui atividades como ajudá-lo a virar-se na cama, a ir para a cama ou a sair da mesma ou a levantar-se e sentar-se numa cadeira de rodas. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre como mover o seu familiar de forma segura?

1 ☐ Sim, sem dúvida
2 ☐ Sim, de certa forma
3 ☐ Não
4 ☐ Não tive de mover o meu familiar

31. A equipa do centro de cuidados paliativos deu-lhe a informação desejada sobre o que esperar enquanto o seu familiar estivesse a morrer?

1 ☐ Sim, sem dúvida
2 ☐ Sim, de certa forma
3 ☐ Não

32. CUIDADOS PALLIATIVOS PRESTADOS EM CASA DE REPÓUSO

Algumas pessoas recebem cuidados paliativos quando estão a viver numa casa de repouso. O seu familiar recebeu cuidados paliativos deste centro quando ele(a) estava a viver numa casa de repouso?

1 ☐ Sim

2 ☐ Não ➔ Se Não, passe para a Questão 35

33. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência as equipas da casa de repouso e do centro de cuidados paliativos colaboraram eficientemente nos cuidados prestados ao seu familiar?

1 ☐ Nunca
2 ☐ Por vezes
3 ☐ Frequentemente
4 ☐ Sempre

34. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a informação que recebeu sobre o seu familiar da equipa da casa de repouso diferiu da informação que recebeu da equipa do centro de cuidados paliativos?

1 ☐ Nunca
2 ☐ Por vezes
3 ☐ Frequentemente
4 ☐ Sempre
A SUA PRÓPRIA EXPERIÊNCIA COM O CENTRO DE CUIDADOS PALIATIVOS

35. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos o escutou atentamente?

   1 ☐ Nunca
   2 ☐ Por vezes
   3 ☐ Frequentemente
   4 ☐ Sempre

36. O apoio às crenças espirituais ou religiosas inclui falar, rezar, tempo de reflexão, ou outras formas de atender às suas necessidades espirituais ou religiosas. Enquanto o seu familiar esteve no centro de cuidados paliativos, quanto apoio recebeu da equipa do centro de cuidados paliativos às suas crenças espirituais ou religiosas?

   1 ☐ Muito pouco
   2 ☐ A quantidade certa
   3 ☐ Demasiado

37. Enquanto o seu familiar esteve no centro de cuidados paliativos, quanto apoio emocional recebeu da equipa do centro de cuidados paliativos?

   1 ☐ Muito pouco
   2 ☐ A quantidade certa
   3 ☐ Demasiado

38. Nas semanas após a morte do seu familiar, quanto apoio emocional recebeu da equipa do centro de cuidados paliativos?

   1 ☐ Muito pouco
   2 ☐ A quantidade certa
   3 ☐ Demasiado
CLASSIFICAÇÃO GERAL DO CENTRO DE CUIDADOS PALLIATIVOS

39. Responda às seguintes questões acerca dos cuidados prestados ao seu familiar pelo centro de cuidados paliativos indicado na carta de apresentação do inquérito. Não inclua nas suas respostas cuidados prestados por outros centros de cuidados paliativos.

Usando qualquer número de 0 a 10, sendo 0 os piores cuidados paliativos possíveis e 10 os melhores cuidados paliativos possíveis, que número selecionaria para classificar os cuidados paliativos do seu familiar?

0 □ 0 Os piores cuidados paliativos possíveis
1 □ 1
2 □ 2
3 □ 3
4 □ 4
5 □ 5
6 □ 6
7 □ 7
8 □ 8
9 □ 9
10 □ 10 Os melhores cuidados paliativos possíveis

40. Recomendaria este centro de cuidados paliativos aos seus amigos e familiares?
1 □ Definitivamente não
2 □ Provavelmente não
3 □ Provavelmente sim
4 □ Definitivamente sim

SOBRE O SEU FAMILIAR

41. Qual foi o nível de escolaridade mais elevado que o seu familiar concluiu?
1 □ 8º ano ou menos
2 □ Frequentou o liceu, mas não acabou
3 □ Acabou o liceu ou fez o exame de Desenvolvimento Educativo Geral (General Educational Development, GED)
4 □ Frequentou o ensino universitário ou completou um curso de 2 anos
5 □ Curso de 4 anos
6 □ Curso superior a 4 anos
7 □ Não sabe
42. **O seu familiar era de origem ou descendência Hispânica, Latina ou Espanhola?**

   1. ☐ Não, não Espanhol/Hispânico/Latino
   2. ☐ Sim, Porto Riquenho
   3. ☐ Sim, Mexicano, Mexicano Americano, Chicano
   4. ☐ Sim, Cubano
   5. ☐ Sim, Outro Espanhol/Hispânico/Latino

43. **Qual era a raça do seu familiar?** Selecione um ou mais.

   1. ☐ Branca
   2. ☐ Negra ou Africano Americano
   3. ☐ Asiática
   4. ☐ Nativo do Havai ou outra Ilha do Pacífico
   5. ☐ Índio Americano ou Nativo do Alasca

---

**SOBRE SI**

44. **Qual a sua idade?**

   1. ☐ 18 a 24
   2. ☐ 25 a 34
   3. ☐ 35 a 44
   4. ☐ 45 a 54
   5. ☐ 55 a 64
   6. ☐ 65 a 74
   7. ☐ 75 a 84
   8. ☐ 85 ou mais

45. **Qual o seu sexo?**

   1. ☐ Masculino
   2. ☐ Feminino
46. Qual foi o nível de escolaridade mais elevado que concluiu?

1 ☐ 8º ano ou menos  
2 ☐ Frequentou o liceu, mas não acabou  
3 ☐ Acabou o liceu ou fez o exame de Desenvolvimento Educativo Geral (General Educational Development, GED)  
4 ☐ Frequentou o ensino universitário ou completou um curso de 2 anos  
5 ☐ Curso de 4 anos  
6 ☐ Curso superior a 4 anos

47. Que língua fala majoritariamente em casa?

1 ☐ Inglês  
2 ☐ Espanhol  
3 ☐ Chinês  
4 ☐ Russo  
5 ☐ Português  
6 ☐ Vietnamita  
7 ☐ Outra língua (escrever em letras de imprensa): ________________________________

OBRIGADO.

Devolva o inquérito preenchido no envelope com portes pagos.

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
Inquérito CAHPS® Sobre Centros de Cuidados Paliativos

Responda às questões do inquérito sobre os cuidados que o doente recebeu neste centro de cuidados paliativos:

[TNAME OF HOSPICE]

Todas as questões deste inquérito irão cobrir as experiências neste centro de cuidados paliativos.

Se desejar obter mais informações sobre este inquérito, ligue para [TOLL FREE NUMBER]. Todas as chamadas para este número são grátis.

OMB# 0938-1257
Dê este inquérito à pessoa no seu agregado familiar que melhor conhece os cuidados paliativos recebidos pela pessoa indicada na carta de apresentação do inquérito.

**INSTRUÇÕES DO INQUÉRITO**

♦ Utilize uma caneta de cor escura para preencher o inquérito.

♦ Escreva as suas respostas às perguntas de resposta longa em letra de imprensa.

♦ Coloque um X diretamente dentro da oval indicando a resposta, como no exemplo a seguir.

  ◆ Sim
  ◆ Não

♦ Por vezes, ser-lhe-á pedido que salte algumas questões neste inquérito. Quando tal acontecer, verá uma seta com uma nota indicando que questão deve responder a seguir, como se mostra a seguir:

  ◆ Sim ➔ Se Sim, passe para a Questão 1
  ◆ Não

---

**O DOENTE DO CENTRO DE CUIDADOS PALIATIVOS**

1. Qual a sua relação com a pessoa indicada na carta de apresentação do inquérito?

   1 0 Meu cônjuge ou parceiro
   2 0 Meu pai ou mãe
   3 0 Meu sogro ou sogra
   4 0 Meu avô ou avó
   5 0 Meu tio ou tia
   6 0 Meu irmão ou irmã
   7 0 Meu filho ou filha
   8 0 Meu amigo ou amiga
   9 0 Outro (escrever em letras de imprensa):

2. Neste inquérito, "familiar" refere-se à pessoa indicada na carta de apresentação do inquérito. Em que locais o seu familiar recebeu cuidados neste centro? Selecione um ou mais.

   1 0 Casa
   2 0 Unidades de residência assistida
   3 0 Casa de repouso
   4 0 Hospital
   5 0 Unidades de cuidados paliativos
   6 0 Outro (escrever em letras de imprensa):

   ___________________________________________
**O SEU PAPEL**

3. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência participou ou supervisionou os cuidados prestados?

   1 0 Nunca ➔ Se Nunca, passe para a Questão 41
   2 0 Por vezes
   3 0 Frequentemente
   4 0 Sempre

**OS CUIDADOS PALIATIVOS DO SEU FAMILIAR**

Ao responder às restantes questões deste inquérito, pense na experiência do seu familiar no centro de cuidados paliativos indicado na carta de apresentação.

4. Neste inquérito, a equipa do centro de cuidados paliativos inclui todos os enfermeiros, médicos, assistentes sociais, capelães e outras pessoas que prestaram cuidados paliativos ao seu familiar. Enquanto o seu familiar esteve no centro de cuidados paliativos, precisou de contactar a equipa do centro durante a noite, fins de semana ou feriados para tirar dúvidas ou obter assistência com os cuidados do seu familiar?

   1 0 Sim
   2 0 Não ➔ Se Não, passe para a Questão 6

5. Com que frequência obteve a assistência de que necessitou da parte da equipa do centro de cuidados paliativos durante a noite, fins de semana ou feriados?

   1 0 Nunca
   2 0 Por vezes
   3 0 Frequentemente
   4 0 Sempre

6. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos o manteve informado sobre quando iria chegar para prestar cuidados ao seu familiar?

   1 0 Nunca
   2 0 Por vezes
   3 0 Frequentemente
   4 0 Sempre

7. Enquanto o seu familiar esteve no centro de cuidados paliativos, quando pediu ou quando o seu familiar pediu assistência da parte da equipa do centro de cuidados paliativos, com que frequência a obteve assim que precisou dela?

   1 0 Nunca
   2 0 Por vezes
   3 0 Frequentemente
   4 0 Sempre

8. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos explicou as coisas de uma forma fácil de compreender?

   1 0 Nunca
   2 0 Por vezes
   3 0 Frequentemente
   4 0 Sempre
9. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos o manteve informado sobre a condição do seu familiar?

   1 0 Nunca  
   2 0 Por vezes  
   3 0 Frequentemente  
   4 0 Sempre

10. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência um membro da equipa do centro de cuidados paliativos lhe deu informação confusa ou contraditória sobre a condição ou cuidados do seu familiar?

   1 0 Nunca  
   2 0 Por vezes  
   3 0 Frequentemente  
   4 0 Sempre

11. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos tratou o seu familiar com dignidade e respeito?

   1 0 Nunca  
   2 0 Por vezes  
   3 0 Frequentemente  
   4 0 Sempre

12. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência sentiu que a equipa do centro de cuidados paliativos realmente se importava com o seu familiar?

   1 0 Nunca  
   2 0 Por vezes  
   3 0 Frequentemente  
   4 0 Sempre

13. Enquanto o seu familiar esteve no centro de cuidados paliativos, falou com a equipa do centro de cuidados paliativos sobre quaisquer problemas com os cuidados paliativos prestados ao seu familiar?

   1 0 Sim  
   2 0 Não ➔ Se Não, passe para a Questão 15

14. Com que frequência a equipa do centro de cuidados paliativos o escutou atentamente quando lhe falou sobre problemas com os cuidados paliativos prestados ao seu familiar?

   1 0 Nunca  
   2 0 Por vezes  
   3 0 Frequentemente  
   4 0 Sempre

15. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) sentiu qualquer dor?

   1 0 Sim  
   2 0 Não ➔ Se Não, passe para a Questão 17
16. O seu familiar recebeu a assistência para as dores que necessitava?
   1 0 Sim, sem dúvida
   2 0 Sim, de certa forma
   3 0 Não

17. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) tomou algum medicamento para as dores?
   1 0 Sim
   2 0 Não ➔ Se Não, passe para a Questão 21

18. Os efeitos secundários dos medicamentos para as dores incluem efeitos secundários, como sonolência. Algum membro da equipa do centro de cuidados paliativos discutiu consigo, ou com o seu familiar, os efeitos secundários dos medicamentos para as dores?
   1 0 Sim, sem dúvida
   2 0 Sim, de certa forma
   3 0 Não

19. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre que efeitos secundários dos medicamentos para as dores deveria vigiar?
   1 0 Sim, sem dúvida
   2 0 Sim, de certa forma
   3 0 Não

20. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre se e quando deveria dar mais medicamentos para as dores ao seu familiar?
   1 0 Sim, sem dúvida
   2 0 Sim, de certa forma
   3 0 Não
   4 0 Não tive de dar medicamento para as dores ao meu familiar

21. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) teve problemas a respirar ou recebeu tratamento para a dificuldade em respirar?
   1 0 Sim
   2 0 Não ➔ Se Não, passe para a Questão 24

22. Com que frequência o seu familiar obteve a assistência necessária para a dificuldade em respirar?
   1 0 Nunca
   2 0 Por vezes
   3 0 Frequentemente
   4 0 Sempre

23. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre como ajudar o seu familiar caso ele(a) tivesse problemas a respirar?
   1 0 Sim, sem dúvida
   2 0 Sim, de certa forma
   3 0 Não
   4 0 Não precisei de dar assistência ao meu familiar para a dificuldade em respirar
24. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) teve problemas de prisão de ventre?
   1 0 Sim
   2 0 Não ➔ Se Não, passe para a Questão 26

25. Com que frequência o seu familiar obteve a assistência necessária para problemas de prisão de ventre?
   1 0 Nunca
   2 0 Por vezes
   3 0 Frequentemente
   4 0 Sempre

26. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) mostrou sentimentos de ansiedade ou tristeza?
   1 0 Sim
   2 0 Não ➔ Se Não, passe para a Questão 28

27. Com que frequência o seu familiar obteve a assistência necessária por parte da equipa do centro de cuidados paliativos para sentimentos de ansiedade ou tristeza?
   1 0 Nunca
   2 0 Por vezes
   3 0 Frequentemente
   4 0 Sempre

28. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) alguma vez ficou inquieto(a) ou agitado(a)?
   1 0 Sim
   2 0 Não ➔ Se Não, passe para a Questão 30

29. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre o que fazer se o seu familiar ficasse inquieto ou agitado?
   1 0 Sim, sem dúvida
   2 0 Sim, de certa forma
   3 0 Não

30. Mover o seu familiar inclui atividades como ajudá-lo a virar-se na cama, a ir para a cama ou a sair da mesma ou a levantar-se e sentar-se numa cadeira de rodas. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre como mover o seu familiar de forma segura?
   1 0 Sim, sem dúvida
   2 0 Sim, de certa forma
   3 0 Não
   4 0 Não tive de mover o meu familiar

31. A equipa do centro de cuidados paliativos deu-lhe a informação desejada sobre o que esperar enquanto o seu familiar estivesse a morrer?
   1 0 Sim, sem dúvida
   2 0 Sim, de certa forma
   3 0 Não
**CUIDADOS PALIATIVOS PRESTADOS EM CASA DE REPUSO**

32. Algumas pessoas recebem cuidados paliativos quando estão a viver numa casa de repouso. O seu familiar recebeu cuidados paliativos deste centro quando ele(a) estava a viver numa casa de repouso?

1. Sim
2. Não → Se Não, passe para a Questão 35

33. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência as equipas da casa de repouso e do centro de cuidados paliativos colaboraram eficientemente nos cuidados prestados ao seu familiar?

1. Nunca
2. Por vezes
3. Frequentemente
4. Sempre

34. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a informação que recebeu sobre o seu familiar da equipa da casa de repouso diferiu da informação que recebeu da equipa do centro de cuidados paliativos?

1. Muito pouco
2. A quantidade certa
3. Demasiado

**A SUA PRÓPRIA EXPERIÊNCIA COM O CENTRO DE CUIDADOS PALIATIVOS**

35. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos o escutou atentamente?

1. Nunca
2. Por vezes
3. Frequentemente
4. Sempre

36. O apoio às crenças espirituais ou religiosas inclui falar, rezar, tempo de reflexão, ou outras formas de atender às suas necessidades espirituais ou religiosas. Enquanto o seu familiar esteve no centro de cuidados paliativos, quanto apoio recebeu da equipa do centro de cuidados paliativos às suas crenças espirituais ou religiosas?

1. Muito pouco
2. A quantidade certa
3. Demasiado

37. Enquanto o seu familiar esteve no centro de cuidados paliativos, quanto apoio emocional recebeu da equipa do centro de cuidados paliativos?

1. Muito pouco
2. A quantidade certa
3. Demasiado
38. Nas semanas após a morte do seu familiar, quanto apoio emocional recebeu da equipa do centro de cuidados paliativos?

1 0 Muito pouco
2 0 A quantidade certa
3 0 Demasiado

39. Responda às seguintes questões acerca dos cuidados prestados ao seu familiar pelo centro de cuidados paliativos indicado na carta de apresentação do inquérito. Não inclua nas suas respostas cuidados prestados por outros centros de cuidados paliativos.

Usando qualquer número de 0 a 10, sendo 0 os piores cuidados paliativos possíveis e 10 os melhores cuidados paliativos possíveis, que número selecionaria para classificar os cuidados paliativos do seu familiar?

0 0 Os piores cuidados paliativos possíveis
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 Os melhores cuidados paliativos possíveis

40. Recomendaria este centro de cuidados paliativos aos seus amigos e familiares?

1 0 Definitivamente não
2 0 Provavelmente não
3 0 Provavelmente sim
4 0 Definitivamente sim

41. Qual foi o nível de escolaridade mais elevado que o seu familiar concluiu?

1 0 8º ano ou menos
2 0 Frequentou o liceu, mas não acabou
3 0 Acabou o liceu ou fez o exame de Desenvolvimento Educativo Geral (General Educational Development, GED)
4 0 Frequentou o ensino universitário ou completou um curso de 2 anos
5 0 Curso de 4 anos
6 0 Curso superior a 4 anos
7 0 Não sabe

42. O seu familiar era de origem ou descendência Hispânica, Latina ou Espanhola?

1 0 Não, não Espanhol/Hispânico/Latino
2 0 Sim, Porto Riquenho
3 0 Sim, Mexicano, Mexicano Americano, Chicano
4 0 Sim, Cubano
5 0 Sim, Outro Espanhol/Hispânico/Latino
43. Qual era a raça do seu familiar? Selecione um ou mais.
   1 0 Branca
   2 0 Negra ou Africano Americano
   3 0 Asiática
   4 0 Nativo do Havai ou outra Ilha do Pacífico
   5 0 Índio Americano ou Nativo do Alasca

44. Qual a sua idade?
   1 0 18 a 24
   2 0 25 a 34
   3 0 35 a 44
   4 0 45 a 54
   5 0 55 a 64
   6 0 65 a 74
   7 0 75 a 84
   8 0 85 ou mais

45. Qual o seu sexo?
   1 0 Masculino
   2 0 Feminino

46. Qual foi o nível de escolaridade mais elevado que concluiu?
   1 0 8º ano ou menos
   2 0 Frequentou o liceu, mas não acabou
   3 0 Acabou o liceu ou fez o exame de Desenvolvimento Educativo Geral (General Educational Development, GED)
   4 0 Frequentou o ensino universitário ou completou um curso de 2 anos
   5 0 Curso de 4 anos
   6 0 Curso superior a 4 anos

47. Que língua fala maioritariamente em casa?
   1 0 Inglês
   2 0 Espanhol
   3 0 Chinês
   4 0 Russo
   5 0 Português
   6 0 Vietnamita
   7 0 Outra língua (escrever em letras de imprensa):

OBRIGADO.

Devolva o inquérito preenchido no envelope com portes pagos.

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
Inquérito CAHPS® Sobre Centros de Cuidados Paliativos

Responda às questões do inquérito sobre os cuidados que o doente recebeu neste centro de cuidados paliativos:

[TNAME OF HOSPICE]

_Todas as questões deste inquérito irão cobrir as experiências neste centro de cuidados paliativos._

Se desejar obter mais informações sobre este inquérito, ligue para [TOLL FREE NUMBER]. Todas as chamadas para este número são grátis.

OMB# 0938-1257
Dê este inquérito à pessoa no seu agregado familiar que melhor conhece os cuidados paliativos recebidos pela pessoa indicada na carta de apresentação do inquérito.

**INSTRUÇÕES DO INQUÉRITO**

♦ Utilize uma caneta de cor escura para preencher o inquérito.
♦ Escreva as suas respostas às perguntas de resposta longa em letra de imprensa.
♦ Coloque um X diretamente dentro do círculo indicando a resposta, como no exemplo a seguir.
  - ● Sim
  - ○ Não
♦ Por vezes, ser-lhe-á pedido que salte algumas questões neste inquérito. Quando tal acontecer, verá uma seta com uma nota indicando que questão deve responder a seguir, como se mostra a seguir:
  - ● Sim ➔ Se Sim, passe para a Questão 1
  - ○ Não

---

### O DOENTE DO CENTRO DE CUIDADOS PALLIATIVOS

1. Qual a sua relação com a pessoa indicada na carta de apresentação do inquérito?
   - 1 ○ Meu cônjuge ou parceiro
   - 2 ○ Meu pai ou mãe
   - 3 ○ Meu sogro ou sogra
   - 4 ○ Meu avô ou avó
   - 5 ○ Meu tio ou tia
   - 6 ○ Meu irmão ou irmã
   - 7 ○ Meu filho ou filha
   - 8 ○ Meu amigo ou amiga
   - 9 ○ Outro (escrever em letras de imprensa):

2. Neste inquérito, "familiar" refere-se à pessoa indicada na carta de apresentação do inquérito. Em que locais o seu familiar recebeu cuidados neste centro? Selecione um ou mais.
   - 1 ○ Casa
   - 2 ○ Unidades de residência assistida
   - 3 ○ Casa de repouso
   - 4 ○ Hospital
   - 5 ○ Unidades de cuidados paliativos
   - 6 ○ Outro (escrever em letras de imprensa):
         ________________________________
O SEU PAPEL

3. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência participou ou supervisionou os cuidados prestados?

   1  O Nunca ➔ Se Nunca, passe para a Questão 41
   2  O Por vezes
   3  O Frequentemente
   4  O Sempre

OS CUIDADOS PALIATIVOS DO SEU FAMILIAR

Ao responder às restantes questões deste inquérito, pense na experiência do seu familiar no centro de cuidados paliativos indicado na carta de apresentação.

4. Neste inquérito, a equipa do centro de cuidados paliativos inclui todos os enfermeiros, médicos, assistentes sociais, capelães e outras pessoas que prestaram cuidados paliativos ao seu familiar. Enquanto o seu familiar esteve no centro de cuidados paliativos, precisou de contactar a equipa do centro durante a noite, fins de semana ou feriados para tirar dúvidas ou obter assistência com os cuidados do seu familiar?

   1  O Sim
   2  O Não ➔ Se Não, passe para a Questão 6

5. Com que frequência obteve a assistência de que necessitou da parte da equipa do centro de cuidados paliativos durante a noite, fins de semana ou feriados?

   1  O Nunca
   2  O Por vezes
   3  O Frequentemente
   4  O Sempre

6. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos o manteve informado sobre quando iria chegar para prestar cuidados ao seu familiar?

   1  O Nunca
   2  O Por vezes
   3  O Frequentemente
   4  O Sempre

7. Enquanto o seu familiar esteve no centro de cuidados paliativos, quando pediu ou quando o seu familiar pediu assistência da parte da equipa do centro de cuidados paliativos, com que frequência a obteve assim que precisou dela?

   1  O Nunca
   2  O Por vezes
   3  O Frequentemente
   4  O Sempre

8. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos explicou as coisas de uma forma fácil de compreender?

   1  O Nunca
   2  O Por vezes
   3  O Frequentemente
   4  O Sempre
9. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos o manteve informado sobre a condição do seu familiar?

1 ○ Nunca
2 ○ Por vezes
3 ○ Frequentemente
4 ○ Sempre

10. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência um membro da equipa do centro de cuidados paliativos lhe deu informação confusa ou contraditória sobre a condição ou cuidados do seu familiar?

1 ○ Nunca
2 ○ Por vezes
3 ○ Frequentemente
4 ○ Sempre

11. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos tratou o seu familiar com dignidade e respeito?

1 ○ Nunca
2 ○ Por vezes
3 ○ Frequentemente
4 ○ Sempre

12. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência sentiu que a equipa do centro de cuidados paliativos realmente se importava com o seu familiar?

1 ○ Nunca
2 ○ Por vezes
3 ○ Frequentemente
4 ○ Sempre

13. Enquanto o seu familiar esteve no centro de cuidados paliativos, falou com a equipa do centro de cuidados paliativos sobre quaisquer problemas com os cuidados paliativos prestados ao seu familiar?

1 ○ Sim
2 ○ Não ➔ Se Não, passe para a Questão 15

14. Com que frequência a equipa do centro de cuidados paliativos o escutou atentamente quando lhe falou sobre problemas com os cuidados paliativos prestados ao seu familiar?

1 ○ Nunca
2 ○ Por vezes
3 ○ Frequentemente
4 ○ Sempre

15. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) sentiu qualquer dor?

1 ○ Sim
2 ○ Não ➔ Se Não, passe para a Questão 17
16. O seu familiar recebeu a assistência para as dores que necessitava?
   1 □ Sim, sem dúvida
   2 □ Sim, de certa forma
   3 □ Não

17. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) tomou algum medicamento para as dores?
   1 □ Sim
   2 □ Não ➔ Se Não, passe para a Questão 21

18. Os efeitos secundários dos medicamentos para as dores incluem efeitos secundários, como sonolência. Alguém membro da equipa do centro de cuidados paliativos discutiu consigo, ou com o seu familiar, os efeitos secundários dos medicamentos para as dores?
   1 □ Sim, sem dúvida
   2 □ Sim, de certa forma
   3 □ Não

19. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre que efeitos secundários dos medicamentos para as dores deveria vigiar?
   1 □ Sim, sem dúvida
   2 □ Sim, de certa forma
   3 □ Não

20. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre se e quando deveria dar mais medicamentos para as dores ao seu familiar?
   1 □ Sim, sem dúvida
   2 □ Sim, de certa forma
   3 □ Não
   4 □ Não tive de dar medicamento para as dores ao meu familiar

21. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) teve problemas a respirar ou recebeu tratamento para a dificuldade em respirar?
   1 □ Sim
   2 □ Não ➔ Se Não, passe para a Questão 24

22. Com que frequência o seu familiar obteve a assistência necessária para a dificuldade em respirar?
   1 □ Nunca
   2 □ Por vezes
   3 □ Frequentemente
   4 □ Sempre

23. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre como ajudar o seu familiar caso ele(a) tivesse problemas a respirar?
   1 □ Sim, sem dúvida
   2 □ Sim, de certa forma
   3 □ Não
   4 □ Não precisei de dar assistência ao meu familiar para a dificuldade em respirar
24. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) teve problemas de prisão de ventre?
   1 O Sim
   2 O Não ➔ Se Não, passe para a Questão 26

25. Com que frequência o seu familiar obteve a assistência necessária para problemas de prisão de ventre?
   1 O Nunca
   2 O Por vezes
   3 O Frequentemente
   4 O Sempre

26. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) mostrou sentimentos de ansiedade ou tristeza?
   1 O Sim
   2 O Não ➔ Se Não, passe para a Questão 28

27. Com que frequência o seu familiar obteve a assistência necessária por parte da equipa do centro de cuidados paliativos para sentimentos de ansiedade ou tristeza?
   1 O Nunca
   2 O Por vezes
   3 O Frequentemente
   4 O Sempre

28. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) alguma vez ficou inquieto(a) ou agitado(a)?
   1 O Sim
   2 O Não ➔ Se Não, passe para a Questão 30

29. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre o que fazer se o seu familiar ficasse inquieto ou agitado?
   1 O Sim, sem dúvida
   2 O Sim, de certa forma
   3 O Não

30. Mover o seu familiar inclui atividades como ajudá-lo a virar-se na cama, a ir para a cama ou a sair da mesma ou a levantar-se e sentar-se numa cadeira de rodas. A equipa do centro de cuidados paliativos deu-lhe a formação necessária sobre como mover o seu familiar de forma segura?
   1 O Sim, sem dúvida
   2 O Sim, de certa forma
   3 O Não
   4 O Não tive de mover o meu familiar

31. A equipa do centro de cuidados paliativos deu-lhe a informação desejada sobre o que esperar enquanto o seu familiar estivesse a morrer?
   1 O Sim, sem dúvida
   2 O Sim, de certa forma
   3 O Não
<table>
<thead>
<tr>
<th>CUIDADOS PALIATIVOS PRESTADOS EM CASA DE REPOUSO</th>
<th>A SUA PRÓPRIA EXPERIÊNCIA COM O CENTRO DE CUIDADOS PALIATIVOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>32. Algumas pessoas recebem cuidados paliativos quando estão a viver numa casa de repouso. O seu familiar recebeu cuidados paliativos deste centro quando ele(a) estava a viver numa casa de repouso?</td>
<td>35. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a equipa do centro de cuidados paliativos o escutou atentamente?</td>
</tr>
</tbody>
</table>
|   1 ☐ Sim  
   2 ☐ Não ➔ Se Não, passe para a Questão 35 |   1 ☐ Nunca  
   2 ☐ Por vezes  
   3 ☐ Frequentemente  
   4 ☐ Sempre |
| 33. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência as equipas da casa de repouso e do centro de cuidados paliativos colaboraram eficientemente nos cuidados prestados ao seu familiar? | 36. O apoio às crenças espirituais ou religiosas inclui falar, rezar, tempo de reflexão, ou outras formas de atender às suas necessidades espirituais ou religiosas. Enquanto o seu familiar esteve no centro de cuidados paliativos, quanto apoio recebeu da equipa do centro de cuidados paliativos às suas crenças espirituais ou religiosas? |
|   1 ☐ Nunca  
   2 ☐ Por vezes  
   3 ☐ Frequentemente  
   4 ☐ Sempre |   1 ☐ Muito pouco  
   2 ☐ A quantidade certa  
   3 ☐ Demasiado |
| 34. Enquanto o seu familiar esteve no centro de cuidados paliativos, com que frequência a informação que recebeu sobre o seu familiar da equipa da casa de repouso diferiu da informação que recebeu da equipa do centro de cuidados paliativos? | 37. Enquanto o seu familiar esteve no centro de cuidados paliativos, quanto apoio emocional recebeu da equipa do centro de cuidados paliativos? |
|   1 ☐ Nunca  
   2 ☐ Por vezes  
   3 ☐ Frequentemente  
   4 ☐ Sempre |   1 ☐ Muito pouco  
   2 ☐ A quantidade certa  
   3 ☐ Demasiado |
38. Nas semanas após a morte do seu familiar, quanto apoio emocional recebeu da equipa do centro de cuidados paliativos?

1 O Muito pouco
2 O A quantidade certa
3 O Demasiado

CLASSIFICAÇÃO GERAL DO CENTRO DE CUIDADOS PALLIATIVOS

39. Responda às seguintes questões acerca dos cuidados prestados ao seu familiar pelo centro de cuidados paliativos indicado na carta de apresentação do inquérito. Não inclua nas suas respostas cuidados prestados por outros centros de cuidados paliativos.

Usando qualquer número de 0 a 10, sendo 0 os piores cuidados paliativos possíveis e 10 os melhores cuidados paliativos possíveis, que número selecionaria para classificar os cuidados paliativos do seu familiar?

0 O 0 Os piores cuidados paliativos possíveis
1 O 1
2 O 2
3 O 3
4 O 4
5 O 5
6 O 6
7 O 7
8 O 8
9 O 9
10 O 10 Os melhores cuidados paliativos possíveis

40. Recomendaria este centro de cuidados paliativos aos seus amigos e familiares?

1 O Definitivamente não
2 O Provavelmente não
3 O Provavelmente sim
4 O Definitivamente sim

SOBRE O SEU FAMILIAR

41. Qual foi o nível de escolaridade mais elevado que o seu familiar concluiu?

1 O 8º ano ou menos
2 O Frequentou o liceu, mas não acabou
3 O Acabou o liceu ou fez o exame de Desenvolvimento Educativo Geral (General Educational Development, GED)
4 O Frequentou o ensino universitário ou completou um curso de 2 anos
5 O Curso de 4 anos
6 O Curso superior a 4 anos
7 O Não sabe

42. O seu familiar era de origem ou descendência Hispânica, Latina ou Espanhola?

1 O Não, não Espanhol/Hispânico/Latino
2 O Sim, Porto Riquenho
3 O Sim, Mexicano, Mexicano Americano, Chicano
4 O Sim, Cubano
5 O Sim, Outro Espanhol/Hispânico/Latino
43. Qual era a raça do seu familiar? Selecione um ou mais.
   1 O Branca
   2 O Negra ou Africano Americano
   3 O Asiática
   4 O Nativo do Havaí ou outra Ilha do Pacífico
   5 O Índio Americano ou Nativo do Alasca

44. Qual a sua idade?
   1 O 18 a 24
   2 O 25 a 34
   3 O 35 a 44
   4 O 45 a 54
   5 O 55 a 64
   6 O 65 a 74
   7 O 75 a 84
   8 O 85 ou mais

45. Qual o seu sexo?
   1 O Masculino
   2 O Feminino

46. Qual foi o nível de escolaridade mais elevado que concluiu?
   1 O 8º ano ou menos
   2 O Frequentou o liceu, mas não acabou
   3 O Acabou o liceu ou fez o exame de Desenvolvimento Educativo Geral (General Educational Development, GED)
   4 O Frequentou o ensino universitário ou completou um curso de 2 anos
   5 O Curso de 4 anos
   6 O Curso superior a 4 anos

47. Que língua fala maioria em casa?
   1 O Inglês
   2 O Espanhol
   3 O Chinês
   4 O Russo
   5 O Português
   6 O Vietnamita
   7 O Outra língua (escrever em letras de imprensa):

Obrigado.

Devolva o inquérito preenchido no envelope com portes pagos.

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
Sample Initial Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]
[ADDRESS]
[CITY, STATE ZIP]

Caro(a) [SAMPLED CAREGIVER NAME]:

[HOSPICE NAME] está a conduzir um inquérito sobre os serviços prestados pelos centros de cuidados paliativos aos doentes e suas famílias. Foi seleccionado para este inquérito porque foi identificado como sendo o cuidador de [DECEDENT NAME]. Reconhecemos que este possa ser um período difícil para si, mas esperamos que possa ajudar-nos a compreender a qualidade dos cuidados que recebeu, ou que o seu familiar ou amigo recebeu, no centro de cuidados paliativos.

As questões [NOTE THE QUESTION NUMBERS] no inquérito incluso são parte integrante de uma iniciativa a nível nacional, promovida pelo Departamento da Saúde e Serviços Humanos dos Estados Unidos (United States Department of Health and Human Services, HHS) para medir a qualidade dos centros de cuidados paliativos. Os Centros para os Serviços Medicare & Medicaid (Centers for Medicare & Medicaid Services, CMS), que fazem parte do HHS, estão a conduzir este inquérito com o objetivo de melhorar os cuidados prestados nos centros de cuidados paliativos. Os CMS cobrem a maior parte dos cuidados paliativos prestados nos centros de cuidados paliativos nos EUA. É da responsabilidade dos CMS assegurar que os doentes nos centros de cuidados paliativos e os seus familiares e amigos recebem cuidados da melhor qualidade. Uma das formas de cumprirem a sua responsabilidade consiste em obter, diretamente de si, informação sobre os cuidados paliativos que o seu familiar ou amigo recebeu no centro. A sua participação é voluntária e não irá afetar quaisquer cuidados de saúde ou benefícios que receba.

Esperamos que dedique algum tempo a completar este inquérito. Após completar este inquérito, devolva-o no envelope com portes pagos. As suas respostas poderão ser partilhadas com o centro de cuidados paliativos para fins de melhoria de qualidade. [OPTIONAL: Poderá reparar num número no inquérito. Este número é usado para nos informar se devolveu o seu inquérito para que não tenhamos de o lembrar.]

Caso tenha alguma questão sobre o inquérito incluso, ligue para o número grátis 1-800-xxx-xxxx. Obrigado por ajudar a melhorar os centros de cuidados paliativos para todos os consumidores.

Com os melhores cumprimentos,
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]
Sample Follow-up Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]
[ADDRESS]
[CITY, STATE ZIP]

Caro(a) [SAMPLED CAREGIVER NAME]:

Os nossos registos mostram que atuou recentemente como cuidador de [HOSPICE NAME] em [DECEDENT NAME]. Há cerca de três semanas, enviámos-lhe um inquérito relativo aos cuidados que recebeu e que o seu familiar ou amigo recebeu neste centro. Se já nos devolveu o inquérito, queira aceitar o nosso agradecimento e ignore esta carta. No entanto, se ainda não o fez, agradecíamos que disponibilizasse algum tempo para completar este importante inquérito.

Esperamos que aproveite esta oportunidade para nos ajudar a compreender acerca da qualidade dos cuidados que o seu familiar ou amigo recebeu. Os resultados deste inquérito serão usados de modo a garantir que todos os americanos recebem cuidados paliativos da melhor qualidade.

As questões [NOTE THE QUESTION NUMBERS] no inquérito incluso são parte integrante de uma iniciativa a nível nacional, promovida pelo Departamento da Saúde e Serviços Humanos dos Estados Unidos (United States Department of Health and Human Services, HHS) para medir a qualidade dos cuidados nos centros de cuidados paliativos. A sua participação é voluntária e não irá afetar quaisquer cuidados de saúde ou benefícios que receba.

Por favor disponibilize alguns minutos para completar o inquérito incluído. Após completar este inquérito, devolva-o no envelope com portes pagos. As suas respostas poderão ser partilhadas com o centro de cuidados paliativos para fins de melhoria de qualidade. [OPTIONAL: Poderá reparar num número no inquérito. Este número é usado para nos informar se devolveu o seu inquérito para que não tenhamos de o lembrar.]

Caso tenha alguma questão sobre o inquérito incluso, ligue para o número grátis 1-800-xxx-xxxx. Obrigado por ajudar a melhorar os centros de cuidados paliativos para todos os consumidores.

Com os melhores cumprimentos,
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]
OMB Paperwork Reduction Act Language

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. The following is the language that must be used:

Portuguese Version

“De acordo com a Lei de Redução da Burocracia de 1995, nenhuma pessoa é obrigada a responder a uma recolha de informação a menos que exiba um número de controle OMB válido. O número de controle OMB válido para esta recolha de informação é 0938-1257. O tempo necessário para completar esta informação recolhida é estimada a 11 minutos para as perguntas 1 a 40 do inquérito, "Sobre o seu membro de família" e "Sobre Si", incluindo o tempo para revisar as instruções, pesquisa dos recursos de dados existentes, reunir os dados necessários, completar e revisar a recolha de informação. Se tiver algum comentário sobre a exatidão da(s) estimativa(s) de tempo ou sugestões para melhorar este formulário, por favor escreva para: Centers for Medicare & Medicaid Services, 7500 Security Boulevard, C1-25-05, Baltimore, MD 21244-1850.”
Appendix T

Mail Survey Materials (Vietnamese)
**Hospice: Một loại dịch vụ chăm sóc cuối đời.

Vui lòng trả lời các câu hỏi khảo sát về việc chăm sóc bệnh nhân đã được nhận từ Hospice này:

[TITLE]

[TITLE]

Tất cả những câu hỏi trong cuộc khảo sát này sẽ hỏi về những trải nghiệm với Hospice.

Nếu bạn muốn biết thêm về cuộc khảo sát này, xin vui lòng gọi vào [TOLL FREE NUMBER]. Tất cả các cuộc gọi đến số điện thoại này là miễn phí.

OMB#0938-1257
## Hướng dẫn khảo sát

- Xin vui lòng đưa cuộc khảo sát này cho người trong gia đình của bạn, người mà hiểu biết nhiều nhất về việc Hospice care được nhận bởi người được liệt kê trên thư xin khảo sát.

- Sử dụng cây bút màu đen để điền vào bản khảo sát.

- Đánh một dấu X trực tiếp vào bên trong ô vuông để cho biết phản hồi của bạn, như mẫu dưới đây:
  - Có
  - Không

- Đôi khi bạn sẽ bỏ qua một số câu hỏi trong cuộc khảo sát này. Khi điều đó xảy ra, bạn sẽ thấy một mũi tên với một lưu ý cho bạn biết những câu hỏi tiếp theo để bạn trả lời, như sau:
  - Có → Nếu có, trả lời tiếp câu hỏi 1
  - Không

## Bệnh nhân của Hospice

1. Bạn có quan hệ như thế nào đối với người đã được liệt kê trong thư khảo sát?

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<thead>
<tr>
<th>Số</th>
<th>Quan hệ</th>
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<tbody>
<tr>
<td>1</td>
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<td>2</td>
<td>Cha/ mẹ của tôi</td>
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<td>3</td>
<td>Cha/Mẹ vợ của tôi hoặc Cha/ Mẹ chồng của tôi</td>
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<td>Ông bà nội/ngoại của tôi</td>
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<td>Cô/chú của tôi</td>
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<td>6</td>
<td>Anh/ chị/ em của tôi</td>
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<tr>
<td>7</td>
<td>Con của tôi</td>
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<tr>
<td>8</td>
<td>Bạn bè của tôi</td>
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<tr>
<td>9</td>
<td>Khác (vui lòng viết ra):</td>
</tr>
</tbody>
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2. Đối với cuộc điều tra này, cụm từ "thành viên gia đình" đề cập đến những người có tên trong thư khảo sát. Ở những địa điểm nào thành viên gia đình bạn được chăm sóc từ Hospice này? Vui lòng chọn một hoặc nhiều.

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<tr>
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<tr>
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<td>Viên dưỡng lão</td>
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<td>4</td>
<td>Bệnh viện</td>
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<td>5</td>
<td>Cơ sở/ viện tế bẩm</td>
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<tr>
<td>6</td>
<td>Khác (vui lòng viết ra):</td>
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___________________________
Vai trò của bạn

3. Trong khi thành viên gia đình của bạn đang được chăm sóc của Hospice care, bạn có thường xuyên tham gia chăm sóc hoặc quan sát người thân của bạn hay không:

   1.  Không bao giờ ➔ Nếu không bao giờ, trả lời tiếp câu 41
   2.  Thỉnh thoảng
   3.  Thường thường
   4.  Luôn luôn

Thành viên gia đình bạn của Hospice Care

Khi bạn trả lời các câu hỏi còn lại của cuộc điều tra này, xin vui lòng chỉ nghĩ về kinh nghiệm của thành viên gia đình bạn với Hospice được đặt tên trên bìa khảo sát.

4. Đối với khảo sát này, nhóm Hospice bao gồm tất cả các y tá, bác sĩ, nhân viên xã hội, giáo sĩ và những người khác, người mà cung cấp dịch vụ Hospice Care cho thành viên gia đình của bạn. Trong thời gian thành viên gia đình của bạn đang được Hospice chăm sóc, bạn có cần gap gò hay liên lạc với nhóm Hospice trong thời gian buổi tối, ngày nghỉ cuối tuần, hoặc ngày lễ cho những vấn đề hoặc cần giúp đỡ chăm sóc thành viên gia đình của bạn?

   1.  Có
   2.  Không ➔ Nếu không, trả lời tiếp câu 6

5. Bạn có thường xuyên nhận được sự giúp đỡ mà bạn cần từ nhóm Hospice vào buổi tối, cuối tuần hoặc là những ngày nghỉ hay không?

   1.  Không bao giờ
   2.  Thỉnh thoảng
   3.  Thường thường
   4.  Luôn luôn

6. Trong khi thành viên gia đình bạn đang được Hospice Care chăm sóc, nhóm Hospice có thường xuyên thông tin cho bạn biết về việc khi nào họ sẽ đến để chăm sóc thành viên gia đình của bạn?

   1.  Không bao giờ
   2.  Thỉnh thoảng
   3.  Thường thường
   4.  Luôn luôn

7. Trong thời gian thành viên gia đình của bạn được Hospice Care chăm sóc, khi bạn hay thành viên gia đình của bạn yêu cầu sự giúp đỡ từ nhóm Hospice, bạn có thường xuyên nhận được sự giúp đỡ sớm nhất như bạn cần không?

   1.  Không bao giờ
   2.  Thỉnh thoảng
   3.  Thường thường
   4.  Luôn luôn

8. Trong thời gian thành viên gia đình của bạn được Hospice Care chăm sóc, nhóm Hospice có thường xuyên giải thích những vấn đề một cách dễ hiểu không?

   1.  Không bao giờ
   2.  Thỉnh thoảng
   3.  Thường thường
   4.  Luôn luôn

9. Trong thời gian thành viên của gia đình bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên thông báo tình trạng của thành viên gia đình bạn không?

   1.  Không bao giờ
   2.  Thỉnh thoảng
   3.  Thường thường
   4.  Luôn luôn
10. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên cung cấp cho bạn thông tin nhằm làm hoà mâu thuẫn về tình trạng hay sự chăm sóc thành viên trong gia đình bạn hay không?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường thường
   4. Luôn luôn

11. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên đối xử tốt và tôn trọng với thành viên của gia đình bạn?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường thường
   4. Luôn luôn

12. Trong thời gian thành viên của gia đình bạn được Hospice chăm sóc, bạn có thường cảm thấy rằng nhóm Hospice thực sự quan tâm đến gia đình của bạn?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường thường
   4. Luôn luôn

13. Trong thời gian thành viên gia đình của bạn đang ở Hospice care, bạn có từng nói chuyện với nhóm Hospice về bất kỳ vấn đề về thành viên gia đình bạn?
   1. Có
   2. Không ➞ Nếu không, trả lời tiếp câu hỏi 15

14. Nhóm Hospice có thường xuyên lắng nghe can thiệp khi bạn nói chuyện với họ về các vấn đề về thành viên của bạn khi đang ở Hospice care?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường thường
   4. Luôn luôn

15. Trong thời gian được Hospice chăm sóc, người thân của bạn có bất kỳ cơn đau nào không?
   1. Có
   2. Không ➞ Nếu không, trả lời tiếp câu hỏi 17

16. Thành viên gia đình bạn có nhận được nhiều sự giúp đỡ khi anh ấy/ cô ấy có những cơn đau hay không?
   1. Có, chắc chắn rồi
   2. Có, một chút
   3. Không

17. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, họ có nhận bất kỳ thuốc giảm đau nào không?
   1. Có
   2. Không ➞ Nếu không, trả lời tiếp câu hỏi 21

18. Tác dụng phụ của thuốc giảm đau bao gồm những việc như gây buồn ngủ. Đã bất kỳ thành viên nào của nhóm Hospice thảo luận về tác dụng phụ của thuốc giảm đau với bạn hoặc thành viên gia đình của bạn?
   1. Có, chắc chắn rồi
   2. Có, một chút
   3. Không
19. Nhóm Hospice có dạy hoặc hướng dẫn cho bạn về những tác dụng phụ của thuốc giảm đau không?

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<td>Không</td>
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20. Nhóm Hospice có hướng dẫn cho bạn khi đưa nhiều hơn thuốc giảm đau cho thành viên gia đình bạn hay không?

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<td>Không</td>
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<td>4</td>
<td>Tôi đã không cần thuốc giảm đau cho thành viên gia đình tôi</td>
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21. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, họ có từng bị khó thở hoặc nhận được sự điều trị khi bị khó thở không?

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22. Thành viên gia đình của bạn có thường xuyên nhận được sự giúp đỡ khi họ cảm thấy khó thở hay không?

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<tbody>
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<td>1</td>
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<td>3</td>
<td>Thường thường</td>
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<tr>
<td>4</td>
<td>Luôn luôn</td>
</tr>
</tbody>
</table>

23. Nhóm Hospice có hướng dẫn hoặc dạy cho bạn cách xử lý khi thành viên gia đình của bạn gặp vấn đề khó thở hay không?

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<td>1</td>
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<td>3</td>
<td>Không</td>
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<td>4</td>
<td>Tôi đã không cần trợ giúp thành viên gia đình tôi khi gặp vấn đề khó thở</td>
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24. Trong thời gian được Hospice chăm sóc, có bao giờ thành viên gia đình bạn gặp vấn đề táo bón?

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25. Thành viên gia đình bạn có thường xuyên nhận được sự giúp đỡ hoặc họ có cần sự giúp đỡ khi gặp vấn đề táo bón không?

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26. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, họ có thể hiện bất kỳ sự lo lắng hay buồn bã nào không?

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27. Thành viên gia đình bạn có thường xuyên nhận được sự giúp đỡ hay họ cần sự giúp đỡ từ nhóm Hospice khi họ lo lắng hay khi họ buồn hay không?

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28. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, có bao giờ anh ấy/cô ấy trở nên không ngừng được hoặc bị kích động không?

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29. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, có bao giờ anh ấy/cô ấy trở nên không muốn được hoặc bị kích động không?

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30. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, có bao giờ anh ấy/cô ấy trở nên không muốn được hoặc bị kích động không?

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Centers for Medicare & Medicaid Services
CAHPS Hospice Survey Quality Assurance Guidelines V3.0
29. Nhóm Hospice có hướng dẫn cho bạn cách xử lý nếu thành viên của gia đình bạn trở nên không ngụ được hoặc bị kích động không?
   1. Có, chắc chắn rồi
   2. Có, một chút
   3. Không

30. Di chuyển thành viên gia đình bạn bao gồm những việc như giúp anh/ cô ấy lật người trên giường, hoặc lên xuống giường hay xe lăn. Nhóm Hospice có hướng dẫn cho bạn cách di chuyển thành viên gia đình bạn một cách toàn không?
   1. Có, chắc chắn rồi
   2. Có, một chút
   3. Không
   4. Tôi không cần dịch chuyển thành viên gia đình tôi

31. Nhóm Hospice có thông báo cho bạn nhiều thông tin như bạn muốn về những điều mong đợi khi thành viên gia đình bạn đang hấp hối?
   1. Có, chắc chắn rồi
   2. Có, một chút
   3. Không

32. Vài người nhận được sự chăm sóc từ Hospice khi họ đang sống ở viện dưỡng lão. Gia đình bạn có nhận được chăm sóc từ Hospice này trong khi anh/ cô ấy đang sống ở viện dưỡng lão hay không?
   1. Có
   2. Không → Nếu không, trả lời tiếp câu 35

33. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, nhân viên viện dưỡng lão và nhóm Hospice có thường xuyên làm việc chung để chăm sóc tốt cho thành viên gia đình bạn hay không?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường xuyên
   4. Luôn luôn

34. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, có bao giờ thông tin được cung cấp cho thành viên gia đình bạn từ nhân viên của viện dưỡng lão và nhóm Hospice là khác nhau không?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường xuyên
   4. Luôn luôn

KINH NGHIỆM CỦA BẢN THÂN BẠN VỚI HOSPICE

35. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên lắng nghe ý kiến của bạn một cách cẩn thận không?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường xuyên
   4. Luôn luôn
36. Về việc hỗ trợ cho các hoạt động về tôn giáo hay tín ngưỡng tâm linh bao gồm việc trò chuyện, cầu nguyện, thời gian yên tĩnh, hoặc các hoạt động hội họp về tôn giáo và các nhu cầu tín ngưỡng. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, nhóm Hospice có hỗ trợ các hoạt động về tôn giáo hay tín ngưỡng tâm linh cho bạn không?

1 □ Rất ít
2 □ Đúng mức, vừa phải
3 □ Rất nhiều

37. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, mức độ hỗ trợ nhiệt tình từ nhóm Hospice đối với gia đình bạn như thế nào?

1 □ Rất ít
2 □ Đúng mức, vừa phải
3 □ Rất nhiều

38. Trong những tuần sau khi thành viên của gia đình bạn qua đời, mức độ hỗ trợ nhiệt tình từ nhóm Hospice đối với gia đình bạn như thế nào?

1 □ Rất ít
2 □ Đúng mức, vừa phải
3 □ Rất nhiều

ĐÁNH GIÁ TỔNG THỂ VỀ HOSPICE CARE


Sử dụng số từ 0 đến 10, số 0 thể hiện mức độ chăm sóc tệ nhất, 10 thể hiện mức độ chăm sóc tốt nhất, con số nào để bạn đánh giá mức độ chăm sóc từ Hospice cho thành viên gia đình bạn?

0 □ 0 Hospice chăm sóc tồi tệ nhất có thể
1 □ 1
2 □ 2
3 □ 3
4 □ 4
5 □ 5
6 □ 6
7 □ 7
8 □ 8
9 □ 9
10 □ 10 Hospice chăm sóc tốt nhất có thể

40. Bạn có đề xuất Hospice care này cho bạn bè và gia đình bạn không?

1 □ Chắc chắn là không
2 □ Có thể không
3 □ Có thể có
4 □ Chắc chắn là có
### THÔNG TIN THÀNH VIÊN GIA ĐÌNH CỦA BẠN

41. **Trình độ học vấn cao nhất của thành viên gia đình bạn đã hoàn thành là gì?**

1. ☐ Lớp 8 hoặc thấp hơn
2. ☐ Trung học phổ thông, nhưng chưa tốt nghiệp phổ thông
3. ☐ Tốt nghiệp trung học phổ thông hoặc tương đương GED
4. ☐ Cao đẳng hoặc Khoa học 2 năm
5. ☐ Tốt nghiệp cao đẳng hai năm học
6. ☐ Tốt nghiệp cao đẳng trên 4 năm học
7. ☐ Không biết

42. **Thành viên gia đình bạn là người Tây Ban Nha, La tinh/ hay có gốc Nam Mỹ không?**

1. ☐Không, không phải người Tây Ban Nha/ gốc Nam Mỹ/ người La Tinh
2. ☐Phải, Puerto Rican
3. ☐Phải, người Mỹ Tây Cô, người Mỹ gốc Mễ Tây Cơ, người Chicano (người gốc Mễ Tây Cô sinh tại Mỹ)
4. ☐Phải, Cuba
5. ☐Phải, người Tây Ban Nha, người gốc Nam Mỹ/ La Tinh

43. **Chủng tộc của thành viên gia đình bạn là gì? Vui lòng chọn một hoặc nhiều hơn.**

1. ☐Người da Trắng
2. ☐Người da Đen hoặc người Mỹ gốc Phi
3. ☐Người Châu Á
4. ☐Người có nguồn gốc đảo Hawaii hay đảo khác ở Thái Bình Dương
5. ☐Người có nguồn gốc từ bất cứ sắc dân bản địa nào ở Bắc Mỹ và Nam Mỹ

### THÔNG TIN VỀ BẠN

44. **Bạn bao nhiêu tuổi?**

1. ☐ 18 đến 24
2. ☐ 25 đến 34
3. ☐ 35 đến 44
4. ☐ 45 đến 54
5. ☐ 55 đến 64
6. ☐ 65 đến 74
7. ☐ 75 đến 84
8. ☐ 85 hoặc trên 85

45. **Bạn là nam hay nữ?**

1. ☐ Nam
2. ☐ Nữ
46. Trình độ học vấn cao nhất mà bạn đã hoàn thành là gì?

1 □ Lớp 8 hoặc thấp hơn
2 □ Trung học phổ thông, nhưng chưa tốt nghiệp
3 □ Tốt nghiệp trung học phổ thông hoặc GED
4 □ Cao đẳng hoặc khóa học 2 năm
5 □ Tốt nghiệp cao đẳng hệ 4 năm học
6 □ Tốt nghiệp cao đẳng hệ trên 4 năm học

47. Ngôn ngữ bạn sử dụng chính để giao tiếp ở nhà là gì?

1 □ Tiếng Anh
2 □ Tiếng Tây Ban Nha
3 □ Tiếng Trung Quốc
4 □ Tiếng Nga
5 □ Tiếng Bồ Đào Nha
6 □ Tiếng Việt
7 □ Ngôn ngữ khác (vui lòng viết ra):

________________________

CHÂN THÀNH CÁM ƠN QUÝ VỊ

Vui lòng dùng bao thư đính kèm có sẵn bưu phí và gửi trở lại bản thăm dò ý kiến sau khi trả lời đầy đủ.

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
**Hospice: Một loại dịch vụ chăm sóc cuối đời.

Vui lòng trả lời các câu hỏi khảo sát về việc chăm sóc bệnh nhân đã được nhận từ Hospice này:

[TITLE]

Tất cả những câu hỏi trong cuộc khảo sát này sẽ hỏi về những trải nghiệm với Hospice.

Nếu bạn muốn biết thêm về cuộc khảo sát này, xin vui lòng gọi vào [TOLL FREE NUMBER]. Tất cả các cuộc gọi đến số điện thoại này là miễn phí.

OMB#0938-1257
Khảo sát về CAHPS® Hospice

HƯỚNG DẪN KHẢO SÁT

◆ Xin vui lòng đưa cuộc khảo sát này cho người trong gia đình của bạn, người mà hiểu biết nhiều nhất về việc Hospice care được nhận bởi người được liệt kê trên thư xin khảo sát.

◆ Sử dụng cây bút màu đen để điền vào bản khảo sát.

◆ Trả lời tất cả các câu hỏi bằng cách điền đầy đủ vào ô bầu dục ở phía trái câu trả lời của bạn.

   ♦ Có
   0 Không

◆ Đôi khi bạn sẽ bỏ qua một số câu hỏi trong cuộc khảo sát này. Khi điều đó xảy ra, bạn sẽ thấy một mũi tên với một lưu ý cho bạn biết những câu hỏi tiếp theo để bạn trả lời, như sau:

   ♦ Có → Nêu có, trả lời tiếp câu hỏi 1
   0 Không

---

BỆNH NHÂN CỦA HOSPICE

1. Bạn có quan hệ như thế nào đối với người đã được liệt kê trong thư khảo sát?

   1. Vợ hoặc chồng của tôi
   2. Cha/ mẹ của tôi
   3. Cha/Mẹ vợ của tôi hoặc Cha/ Mẹ chồng
   4. Ông bà nội/ngoại của tôi
   5. Cô/chú của tôi
   6. Anh/ chị/ em của tôi
   7. Con của tôi
   8. Bạn bè của tôi
   9. Khác (vui lòng viết ra):

---

2. Đối với cuộc điều tra này, cụm từ "thành viên gia đình" đề cập đến những người có tên trong thư khảo sát. Ở những địa điểm nào thành viên gia đình bạn được chăm sóc từ Hospice này? Vui lòng chọn một hoặc nhiều.

   1. Nhà
   2. Trung tâm trợ sinh
   3. Viện dưỡng lão
   4. Bệnh viện
   5. Cơ sở/ viện tế bần
   6. Khác (vui lòng viết ra):

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Centers for Medicare & Medicaid Services
CAHPS Hospice Survey Quality Assurance Guidelines V3.0
3. Trong khi thành viên gia đình của bạn đang được chăm sóc của Hospice care, bạn có thường xuyên tham gia chăm sóc hoặc quan sát người thân của bạn hay không:

1. Không bao giờ → Nếu không bao giờ, trả lời tiếp câu 41

2. Thỉnh thoảng

3. Thường thường

4. Luôn luôn

4. Đối với khảo sát này, nhóm Hospice bao gồm tất cả các y tá, bác sĩ, nhân viên xã hội, giáo sĩ và những người khác, người mà cung cấp dịch vụ Hospice Care cho thành viên gia đình của bạn. Trong thời gian thành viên gia đình của bạn đang được Hospice chăm sóc, bạn có cần gặp gỡ hay liên lạc với nhóm Hospice trong thời gian buổi tối, ngày nghỉ cuối tuần, hoặc ngày lễ cho những vấn đề hoặc cần giúp đỡ chăm sóc thành viên gia đình của bạn?

1. Không bao giờ

2. Thỉnh thoảng

3. Thường thường

4. Luôn luôn

5. Bạn có thường xuyên nhận được sự giúp đỡ mà bạn cần từ nhóm Hospice vào buổi tối, cuối tuần hoặc là những ngày nghỉ hay không?

1. Không bao giờ

2. Thỉnh thoảng

3. Thường thường

4. Luôn luôn

6. Trong khi thành viên gia đình bạn đang được Hospice Care chăm sóc, nhóm Hospice có thường xuyên thông tin cho bạn biết về việc khi nào họ sẽ đến để chăm sóc thành viên gia đình của bạn?

1. Không bao giờ

2. Thỉnh thoảng

3. Thường thường

4. Luôn luôn

7. Trong thời gian thành viên gia đình của bạn đang được Hospice Care chăm sóc, khi bạn hay thành viên gia đình của bạn yêu cầu sự giúp đỡ từ nhóm Hospice, bạn có thường xuyên nhận được sự giúp đỡ sớm nhất như bạn cần không?

1. Không bao giờ

2. Thỉnh thoảng

3. Thường thường

4. Luôn luôn

8. Trong thời gian thành viên gia đình của bạn đang được Hospice Care chăm sóc, nhóm Hospice có thường xuyên giải thích những vấn đề một cách dễ hiểu không?

1. Không bao giờ

2. Thỉnh thoảng

3. Thường thường

4. Luôn luôn

9. Trong thời gian thành viên của gia đình bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên thông báo tình trạng của thành viên gia đình bạn không?

1. Không bao giờ

2. Thỉnh thoảng

3. Thường thường

4. Luôn luôn
10. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên cung cấp cho bạn thông tin nhằm làm rõ hoặc mâu thuẫn về tình trạng hay sự chăm sóc thành viên trong gia đình bạn hay không?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường thường
   4. Luôn luôn

11. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên đối xử tốt và tôn trọng với thành viên của gia đình bạn?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường thường
   4. Luôn luôn

12. Trong thời gian thành viên của gia đình bạn được Hospice chăm sóc, bạn có thường cảm thấy rằng nhóm Hospice thực sự quan tâm đến gia đình của bạn?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường thường
   4. Luôn luôn

13. Trong thời gian thành viên gia đình của bạn đang ở Hospice care, bạn có từng nói chuyện với nhóm Hospice care về bất kỳ vấn đề về thành viên gia đình bạn với Hospice care?
   1. Có
   2. Không ➔ Nếu không, trả lời tiếp câu 15

14. Nhóm Hospice có thường xuyên lắng nghe câu thắc mắc khi bạn nói chuyện với họ về các vấn đề về thành viên của bạn khi đang ở Hospice care?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường thường
   4. Luôn luôn

15. Trong thời gian được Hospice chăm sóc, người thân của bạn có bất kỳ cơn đau nào không?
   1. Có
   2. Không ➔ Nếu không, trả lời tiếp câu 17

16. Thành viên gia đình bạn có nhận được nhiều sự giúp đỡ khi anh ấy/ cô ấy có những cơn đau hay không?
   1. Có, chắc chắn rồi
   2. Có, một chút
   3. Không

17. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, họ có nhận bất kỳ thuốc giảm đau nào không?
   1. Có
   2. Không ➔ Nếu không, trả lời tiếp câu hỏi 21

18. Tác dụng phụ của thuốc giảm đau bao gồm những việc như gây buồn ngủ. Đã bất kỳ thành viên nào của nhóm Hospice thảo luận về tác dụng phụ của thuốc giảm đau với bạn hoặc thành viên gia đình của bạn?
   1. Có, chắc chắn rồi
   2. Có, một chút
   3. Không
19. Nhóm Hospice có dạy hoặc hướng dẫn cho bạn về những tác dụng phụ của thuốc giảm đau không?
   1. Có, chắc chắn rồi
   2. Có, một chút
   3. Không

20. Nhóm Hospice có hướng dẫn cho bạn khi đưa nhiều hơn thuốc giảm đau cho thành viên gia đình hay không?
   1. Có, chắc chắn rồi
   2. Có, một chút
   3. Không
   4. Tôi đã không cần thuốc giảm đau cho thành viên gia đình tôi

21. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, họ có từng bị khó thở hoặc nhận được sự điều trị khi bị khó thở không?
   1. Có
   2. Không → Nếu không, trả lời tiếp câu hỏi 24

22. Thành viên gia đình của bạn có thường xuyên nhận được sự giúp đỡ khi họ cảm giác khó thở hay không?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường thường
   4. Luôn luôn

23. Nhóm Hospice có hướng dẫn hoặc dạy cho bạn cách xử lý khi thành viên gia đình của bạn gặp vấn đề khó thở hay không?
   1. Có, chắc chắn rồi
   2. Có, một chút
   3. Không
   4. Tôi đã không cần trợ giúp thành viên gia đình tôi khi gặp vấn đề khó thở

24. Trong thời gian được Hospice chăm sóc, có bao giờ thành viên gia đình bạn gặp vấn đề táo bón?
   1. Có
   2. Không → Nếu không, trả lời tiếp câu 26

25. Thành viên gia đình bạn có thường xuyên nhận được sự giúp đỡ hay có cần sự giúp đỡ khi gặp vấn đề táo bón không?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường thường
   4. Luôn luôn

26. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, họ có thể hiện bất kỳ sự lo lắng hay buồn bã nào không?
   1. Có
   2. Không → Nếu không, trả lời tiếp câu 28

27. Thành viên gia đình bạn có thường xuyên nhận được sự giúp đỡ hay có cần sự giúp đỡ từ nhóm Hospice khi họ lo lắng hay họ buồn hay không?
   1. Không bao giờ
   2. Thỉnh thoảng
   3. Thường thường
   4. Luôn luôn

28. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, có bao giờ anh/đó trở nên không ngủ được hoặc bị kích động không?
   1. Có
   2. Không → Nếu không, trả lời tiếp câu 30
29. Nhóm Hospice có hướng dẫn cho bạn cách xử lý nếu thành viên của gia đình bạn trở nên không ngủ được hoặc bị kích động không?

1 0 Có, chắc chắn rồi
2 0 Có, một chút
3 0Không

30. Di chuyển thành viên gia đình bạn bao gồm những việc như giúp anh ấy/cô ấy lật người trên giường, hoặc lên xuống giường hay xe lăn. Nhóm Hospice có hướng dẫn cho bạn cách di chuyển thành viên gia đình bạn một cách toàn không?

1 0 Có, chắc chắn rồi
2 0 Có, một chút
3 0 Không
4 0 Tôi không cần dịch chuyển thành viên gia đình tôi

31. Nhóm Hospice có thông báo cho bạn nhiều thông tin như bạn muốn về những điều mong đợi khi thành viên gia đình bạn đang hấp hối?

1 0 Có, chắc chắn rồi
2 0 Có, một chút
3 0 Không

32. Vài người nhận được sự chăm sóc từ Hospice khi họ đang sống ở viện dưỡng lão. Gia đình bạn có nhận được chăm sóc từ Hospice này trong khi anh ấy/cô ấy đang sống ở viện dưỡng lão hay không?

1 0 Có
2 0 Không ➔ Nếu không, trả lời tiếp câu 35

33. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, nhân viên viện dưỡng lão và nhóm Hospice có thường xuyên làm việc chung để chăm sóc tốt cho thành viên gia đình bạn hay không?

1 0 Không bao giờ
2 0 Thỉnh thoảng
3 0 Thường thường
4 0 Luôn luôn

34. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, có bao giờ thông tin được cung cấp cho thành viên gia đình bạn từ nhân viên của viện dưỡng lão và nhóm Hospice là khác nhau không?

1 0 Không bao giờ
2 0 Thỉnh thoảng
3 0 Thường thường
4 0 Luôn luôn

KINH NGHIỆM CỦA BẢN THÂN BẠN VỚI HOSPICE

35. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên lắng nghe ý kiến của bạn một cách tận tâm không?

1 0 Không bao giờ
2 0 Thỉnh thoảng
3 0 Thường thường
4 0 Luôn luôn

NHẬN DƯỠNG SỰ CHÂM SÓC CỦA HOSPICE CARE TRONG VIỆN DƯỠNG LÃO

32. Vài người nhận được sự chăm sóc từ Hospice khi họ đang sống ở viện dưỡng lão. Gia đình bạn có nhận được chăm sóc từ Hospice này trong khi anh ấy/cô ấy đang sống ở viện dưỡng lão hay không?

1 0 Có
2 0 Không ➔ Nếu không, trả lời tiếp câu 35
36. Về việc hỗ trợ cho các hoạt động về tôn giáo hay tín ngưỡng tâm linh bao gồm việc trò chuyện, cầu nguyện, thời gian yên tĩnh, hoặc các hoạt động hội họp về tôn giáo và các nhu cầu tín ngưỡng. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, nhóm Hospice có hỗ trợ các hoạt động về tôn giáo hay tín ngưỡng tâm linh cho bạn không?

1 0 Rất ít
2 0 Đúng mức, vừa phải
3 0 Rất nhiều

37. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, mức độ hỗ trợ nhiệt tình từ nhóm Hospice đối với gia đình bạn như thế nào?

1 0 Rất ít
2 0 Đúng mức, vừa phải
3 0 Rất nhiều

38. Trong những tuần sau khi thành viên của gia đình bạn qua đời, mức độ hỗ trợ nhiệt tình từ nhóm Hospice đối với gia đình bạn như thế nào?

1 0 Rất ít
2 0 Đúng mức, vừa phải
3 0 Rất nhiều

ĐÁNH GIÁ TỔNG THỂ VỀ HOSPICE CARE


Sử dụng số từ 0 đến 10, số 0 thể hiện mức độ chăm sóc tệ nhất, 10 thể hiện mức độ chăm sóc tốt nhất, con số nào để bạn đánh giá mức độ chăm sóc từ Hospice cho thành viên gia đình bạn?

0 0 0 Hospice chăm sóc tồi tệ nhất có thể
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 Hospice chăm sóc tốt nhất có thể

40. Bạn có đề xuất Hospice care này cho bạn bè và gia đình bạn không?

1 0 Chắc chắn là không
2 0 Có thể không
3 0 Có thể có
4 0 Chắc chắn là có
## THÔNG TIN THÀNH VIÊN GIA ĐÌNH CỦA BẠN

41. Trình độ học vấn cao nhất của thành viên gia đình bạn đã hoàn thành là gì?

<table>
<thead>
<tr>
<th>Số</th>
<th>Mô tả</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Lớp 8 hoặc thấp hơn</td>
</tr>
<tr>
<td>2</td>
<td>Trung học phổ thông, nhưng chưa tốt nghiệp phổ thông</td>
</tr>
<tr>
<td>3</td>
<td>Tốt nghiệp trung học phổ thông hoặc tương đương GED</td>
</tr>
<tr>
<td>4</td>
<td>Cao đẳng hoặc Khoa học 2 năm</td>
</tr>
<tr>
<td>5</td>
<td>Tốt nghiệp cao đẳng hệ 4 năm</td>
</tr>
<tr>
<td>6</td>
<td>Tốt nghiệp cao đẳng trên 4 năm học</td>
</tr>
<tr>
<td>7</td>
<td>Không biết</td>
</tr>
</tbody>
</table>

42. Thành viên gia đình bạn là người Tây Ban Nha, La tinh/ hay có gốc Nam Mỹ không?

<table>
<thead>
<tr>
<th>Số</th>
<th>Mô tả</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Không, không phải người Tây Ban Nha/ gốc Nam Mỹ/ người La Tinh</td>
</tr>
<tr>
<td>2</td>
<td>Phải, Puerto Rican</td>
</tr>
<tr>
<td>3</td>
<td>Phải, người Mỹ Tây Cơ, người Mỹ gốc Mễ Tây Cơ, người Chicano (người gốc Mễ Tây Cơ sinh tại Mỹ)</td>
</tr>
<tr>
<td>4</td>
<td>Phải, Cuba</td>
</tr>
<tr>
<td>5</td>
<td>Phải, người Tây Ban Nha, người gốc Nam Mỹ/ La Tinh</td>
</tr>
</tbody>
</table>

43. Chủng tộc của thành viên gia đình bạn là gì? Vui lòng chọn một hoặc nhiều hơn.

<table>
<thead>
<tr>
<th>Số</th>
<th>Mô tả</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Người da Trắng</td>
</tr>
<tr>
<td>2</td>
<td>Người da Đen hoặc người Mỹ gốc Phi</td>
</tr>
<tr>
<td>3</td>
<td>Người Châu Á</td>
</tr>
<tr>
<td>4</td>
<td>Người có nguồn gốc đảo Hawaii hay đảo khác ở Thái Bình Dương</td>
</tr>
<tr>
<td>5</td>
<td>Người có nguồn gốc từ bất cứ sắc dân bản địa nào ở Bắc Mỹ và Nam Mỹ</td>
</tr>
</tbody>
</table>

## THÔNG TIN VỀ BẠN

44. Bạn bao nhiêu tuổi?

<table>
<thead>
<tr>
<th>Số</th>
<th>Mô tả</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>18 đến 24</td>
</tr>
<tr>
<td>2</td>
<td>25 đến 34</td>
</tr>
<tr>
<td>3</td>
<td>35 đến 44</td>
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<td>4</td>
<td>45 đến 54</td>
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<td>55 đến 64</td>
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<td>6</td>
<td>65 đến 74</td>
</tr>
<tr>
<td>7</td>
<td>75 đến 84</td>
</tr>
<tr>
<td>8</td>
<td>85 hoặc trên 85</td>
</tr>
</tbody>
</table>

45. Bạn là nam hay nữ?

<table>
<thead>
<tr>
<th>Số</th>
<th>Mô tả</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Nam</td>
</tr>
<tr>
<td>2</td>
<td>Nữ</td>
</tr>
</tbody>
</table>
46. Trình độ học vấn cao nhất mà bạn đã hoàn thành là gì?

1 0 Lớp 8 hoặc thấp hơn
2 0 Trung học phổ thông, nhưng chưa tốt nghiệp
3 0 Tốt nghiệp trung học phổ thông hoặc GED
4 0 Cao đẳng hoặc khoá học 2 năm
5 0 Tốt nghiệp cao đẳng hệ 4 năm học
6 0 Tốt nghiệp cao đẳng hệ trên 4 năm học

47. Ngôn ngữ bạn sử dụng chính để giao tiếp ở nhà là gì?

1 0 Tiếng Anh
2 0 Tiếng Tây Ban Nha
3 0 Tiếng Trung Quốc
4 0 Tiếng Nga
5 0 Tiếng Bồ Đào Nha
6 0 Tiếng Việt
7 0 Ngôn ngữ khác (vui lòng viết ra):
_______________________________

CHÂN THÀNH CÁM ƠN QUÝ VỊ

Vui lòng dùng bao thư đính kèm có sẵn bưu phí và gửi trở lại bản thăm dò ý kiến sau khi trả lời đầy đủ.

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
Khảo sát về CAHPS® Hospice

**Hospice: Một loại dịch vụ chăm sóc cuối đời.

Vui lòng trả lời các câu hỏi khảo sát về việc chăm sóc bệnh nhân đã được nhận từ Hospice này:

[TITLE OF HOSPICE]

Tất cả những câu hỏi trong cuộc khảo sát này sẽ hỏi về những trải nghiệm với Hospice.

Nếu bạn muốn biết thêm về cuộc khảo sát này, xin vui lòng gọi vào [TOLL FREE NUMBER]. Tất cả các cuộc gọi đến số điện thoại này là miễn phí.

OMB#0938-1257
Khảo sát về CAHPS® Hospice

HƯỚNG DẪN KHẢO SÁT

♦ Xin vui lòng đưa cuộc khảo sát này cho người trong gia đình của bạn, người mà hiểu biết nhiều nhất về việc Hospice care được nhận bởi người được liệt kê trên thư xin khảo sát.

♦ Sử dụng cây bút màu đen để điền vào bản khảo sát.

♦ Trả lời tất cả các câu hỏi bằng cách điền đầy đủ vào hình tròn ở phía trái câu trả lời của bạn.
  - Có
  - Không

♦ Đôi khi bạn sẽ bỏ qua một số câu hỏi trong cuộc khảo sát này. Khi điều đó xảy ra, bạn sẽ thấy một mũi tên với một lưu ý cho bạn biết những câu hỏi tiếp theo để bạn trả lời, như sau:
  - Có → Nếu có, trả lời tiếp câu hỏi 1
  - Không

1. Bạn có quan hệ như thế nào đối với người đã được liệt kê trong thư khảo sát?

   1 O Vợ hoặc chồng của tôi
   2 O Cha/ mẹ của tôi
   3 O Cha /Mẹ vợ của tôi hoặc Cha/ Mẹ chồng của tôi
   4 O Ông bà nội/ngoại của tôi
   5 O Cô/chú của tôi
   6 O Anh/ chị/ em của tôi
   7 O Con của tôi
   8 O Bạn bè của tôi
   9 O Khác (vui lòng viết ra):

2. Đối với cuộc điều tra này, cụm từ "thành viên gia đình" đề cập đến những người có tên trong thư khảo sát. Ở những địa điểm nào thành viên gia đình bạn được chăm sóc từ Hospice này? Vui lòng chọn một hoặc nhiều.

   1 O Nhà
   2 O Trung tâm trợ sinh
   3 O Viên dưỡng lão
   4 O Bệnh viện
   5 O Cô số/ viện tế bán
   6 O Khác (vui lòng viết ra):

______________________________
VAI TRÒ CỦA BẠN

3. Trong khi thành viên gia đình của bạn đang được chăm sóc của Hospice care, bạn có thường xuyên tham gia chăm sóc hoặc quan sát người thân của bạn hay không:

1️⃣ Không bao giờ ➔ Nếu không bao giờ, trả lời tiếp câu 41
2️⃣ Thỉnh thoảng
3️⃣ Thường
4️⃣ Luôn luôn

THÀNH VIÊN GIA ĐÌNH BẠN CỦA HOSPICE CARE

Khi bạn trả lời các câu hỏi còn lại của cuộc điều tra này, xin vui lòng tôi nghĩ về kinh nghiệm của thành viên gia đình bạn với Hospice được đặt tên trên bìa khảo sát.

4. Đối với khảo sát này, nhóm Hospice bao gồm tất cả các y tá, bác sĩ, nhân viên xã hội, giáo sĩ và những người khác, người mà cung cấp dịch vụ Hospice Care cho thành viên gia đình của bạn. Trong thời gian thành viên gia đình của bạn đang được Hospice chăm sóc, bạn có cần gặp gỡ hay liên lạc với nhóm Hospice trong thời gian buổi tối, ngày nghỉ cuối tuần, hoặc ngày lễ cho những vấn đề hoặc cần giúp đỡ chăm sóc thành viên gia đình của bạn?

1️⃣ Không bao giờ
2️⃣ Thỉnh thoảng
3️⃣ Thường
4️⃣ Luôn luôn

5. Bạn có thường xuyên nhận được sự giúp đỡ mà bạn cần từ nhóm Hospice vào buổi tối, cuối tuần hoặc là những ngày nghỉ hay không?

1️⃣ Không bao giờ
2️⃣ Thỉnh thoảng
3️⃣ Thường
4️⃣ Luôn luôn

6. Trong khi thành viên gia đình bạn đang được Hospice Care chăm sóc, nhóm Hospice có thường xuyên thông tin cho bạn biết về việc khi nào họ sẽ đến để chăm sóc thành viên gia đình của bạn?

1️⃣ Không bao giờ
2️⃣ Thỉnh thoảng
3️⃣ Thường
4️⃣ Luôn luôn

7. Trong thời gian thành viên gia đình của bạn được Hospice Care chăm sóc, khi bạn hay thành viên gia đình của bạn yêu cầu sự giúp đỡ từ nhóm Hospice, bạn có thường xuyên nhận được sự giúp đỡ sớm nhất như bạn cần không?

1️⃣ Không bao giờ
2️⃣ Thỉnh thoảng
3️⃣ Thường
4️⃣ Luôn luôn

8. Trong thời gian thành viên gia đình của bạn được Hospice Care chăm sóc, nhóm Hospice có thường xuyên giải thích những vấn đề một cách dễ hiểu không?

1️⃣ Không bao giờ
2️⃣ Thỉnh thoảng
3️⃣ Thường
4️⃣ Luôn luôn

9. Trong thời gian thành viên của gia đình bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên thông báo tình trạng của thành viên gia đình bạn không?

1️⃣ Không bao giờ
2️⃣ Thỉnh thoảng
3️⃣ Thường
4️⃣ Luôn luôn
10. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên cung cấp cho bạn thông tin nhằm lănhoc mau thuận về tình trạng hay sự chăm sóc thành viên trong gia đình bạn hay không?

1 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O Luôn luôn

11. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên đối xử tốt và tôn trọng với thành viên của gia đình bạn?

1 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O Luôn luôn

12. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, bạn có thường cảm thấy rằng nhóm Hospice thực sự quan tâm đến gia đình của bạn?

1 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O Luôn luôn

13. Trong thời gian thành viên gia đình của bạn đang ở Hospice care, bạn có từng nói chuyện với nhóm Hospice care về bất cứ vấn đề về thành viên gia đình bạn?

1 O Có
2 O Không ➔ Nếu không, trả lời tiếp câu 15

14. Nhóm Hospice có thường xuyên lắng nghe cảnh thận khi bạn nói chuyện với họ về các vấn đề về thành viên của bạn khi đang ở Hospice care?

1 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O Luôn luôn

15. Trong thời gian được Hospice chăm sóc, người thân của bạn có bất kỳ cơn đau nào không?

1 O Có
2 O Không ➔ Nếu không, trả lời tiếp câu 17

16. Thành viên gia đình bạn có nhận được nhiều sự giúp đỡ khi anh ấy/ cô ấy có những cơn đau hay không?

1 O Có, chắc chắn rồi
2 O Có, một chút
3 O Không

17. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, họ có nhận bất kỳ thuốc giảm đau nào không?

1 O Có
2 O Không ➔ Nếu không, trả lời tiếp câu hỏi 21

18. Tác dụng phụ của thuốc giảm đau bao gồm những việc như gây buồn ngủ. Đã bất kỳ thành viên nào của nhóm Hospice thảo luận về tác dụng phụ của thuốc giảm đau với bạn hoặc thành viên gia đình của bạn?

1 O Có, chắc chắn rồi
2 O Có, một chút
3 O Không
19. Nhóm Hospice có dạy hoặc hướng dẫn cho bạn về những tác dụng phụ của thuốc giảm đau không?
   1 ☐ Có, chắc chắn rồi
   2 ☐ Có, một chút
   3 ☐ Không

20. Nhóm Hospice có hướng dẫn cho bạn khi đưa nhiều hơn thuốc giảm đau cho thành viên gia đình bạn hay không?
   1 ☐ Có, chắc chắn rồi
   2 ☐ Có, một chút
   3 ☐ Không
   4 ☐ Tôi đã không cần thuốc giảm đau cho thành viên gia đình tôi

21. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, họ có từng bị khó thở hoặc nhận được sự điều trị khi bị khó thở không?
   1 ☐ Có
   2 ☐ Không → Nếu không, trả lời tiếp câu hỏi 24

22. Thành viên gia đình của bạn có thường xuyên nhận được sự giúp đỡ khi họ lo lắng hay không?
   1 ☐ Không bao giờ
   2 ☐ Thỉnh thoảng
   3 ☐ Thường thường
   4 ☐ Luôn luôn

23. Nhóm Hospice có hướng dẫn hoặc dạy cho bạn cách xử lý khi thành viên gia đình của bạn gặp vấn đề khó thở hay không?
   1 ☐ Có, chắc chắn rồi
   2 ☐ Có, một chút
   3 ☐ Không
   4 ☐ Tôi đã không cần trợ giúp thành viên gia dinh tôi khi gặp vấn đề khó thở

24. Trong thời gian được Hospice chăm sóc, có bao giờ thành viên gia đình bạn gặp vấn đề táo bón?
   1 ☐ Có
   2 ☐ Không → Nếu không, trả lời tiếp câu 26

25. Thành viên gia đình bạn có thường xuyên nhận được sự trợ giúp hoặc họ có cần sự trợ giúp khi gặp vấn đề táo bón không?
   1 ☐ Không bao giờ
   2 ☐ Thỉnh thoảng
   3 ☐ Thường thường
   4 ☐ Luôn luôn

26. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, họ có thể hiện bất kỳ sự lo lắng hay buồn bã nào không?
   1 ☐ Có
   2 ☐ Không → Nếu không, trả lời tiếp câu 28

27. Thành viên gia đình bạn có thường xuyên nhận được sự giúp đỡ hay họ cần sự giúp đỡ từ nhóm Hospice khi họ lo lắng hay khi họ buồn hay không?
   1 ☐ Không bao giờ
   2 ☐ Thỉnh thoảng
   3 ☐ Thường thường
   4 ☐ Luôn luôn
28. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, có bao giờ anh ấy/cô ấy trở nên không ngủ được hoặc bị kích động không?

1 ○ Có
2 ○ Không → Nếu không, trả lời tiếp câu 30

29. Nhóm Hospice có hướng dẫn cho bạn cách xử lý nếu thành viên của gia đình bạn trở nên không ngủ được hoặc bị kích động không?

1 ○ Có, chắc chắn rồi
2 ○ Có, một chút
3 ○ Không

30. Di chuyển thành viên gia đình bạn bao gồm những việc như giúp anh ấy/cô ấy lật người trên giường, hoặc lên xuống giường hay xe lăn. Nhóm Hospice có hướng dẫn cho bạn cách di chuyển thành viên gia đình bạn một cách toàn không?

1 ○ Có, chắc chắn rồi
2 ○ Có, một chút
3 ○ Không
4 ○ Tôi không cần dịch chuyển thành viên gia đình tôi

31. Nhóm Hospice có thông báo cho bạn nhiều thông tin như bạn muốn về những điều mong đợi khi thành viên gia đình bạn đang hấp hối?

1 ○ Có, chắc chắn rồi
2 ○ Có, một chút
3 ○ Không
4 ○ Tôi không cần dịch thông tin về thành viên gia đình tôi

32. Vài người nhận được sự chăm sóc từ Hospice khi họ đang sống ở viện dưỡng lão. Gia đình bạn có nhận được chăm sóc từ Hospice này trong khi anh ấy/cô ấy đang sống ở viện dưỡng lão hay không?

1 ○ Có
2 ○ Không → Nếu không, trả lời tiếp câu 35

33. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, nhân viên viện dưỡng lão và nhóm Hospice có thường xuyên làm việc chung để chăm sóc tốt cho thành viên gia đình bạn hay không?

1 ○ Không bao giờ
2 ○ Thỉnh thoảng
3 ○ Thường thường
4 ○ Luôn luôn

34. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, có bao giờ thông tin được cung cấp cho thành viên gia đình bạn từ nhân viên của viện dưỡng lão và nhóm Hospice là khác nhau không?

1 ○ Không bao giờ
2 ○ Thỉnh thoảng
3 ○ Thường thường
4 ○ Luôn luôn
KINH NGHIỆM CỦA BÀN THÀNH VIỆN VỚI HOSPICE

35. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, nhóm Hospice có thường xuyên lắng nghe ý kiến của bạn một cách cần thận không?

1  O Không bao giờ
2  O Thỉnh thoảng
3  O Thường thường
4  O Luôn luôn

36. Vế việc hỗ trợ cho các hoạt động về tôn giáo hay tinh tàng tâm linh bao gồm việc trò chuyện, cầu nguyện, thời gian yên tĩnh, hoặc các hoạt động hội họp về tôn giáo và các nhu cầu tinh tàng. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, nhóm Hospice có hỗ trợ các hoạt động về tôn giáo hay tinh tàng tâm linh cho bạn không?

1  O Rất ít
2  O Đúng mức, vừa phải
3  O Rất nhiều

37. Trong thời gian thành viên gia đình bạn được Hospice chăm sóc, mức độ hỗ trợ nhiệt tình từ nhóm Hospice đối với gia đình bạn như thế nào?

1  O Rất ít
2  O Đúng mức, vừa phải
3  O Rất nhiều

38. Trong những tuần sau khi thành viên của gia đình bạn qua đời, mức độ hỗ trợ nhiệt tình từ nhóm Hospice đối với gia đình bạn như thế nào?

1  O Rất ít
2  O Đúng mức, vừa phải
3  O Rất nhiều

ĐÁNH GIÁ TỔNG THỂ VỀ HOSPICE CARE


Sử dụng số từ 0 đến 10, số 0 thể hiện mức độ chăm sóc tồi tệ nhất, 10 thể hiện mức độ chăm sóc tốt nhất, con số nào bạn đánh giá mức độ chăm sóc từ Hospice cho thành viên gia đình bạn?

0  O 0 Hospice chăm sóc tồi tệ nhất có thể
1  O 1
2  O 2
3  O 3
4  O 4
5  O 5
6  O 6
7  O 7
8  O 8
9  O 9
10  O 10 Hospice chăm sóc tốt nhất có thể

40. Bạn có đề xuất Hospice care này cho bạn bè và gia đình bạn không?

1  O Chắc chắn là không
2  O Có thể không
3  O Có thể có
4  O Chắc chắn là có
### Thông tin thành viên gia đình của bạn

41. Trình độ học vấn cao nhất của thành viên gia đình bạn đã hoàn thành là gì?

<table>
<thead>
<tr>
<th>Số</th>
<th>Niên độ học vấn</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Lớp 8 hoặc thấp hơn</td>
</tr>
<tr>
<td>2</td>
<td>Trung học phổ thông, nhưng chưa tốt nghiệp phổ thông</td>
</tr>
<tr>
<td>3</td>
<td>Tốt nghiệp trung học phổ thông hoặc tương đương GED</td>
</tr>
<tr>
<td>4</td>
<td>Cao đẳng hoặc Khoa học 2 năm</td>
</tr>
<tr>
<td>5</td>
<td>Tốt nghiệp cao đẳng hệ 4 năm</td>
</tr>
<tr>
<td>6</td>
<td>Tốt nghiệp cao đẳng trên 4 năm</td>
</tr>
<tr>
<td>7</td>
<td>Không biết</td>
</tr>
</tbody>
</table>

42. Thành viên gia đình bạn là người Tây Ban Nha, La tinh/ hay có gốc Nam Mỹ không?

<table>
<thead>
<tr>
<th>Số</th>
<th>Ghi chú</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Không, không phải người Tây Ban Nha/ gốc Nam Mỹ/ người La Tinh</td>
</tr>
<tr>
<td>2</td>
<td>Phải, Puerto Rican</td>
</tr>
<tr>
<td>3</td>
<td>Phải, người Mễ Tây Cơ, người Mỹ gốc Mễ Tây Cơ, người Chicano (người gốc Mễ Tây Cơ sinh tại Mỹ)</td>
</tr>
<tr>
<td>4</td>
<td>Phải, Cuba</td>
</tr>
<tr>
<td>5</td>
<td>Phải, người Tây Ban Nha, người gốc Nam Mỹ/ La Tinh</td>
</tr>
</tbody>
</table>

43. Chủng tộc của thành viên gia đình bạn là gì? Vui lòng chọn một hoặc nhiều hơn.

<table>
<thead>
<tr>
<th>Số</th>
<th>Chủng tộc</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Người da Trắng</td>
</tr>
<tr>
<td>2</td>
<td>Người da Đen hoặc người Mỹ gốc Phi</td>
</tr>
<tr>
<td>3</td>
<td>Người Châu Á</td>
</tr>
<tr>
<td>4</td>
<td>Người có nguồn gốc đảo Hawaii hay đảo khác ở Thái Bình Dương</td>
</tr>
<tr>
<td>5</td>
<td>Người có nguồn gốc từ bát chủ sắc dân bán đảo nào ở Bắc Mỹ và Nam Mỹ</td>
</tr>
</tbody>
</table>

### Thông tin về bạn

44. Bạn bao nhiêu tuổi?

<table>
<thead>
<tr>
<th>Số</th>
<th>Tranche</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>18 đến 24</td>
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<td>35 đến 44</td>
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<td>45 đến 54</td>
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<td>55 đến 64</td>
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<tr>
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<td>65 đến 74</td>
</tr>
<tr>
<td>7</td>
<td>75 đến 84</td>
</tr>
<tr>
<td>8</td>
<td>85 hoặc trên 85</td>
</tr>
</tbody>
</table>

45. Bạn là nam hay nữ?

<table>
<thead>
<tr>
<th>Số</th>
<th>Giới tính</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Nam</td>
</tr>
<tr>
<td>2</td>
<td>Nữ</td>
</tr>
</tbody>
</table>
46. Trình độ học vấn cao nhất mà bạn đã hoàn thành là gì?

1 ☐ Lớp 8 hoặc thấp hơn
2 ☐ Trung học phổ thông, nhưng chưa tốt nghiệp
3 ☐ Tốt nghiệp trung học phổ thông hoặc GED
4 ☐ Cao đẳng hoặc khóa học 2 năm
5 ☐ Tốt nghiệp cao đẳng hệ 4 năm học
6 ☐ Tốt nghiệp cao đẳng hệ trên 4 năm học

47. Ngôn ngữ bạn sử dụng chính để giao tiếp ở nhà là gì?

1 ☐ Tiếng Anh
2 ☐ Tiếng Tây Ban Nha
3 ☐ Tiếng Trung Quốc
4 ☐ Tiếng Nga
5 ☐ Tiếng Bồ Đào Nha
6 ☐ Tiếng Việt
7 ☐ Ngôn ngữ khác (vui lòng viết ra):
______________________________

CHÁN THÀNH CÁM ƠN QUÝ VỊ

Vui lòng dùng bao thư đính kèm có sẵn bưu phí và gửi trở lại bản thăm dò ý kiến sau khi trả lời đầy đủ.

[NAME OF SURVEY VENDOR]

[RETURN ADDRESS OF SURVEY VENDOR]
Sample Initial Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]
[ADDRESS]
[CITY, STATE ZIP]

Kính thưa [SAMPLED CAREGIVER NAME]:

[HOSPICE NAME] đang tiến hành một cuộc khảo sát về dịch vụ [BỆNH VIÊN NẤN Y THỜI LÝ CUỐI VIỆT DƯỠNG] mà bệnh nhân và gia đình họ nhận được. Bạn được chọn cho cuộc khảo sát này vì bạn được xác định là người đã chăm sóc cho [DECEDEDENT NAME]. Chúng tôi nhận thấy điều này có thể là thời gian khó khăn đối với bạn, nhưng chúng tôi hy vọng rằng, bạn sẽ giúp chúng tôi tìm hiểu về chất lượng mà bạn và thành viên gia đình hay bạn bè của bạn nhận được sự chăm sóc.


Một trong những cách để họ có thể thực hiện trách nhiệm này là để tìm hiểu trực tiếp từ bạn về dịch vụ chăm sóc [BỆNH VIÊN NẤN Y THỜI LÝ CUỐI VIỆT DƯỠNG] mà người thân hay gia đình bạn nhận được. Sự tham gia của bạn là tình nguyện và sẽ không có bất kỳ ảnh hưởng nào đến vấn đề sức khỏe hay quyền lợi mà bạn nhận được.

Chúng tôi hy vọng rằng, bạn sẽ dành thời gian để hoàn thành cuộc khảo sát này. Sau khi bạn hoàn thành cuộc khảo sát, vui lòng gửi lại vào [BỆNH VIÊN NẤN Y THỜI LÝ CUỐI VIỆT DƯỠNG] cho mục đích cải thiện chất lượng. [OPTIONAL: Bạn có thể chú ý đến con số trong cuộc khảo sát của bạn. Con số này được sử dụng để cho chúng tôi biết nếu bạn hoàn trả bảng khảo sát của bạn, vi vậy, chúng tôi không phải nhắc nhắc bạn.]

Nếu bạn có bất kỳ câu hỏi gì về cuộc khảo sát дính kèm, vui lòng gọi miễn phí tới số điện thoại 1-800-xxx-xxxx. Cảm ơn sự giúp đỡ của bạn để cải thiện dịch vụ chăm sóc của Hospice cho tất cả các khách hàng.

Chân thành cảm ơn,
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]
Sample Follow-up Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[SAMPLED CAREGIVER NAME]
[ADDRESS]
[CITY, STATE ZIP]

Kính thưa [SAMPLED CAREGIVER NAME]:

Hồ sơ của chúng tôi cho thấy rằng, cách đây không lâu, bạn là người chăm sóc cho [DECEDENT NAME] tại [NAME OF HOSPICE]. Khoảng ba tuần trước, chúng tôi đã gửi cho bạn một khảo sát liên quan đến việc chăm sóc mà bạn và các thành viên gia đình hay bạn bè của bạn đã nhận từ Hospice hay BỆNH VIỆN NẠN Y THỜI LÝ CUỐI VIỆT DƯỠNG của chúng tôi. Nếu bạn đã trả lại khảo sát đó cho chúng tôi, xin hãy vui lòng don nhận lời cảm ơn và bỏ qua lá thư này. Tuy nhiên, nếu bạn chưa gửi trả bản khảo sát đó, chúng tôi thực sự cảm kích nếu bạn dành thời gian để hoàn thành bảng câu hỏi quan trọng này.

Chúng tôi hy vọng, bạn sẽ tận dụng cơ hội này để giúp chúng tôi tìm hiểu về chất lượng chăm sóc thành viên gia đình hay bạn bè của bạn đã nhận được. Kết quả từ cuộc khảo sát này sẽ được sử dụng để đảm bảo rằng, tất cả người Mỹ có được sự chăm sóc với chất lượng cao nhất từ VIỆN NẠN Y THỜI LÝ CUỐI VIỆT DƯỠNG.

Những câu hỏi [NOTE THE QUESTION NUMBERS] trong cuộc khảo sát được đính kèm là một phần của một sáng kiến quốc gia được tài trợ bởi Bộ Y tế và Dịch vụ Nhân sinh Hoa Kỳ (HHS) để đo lường chất lượng của việc chăm sóc tại BỆNH VIỆN NẠN Y THỜI LÝ CUỐI VIỆT DƯỠNG.

Vui lòng dành một vài phút và hoàn thành khảo sát được đính kèm. Sau khi bạn hoàn thành bảng khảo sát, vui lòng gửi trả lại vào trong phong bì trả trước. Câu trả lời của bạn có thể được chia sẻ với các Hospice với mục đích cải thiện chất lượng. [OPTIONAL: Bạn có thể chú ý đến con số trong cuộc khảo sát của bạn. Con số này được sử dụng để cho chúng tôi biết nếu bạn hoàn trả bảng khảo sát của bạn, vì vậy, chúng tôi không phải nhắc nhở bạn.]

Nếu bạn có bất kỳ câu hỏi gì về khảo sát đính kèm, vui lòng gọi miễn phí tới số điện thoại 1-800-xxx-xxxx. Cảm ơn sự giúp đỡ của bạn để cải thiện dịch vụ chăm sóc của Hospice cho tất cả các khách hàng.

Chân thành cảm ơn,
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]
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. The following is the language that must be used:

**Vietnamese Version**

Appendix U

Telephone Script (English)
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
  • YES and NO response options are only to be read if necessary

  Note: It is not permissible to capitalize underlined content, as text that appears in
 uppercase letters throughout the CATI script must not be read out loud. Survey vendors
 are permitted to emphasize underlined content in a different manner if underlining is not a
 viable option, such as placing quotes (“”) or asterisks (**”) around the emphasized
 content.

➢ All questions and all answer categories must be read exactly as they are worded
  • During the course of the survey, use of neutral acknowledgment words such as the
    following is permitted:
    o Thank you
    o Alright
    o Okay
    o I understand, or I see
    o Yes, Ma’am
    o Yes, Sir
➢ Read the scripts from the interviewer screens (reciting the survey from memory can lead to
  unnecessary errors and missed updates to the scripts)
➢ Adjust the pace of the CAHPS Hospice Survey interview to be conducive to the needs of the
  respondent
➢ No changes are permitted to the order of the question and answer categories for the “Core,”
  “About Your Family Member” and “About You” CAHPS Hospice Survey questions
  • The first forty “Core” questions must remain together
  • The three “About Your Family Member” questions must remain together
  • The four “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) can 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 caregiver 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 [GO TO 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 a survey that [HE/SHE] started at an earlier date?

CONFIRM RESPONDENT: Before we continue with the survey, I would like to confirm that I am 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 [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 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/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 about the hospice care received by [DECEDEDENT NAME]. ONCE THE MOST KNOWLEDGEABLE PERSON’S NAME IS PROVIDED: [Is he/she OR are you] the most knowledgeable about the hospice care received by [DECEDEDENT NAME]?

IF NEEDED AND SPEAKING WITH THE SAMPLED CAREGIVER:

We received your name from [HOSPICE NAME] because you were listed as the caregiver for [DECEDEDENT 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 [DECEDEDENT 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, OR UNAVAILABLE DURING FIELD PERIOD [GO TO ITEM TO CODE INELIGIBLE, 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]

INELIGIBLE

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 CAREGIVER ANSWERS OUTSIDE OF THE ANSWER CATEGORIES PROVIDED. PROBE BY REPEATING THE ANSWER CATEGORIES ONLY; DO NOT INTERPRET FOR THE CAREGIVER.

Q1 How are you related to [DECEDEDNT NAME]?

READ ANSWER CHOICES ONLY IF NECESSARY

<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 [DECEDEDNT NAME]?

 NOTE: PLEASE DOCUMENT THE RELATIONSHIP AND MAINTAIN IN YOUR INTERNAL RECORDS.

[NOTE: FOR TELEPHONE INTERVIEWING, Q2 IS BROKEN INTO PARTS A – G.]

Q2 For this survey, the phrase “family member” refers to [DECEDEDNT NAME]. Please answer yes or no to each of the categories. I am required to read all six categories. In what locations did your family member receive care from [HOSPICE NAME]?

READ YES/NO RESPONSE CHOICES ONLY IF NECESSARY

Q2A At home?

<1> YES
<0> NO

<M> MISSING/DK
Q2B  At an assisted living facility?

1<1> YES  
1<0> NO  
1%M> MISSING/DK

Q2C  At a nursing home?

1<1> YES  
1<0> NO  
1%M> MISSING/DK

Q2D  At a hospital?

1<1> YES  
1<0> NO  
1%M> MISSING/DK

Q2E  At a hospice facility or hospice house?

1<1> YES  
1<0> NO  
1%M> MISSING/DK

Q2F  At some other place?

1<1> YES [GO TO Q2G]  
1<0> NO [GO TO Q3]  
1%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 Q4_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

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 carefully 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?

[<8> 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?

READ ANSWER CHOICES ONLY IF NECESSARY

<0> 0
<1> 1
<2> 2
<3> 3
<4> 4
<5> 5
<6> 6
<7> 7
<8> 8
<9> 9
<10> 10

[<8> 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?

[OPTIONAL: 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 a 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 your family member was (READ ALL RESPONSE CHOICES)

<2> Puerto Rican,
<3> Mexican, Mexican American, Chicano/a,
<4> Cuban, or
<5> Other Spanish/Hispanic/Latino?

<M> MISSING/DK

[NOTE: FOR TELEPHONE INTERVIEWING, QUESTION 43 IS BROKEN INTO PARTS A – E.]

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.

READ ALL RACE CATEGORIES PAUSING AT EACH RACE CATEGORY TO ALLOW CAREGIVER 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.

READ YES/NO RESPONSE CHOICES ONLY IF NECESSARY
Q43A  Was your family member White?

<1> YES/WHITE
<0> NO/NOT WHITE

<M> MISSING/DK

Q43B  Was your family member Black or African American?

<1> YES/BLACK OR AFRICAN AMERICAN
<0> NO/NOT BLACK OR AFRICAN AMERICAN

<M> MISSING/DK

Q43C  Was your family member Asian?

<1> YES/ASIAN
<0> 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
<0> 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
<0> 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?  
[OPTIONAL: 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 a 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 response choices before you answer. Would you say that you mainly speak…

<1> English, [GO TO END]
<2> Spanish, [GO TO END]
<3> Chinese, [GO TO END]
<4> Russian, [GO TO END]
<5> Portuguese, [GO TO END]
<6> Vietnamese, or [GO TO END]
<7> 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]?

NOTE: 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. [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.

Thank you for your time. [END CALL]
Appendix V

Telephone Script (Spanish)
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
  - YES and NO response options are only to be read if necessary

Note: It is not permissible to capitalize underlined content, as text that appears in uppercase letters throughout the CATI script must not be read out loud. Survey vendors are permitted to emphasize underlined content in a different manner if underlining is not a viable option, such as placing quotes (‘‘) or asterisks (**) around the emphasized content.

- All questions and all answer categories must be read exactly as they are worded
  - During the course of the survey, use of neutral acknowledgment words such as the following is permitted:
    - Thank you
    - Alright
    - Okay
    - I understand, or I see
    - Yes, Ma’am
    - Yes, Sir
- Read the scripts from the interviewer screens (reciting the survey from memory can lead to unnecessary errors and missed updates to the scripts)
- Adjust the pace of the CAHPS Hospice Survey interview to be conducive to the needs of the respondent
- No changes are permitted to the order of the question and answer categories for the “Core”, “About Your Family Member” and “About You” CAHPS Hospice Survey questions
  - The first forty “Core” questions must remain together
  - The three “About Your Family Member” questions must remain together
  - The four “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) can 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 caregiver 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 ENVIÓ LA ENCUESTA 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 Ó 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 (tarde/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 TOME 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 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 11 minutos/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 sobre el cuidado de hospicio recibido por [DECEDENT NAME].

UNA VEZ QUE LE DEN EL NOMBRE DE LA PERSONA QUE ESTÁ MÁS AL TANTO: ¿Puede decírmelo 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 [DECEDEENT 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, NO ESTÁ DISPONIBLE DURANTE PERÍODO DE CAMPO [GO TO ITEM TO CODE INELIGIBLE, 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 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. [FINALICE LA LLAMADA/END CALL]

********

INELEGIBLE

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]?

LEA LAS OPCIONES DE RESPUESTA SÓLO SI ES NECESARIO

<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 ABUELÁ 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.
[NOTA: PARA LA ENTREVISTA TELEFÓNICA, LA PREGUNTA 2 SE DIVIDE EN PARTES, DE LA “A” A LA “G.”]

Q2 Para este estudio, la palabra “familiar” se refiere a [DECEDEDNT NAME]. Por favor, responda sí o no para cada una de las categorías. Estoy obligado a leer las seis categorías. ¿En qué lugar o lugares recibió cuidados de [HOSPICE NAME] su familiar?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO SI ES NECESARIO

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 Q2G]
<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 APLICABLE]
<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 APLICABLE]
<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 APLICABLE]
<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]
<88> NOT APPLICABLE

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

NOTA: SI LA PERSONA QUE CONTESTA DICE, "NO TUVE NINGÚN PROBLEMA," MARQUE "NO."

<1> SÍ
<2> NO [GO TO Q15]

[<88> NOT APPLICABLE]
<88> NOT APPLICABLE

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]
<88> NOT APPLICABLE
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,
<3> No?

[M] NOT APPLICABLE

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.

[M] NOT APPLICABLE

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]

[M] NOT APPLICABLE

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,
<4> Siempre?

[M] 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

[<88> NOT APPLICABLE]
<M> MISSING/DK

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 le escuchó a usted atentamente? ¿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?

LEA LAS OPCIONES DE RESPUESTA SÓLO SI ES NECESARIO

<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? [OPTIONAL: ¿Él(ella)...]

LEA LAS OPCIONES DE RESPUESTA 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 CODIFICASE 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

<X> SÍ
<1> 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
[NOTA: 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.

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO SI ES NECESARIO

Q43A ¿Su familiar era blanco(a)?

<1> SÍ/ERA BLANCO(A)
<0> NO/NO ERA BLANCO(A)

<M> MISSING/DK

Q43B ¿Su familiar era negro(a) o afroamericano(a)?

<1> SÍ/ERA NEGRO(A)/AFROAMERICANO(A)
<0> NO/NO ERA NEGRO(A) NI AFROAMERICAN(A)

<M> MISSING/DK

Q43C ¿Su familiar era asiático(a)?

<1> SÍ/ERA ASIÁTICO(A)
<0> NO/NO ERA ASIÁTICO(A)

<M> MISSING/DK
Q43D ¿Su familiar era nativo(a) de Hawái o de otras islas del Pacífico?

<1> SÍ/ERA NATIVO(A) DE HAWAII/DE OTRAS ISLAS DEL PACÍFICO
<0> NO/NO ERA NATIVO(A) DE HAWAII 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 INDIÓ(A) AMERICANO(A)/NATIVO(A) DE ALASKA
<0> NO/NO ERA INDIÓ(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 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? [OPTIONAL: ¿Usted...]

LEA LAS Opciones DE RESPUESTA 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 CODIFICASE 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 opciones de respuesta antes de contestar. ¿Diría usted que usted habla principalmente...

<1> Inglés, [GO TO END]
<2> Español, [GO TO END]
<3> Chino, [GO TO END]
<4> Ruso, [GO TO END]
<5> Portugués, [GO TO END]
<6> Vietnamita, o [GO TO END]
<7> 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 principalmente (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 principalmente 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. [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

Gracias por su tiempo. [FINALICE LA LLAMADA/END CALL]