# CAHPS® Hospice Survey

# *Quality Assurance Guidelines*

**Version 9.0**

September 2022

# CAHPS® Hospice Survey

# Quality Assurance Guidelines

## ACKNOWLEDGEMENTS

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

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# I. Reader's Guide

## Purpose of Quality Assurance Guidelines

CMS developed the CAHPS Hospice Survey *Quality Assurance Guidelines V9.0* manual to standardize the survey data collection process and to ensure comparability of data reported. 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 V9.0* manual. Readers are directed to the related chapters of the CAHPS Hospice Survey *Quality Assurance Guidelines V9.0* manual for more detail.

## CAHPS Hospice Survey Quality Assurance Guidelines V9.0 Contents

The CAHPS Hospice Survey *Quality Assurance Guidelines V9.0* 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. It also includes an overview of the CAHPS Hospice Survey data collection and submission timeline.

### 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 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.

### Modes of Survey Administration

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 the procedure for assigning CAHPS Hospice Survey "Final Survey Status" codes, information on the requirements for coding and interpreting ambiguous or missing data elements in returned surveys, the definition of a completed survey, and the procedures for calculating the survey response rate.

### 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 vendor processes, the survey vendor data submission registration process, and the data submission process, including the interpretation of the associated CAHPS Hospice Survey Data Submission Reports.

### 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.

### Data Reporting
This chapter describes the process for public reporting of CAHPS Hospice Survey results.

### 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 for standardized reporting.

### 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 Minimum Business Requirements to administer the CAHPS Hospice Survey; survey vendor authorization form; form for accessing the CAHPS Hospice Survey Data Warehouse; data file layout specifications; telephone interviewing guidelines; frequently asked questions for customer support; the survey vendor model QAP; the forms for submitting requests for protocol exceptions, discrepancy reports, participation exemption for size, and attestation statement; suggested supplemental questions; the CAHPS Hospice Survey mail materials (English, Spanish, Traditional Chinese, Simplified Chinese, Russian, Portuguese, Vietnamese, Polish, and Korean); and telephone scripts (English, Spanish, and Russian).

## For More Information

For program information and to view important updates and announcements, visit the CAHPS Hospice Survey Web site (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@hsag.com 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.

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, February, or March) 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 and Public Comment Process

The Office of Management and Budget's (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. In November 2017 and December 2020, the OMB again reviewed and approved the CAHPS Hospice Survey.

## Endorsement of CAHPS Hospice Survey Measures by the National Quality Forum

In March 2016, CMS submitted the six composite measures and two single-item global measures from the 47-item CAHPS Hospice Survey instrument to the National Quality Forum (NQF) for endorsement of performance measures for accountability and quality improvement that address palliative care and end-of-life care. The NQF is a voluntary consensus and standard-setting organization established to standardize healthcare quality measurement and reporting, as defined by the National Technology Transfer and Advancement Act of 1995 and OMB Circular A-119.

The Board of Directors of the NQF formally endorsed the eight CAHPS Hospice Survey measures in both 2016 and 2020. NQF endorsement represents the consensus of many healthcare providers, consumer groups, professional associations, purchasers, federal agencies, and research and quality organizations. The Board of Directors' approval was the final step of vetting through the NQF's formal Consensus Development Process, which included input from multiple stakeholder groups, review and voting. The CAHPS Hospice Survey thereby achieved special legal standing as a voluntary consensus standard.

## Preparation for CAHPS Hospice Survey Data Collection

Survey vendors interested in administering the CAHPS Hospice Survey must apply to participate and 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 sessions and successful completion of the post-training quizzes.

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 <u>required</u> 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 Experiments

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 that survey mode adjustments were needed, and 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.

*Note: In 2021, CMS conducted another mode experiment to test a web-based mode of survey administration, as well as revisions to survey instrument content and administration procedures. CMS will release results of the mode experiment, including any proposed updates to survey instrument content, administration modes and procedures, and mode adjustments, as they become available.*

## CAHPS Hospice Survey Public Reporting

Official CAHPS Hospice Survey scores are publicly reported four times each year on the Care Compare tool on Medicare.gov (https://www.medicare.gov/care-compare/). Scheduled refreshes for CAHPS Hospice Survey data occur in February, May, August, and November. Public reporting of CAHPS Hospice Survey results is comprised of a rolling eight quarters of survey data, with data submitted quarterly by survey vendors via the CAHPS Hospice Survey Data Warehouse.

| Care Compare Tool Refresh Date | CAHPS Quarters Included |
|---|---|
| November 2022 | Q3 2019 – Q4 2019<br>Q3 2020 – Q4 2021 |
| February 2023 | Q4 2019<br>Q3 2020 – Q1 2022 |
| May 2023 | Q3 2020 – Q2 2022 |
| August 2023 | Q4 2020 – Q3 2022 |
| November 2023 | Q1 2021 – Q4 2022 |

The CAHPS Hospice Survey data submitted are reviewed, cleaned, scored, and adjusted (including adjustments for mode and case mix). Data from the 2015 mode experiment, as well as national implementation data, were used to develop the mode adjustments and the variables used in the case-mix model. Documents describing these coefficients and the case-mix adjustment process are available on the Scoring and Analysis page of the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org). This page includes the CAHPS Hospice Survey response rate and the CAHPS Hospice Survey case-mix adjustments for each question composing a publicly reported CAHPS Hospice Survey measure top-, middle-, or bottom-box score.

The CAHPS Hospice Survey results have typically been available for preview by hospices via the Certification and Survey Provider Enhanced Reports (CASPER) system approximately two months before results are publicly reported on the Care Compare tool on Medicare.gov.

To learn more about how to utilize the CASPER system go to: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Downloads/Fact-Sheet_CASPER-QM-Reports_February-2018.pdf. After reviewing their CASPER report, a hospice may request a review of their data by contacting the CAHPS Hospice Survey technical assistance team at: hospicecahpssurvey@hsag.com. Requests for review of Hospice CAHPS® Survey results must be submitted via email. For more information about the review of hospice's CAHPS Hospice Survey data, visit: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Public-Reporting-CAHPS-Preview-Reports-and-Requests-for-CMS-Review-of-CAHPS-Data.html.

The first public reporting of CAHPS Hospice Survey results occurred in February 2018 with 4,550 hospices appearing on Hospice Compare, and 2,795 of those hospices reporting their CAHPS Hospice Survey scores; this is based on 622,320 completed surveys and covered hospice care experiences for patients who died between the second quarter of 2015 and the first quarter of 2017 (4/1/2015 through 3/31/2017). Most recently, the August 2022 public reporting of CAHPS Hospice Survey results included 5,996 hospices, of which 2,996 reported CAHPS Hospice Survey scores; this is based on 645,632 completed surveys and covers hospice care experiences for patients who died between the second and fourth quarters of 2019 (4/1/2019 through 12/31/2019) and the third quarter 2020 and the third quarter 2021 (6/1/2020 through 9/30/2021). Publicly reported scores are available at the Care Compare tool on Medicare.gov. The schedule of public reporting for 2023 can be found in the *Data Reporting* chapter.

### CAHPS Hospice Survey Star Ratings

In the FY 2022 Hospice Final Rule, CMS finalized public reporting of CAHPS Hospice Star Ratings no sooner than FY 2022. The intent of Star Ratings is to provide consumers with an easy-to-understand method for summarizing CAHPS Hospice Survey measure scores, and to make comparisons between hospices more straightforward. Hospices had an opportunity to review their Star Ratings during a dry run period in 2022. Beginning with the August 2022 refresh of Care Compare, a Family Caregiver Survey Rating Summary Star Rating will be publicly reported for all hospices with 75 or more completed surveys over the reporting period. Star Ratings will be updated every other quarter. Hospices will have the opportunity to see their CAHPS Hospice Survey Star Ratings in their official CMS Preview Report during the provider preview period prior to each update of Care Compare.

## CAHPS Hospice Survey Instrument

The CAHPS Hospice Survey mail materials are available in English, Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish, and Korean. 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, Spanish, and Russian.

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 quality measures listed below.

| CAHPS Hospice Survey Quality Measures and Constituent Items |
|---|
| **Composite Measures** |
| **Communication with Family** |
| ➢ 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? |
| ➢ While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand? |
| ➢ How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care? |
| ➢ While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition? |
| ➢ While your family member was in hospice care, how often did the hospice team listen carefully to you? |
| ➢ While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care? |
| **Getting Timely Help** |
| ➢ While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it? |
| ➢ How often did you get the help you needed from the hospice team during evenings, weekends, or holidays? |
| **Treating Patient with Respect** |
| ➢ While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect? |
| ➢ While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member? |
| **Emotional and Spiritual Support** |
| ➢ While your family member was in hospice care, how much emotional support did you get from the hospice team? |
| ➢ In the weeks after your family member died, how much emotional support did you get from the hospice team? |
| ➢ 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? |
| **Help for Pain and Symptoms** |
| ➢ Did your family member get as much help with pain as he or she needed? |
| ➢ How often did your family member get the help he or she needed for trouble breathing? |
| ➢ How often did your family member get the help he or she needed for trouble with constipation? |
| ➢ How often did your family member get the help he or she needed from the hospice team for feelings of anxiety or sadness? |

| Composite Measures *(Cont'd)* |
|---|
| **Training Family to Care for Patient** |
| ➢ Did the hospice team give you the training you needed about what side effects to watch for from pain medicine? |
| ➢ Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member? |
| ➢ Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing? |
| ➢ Did the hospice team give you the training you needed about what to do if your family member became restless or agitated? |
| ➢ 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? |
| **Global Measures** |
| **Rating of this Hospice** |
| ➢ 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? |
| **Willingness to Recommend this Hospice** |
| ➢ Would you recommend this hospice to your friends and family? |

## 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 MD, MS of Brown University, among others, to support these activities.
- April 2014 – Technical Expert Panel convened to discuss national implementation procedures
- May 2014 – Initial notice of CAHPS Hospice Survey published in the FY 2015 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements Proposed Rule

- August 2014 – The FY 2015 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements 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**

- January 2015 to March 2015 – Dry run of the CAHPS Hospice Survey (patient deaths in January – March 2015; survey administration beginning in April – June 2015)
- February 2015 to October 2015 – Mode experiment of the CAHPS Hospice Survey
- 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)
- September 2015 – Russian and Portuguese translations of the survey instrument are made available for Mail Only mode of survey administration

**2016**

- February 2016 – CMS submits CAHPS Hospice Survey measures to NQF for its endorsement
- May 2016 – Vietnamese translation of the survey instrument is made available for Mail Only mode of survey administration
- October 2016 – NQF endorses CAHPS Hospice Survey measures
- December 2016 – Polish and Korean translations of the survey instrument are made available for Mail Only mode of survey administration
- December 2016 – CMS releases national CAHPS Hospice Survey data (national average top-box scores from data collected from caregivers of patients who died while getting hospice care between April 1, 2015 and March 31, 2016)

**2017**

- May 2017 – CMS submits CAHPS Hospice Survey to OMB for re-approval
- November 2017 – OMB re-approved the CAHPS Hospice Survey

**2018**

- February 2018 – First quarterly Public Reporting of CAHPS Hospice Survey results on Hospice Compare, covering hospice care experiences from the second quarter of 2015 through the first quarter of 2017 (4/1/2015 through 3/31/2017)

**2019**

- March 2019 – Russian translation of the survey instrument is made available for Telephone Only and Mixed Mode of survey administration

**2020**

- March 2020 – CMS grants exceptions for hospices participating in quality reporting programs in response to COVID-19. Survey vendors could request approval to conduct survey operations from a remote location (other than their place of business), via the CAHPS Hospice Survey Exception Request process.
- May 2020 – CMS submits CAHPS Hospice Survey to OMB for re-approval
- September 2020 – CMS launched Care Compare (https://www.medicare.gov/carecompare/ [previously Hospice Compare]), which contains CAHPS Hospice Survey results and many other measures, and is a streamlined redesign of eight existing CMS healthcare compare tools available on https://www.medicare.gov
- November 2020 – NQF re-endorses CAHPS Hospice Survey measures
- December 2020 – OMB re-approves the CAHPS Hospice Survey

**2021**

- June 2021 to December 2021 – Mode experiment of the CAHPS Hospice Survey

**2022**

- August 2022 – First Public Reporting of CAHPS Hospice Survey Star Ratings on Care Compare

CMS has published the Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements Final Rule in August, released the CAHPS Hospice Survey *Quality Assurance Guidelines* manual in September, and provided CAHPS Hospice Survey Training sessions in September/October on an annual basis from 2014 forward.

## 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.

| CAHPS Hospice Survey Administration and Data Submission Schedule | | |
|---|---|---|
| **Month of Death** | **Initial Contact with Sampled Decedents/Caregivers** | **Data Submission to the CAHPS Hospice Survey Data Warehouse** |
| April 2022 | July 1, 2022 | November 9, 2022 |
| May 2022 | August 1, 2022 | |
| June 2022 | September 1, 2022 | |
| July 2022 | October 1, 2022 | February 8, 2023 |
| August 2022 | November 1, 2022 | |
| September 2022 | December 1, 2022 | |
| October 2022 | January 1, 2023 | May 10, 2023 |
| November 2022 | February 1, 2023 | |
| December 2022 | March 1, 2023 | |
| January 2023 | April 1, 2023 | August 9, 2023 |
| February 2023 | May 1, 2023 | |
| March 2023 | June 1, 2023 | |
| April 2023 | July 1, 2023 | November 8, 2023 |
| May 2023 | August 1, 2023 | |
| June 2023 | September 1, 2023 | |
| July 2023 | October 1, 2023 | February 14, 2024 |
| August 2023 | November 1, 2023 | |
| September 2023 | December 1, 2023 | |
| October 2023 | January 1, 2023 | May 8, 2024 |
| November 2023 | February 1, 2023 | |
| December 2023 | March 1, 2023 | |
| January 2023 | April 1, 2023 | August 14, 2024 |
| February 2023 | May 1, 2023 | |
| March 2023 | June 1, 2023 | |
| April 2023 | July 1, 2023 | November 13, 2024 |
| May 2023 | August 1, 2023 | |
| June 2023 | September 1, 2023 | |

# 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. Public reporting of CAHPS Hospice Survey results creates 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:

- increase the likelihood that caregivers will respond to the survey, and
- 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 <u>not</u> attempt to influence how caregivers respond to CAHPS Hospice Survey items

CAHPS Hospice Survey results are intended to be used for quality improvement purposes, not for marketing or promotional activities. Only the CAHPS Hospice Survey scores that are published by CMS are the official scores. Scores derived from any other source are unofficial and should be labeled as such.

The CAHPS Hospice Survey and the questions that comprise it are in the public domain and thus can be used outside of official CAHPS Hospice Survey purposes (e.g., for non-CAHPS Hospice Survey eligible decedents/caregivers). However, when used in an unofficial capacity, the CAHPS Hospice Survey OMB Paperwork Reduction Act language must not be used and all references to "CAHPS Hospice Survey" and "CMS" must be removed.

## 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"
- 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
- invite or ask the caregiver if they want to participate in a survey or suggest they can "opt out" of 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

*Note: Hospices may **not** contact caregivers directly regarding survey responses provided by the caregiver in the 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 increase 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 strongly 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 surveys 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")
- 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 hospice care 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/or 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:
  - permit staff to 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/or 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:

- Provides CAHPS Hospice Survey administration protocols through the CAHPS Hospice Survey *Quality Assurance Guidelines*
- Trains survey vendors to administer the CAHPS Hospice Survey
- Provides technical support via CAHPS Hospice Survey Information and Technical Assistance and distributes information about survey administration procedures and policy updates on the CAHPS Hospice Survey Web site at www.hospicecahpssurvey.org
- Processes data files submitted by survey vendors
- Calculates and adjusts CAHPS Hospice Survey data for mode and case-mix effects prior to public reporting
- Generates preview reports containing CAHPS Hospice Survey results for participating hospices prior to public reporting
- Reports CAHPS Hospice Survey results publicly on the Care Compare tool
- Provides 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.

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
- Provide a primary and secondary (backup) CAHPS Hospice Survey contact person to the CAHPS Hospice Survey-approved Survey Vendor so that an organizational representative is always available
- 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 and switch to a different survey vendor

    *Note: If an organization chooses to de-authorize its survey vendor and switch to a different survey vendor, it must contact the CAHPS Hospice Survey Project Team immediately to begin the transition process (refer to Appendix B). 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.*

- Complete and submit a CAHPS Hospice Survey Data Warehouse Access Form for Vendors and Hospices (refer to Appendix C) 90 days prior to the data submission deadline
- 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
- Compile and deliver a complete and accurate decedents/caregivers list to the survey vendor by the agreed-upon date each month with the caregiver information that will enable the survey vendor to administer the survey

  *Note: Hospices must ensure that the counts provided to the survey vendor are accurate, i.e., the total decedent count minus the "no publicity" count **must** equal the number of decedent/caregiver record submitted to the survey vendor.*

- 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
- Preview CAHPS Hospice Survey results prior to public reporting
- 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 <u>all</u> caregivers.*

- Understand the hospice's responsibilities regarding participation in the HQRP, including key date ranges and deadline dates

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) 2023 data collection period, Medicare-certified hospices that have served fewer than 50 survey-eligible decedents/caregivers in the period from January 1, 2022 through December 31, 2022 can apply for an exemption from CAHPS Hospice Survey CY 2023 data collection and reporting requirements. To qualify for the survey exemption for CY 2023, hospices must submit a Participation Exemption for Size Form online via the Participation Exemption for Size page of the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org). For the CY 2023 data collection period, this form must be submitted no later than December 31, 2023. The form must be completed in its entirety and must be submitted each year the hospice intends to be considered for the Participation Exemption for Size. **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**. Hospices that are eligible to apply for an exemption are encouraged to apply, even if they are participating in CAHPS Hospice Survey data collection. Please see Appendix K 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 2022, 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 or paid caregiver, caregiver has a foreign home address, and no publicity decedents/caregivers).

  *Note: "No publicity" status is a rare and unusual request. "No publicity" decedents/caregivers are those who* ***initiate or voluntarily*** *request at any time during their hospice stay 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 Participation 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, 2023 to be eligible for the Participation Exemption for Newness for CY 2023. CMS will identify hospices eligible for this exemption. There is no form for hospices to submit.

  *Note: The Participation 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 must begin participating during January of the year after their CCN is*

*assigned. For example, if a hospice received its CCN any time in 2023, whether it is in January 2023 or December 2023, it is exempt from survey administration for the remainder of 2023. A hospice that receives its CCN any time in 2023 is required to start participating in the CAHPS Hospice Survey beginning with January 2024 decedents.*

## 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 and any other organizations, if applicable).
  - CMS approval is required prior to performing any survey administrative activities outside of a secure commercial environment
- Have appropriate organizational back-up staff for coverage of key staff to administer the CAHPS Hospice Survey
- 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 successfully 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
- Follow the Rules of Participation, found later in this chapter, 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
- Update all decedent/caregiver administrative information available when updated decedents/caregivers lists are received. In addition, 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
  - 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 by submitting a notarized CAHPS Hospice Survey Vendor Authorization Form at least 90 days prior to the first data submission deadline
- Submit data files to the CAHPS Hospice Survey Data Warehouse in accordance with the survey file layouts by the data submission deadlines
- Request client hospices gain access to the CAHPS Hospice Survey Data Warehouse and review CAHPS Hospice Survey Data Submission Reports
- 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)
- Complete and submit an annual Attestation Statement by the due date specified during training and posted on the CAHPS Hospice Survey Web site

*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 FY. 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. Survey vendors conducting Telephone Only survey administration must have a process in place to address caregivers' requests to verify the legitimacy of the survey and/or answer questions about the survey.

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 two 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
- Must be ready to support calls from the deaf or hearing impaired
- Should be routinely monitored to assure the guidelines are followed and the line is working

**Providing Customer Support via the Internet (Optional)**

In addition to customer support telephone lines, survey vendors may also choose to implement systems to support electronic queries from surveyed caregivers. For example, survey vendors may establish an email address for sampled caregivers to use to submit questions about the survey. Survey vendors should respond to email inquiries within two business days. Survey vendors must document questions and responses via a database or tracking log.

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

## Survey Vendor Analysis of CAHPS Hospice Survey Data

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. A Consent to Share question is not required by CMS in order to share identifiable caregiver responses with hospices. 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. This is done as follows:

1. The introduction or executive summary of such reports must include the following statement:
   - "This report has been produced by [Survey Vendor] and does not represent official CAHPS Hospice Survey results, which are published on Care Compare on Medicare.gov (https://www.medicare.gov/care-compare)."
2. Each page of the report provided to hospices where unofficial results are displayed (print or electronic) must contain the following statement:
   - "This report has been produced by [Survey Vendor] and does not represent official CAHPS Hospice Survey results."

In addition, hospices should be informed by the survey vendor that any responses that would identify a particular decedent/caregiver case **must not** be shared with direct care staff. These results should be limited to management and/or quality improvement personnel.

Survey vendors are encouraged to apply case mix and mode adjustments to unofficial scores reported to hospices, so that scores are comparable with the official CMS CAHPS Hospice Survey scores.

CMS guidance regarding scoring and analysis (including adjustment for case mix and mode of survey administration) is available on the Scoring and Analysis page of the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org).

## 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 or any other organization's survey administration experience does not substitute for a survey vendor's).

- Approved CAHPS Hospice Survey vendors must fully comply with the CAHPS Hospice Survey oversight activities
  - The FY 2016 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements Final Rule codified that approved CAHPS Hospice Survey vendors are required to participate in CAHPS Hospice Survey oversight activities to ensure compliance with CAHPS Hospice Survey requirements *(Federal Register / Vol. 80, No. 151 / Thursday, August 6, 2015 / Rules and Regulations)*

The CAHPS Hospice Survey Minimum Business Requirements for an organization to become approved to administer the CAHPS Hospice Survey are as follows:

**Management Relationships:**

| Criteria | Survey Vendor |
|---|---|
| **Current/Future Relationships with Hospices** | ➢ The following types of organizations are **not** eligible to administer the CAHPS Hospice Survey (as an approved CAHPS Hospice Survey vendor):<br>• 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;<br>• organizations that provide telehealth, monitoring of hospice patients, or teleprompting services for the hospice; and<br>• organizations that provide staffing to hospices for providing care to hospice patients, whether personal care aides or skilled services staff |

**Relevant Survey Experience:**
Demonstrated recent continuous experience in fielding patient-specific surveys in the requested mode(s) (i.e., Mail, Telephone, Mixed Mode [mail followed by telephone]).

| Criteria | Survey Vendor |
|---|---|
| **Number of Years in Business** | ➢ Minimum four years |
| **Number of Years Conducting Patient-Specific Surveys** | ➢ Minimum of three consecutive years Mail, and/or Telephone, and/or Mixed Mode (mail followed by telephone) patient-specific survey experience within the most recent three-year time period<br>➢ Prior experience in conducting surveys in English (required) and Spanish (preferred) |
| **Sampling Experience** | ➢ Two years prior experience selecting a random sample based on specific eligibility criteria within the most recent two-year time period<br>➢ Work with contracted client(s) to obtain patient data for sampling via Health Insurance Portability and Accountability Act-(HIPAA) compliant electronic data transfer processes<br>➢ Adequately document sampling process<br>➢ Survey vendors are responsible for conducting the sampling process and must not subcontract this activity |

**Survey Capability and Capacity:**
Capability and capacity to handle the required volume of mail questionnaires and/or conduct standardized telephone interviewing in specified time frame.

| Criteria | Survey Vendor |
|---|---|
| **Personnel** | ➢ Designated CAHPS Hospice Survey personnel:<br>• Project Director with minimum two years prior experience conducting patient-specific surveys in the requested mode(s)<br>• Staff with minimum one year prior experience in sample frame development and sample selection<br>• 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<br>• Call Center/Mail Center Supervisor (subcontractor designee, if applicable) with minimum one year prior experience in role<br>➢ Have appropriate organizational back-up staff for coverage of key staff<br>➢ Volunteers are not permitted to be involved in any aspect of the CAHPS Hospice Survey administration process |

| Criteria | Survey Vendor |
|---|---|
| **Physical Plant and System Resources** | ➢ Physical plant resources available to handle the volume of surveys being administered, including computer and technical equipment:<br>• A secure commercial work environment<br>• Home-based or virtual interviewers cannot be used to administer the CAHPS Hospice Survey, nor may they conduct any survey administration processes unless an Exception Request has been submitted and approved by CMS<br>• Physical facilities, electronic equipment and software to collect, process, and report data securely<br>• If offering telephone surveys, must have the equipment, software and facilities to conduct computer-assisted telephone interviewing (CATI) and to monitor interviewers<br>➢ Electronic or alternative survey management system to:<br>• Track fielded surveys throughout the protocol, avoiding respondent burden and losing respondents<br>• Assign random, unique, de-identified identification number (Tracking ID) to track each sampled decedent/primary informal caregiver (i.e., family member or friend of the hospice patient)<br>➢ 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 or other organizations involved in survey administration.<br>➢ All System Resources are subject to oversight activities, including site visits to physical locations |
| **Sample Frame Creation** | ➢ A minimum of two years prior experience selecting a random sample based on specific eligibility criteria in the most recent two-year time period<br>➢ Generate the sample frame data file that contains all individuals who meet the eligible population criteria<br>➢ Draw random sample of individuals for the survey who meet the eligible population criteria |

| Criteria | Survey Vendor |
|---|---|
| **Mail Administration** | ➢ Mail survey administration activities are not to be conducted from a residence, nor from a virtual office unless an Exception Request has been submitted and approved by CMS<br>➢ Obtain and update addresses of sampled caregivers of hospice decedents<br>➢ Produce and print professional quality survey instruments and materials according to guidelines; a sample of all mailing materials must be submitted for review<br>➢ Merge and print sample name and address on personalized mail survey cover letters and print unique Tracking ID on the survey questionnaire<br>➢ Mail survey materials<br>➢ Receive and process (key-enter or scan) completed questionnaires<br>➢ Track and identify non-respondents for follow-up mailing<br>➢ Assign final survey status codes to describe the final result of work on each sampled record |
| **Telephone Administration** | ➢ Telephone interviews are not to be conducted from a residence, nor from a virtual office unless an Exception Request has been submitted and approved by CMS<br>➢ Obtain, verify, and update telephone numbers<br>➢ Develop CATI system<br>➢ Collect telephone interview data for the survey using CATI system; a sample of the telephone script and interviewer screenshots must be submitted for review<br>➢ Identify non-respondents for follow-up telephone calls<br>➢ Schedule and conduct callbacks to non-respondents at varying times of the day and different days of the week<br>➢ Assign final survey status codes to reflect the final result of attempts to obtain a completed interview with each sampled record |
| **Mixed Mode Administration (Mail with Telephone Follow-up)** | ➢ Mail survey administration and telephone interviews are not to be conducted from a residence, nor from a virtual office unless an Exception Request has been submitted and approved by CMS<br>➢ Adhere to all Mail Only and Telephone Only survey administration requirements (described above)<br>➢ Track cases from mail survey through telephone follow-up activities |

| Criteria | Survey Vendor |
|---|---|
| **Data Submission** | ➢ Two years prior experience transmitting data via secure methods (HIPAA-compliant)<br>➢ Survey vendors are responsible for conducting data submission and must not subcontract this process<br>➢ Survey vendors must have the capacity to do the following actions to submit quarterly data files:<br>• Register as a user of the CAHPS Hospice Survey Data Warehouse<br>• Confirm contracted hospices have authorized survey vendor to submit data on behalf of the hospice<br>• Import scanned or key-entered data from completed mail surveys into a data file, if applicable<br>• Import (as necessary) data from CATI system into a data file, if applicable<br>• Develop data files and edit and clean data according to standard protocols<br>• Follow all data cleaning and data submission rules, including verifying that data files are de-identified and contain no duplicate cases<br>• 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<br>• Encrypt and submit data electronically in the specified format to the CAHPS Hospice Survey Data Warehouse<br>• Work with CMS' contractor to resolve data problems and data submission issues |
| **Data Security** | ➢ Survey vendors must have the capacity to do the following actions to secure electronic data:<br>• Use a firewall and/or other mechanisms for preventing unauthorized access to electronic files<br>• Implement access levels and security passwords so that only authorized users have access to sensitive data<br>• Implement daily data back-up procedures that adequately safeguard system data<br>• Test back-up files on a quarterly basis, at a minimum, to make sure the files are easily retrievable and working<br>• Perform frequent saves to media to minimize data losses in the event of power interruption<br>• Develop procedures for identifying and handling breaches of confidential data<br>• Develop a disaster recovery plan for conducting ongoing business operations in the event of a disaster |

| Criteria | Survey Vendor |
|---|---|
| **Data Retention and Storage** | ➢ Survey vendors must have the capacity to do the following actions to securely store all data related to survey administration:<br>• Store CAHPS Hospice Survey-related data files, including decedents/caregivers lists and de-identified electronic data files (e.g., sample frame, XML files, etc.), for all applicable survey modes for a minimum of three years. Archived electronic data files must be easily retrievable.<br>• 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.<br>• Destroy CAHPS Hospice Survey related data files, including paper copies or scanned images of the questionnaires and electronic data files in a secure and environmentally safe location. Obtain a certificate of the destruction of data. |
| **Technical Assistance/ Customer Support** | ➢ Two years prior experience providing telephone customer support<br>➢ Provide toll-free customer support line:<br>• Offering customer support in all languages that the survey vendor administers the survey in<br>• Returning calls within 24 - 48 hours |
| **Organizational Confidentiality Requirements** | ➢ Survey vendors must have the capacity to do all of the following actions:<br>• Develop confidentiality agreements which include language related to HIPAA regulations and the protection of personal identifying information (PII) and obtain signatures from all personnel with access to survey information, including staff and subcontractors or any other organizations 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.<br>• Execute Business Associate Agreements (BAA) in accordance with HIPAA regulations<br>• Confirm that staff and subcontractors or other organizations involved in survey administration are compliant with HIPAA regulations in regard to decedent/caregiver protected health information (PHI) and PII<br>• Establish protocols for secure file transmission. Emailing of PHI or PII via unsecure email is prohibited. |

**Participation in Quality Control Activities and Documentation Requirements:**
Personnel training and quality control mechanisms employed to collect valid, reliable survey data.

| Criteria | Survey Vendor |
|---|---|
| **Demonstrated Quality Control Procedures** | ➢ Incorporate well-documented quality control procedures (as applicable) for:<br>• Training of in-house staff and subcontractors or other organizations involved in survey operations<br>• Printing, mailing, and recording receipt of survey questionnaires, if applicable<br>• Telephone administration of survey, if applicable<br>• Coding and verifying of survey data and survey-related materials<br>• Scanning or keying-in survey data<br>• Preparation of final person-level data files for submission<br>• Submitting Discrepancy Reports immediately upon discovering a discrepancy in following CAHPS Hospice Survey protocols<br>• All other functions and processes that affect the administration of the CAHPS Hospice Survey<br>➢ Participate in any conference calls and site visits as part of overall quality monitoring activities:<br>• Provide documentation as requested for site visits and conference calls, including but not limited to: staff training records, telephone interviewer monitoring records, and file construction documentation |
| **Documentation Requirements** | ➢ Keep electronic or hard copy files of staff training and training dates<br>➢ Maintain electronic documentation of telephone monitoring, if applicable<br>➢ Maintain documentation of mail production quality checks, if applicable<br>➢ Maintain documentation of all survey administration activities and related quality checks for review during site visits<br>➢ Develop a Quality Assurance Plan (QAP) for survey administration in accordance with CAHPS Hospice Survey *Quality Assurance Guidelines* and update the QAP at the time of process and/or key personnel changes as part of retaining participation status |

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

| Criteria | Survey Vendor |
|---|---|
| **Survey Training** | ➢ Attend the Introduction to CAHPS Hospice Survey Training session and all CAHPS Hospice Survey Update Training sessions (at a minimum, survey vendor's Project Manager and subcontractors or other organizations involved in survey administration assigned key roles must attend training)<br>➢ Successfully complete the post-training quiz measuring comprehension of CAHPS Hospice Survey protocols |
| **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)<br>➢ Fully comply with the CAHPS Hospice Survey oversight activities<br>➢ 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.<br>• 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<br>• 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<br>o If a survey vendor chooses to not re-apply at this time, then a 24-month wait period will be required before the organization is eligible to apply again<br>o If a CAHPS Hospice Survey vendor is approved for a second term and does not have any contracted hospice clients by the end of the second 24-month approved period, a 24-month wait period will be required before the organization is eligible to apply again |

## 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 on an annual basis several months prior to training. 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.

  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. Once conditionally approved, the survey vendor must then participate in the CAHPS Hospice Survey Training sessions. Survey vendors will be eligible to receive full approval following participation in the CAHPS Hospice Survey Training sessions and successful completion of the post-training quizzes.

  *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. Consideration will be given to the applicant's prior experience administering other CMS CAHPS surveys, if any.*

- **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.
- **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 subcontractors and any other organizations, if applicable, have received training on HIPAA regulations.
- **Execute Business Associate Agreements**
  Survey vendors must execute Business Associate Agreements (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*

  Planned variations from survey administration protocols must be pre-approved by CMS through the Exception Request process (see Appendix I). 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 J). 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 H) must be used for developing the QAP. The QAP must be updated at minimum annually, after the CAHPS Hospice Survey training sessions, and as necessary, to reflect changes in key personnel, resources, and processes (see *Oversight Activities* chapter for more information).
  - **Change in Organizational Structure or Ownership**
    A survey vendor must immediately notify the CAHPS Hospice Survey Project Team of changes in its organizational structure or ownership (i.e., changes due to mergers or acquisitions, name, or address) via email at hospicecahpssurvey@hsag.com
  - **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 (i.e., changes in key CAHPS Hospice Survey personnel) via email at hospicecahpssurvey@hsag.com

  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) for review by the CAHPS Hospice Survey Project Team.
- **Become a registered user of the CAHPS Hospice Survey Data Warehouse**
  Survey vendors must submit CAHPS Hospice Survey data electronically via the CAHPS Hospice Survey Data Warehouse using the prescribed file specifications. All survey vendors participating in the CAHPS Hospice Survey must be registered users of the CAHPS Hospice Survey Data Warehouse.

- **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.***

# 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@hsag.com
- 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 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
- via telephone at 1-703-413-1100, extension 5599

## 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, 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" section 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

"No publicity" status is a rare and unusual request. "No publicity" decedents/caregivers are those who initiate or voluntarily request at any time during their stay 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.

The vendor should review the definition of a "no publicity" decedent/caregiver with each hospice to ensure the hospice understands when this may be used. If the number of "no publicity" decedents/caregivers from any hospice is consistently high, the vendor should confirm the "no publicity" count is correct. It is expected that most hospice agencies will have very few, if any, "no publicity" decedent/caregivers during any given calendar year.

## 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 **must** be accurate and add up correctly. If the counts submitted by the hospice appear to be inaccurate based on the number of decedent/caregiver records submitted by that hospice, the vendor must follow-up with the hospice to confirm the counts are correct. The hospice must update the counts if they are determined to be inaccurate.

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, as well as 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, as well as 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.

*Note: Hospices will submit three patient counts: total decedents (the number of all decedents served in the month, which includes the number of "no publicity" decedents/caregivers), the number of "no publicity" decedents/caregivers and the number of live discharge patients. These counts must include only hospice patients served by the CCN.*

## Decedents/Caregivers List

Hospices are required to supply a decedents/caregivers list to their survey vendor containing the data elements below for each decedent, excluding "no publicity" decedents/caregivers, who died within a calendar month while under the care of the hospice program (first day of month through last day of month). The hospice must not apply eligibility criteria prior to providing the decedents/caregivers list to their survey vendor. **All** decedents/caregivers in the month with the exception of non-publicity decedents/caregivers must be submitted to the survey vendor.

- 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)
  - The CAHPS Hospice Survey is intended to reflect the care received by decedents of all payer types, not just Medicare. Therefore, decedents of all payer types are eligible for sampling.
- 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), and email address (if available)
- Caregiver relationship to decedent (e.g., spouse/partner, child, sibling, other)
- Caregiver language

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), even if the caregiver was not physically present during the decedent's hospice care. The hospice is responsible for identifying one primary informal caregiver who is 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 or non-familial paid caregiver who does not fall into one of these categories cannot be considered a primary informal caregiver for the purposes of the CAHPS Hospice Survey.
  - A caregiver relationship of "8 - No caregiver of record" must be used to identify decedents who have no caregiver of record
- One caregiver category <u>does not</u> 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 <u>be administered to the person most knowledgeable</u> about the care the decedent received at the hospice.
- Staff members, employees of the hospice or the care setting in which the patient received hospice care, non-familial legal guardians, or contracted/hired non-familial caregivers should not be considered primary informal caregivers, and are not eligible to be sampled for the CAHPS Hospice Survey

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 survey vendor must use the information that the hospice provides in the decedents/caregivers list 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 prior to survey administration. It is permissible for survey vendors to request updated information about specific decedents/caregivers, rather than requesting a complete

updated list. 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 after the survey vendor has initiated contact.*

*Note: Survey vendors must not assume that if a hospice does not submit a monthly sample file that there are zero survey-eligible decedents/caregivers for the month. The hospice must confirm in writing that there are zero survey-eligible decedents/caregivers for the month. If no written confirmation is received, then a Hospice Record for the hospice must not be uploaded and a Discrepancy Report must be submitted.*

### 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" status is a rare and unusual request. "No publicity" decedents/caregivers are those who initiate or voluntarily request at any time during their stay that the hospice: 1) not reveal the patient's identity; and/or 2) not survey him or her.)

## Eligibility for the CAHPS Hospice Survey

Decedents/caregivers are eligible for inclusion in the sample frame if they meet all of the following criteria:

- Decedents age 18 and over at time of death
  - To determine if the decedent was age 18 or older at the time of death, use the date of birth and date of death provided by the hospice to calculate the decedent's age
- 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

- A caregiver relationship of "8 - No caregiver of record" must be used to identify decedents who have no caregiver of record

➢ Decedents whose caregiver is a ***familial legal guardian***
- A ***familial legal guardian*** falls into one of the six answer categories provided in the Sample File Layout of Appendix D (1 = Spouse/partner; 2 = Parent; 3 = Child; 4 = Other family member; 5 = Friend; 7 = Other).
- Decedents whose caregiver is a ***non-familial legal guardian*** or ***non-familial paid caregiver*** are **not** eligible. The hospice should only indicate the caregiver relationship as 6 = Legal guardian or 9 = Paid caregiver if the caregiver is a **non-familial** legal guardian or paid caregiver

➢ Decedents for whom the caregiver has a U.S. or U.S. Territory home address

If a survey vendor becomes aware that a decedent/caregiver case should have a "no publicity" classification, then the "no publicity" decedent/caregiver must be excluded from the sample frame. "No publicity" status is a rare and unusual request. "No publicity" decedents/caregivers are those who initiate or voluntarily request at any time during their stay 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.*

## De-duplication

To ensure accurate counts are submitted to CMS, hospices/survey vendors must review the decedents/caregivers files for patients with repeat entries (patients that are included in the file more than once for the same service dates) and patients with duplicate admissions (patients with multiple hospice admissions during a given calendar month).The de-duplication process should include reviewing decedent names, along with secondary fields, such as date of birth and date of death, before any sampling activities are performed. For example:

➢ If one record has the decedent name as Robert E. Smith and another record is Robert Smith, and the date of birth and the date of death match for both records, the hospice should be contacted to determine if the records are repeat entries. If so, the record with the most complete information for the fields required to sample and survey the decedent/caregiver should be retained and sampled. If both records have the same amount of information, one should be randomly selected.

Patients who have multiple hospice admissions and are discharged alive are considered ineligible. The episode of care that results in the patient's death is the record that is retained for sampling, unless the decedent is otherwise determined to be ineligible. 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 the same month (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 provided to the survey vendor. Additionally, the patient will be included in the February decedents/caregivers list as a decedent.

If a vendor identifies that the sample frame contains a repeat or duplicate record after the creation of the sample frame, the duplicate case must be assigned the Final Survey Status code of "16: Sampling Error" and survey administration activities must be stopped for the duplicate case(s).

## 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 included 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:
    - "3 – Ineligible: Not in Eligible Population" if the caregiver name is completely missing, regardless of the inclusion of an address or telephone number
    - "10 – Non-response: Bad/No Address" if the address is completely missing and the hospice is using the Mail Only Mode
    - "11 – Non-response: Bad/No Telephone Number" when there is evidence that a caregiver's telephone number is bad or missing (e.g., no telephone number available or a disconnected telephone number) and the hospice is using the

Telephone Only Mode. For the Mixed Mode, "11 – Non-response: Bad/No Telephone Number" is used when the mail survey is not returned and there is evidence that a caregiver's telephone number is bad or missing, or if both the address and the telephone number are bad or missing.

- "12 – Non-response: Incomplete Caregiver Name" if part of the caregiver name is missing
- "13 – Non-response: Incomplete Decedent Name" if all or part of the decedent name is missing

(For more information, see the *Data Coding and Data File Preparation* chapter.)

Survey vendors are required to provide counts of the (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 cases available to be sampled, (f) total number of cases actually drawn into the sample, (g) 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 (h) total number of ineligible decedents/caregivers as determined by the survey vendor by applying the following criteria:

- Decedent was under the age of 18 at time of death
- Decedent's death was less than 48 hours following last admission to hospice care
- Decedent has no caregiver of record (must be identified by the caregiver relationship of "8 - No caregiver of record")
- Decedent's caregiver is a non-familial legal guardian or paid caregiver
- 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). This documentation is subject to review.*

*Note: The total number of ineligible decedents/caregivers should <u>not</u> 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 <u>fewer</u> 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 are 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 eligible decedents/caregivers from the survey sample frame, or for those hospices conducting a census, all eligible decedents/caregivers from the survey sample frame.

## 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

Simple random sampling (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
  - Suppose **Hospice A** has 150 survey-eligible decedents/caregivers for a given month and wishes to use a 50 percent sampling rate
    - **Randomly sort** all 150 survey-eligible decedents/caregivers prior to sampling
    - 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

- Suppose **Hospice B** has 60 survey-eligible decedents/caregivers for a given month. Since this hospice is using census sampling, each of the 60 survey-eligible decedents/caregivers is included in the hospice's CAHPS Hospice Survey sample.

- Census sampling 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

*Note: Other sampling scenarios may exist and the survey vendor should contact the CAHPS Hospice Survey Project Team with any questions via email at hospicecahpssurvey@hsag.com or call 1-844-472-4621.*

## 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 records 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, these **must not** be combined in any manner to generate the Decedent ID:
  - the date of death (month, date and/or year),
  - the birth date (month, date and/or year) and
  - hospice ID number (e.g., decedent record number received from the hospice)

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.

# VI. Mail Only Survey Administration

## Overview

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

Data collection for sampled decedents/caregivers must be initiated two months following the month of patient death. Mail survey activities are not to be conducted from a residence, nor from a virtual office, unless an Exception Request has been submitted and approved by CMS. 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.

If survey administration is not initiated within the first seven days, it may be initiated by the survey vendor from the eighth to the tenth of the month without requesting prior approval from CMS. In this situation, a Discrepancy Report must be submitted to notify CMS of the late survey administration. In addition, the survey vendor must keep documentation regarding why the survey administration was initiated late. After the tenth of the month, approval must be requested from CMS before the survey can be administered and a Discrepancy Report must be submitted if survey administration begins late or does not occur for any month.

*Note: If after the first mailing the survey vendor learns that a sampled decedent/caregiver is ineligible for the CAHPS Hospice Survey or has been incorrectly drawn into the sample, the survey vendor must not send the caregiver the second questionnaire. In the case of a duplicate or repeat caregiver that was incorrectly drawn into the sample, the correctly sampled caregiver should still receive the second questionnaire. After the sample has been drawn, any decedents/caregivers who are found to be ineligible or incorrectly sampled 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) or sampling error (16). A Decedent/Caregiver Administrative Record must be submitted for these decedents/caregivers. See the Data Coding and Data File Preparation chapter for more information on assigning the "Final Survey Status" codes.*

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 contact with potential respondents until the data collection protocol is completed.

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

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

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 mailing. To illustrate the timing of the survey mailing, the example below is provided of a patient who died on April 18 while in hospice care.

**Example:**

- Patient's date of death is April 18
- 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
  - An optional reply-by-date on the **follow-up cover letter** with the second survey mailing will be August 5 (35 days from initial mailing)
- Data collection must be closed out on August 12 for this caregiver, which is six weeks (42 calendar days) from the July 1 initial mailing 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, Vietnamese, Polish, and Korean. Survey vendors are provided with the CAHPS Hospice Survey questionnaires in English, Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish, and Korean, and initial and follow-up cover letters in English, Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish, and Korean. 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, Vietnamese, Polish, or Korean to offer the CAHPS Hospice Survey in all applicable languages. 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 (i.e., questionnaires, cover letters, and outgoing/return envelopes) by the specified due date for review by the CAHPS Hospice Survey Project Team. The due date 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 name of the decedent, caregiver, and hospice. 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 (OMB#0938-1257) and expiration date) must appear on the front page of the questionnaire. The current expiration date text is "Expires December 31, 2023."

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 through V). 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**") must be included on the questionnaire and must be bolded and capitalized, including the "**SURVEY INSTRUCTIONS**" heading
- Response options on the questionnaire may be incorporated as circles, ovals, or squares with no mixing of the characters within the questionnaire
- 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).
- 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
- May include the specific hospice inpatient unit, acute care hospital, or nursing home facility in which their family member or friend resided
- Language such as one of the following may be added to the bottom of each page of the survey:
  - Continue on next page
  - Continue on reverse side
  - Turn over to continue
  - ➔ to continue
  - Continue on back
  - Turn over

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 through V
- 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."
- Supplemental questions should be integrated into the CAHPS Hospice Survey and not be a separate insert
  - If the supplemental questions are printed on a separate sheet, then they must be included as the last page of the materials
- Hospice-specific supplemental questions must be identical for both mail wave attempts

Survey vendors must avoid hospice-specific supplemental questions that:

- pose a burden to the caregiver (e.g., length and complexity of supplemental questions)
- are worded very similarly to the CAHPS Hospice Survey Core questions
- may cause the caregiver to terminate the survey (e.g., items that ask about sensitive medical, health, or personal topics)
- 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, even if they are anonymous, as testimonials or for marketing purposes.*

The number of supplemental questions added is left to the discretion of the survey vendor (up to 15 hospice-specific supplemental questions). The survey vendor must submit the maximum number of supplemental survey items included in the survey in the "supplemental-question-count" element in the Decedent/Caregiver Administrative Record for each survey (see Appendix E).

- Each potential supplemental item counts as one question, whether or not the item is phrased as a sentence or as a question
- Each open-ended or free response question counts as one supplemental item

## Cover Letters

Survey vendors are strongly encouraged to use the text in the body of the sample cover letters provided (see Appendices N through V). 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
  - An electronic signature is permissible
- Use of the Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish, or Korean cover letter is required if the survey vendor is sending a Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish, or Korean 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 both the initial and follow-up cover letter:
  - Name and address of the sampled caregiver ("To Whom It May Concern" and "To the caregiver of [Decedent Name]" are <u>not</u> 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 they 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
  - Wording stating that the caregiver's healthcare or benefits will not be affected whether or not they participate in the survey
  - 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:
    - 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

    *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 through V) <u>must</u> appear on either the questionnaire or cover letter, and may appear on both, in a readable font (e.g., Arial) at a minimum of 10-point

- Cover letter must not:
  - be attached to the survey; doing so could compromise confidentiality
  - attempt to bias, influence, or encourage caregivers to answer CAHPS Hospice Survey questions in a particular way
  - imply that the hospice, its personnel, or its agents will be rewarded or gain benefits if caregivers answer CAHPS Hospice Survey questions in a particular way
  - ask or imply that caregivers should choose certain responses; indicate that the hospice is hoping for a given response, such as a "10," "Definitely yes," or an "Always"
  - indicate that the hospice's goal is for all caregivers to rate them as a "10," "Definitely yes," or an "Always"
  - offer incentives of any kind for participation in the survey
  - include any content that attempts to advertise or market the hospice's mission or services
  - offer caregivers the opportunity to complete the survey over the telephone
  - include extraneous titles for caregiver (e.g., Aunt, Uncle)
  - include dates (e.g., print date, mail date)
  - include any promotional or marketing text

### Optional for the Cover Letter

- Cover letters may be double sided (English/Spanish, English/Chinese, English/Russian, English/Portuguese, English/Vietnamese, English/Polish, or English/Korean)
- Information may be added to the cover letters that indicates that the caregiver may request a mail survey in English, Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish, or Korean
- 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
- May include the specific hospice inpatient unit, acute care hospital, or nursing home facility in which their family member or friend resided
- A bereavement customer support number (i.e., hospice bereavement contact number) may appear on the cover letter
- A reply-by date may be added to the **follow-up cover letter**. It is recommended that the reply-by date be calculated as 35 days from the initial mailing to make sure the survey is returned before the data collection closes.
  - There are two options for adding the reply-by date to the **follow-up cover letter** in a readable font size at a minimum of 12-point. (See Appendices N through V for the exact text and placement.)

### Required for the Envelopes

- The envelope in which the survey is mailed must be printed with the survey vendor's address as the return address
- All envelopes must be in a readable font (e.g., Arial) in a font size of 10-point or larger

- A self-addressed, stamped business return envelope must be enclosed in the survey envelope along with the cover letter and questionnaire

### Optional for the Envelopes

- The outgoing envelope may be printed with the banner, "Important – Open Immediately." No other banners may be used.
  - Other messages, marketing, or promotional text such as, "Survey Enclosed," "Important Information from the Centers for Medicare & Medicaid Services Enclosed," or "We always strive to provide excellent service" on either side (front or back) are not permitted
- The envelope should be printed with the survey vendor logo, the hospice logo, or both
- 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

*Note: Any variations to the survey materials, 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

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 re-contact the hospice client to inquire about an address update for caregivers with no mailing address. It is permissible for survey vendors to request updated information about specific decedents/caregivers, rather than requesting a complete updated list. These decedent/caregiver cases must not be removed or replaced in the sample.

  *Note: It is strongly recommended that survey vendors check the accuracy of sampled caregivers' contact information prior to survey fielding by performing a check of several of the sampled caregivers to ensure that the name corresponds to the address provided by the hospice.*

- 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 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 the first wave mail survey is returned with all missing responses (i.e., without any questions answered – blank questionnaire), and there is no indication that the case is a refusal, ineligible, or otherwise final, 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 with responses.

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. Data from each survey must be key-entered independently by at least two staff members, and 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).
- 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. If the respondent writes Caucasian code as "1 – White."

*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 9) in Question 47, is up to each survey vendor. 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 Project Team about adding additional preprinted response options to these survey items, if needed.*

## Staff Training

Training of personnel on the CAHPS Hospice Survey data collection protocols is key to successful survey administration. Training of staff must be documented. This documentation must be available for review upon request by the CAHPS Hospice Survey Project Team. The following section addresses training provided to:

- Project staff
- Customer support personnel
- Mail data entry personnel
- Subcontractors and any other organizations responsible for major survey administration functions

### Training of Project Staff

At a minimum, the survey vendor's Project Manager, subcontractors, and any other organizations responsible for major survey administration functions (e.g., mail/telephone operations), if applicable, 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) 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 FAQ. 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 customer support personnel 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, the CAHPS Hospice Survey Project Team recommends 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 and/or scanning procedures
- Validation programs
- Decision rules/ambiguous responses

### Training of Subcontractors and Any Other Organizations Responsible for Major Survey Administration Functions

Survey vendors are responsible for the training and performance of subcontractors and any other organizations they use. In addition, during survey administration, survey vendors are responsible for providing quality oversight and monitoring of their subcontractor's and/or other organization's work to confirm that they are in compliance with CAHPS Hospice Survey guidelines.

Subcontractors and any other organizations that are responsible for major CAHPS Hospice Survey administration functions (e.g., mail/telephone operations) must attend the CAHPS Hospice Survey Training.

*Note: Survey vendors are responsible for sampling and data submission; and therefore, must not subcontract these processes.*

## Quality Control Guidelines

Survey vendors are responsible for the quality of work performed by all staff members, subcontractors, and any other organizations, if applicable. Survey vendors must conduct **on-site** verification of printing and mailing processes (strongly recommended on an annual basis, at a minimum) and document the quality check activities conducted during the visit, regardless of whether they are using internal staff, subcontractors, or any other organizations 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 at least 10 percent (on an ongoing and continuous basis throughout the survey administration period) of all 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 minimum on 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
    - Quality checks of seeded mailing materials must be documented and retained in a log or database
  - 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
  - It is permissible for survey vendors to request updated information about specific decedents/caregivers, rather than requesting a complete updated list
  - In addition to working with client hospices to obtain the most current caregiver contact information, survey vendors must employ other methods, 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

*Note: If automated processes are being used to perform interval checks, then checks of the system or equipment must be performed regularly. 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 subcontractors and any other organizations. 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.

- Perform and document quality checks of electronic programming code periodically, on an annual basis, at a minimum
- 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, including conducting on-site verification of processes (strongly recommended on an annual basis, at a minimum)
- Ensure that staff, subcontractors, and any other organizations are compliant with HIPAA regulations
- Monitor the performance of subcontractors and any other organizations, including conducting on-site verification of subcontractor processes (strongly recommended on an annual basis, at a minimum)
- Provide performance feedback to all project staff, subcontractors, and any other organizations 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, their subcontractors and any other organizations, 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)
  - Store returned mail paper questionnaires and/or electronically scanned questionnaires in a secure and environmentally safe location for a minimum of three years
- Develop a confidentiality agreement which includes language related to HIPAA regulations and the protection of PII, and obtain signatures from all personnel with access to survey information, including staff and subcontractors, and any other organizations, 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.*

- Execute BAAs in accordance with HIPAA regulations
- Provide HIPAA training to staff prior to providing access to decedent/caregiver PHI and PII
- Confirm that staff, subcontractors, and any other organizations, if applicable, are compliant with HIPAA regulations in regard to decedent/caregiver PHI

- Establish protocols for secure file transmission. Emailing of PHI via unsecure email is prohibited.
- Establish protocols for identifying security breaches and instituting corrective actions

*Note: It is strongly recommended that the method used by contracted hospices to transmit information (e.g., decedents/caregivers lists) to the survey vendor be reviewed by the hospice's HIPAA/Privacy Officer to confirm compliance with HIPAA regulations. Any materials (e.g., QAP, questionnaires, cover letters, tracking forms) submitted by the survey vendor to the CAHPS Hospice Survey Project Team must be blank templates and must <u>not</u> 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. Survey vendors who were approved for remote operations must ensure that these actions apply to all remote activities.

- Use a firewall, VPN, and/or other mechanisms for preventing unauthorized access to the electronic files
  - Survey vendors must notify the CAHPS Hospice Survey Project Team within 24 hours upon discovery of a data breach that potentially affects CAHPS Hospice Survey administration within their organization or at a client hospice
- 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. The plan must be made available to the CAHPS Hospice Survey Project Team upon request.

## Data Retention and Storage

Survey vendors must store all CAHPS Hospice Survey files and survey administration related data in a secure and environmentally controlled location for a minimum of three years, and it must be easily retrievable, when needed. Survey vendors must destroy survey-related data files, including paper copies or scanned images of the questionnaires and electronic data files in a secure and environmentally safe location and obtain a certificate of the destruction of data.

# VII. Telephone Only Survey Administration

## Overview

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

Data collection for sampled decedents/caregivers must be initiated two months following the month of patient death. Data collection may be completed by telephone only. Telephone survey activities are not to be conducted from a residence, nor from a virtual office, unless an Exception Request has been submitted and approved by CMS. 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.

If survey administration is not initiated within the first seven days, it may be initiated by the survey vendor from the eighth to the tenth of the month without requesting prior approval from CMS. In this situation, a Discrepancy Report must be submitted to notify CMS of the late survey administration. In addition, the survey vendor must keep documentation regarding why the survey administration was initiated late. After the tenth of the month, approval must be requested from CMS before the survey can be administered and a Discrepancy Report must be submitted if survey administration begins late or does not occur for any month.

*Note: If the survey vendor learns that a sampled decedent/caregiver is ineligible for the CAHPS Hospice Survey or has been incorrectly drawn into the sample, the survey vendor must not make further attempts to contact that caregiver. In the case of a duplicate or repeat caregiver that was incorrectly drawn into the sample, the correctly sampled caregiver should still receive additional call attempts, up to five total call attempts. After the sample has been drawn, any decedents/caregivers who are found to be ineligible or incorrectly sampled 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) or sampling error (16). A Decedent/Caregiver Administrative Record must be submitted for these decedents/caregivers. See the Data Coding and Data File Preparation chapter for more information on assigning the "Final Survey Status" codes.*

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.

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

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:**

- Patient's date of death is April 1
- 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 English, Spanish, and Russian. 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 English, Spanish, and Russian (Appendices W, X, and Y) 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 or Russian to offer the CAHPS Hospice Survey in these languages. 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 date 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 or italicizing the emphasized words.*

- All punctuation for the question and answer categories located in Appendices W, X, and Y must be programmed
- Only one language (English, Spanish, or Russian) 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 CAHPS Hospice Survey Core 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 [ABC Hospice]."
  - "This next set of questions is to provide the hospice additional feedback about your family member's hospice care."

Survey vendors must avoid hospice-specific supplemental questions that:

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

- may cause the caregiver to terminate the survey (e.g., items that ask about sensitive medical, health, or personal topics)
- 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, even if they are anonymous, as testimonials or for marketing purposes.*

The number of supplemental questions added is left to the discretion of the survey vendor (up to 15 hospice-specific supplemental questions). The survey vendor must submit the maximum number of supplemental survey items included in the survey in the "supplemental-question-count" element in the Decedent/Caregiver Administrative Record for each survey (see Appendix E).

- Each potential supplemental item counts as one question, whether or not the item is phrased as a sentence or as a question
- Each open-ended or free response question counts as one supplemental item

## Interviewing Systems

Telephone data collection must be conducted using CATI and 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.

- Survey administration must be conducted in accordance with the Telephone Consumer Protection Act (TCPA) regulations
  - Cell phone numbers must be identified so that CATI systems with auto dialers do not call cell phone numbers without the permission of the respondent. Survey vendors may identify cell phone numbers through a commercial database and hospices may identify cell phone numbers upon patient admission.
  - 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 <u>not</u> program the caller ID to display only "[HOSPICE NAME]."

## Monitoring/Recording Telephone Calls

Survey vendors must be aware of and follow applicable state regulations when monitoring and/or recording telephone attempts, including those that permit monitoring/recording of telephone calls only 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 W, X, and Y.

## Telephone Attempts

Survey vendors must attempt to reach each and every caregiver in the sample. It is strongly recommended that survey vendors use both the primary (Caregiver Telephone Number 1) and secondary (Caregiver Telephone Number 2) numbers provided by the hospice. If the first telephone number is found to be bad/non-working, then the second telephone number should be used. It is up to the survey vendors' discretion to determine the number of attempts made to each telephone number; however, no more than a total of five call attempts can be made to a sampled caregiver.

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 or a business 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 and is asked to call back at a more convenient time
  - The call back must be scheduled at the caregiver's convenience, if at all possible. When requested, survey vendors must schedule a telephone call back that accommodates a caregiver's request for a specific day and time (i.e., between the hours of 9 AM and 9 PM respondent time within the 42 calendar day data collection period). If survey vendors schedule a specific time to call back the caregiver, then an attempt to reach the caregiver **must** be made at the scheduled time.
- The interviewer gets a busy signal
  - At the discretion of the survey vendor a single telephone attempt can consist of three consecutive busy signals obtained at approximately 20-minute intervals
- The interviewer reaches a "screening" number (e.g., privacy screen, privacy manager, phone intercept, or blocked call)
  - Survey vendors count this as one telephone attempt and continue to make additional attempts (up to five) to reach the caregiver before dispositioning the call as "9 – Non-response: Non-response after maximum attempts"
- 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
- 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

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) and it is strongly recommended that call attempts also include weekends, 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 "number-survey-attempts-telephone" for data submission.

  *Note: The call back must be scheduled at the caregiver's convenience, if at all possible. When requested, survey vendors must schedule a telephone call back that accommodates a caregiver's request for a specific day and time (i.e., between the hours of 9 AM and 9 PM respondent time within the 42 calendar day data collection period), 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 will not be available during the data collection period, and no proxy is identified, the caregiver should <u>not</u> receive any further telephone attempts and the case should be coded appropriately (8 – Non-response: Refusal)
- 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.
- If the interviewer reaches a healthcare facility staff member, the interviewer must request to get in touch with the sampled caregiver. Inform the healthcare facility staff member that the survey is part of a national initiative sponsored by the United States Department of Health and Human Services. The results of the survey will help hospices understand what they are doing well and what needs improvement.

  If the staff member indicates that the caregiver is unable to complete the survey (e.g., due to mental or physical incapacity), the interviewer should thank the staff member and code the attempt appropriately.

  *Note: Caregivers, if otherwise eligible, residing in healthcare facilities such as an assisted living facility, long-term care facility, or nursing home are to be included in the CAHPS Hospice Survey sample frame and attempts to contact the caregiver to administer the survey must be made to those decedents/caregivers drawn into the sample.*

  *Note: Healthcare facility telephone numbers cannot be placed on the survey vendor's do-not-call list, even if requested by the healthcare facility staff.*

- If the interviewer reaches a number that appears to be a business, the interviewer must request to speak to the caregiver
  - If asked who is calling, the interviewer should respond by providing their name and the survey vendor's name
  - If asked what they are calling about, the interviewer should respond by stating they are working with the hospice and the U.S. Department of Health and Human Services to conduct a survey about hospice care
  - If speaking with the caregiver who states they are at work and cannot speak, the interviewer should attempt to reschedule the call for a time that is more convenient for the caregiver, or obtain an alternate phone number at which to reach the caregiver

## 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 methods for updating telephone numbers:

- Running update program software against the sample file just before or after uploading data to survey management systems
- Contacting the hospice to request updated telephone numbers. If contacting the hospice to request updated contact information, it is permissible for survey vendors to request updated information about specific decedents/caregivers, rather than requesting a complete updated list.
- Utilizing commercial software, internet directories, and/or directory assistance

*Note: It is strongly recommended that survey vendors check the accuracy of sampled caregivers' contact information prior to survey fielding.*

## 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 files and survey administration related data collected through an electronic telephone interviewing system in a secure and environmentally controlled location for a minimum of three years, and it must be easily retrievable, when needed. Survey vendors must destroy survey-related data files, including paper copies or scanned images of the questionnaires and electronic data files in a secure and environmentally safe location and obtain a certificate of the destruction of data.

## Quality Control Guidelines

Survey vendors are responsible for the quality of work performed by all staff members, subcontractors, and any other organizations, if applicable. Survey vendors must employ the following guidelines for proper interviewer training, monitoring, and oversight regardless of whether they are using internal staff, subcontractors, or any other organizations to perform this work.

## Interviewer Training

Properly trained and consistently monitored interviewers ensure that standardized, non-directive interviews are conducted. Interviewers conducting the telephone survey must be trained prior to interviewing (see Appendices F and G for more information on interviewing guidelines). Interviewers must be trained to:

- read questions exactly as worded in the script, use non-directive probes, and maintain a neutral and professional relationship with the caregiver
  - The interviewer may use the pronoun appropriate to the decedent's gender ("he or she" or "him or her" if the caregiver mentions the decedent's gender
  - 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 script from the telephone screens (reciting the survey from memory can lead to unnecessary errors and missed updates to the scripts)
- read response options exactly as worded and at an even pace without emphasis on any particular response category
- record responses to survey questions only after the caregiver has responded to the questions; that is, interviewers must <u>not</u> pre-code response choices
  - The interviewer may accept any alternative positive or negative response from the caregiver
    - Interviewers must clarify the caregiver response if accepting alternative positive and/or negative responses (Definitely yes, Probably yes, etc.)
- understand the definition of each disposition code and appropriately assign interim or final call disposition codes, when applicable
- redirect calls to another interviewer when the decedent or caregiver is personally or professionally known to the initial interviewer
- adjust the pace of the CAHPS Hospice Survey interview to be conducive to the needs of the caregiver
- **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 customer support personnel 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, the CAHPS Hospice Survey Project Team recommends 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) or any other organization(s) to conduct telephone interviewing, then the survey vendor is responsible for attending/participating in the subcontractor's or other organization's telephone interviewer training to confirm compliance with CAHPS Hospice Survey protocols and guidelines. Survey vendors must conduct on-site verification of subcontractor's interviewing processes (strongly recommended on an annual basis, at a minimum).*

## Telephone Monitoring and Oversight

Each survey vendor employing the Telephone Only mode of survey administration must institute a telephone monitoring and evaluation program. Telephone monitoring is not to be conducted from a residence, nor from a virtual office, unless an Exception Request has been submitted and approved by CMS. 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 (on an ongoing and continuous basis throughout the survey administration period) of all CAHPS Hospice Survey interviews, interviewer survey response coding, dispositions, and call attempts in their entirety (English, Spanish, and Russian) 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 live, both on-site and from remote locations. All staff conducting CAHPS Hospice Survey interviews must be included in the monitoring. Additionally, it is required 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) or any other organization(s) must monitor at least 10 percent (on an ongoing and continuous basis throughout the survey administration period) of the subcontractor's or other organization's CAHPS Hospice Survey telephone interviews, interviewer survey response coding, dispositions, and call attempts in their entirety (English, Spanish, and Russian) 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 live, both on-site and from remote locations. Survey vendors must provide feedback to the subcontractor's or other organization's interviewers about their performance, and confirm that the subcontractor's or other organization'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' or other organizations' interviews, the CAHPS Hospice Survey Project Team also expects that a survey vendor's subcontractor(s) or other organization(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) or other organization(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, its subcontractor(s), and other organization(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, its subcontractor(s), and other organization(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

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 PII, and obtain signatures from all personnel with access to survey information, including staff, subcontractors, and any other organizations, 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.*

- Execute BAAs in accordance with HIPAA regulations
- Provide HIPAA training to staff prior to providing access to decedent/caregiver PHI and PII
- Confirm that staff, subcontractors, and any other organizations, if applicable, are compliant with HIPAA regulations in regard to decedent/caregiver PHI
- Establish protocols for secure file transmission. Emailing of PHI via unsecure email is prohibited.
- Establish protocols for identifying security breaches and instituting corrective actions

*Note: It is strongly recommended that the method used by contracted hospices to transmit information (e.g., decedents/caregivers lists) to the survey vendor be reviewed by the hospice's HIPAA/Privacy Officer to confirm compliance with HIPAA regulations. Any materials (e.g., QAP, questionnaires, cover letters, tracking forms) submitted by the survey vendor to the CAHPS*

*Hospice Survey Project Team must be blank templates and must not contain any decedent/caregiver PHI.*

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

## 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. Survey vendors who were approved for remote operations must ensure that these actions apply to all remote activities.

- Use a firewall, VPN, and/or other mechanisms for preventing unauthorized access to the electronic files
  - Survey vendors must notify the CAHPS Hospice Survey Project Team within 24 hours upon discovery of a data breach that potentially affects CAHPS Hospice Survey administration within their organization or at a client hospice
- 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. The plan must be made available to the CAHPS Hospice Survey Project Team upon request.

# 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. Mail survey activities are not to be conducted from a residence, nor from a virtual office, unless an Exception Request has been submitted and approved by CMS. Survey vendors must send sampled caregivers a questionnaire with a cover letter within the first seven calendar days of the field period, then conduct a maximum of five telephone attempts to non-respondents beginning approximately 21 calendar days after mailing the questionnaire.

If survey administration is not initiated within the first seven days, it may be initiated by the survey vendor from the eighth to the tenth of the month without requesting prior approval from CMS. In this situation, a Discrepancy Report must be submitted to notify CMS of the late survey administration. In addition, the survey vendor must keep documentation regarding why the survey administration was initiated late. After the tenth of the month, approval must be requested from CMS before the survey can be administered and a Discrepancy Report must be submitted if survey administration begins late or does not occur for any month.

*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 or has been incorrectly drawn into the sample, no further attempts can be made to contact that caregiver. In the case of a duplicate or repeat caregiver that was incorrectly drawn into the sample, the correctly sampled caregiver should still receive call attempts, up to five total call attempts. After the sample has been drawn, any decedents/caregivers who are found to be ineligible or incorrectly sampled 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) or sampling error (16). A Decedent/Caregiver Administrative Record must be submitted for these decedents/caregivers. See the Data Coding and Data File Preparation chapter for more information on assigning the "Final Survey Status" codes.*

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." If the survey is completed/dispositioned during the telephone phase of the Mixed Mode, the "number-survey-attempts-telephone" captures the telephone attempt in which the final disposition of the survey is determined. More information regarding the survey attempts field is presented in the *Data Coding and Data File Preparation* chapter.

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

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

| Activity | Timing |
|---|---|
| Send mail questionnaire with cover letter to sampled caregiver | Two months after the month of patient death within the first seven calendar days of the field period |
| Initiate systematic telephone contact for all non-respondents to the survey mailing | Approximately 21 calendar days after mailing of the questionnaire. The first telephone attempt must be made in the first seven days of the telephone field period (i.e., from 21 to 28 calendar days after mailing the questionnaire). |
| Complete data collection | Over the next 21 calendar days and within six weeks (42 calendar days) after the initial mailing |
| Submit data files to the CAHPS Hospice Survey Data Warehouse by the data submission deadline. No files will be accepted after the submission deadline date. | See the quarterly data submission deadlines in the *Introduction and Overview* chapter |

To reiterate, the mailing 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) <u>after the mailing of the questionnaire</u>. The first telephone attempt must be made in the first seven days of the telephone field period (i.e., from 21 to 28 calendar days after mailing the questionnaire). If the mail questionnaire is received during the telephone field period, telephone attempts must cease.

To illustrate the timing of survey mailing and telephone follow-up, the following example is provided of a patient who died on April 30 while in hospice care.

**Example:**

- Patient's date of death is April 30
- The survey is mailed out on July 1 (two months after patient's 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 mailing 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, Spanish and Russian. Survey vendors are provided with the CAHPS Hospice Survey questionnaires and cover letters in English, Spanish, and Russian (Appendices N, O, and R). 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 or Russian to offer the CAHPS Hospice Survey in those languages. 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 (i.e., questionnaires, cover letters, and outgoing/return envelopes) by the specified due date for review by the CAHPS Hospice Survey Project Team. The due date 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 English, Spanish, and Russian and may be two-sided, English on

one side and Spanish or Russian on the other. Cover letters sent to respondents must be personalized with the name of the decedent, caregiver, and hospice. 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 (OMB#0938-1257) and expiration date (Expires December 31, 2023) 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, and R). 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**") must be included on the questionnaire and must be bolded and capitalized, including the "**SURVEY INSTRUCTIONS**" heading
- Response options on the questionnaire may be incorporated as circles, ovals, or squares with no mixing of the characters within the questionnaire
- 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).
- 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

## 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
- May include the specific hospice inpatient unit, acute care hospital, or nursing home facility in which their family member or friend resided

- Language such as one of the following may be added to the bottom of each page of the survey:
  - Continue on next page
  - Continue on reverse side
  - Turn over to continue
  - ➔ to continue
  - Continue on back
  - Turn over

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, and R
- 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 still be placed prior to the "About Your Family Member" questions
- Phrases <u>must</u> 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."
- Supplemental questions should be integrated into the CAHPS Hospice Survey and not be a separate insert
  - If the supplemental questions are printed on a separate sheet, then they must be included as the last page of the materials

Survey vendors must avoid hospice-specific supplemental questions that:

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

- may cause the caregiver to terminate the survey (e.g., items that ask about sensitive medical, health, or personal topics)
- 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, even if they are anonymous, as testimonials or for marketing purposes.*

The number of supplemental questions added is left to the discretion of the survey vendor (up to 15 hospice-specific supplemental questions). The survey vendor must submit the maximum number of supplemental survey items included in the survey in the "supplemental-question-count" element in the Decedent/Caregiver Administrative Record for each survey (see Appendix E).

- Each potential supplemental item counts as one question, whether or not the item is phrased as a sentence or as a question
- Each open-ended or free response question counts as one supplemental item

## Cover Letter

Survey vendors are strongly encouraged to use the text in the body of the sample initial cover letter (see Appendices N, O, and R). 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
  - An electronic signature is permissible
- Use of the Spanish cover letter is required if the survey vendor is sending a Spanish questionnaire and a Russian cover letter is required if the survey vendor is sending a Russian 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 <u>not</u> 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 they 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
- Wording stating that the caregiver's healthcare or benefits will not be affected whether or not they participate in the survey
- 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:
  - 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

  *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, and R) must appear on either the questionnaire or cover letter, and may appear on both, in a readable font (e.g., Arial) at a minimum of 10-point
- Cover letter must <u>not</u>:
  - be attached to the survey; doing so could compromise confidentiality
  - attempt to bias, influence, or encourage caregivers to answer CAHPS Hospice Survey questions in a particular way
  - imply that the hospice, its personnel, or its agents will be rewarded or gain benefits if caregivers answer CAHPS Hospice Survey questions in a particular way
  - ask or imply that caregivers should choose certain responses; indicate that the hospice is hoping for a given response, such as a "10," "Definitely yes" or an "Always"
  - indicate that the hospice's goal is for all caregivers to rate them as a "10," "Definitely yes," or an "Always"
  - offer incentives of any kind for participation in the survey
  - include any content that attempts to advertise or market the hospice's mission or services
  - offer caregivers the opportunity to complete the survey over the telephone
  - include extraneous titles for caregiver (e.g., Aunt, Uncle)
  - include dates (e.g., print date, mail date)
  - include any promotional or marketing text

### Optional for the Cover Letter

- Cover letters may be double sided (English on one side and Spanish or Russian on the other)
- Information may be added to the English cover letter (in English, Spanish, or Russian) that indicates that the caregiver may request a mail survey in Spanish or Russian
- 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
- May include the specific hospice inpatient unit, acute care hospital, or nursing home facility in which their family member or friend resided
- A bereavement customer support number (i.e., hospice bereavement contact number) may appear on the cover letter

### Required for the Envelopes

- The envelope in which the survey is mailed must be printed with the survey vendor's address as the return address
- All envelopes must be in a readable font (e.g., Arial) in a font size of 10-point or larger
- A self-addressed, stamped business return envelope must be enclosed in the survey envelope along with the cover letter and questionnaire

### Optional for the Envelopes

- The outgoing envelope may be printed with the banner, "Important – Open Immediately." No other banners may be used.
  - Other messages, marketing, or promotional text such as, "Survey Enclosed," "Important Information from the Centers for Medicare & Medicaid Services Enclosed," or "We always strive to provide excellent service" on either side (front or back) are not permitted
- The envelope should be printed with the survey vendor logo, the hospice logo, or both
- 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

*Note: Any variations to the survey materials, 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

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 sent to the telephone portion of Mixed Mode.) 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 re-contact the hospice client to inquire about an address update for caregivers with no mailing address. If contacting the hospice to request updated contact information, it is permissible for survey vendors to request updated information about specific decedents/caregivers, rather than requesting a complete updated list. These decedent/caregiver cases must not be removed or replaced in the sample.

*Note: It is strongly recommended that survey vendors check the accuracy of sampled caregivers' contact information prior to survey fielding by performing a check on several of the sampled caregivers to ensure that the name corresponds to the address provided by the hospice.*

- 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),and there is no indication that the case is a refusal, ineligible, or otherwise final, 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 key-entered data. Survey vendors must confirm that key-entered data accurately capture the responses on the original survey. Data from each survey must be key-entered independently by at least two staff members, and 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 <u>not</u> impute a response (see *Data Coding and Data File Preparation* chapter for information on coding skip pattern 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. If the respondent writes Caucasian code as "1 – White."

*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 9) in Question 47, is up to each survey vendor. 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 Project Team about adding additional preprinted response options to these survey items, if needed.*

### 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. Survey vendors must destroy survey-related data files, including paper copies or scanned images of the questionnaires, and electronic data files in a secure and environmentally safe location and obtain a certificate of the destruction of data.

## Quality Control Guidelines for Mail Data

Survey vendors are responsible for the quality of work performed by all staff members, subcontractors, and any other organizations, if applicable. Survey vendors must conduct **on-site** verification of printing and mailing processes (strongly recommended on an annual basis, at a minimum) and document the quality check activities conducted during the visit, regardless of whether they are using internal staff, subcontractors, or any other organizations 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 at least 10 percent (on an ongoing and continuous basis throughout the survey administration period) of all 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 minimum on 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
        - Quality checks of seeded mailing materials must be documented and retained in a log or database
    - 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 <u>all</u> 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 methods, 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

*Note: If automated processes are being used to perform interval checks, then checks of the system or equipment must be performed regularly. Survey vendors <u>must</u> 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 mailing to sampled caregivers and there is no indication that the case is a refusal, ineligible, or otherwise final, survey vendors must follow the CAHPS Hospice Survey telephone survey protocol. Telephone survey activities are not to be conducted from a residence, nor from a virtual office, unless an Exception Request has been submitted and approved by CMS. 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. The first telephone attempt must be made in the first seven days of the telephone field period (i.e., from 21 to 28 calendar days after mailing the questionnaire).

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 English, Spanish, and Russian. 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 English, Spanish, and Russian (Appendices W, X, and Y) 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 or Russian 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 date 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, or italicizing the emphasized words.*

- All punctuation for the question and answer categories located in Appendices W, X, and Y must be programmed
- Only one language (English, Spanish, or Russian) 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 supplemental 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 CAHPS Hospice Survey Core questions (Q1 – Q40) or at the end of all the CAHPS Hospice Survey questions (Q1 – Q47)
- Phrases <u>must</u> 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."

Survey vendors must avoid hospice-specific supplemental questions that:

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

- may cause the caregiver to terminate the survey (e.g., items that ask about sensitive medical, health, or personal topics)
- 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, even if they are anonymous, as testimonials or for marketing purposes.*

The number of supplemental questions added is left to the discretion of the survey vendor (up to 15 hospice-specific supplemental questions). The survey vendor must submit the maximum number of supplemental survey items included in the survey in the "supplemental-question-count" element in the Decedent/Caregiver Administrative Record for each survey (see Appendix E).

- Each potential supplemental item counts as one question, whether or not the item is phrased as a sentence or as a question
- Each open-ended or free response question counts as one supplemental item

## Interviewing Systems

Telephone data collection must be conducted using CATI and 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 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.

- Survey administration must be conducted in accordance with the TCPA regulations
  - Cell phone numbers must be identified so that CATI systems with auto dialers do not call cell phone numbers without the permission of the respondent. Survey vendors may identify cell phone numbers through a commercial database and hospices may identify cell phone numbers upon patient admission.
  - 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 <u>not</u> program the caller ID to display only "[HOSPICE NAME]."

## Monitoring/Recording Telephone Calls

Survey vendors must be aware of and follow applicable state regulations when monitoring and/or recording telephone attempts, including those that permit monitoring/recording of telephone calls only 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 W, X, and Y.

## Telephone Attempts

Survey vendors must attempt to reach each and every non-respondent to the mail survey. It is strongly recommended that survey vendors use both the primary (Caregiver Telephone Number 1) and secondary (Caregiver Telephone Number 2) numbers provided by the hospice. If the first telephone number is found to be bad/non-working, then the second telephone number should be used. It is up to the survey vendors' discretion to determine the number of attempts made to each telephone number; however, no more than a total of five call attempts can be made to a sampled caregiver.

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 or a business 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 and is asked to call back at a more convenient time
  - The call back must be scheduled at the caregiver's convenience, if at all possible. When requested, survey vendors must schedule a telephone call back that accommodates a caregiver's request for a specific day and time (i.e., between the hours of 9 AM and 9 PM respondent time within the 42 calendar day data collection period). If survey vendors schedule a specific time to call back the caregiver, then an attempt to reach the caregiver **must** be made at the scheduled time.
- The interviewer gets a busy signal
  - At the discretion of the survey vendor a single telephone attempt can consist of three consecutive busy signals obtained at approximately 20-minute intervals
- The interviewer reaches a "screening" number (e.g., privacy screen, privacy manager, phone intercept, or blocked call)
  - Survey vendors count this as one telephone attempt and continue to make additional attempts (up to five) to reach the caregiver before dispositioning the call as "9 – Non-response: Non-response after maximum attempts"
- 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
- 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 caregiver's mail survey is received by the survey vendor after calling begins, 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) and it is strongly recommended that call attempts also include weekends, 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 "number-survey-attempts-telephone" for data 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 will not be available during the data collection period, and no proxy is identified, the caregiver should not receive any further telephone attempts and the case should be coded appropriately (8 – Non-response: Refusal)
- 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.
- If the interviewer reaches a healthcare facility staff member, the interviewer must request to get in touch with the sampled caregiver. Inform the healthcare facility staff member that the survey is part of a national initiative sponsored by the United States Department of Health and Human Services. The results of the survey will help hospices understand what they are doing well and what needs improvement.

  If the staff member indicates that the caregiver is unable to complete the survey (e.g., due to mental or physical incapacity), the interviewer should thank the staff member and code the attempt appropriately.

  *Note: Caregivers, if otherwise eligible, residing in healthcare facilities such as an assisted living facility, long-term care facility, or nursing home are to be included in the CAHPS Hospice Survey sample frame and attempts to contact the caregiver to administer the survey must be made to those decedents/caregivers drawn into the sample.*

  *Note: Healthcare facility telephone numbers cannot be placed on the survey vendor's do-not-call list, even if requested by the healthcare facility staff.*

- If the interviewer reaches a number that appears to be a business, the interviewer must request to speak to the caregiver.
  - If asked who is calling, the interviewer should respond by providing their name and the survey vendor's name
  - If asked what they are calling about, the interviewer should respond by stating they are working with the hospice and the U.S. Department of Health and Human Services to conduct a survey about hospice care
  - If speaking with the caregiver who states they are at work and cannot speak, the interviewer should attempt to reschedule the call for a time that is more convenient for the caregiver, or obtain an alternate phone number at which to reach the caregiver

### 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 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 methods 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
- Contacting the hospice to request updated telephone numbers. If contacting the hospice to request updated contact information, it is permissible for survey vendors to request updated information about specific decedents/caregivers, rather than requesting a complete updated list.

*Note: It is strongly recommended that survey vendors check the accuracy of sampled caregivers' contact information prior to survey fielding.*

## 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 files and survey administration related data collected through an electronic telephone interviewing system in a secure and environmentally controlled location for a minimum of three years, and it must be easily retrievable, when needed. Survey vendors must destroy survey-related data files, including paper copies or scanned images of the questionnaires, and electronic data files in a secure and environmentally safe location and obtain a certificate of the destruction of data.

## Quality Control Guidelines for Telephone Data Collection

Survey vendors are responsible for the quality of work performed by all staff members, subcontractors, and any other organizations, if applicable. Survey vendors must employ the following guidelines for proper interviewer training, monitoring, and oversight regardless of whether they are using internal staff, subcontractors, or any other organizations to perform this work.

### Interviewer Training

Properly trained and consistently monitored interviewers ensure that standardized, non-directive interviews are conducted. Interviewers conducting the telephone survey must be trained prior to interviewing (see Appendices F and G for more information on interviewing guidelines). Interviewers must be trained to:

- read questions exactly as worded in the script, use non-directive probes, and maintain a neutral and professional relationship with the caregiver
  - The interviewer may use the pronoun appropriate to the decedent's gender ("he or she" or "him or her" if the caregiver mentions the decedent's gender
  - 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 script from the telephone screens (reciting the survey from memory can lead to unnecessary errors and missed updates to the scripts)
- read response options exactly as worded and at an even pace without emphasis on any particular response category
- record responses to survey questions only after the caregiver has responded to the questions; that is, interviewers must <u>not</u> pre-code response choices
  - The interviewer may accept any alternative positive or negative response from the caregiver
    - Interviewers must clarify the caregiver response if accepting alternative positive and/or negative responses (Definitely yes, Probably yes, etc.)
- understand the definition of each disposition code and appropriately assign interim or final call disposition codes, when applicable
- redirect calls to another interviewer when the decedent or caregiver is personally or professionally known to the initial interviewer

- adjust the pace of the CAHPS Hospice Survey interview to be conducive to the needs of the caregiver
- **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 customer support personnel 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, the CAHPS Hospice Survey Project Team recommends 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) or any other organization(s) to conduct telephone interviewing, then the survey vendor is responsible for attending/participating in the subcontractor's or other organization's telephone interviewer training to confirm compliance with CAHPS Hospice Survey protocols and guidelines. Survey vendors must conduct on-site verification of subcontractor's interviewing processes (strongly recommended on an annual basis, at a minimum).*

### 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. Telephone monitoring is not to be conducted from a residence, nor from a virtual office, unless an Exception Request has been submitted and approved by CMS. 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 (on an ongoing and continuous basis throughout the survey administration period) of all CAHPS Hospice Survey interviews, interviewer survey response coding, dispositions, and call attempts in their entirety (English, Spanish, and Russian) 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 live, both on-site and from remote locations. All staff conducting CAHPS Hospice Survey interviews must be included in the monitoring. Additionally, it is required 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) or any other organization(s) must monitor at least 10 percent (on an ongoing and continuous basis throughout the survey administration period) of the subcontractor's or other organization's CAHPS Hospice Survey telephone interviews, interviewer survey response coding, dispositions, and call attempts in their entirety (English, Spanish, and Russian) 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 live, both on-site and from remote locations. Survey vendors must provide feedback to the subcontractor's or other organization's interviewers about their performance, and confirm that the subcontractor's or other organization'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' or other organizations' interviews, the CAHPS Hospice Survey Project Team also expects that a survey vendor's subcontractor(s) or other organization(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) or other organization(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, its subcontractor(s), and other organization(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, its subcontractor(s,) and other organization(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

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)
  - Store returned mail paper questionnaires and/or electronically scanned questionnaires in a secure and environmentally safe location for a minimum of three years
- Develop a confidentiality agreement which includes language related to HIPAA regulations and the protection of PII, and obtain signatures from all personnel with access to survey information, including staff, subcontractors, and any other organizations, 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.*

- Execute BAAs in accordance with HIPAA regulations
- Provide HIPAA training to staff prior to providing access to decedent/caregiver PHI and PII
- Confirm that staff, subcontractors, and any other organizations, if applicable, are compliant with HIPAA regulations in regard to decedent/caregiver PHI
- Establish protocols for secure file transmission. Emailing of PHI via unsecure email is prohibited.
- Establish protocols for identifying security breaches and instituting corrective actions

*Note: It is strongly recommended that the method used by contracted hospices to transmit information (e.g., decedents/caregivers lists) to the survey vendor be reviewed by the hospice's HIPAA/Privacy Officer to confirm compliance with HIPAA regulations. Any materials (e.g., QAP, questionnaires, cover letters, tracking forms) submitted by the survey vendor to the CAHPS Hospice Survey Project Team must be blank templates and must <u>not</u> 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. Survey vendors who were approved for remote operations must ensure that these actions apply to all remote activities.

- Use a firewall, VPN, and/or other mechanisms for preventing unauthorized access to the electronic files
  - Survey vendors must notify the CAHPS Hospice Survey Project Team within 24 hours upon discovery of a data breach that potentially affects CAHPS Hospice Survey administration within their organization or at a client hospice
- 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. The plan must be made available to the CAHPS Hospice Survey Project Team upon request.

# 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 records 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, these **must not** be combined in any manner to generate the Decedent ID:
  - the date of death (month, date and/or year),
  - the birth date (month, date and/or year) and
  - hospice ID number (e.g., decedent record number received from the hospice)

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, and files must be encrypted prior to submission.

Survey vendors must submit a Vendor Record and Hospice Record for hospices with zero survey-eligible decedents/caregivers (zero cases) in a month, as long as the hospice confirms in writing that it had zero eligible cases during the 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, or do not confirm in writing that the hospice had zero eligible decedents/caregivers in a month. In situations such as these, a Hospice Record must not be uploaded for the CCN/month, and a Discrepancy Report must be completed and submitted. Survey vendors must confirm if a hospice had any decedents/caregivers in a month if the hospice does not submit a sample file for any month.*

## 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 one XML file. 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. **For the vendor's final submission(s) each quarter, a separate file for each month of data is not permitted.**

If a survey vendor submits multiple data files for a CCN in any quarter, the most recent submission for that CCN will completely overwrite any previous submission for that CCN, and only the CCN's data in the most recent submission will be stored in the CAHPS Hospice Survey Data Warehouse. If, for example, a survey vendor submits an XML file containing 10 CCNs, and later in the same quarter submits a new XML file containing one of those 10 CCNs, the one CCN that appeared in both files will be overwritten by the later submission.

No substitutions for valid data element values are acceptable. For the full listing of valid values, details on the XML file specifications and a sample XML file layout, see Appendix E.

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.

- 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.

### 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 (which must correspond with the total decedent count provided by the hospice); 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); the number of available cases for the sample and the number of sampled cases; the sample size for the month; and the number of hospice offices.

*Note: Survey vendors must not assume that if a hospice does not submit a monthly sample file that there are zero survey-eligible decedents/caregivers for the month. The hospice must confirm in writing that there are zero survey-eligible decedents/caregivers for the month. If no written confirmation is received, then a Hospice Record for that month must not be uploaded and a Discrepancy Report must be submitted.*

*Note: If the "total decedents" count minus the number of "no publicity" decedents/caregivers does not equal the number of records submitted by the hospice and the survey vendor has been unsuccessful in resolving the counts with the hospice, a Discrepancy Report must be submitted.*

The "available-sample," "sampled-cases," and "sample-size" variables are calculated as follows:

- The "available-sample" field should equal the total number of decedents served by the CCN in the month ("total-decedents"), 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 Pre-sample)

- 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

- 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" code 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," "14 – Ineligible: Institutionalized"), or incorrectly sampled ("16 – Sampling Error"), 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.

"sample-size" should be calculated as:

Sample Size = Sampled Cases – Any cases with an ineligible "Final Survey Status" code (2, 3, 4, 5, 6, and/or 14) or incorrectly sampled (16)

- When hospices sample 100 percent of the survey-eligible decedents/caregivers (i.e., a census), the "sample-type" must be coded as "2 – Census Sample." See the *Sampling Protocol* chapter for information on sampling options.

The chart below contains examples of the correct calculations of the decedent/caregiver counts included in the Hospice Record:

| Sample Type | Total Decedents | No Publicity | Missing Date of Death | Ineligible Pre-sample | Available Sample | Sampled Cases | Ineligible Post-sample | Sample Size |
|---|---|---|---|---|---|---|---|---|
| *<sample-type>* | *<total-decedents>* | *<no-publicity>* | *<missing-dod>* | *<ineligible-presample>* | *<available-sample>* | *<sampled-cases>* | *<ineligible-postsample>* | *<sample-size>* |
| **Census** | 100 | 1 | 1 | 5 | 93 | 93 | 13 | 80 |
| **Census** | 10 | 0 | 0 | 1 | 9 | 9 | 2 | 7 |
| **Simple Random Sample** | 100 | 2 | 0 | 3 | 95 | 75 | 5 | 70 |
| **Simple Random Sample** | 500 | 5 | 1 | 24 | 470 | 200 | 50 | 150 |

### 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; lag time; and supplemental question count. 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 following guidelines must be followed when submitting the Decedent/Caregiver Administrative Records:

- All fields in the Decedent/Caregiver Administrative Record must have a valid value. Use the appropriate code (e.g., "M – Missing/Don't Know," "8888") 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 survey administration was attempted (English, Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish, or Korean), 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 (e.g., cases included in the "sampled-cases" count), including decedents/caregivers found to be incorrectly sampled or ineligible after the start of survey administration ("ineligible-post-sample")
- 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" may be "88 - Not Applicable" for "survey-mode" of "1 – Mail Only" and "2 – Telephone Only."*

- The "number-survey-attempts-telephone" field is coded with the attempt that corresponds to the time of final survey status determination and 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"

  *Note: "number-survey-attempts-telephone" may be "88 - Not Applicable" 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."*

  *Note: "number-survey-attempts-telephone" may be "0" for "survey mode" of "3 – Mixed Mode" if the survey was completed by mail.*

- The "number-survey-attempts-mail" field is coded with the attempt that corresponds to the time of final survey status determination and must be submitted when:
  - the "survey-mode" in the Hospice Record is "1 – Mail Only"

  *Note: "number-survey-attempts-mail" may be "88 - Not Applicable" 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, 16, or M) <u>must</u> contain the actual lag time

  *Note: If the code "33 – No response Collected" 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"):
  - **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 and mixed: 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
- **Sampling Error** (code 16): Lag time is the number of days between the decedent's date of death and the date the survey vendor learned the case should not have been drawn into the sample

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

| Example A: Lag Time Calculation – Mail | |
|---|---|
| **Mode of Survey Administration** | Mail Only |
| **Decedent Date of Death** | March 16 |
| **Date of First Mail Attempt** | June 1(77 days after death) |
| **Date of Follow-up Mail Attempt** | June 22 (21 days after first mail attempt) |
| **Date Data Collection Activities Ended for this Decedent/Caregiver** | July 13 (42 calendar days after first mail attempt) Caregiver **never** returned the CAHPS Hospice Survey |
| **CAHPS Hospice Survey Final Status** | Code as "9 – Non-response: Non-response after Maximum Attempts" because the data collection protocol of 42 days has been reached and the caregiver has not returned the CAHPS Hospice Survey |
| **Lag Time** | Calculated as 119 days (number of days between the patient's death [March 16] to the date data collection activities ended [July 13]) |

| Example B: Lag Time Calculation – Telephone | |
|---|---|
| **Mode of Survey Administration** | Telephone Only |
| **Decedent Date of Death** | March 16 |
| **Date of First Attempt** | June 1 (77 days after decedent death) |
| **Date Data Collection Activities Ended for this Decedent/Caregiver** | July 13 (42 calendar days after the first telephone attempt) |
| **CAHPS Hospice Survey Final Status** | Code as "9 – Non-response: Non-response after Maximum Attempts" because the data collection protocol of 42 calendar days had ended and the caregiver had not been reached although five attempts were made |
| **Lag Time** | Calculated as 119 days (number of days between the decedent's death [March 16] to the date data collection activities ended [July 13]) |

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

| Example C: Lag Time Calculation – Mail | |
|---|---|
| **Mode of Survey Administration** | Mail Only |
| **Decedent Date of Death** | March 16 |
| **Date of First Mail Attempt** | June 1 (77 days after death) |
| **Date of Response** | June 14 |
| **CAHPS Hospice Survey Final Status** | Code as "1 – Completed Survey," "6 – Ineligible: Never Involved in Decedent Care," or "7 – Non-response: Break-off" |
| **Lag Time** | Calculated as 90 days (number of days between the patient's death [March 16] to the date response was received [June 14]) |

- The "supplemental-question-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 or contained responses).

### 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.*

The following guidelines must be followed when submitting the Survey Results Records:

- Enter all survey responses as provided by the caregiver for each survey item
- 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."*
  - For mail and telephone surveys, enter **all** of the categories that the caregiver has selected. If the caregiver responds "Yes" to a category, enter "1." If the caregiver responds "No" to a category, enter "0." If the caregiver does not provide a response to any of the categories or skips the question, enter "M – Missing/Don't Know."

*Note: A Valid Value must be submitted for each category in Question 2 and Question 43.*

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

## 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 "M – Missing/Don't Know."
  - Appropriately skipped dependent questions should be coded as "88 – Not Applicable"

*Note: For telephone administration, 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.*

## 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 the survey 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 applicable to all (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 the survey vendor learns after survey administration begins that the decedent/caregiver <u>does not</u> meet the eligibility criteria.

- This may occur if:
  - The caregiver name is completely missing and the vendor is unable to obtain a caregiver name after re-contacting the hospice
  - The vendor learns that the sampled caregiver is a non-familial legal guardian or non-familial paid caregiver and there is no other eligible caregiver residing in the household
  - It is determined that a patient is still living or that his or her last admission to the hospice resulted in a live discharge

*Note: Cases ineligible due to live discharge or "no publicity" should not be included in decedents/caregivers lists 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, and the survey results should be submitted.*

*Note: If a caregiver will not be available during the fielding period, a proxy is not identified, and the maximum number of calls have not been made, the case should be coded as "8 – Non-response: Refusal."*

*Note: Respondents who reside outside of the household of the sampled caregiver are not permitted. In the event that it is determined a survey has been completed by a respondent outside of the sampled caregiver household, the decedent/caregiver is assigned a "Final Survey Status" code of "8 – Non-response: Refusal." The survey vendor submits the Decedent/Caregiver Administrative Record but does not submit the survey responses. The survey vendor retains a copy of such a survey and any accompanying documentation. If a survey is returned with a note or someone verbally refuses on behalf of the decedent/caregiver, the 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), the caregiver has not returned the survey by the end of the survey administration time period (i.e., 42 calendar days from initial contact), or
- If after the maximum number of attempts (five) for Telephone Only; and one mail attempt and five telephone attempts for Mixed Mode; the caregiver has not completed the survey, 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 survey vendor) or no address is available for the caregiver.

**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 or missing (e.g., no telephone number available or a disconnected telephone number).
- For the Mixed Mode, "11 – Non-response: Bad/No Telephone Number" is used when the mail survey is not returned and there is evidence that a caregiver's telephone number is bad or missing, or if both the address and the telephone number are bad or missing.

**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 partial name information).

*Note: If the caregiver name is completely missing after re-contacting the hospice client, the final survey status is "3 - Ineligible: Not in Eligible Population."*

**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 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.

**16 Sampling Error**
Survey vendors assign a "Final Survey Status" code of "16 – Sampling Error" when a decedent/caregiver is incorrectly drawn into the sample, such as being sampled from the incorrect hospice CCN or as a duplicate. This code should **not** be used for ineligible cases (as outlined in code "3 – Ineligible: Not in Eligible Population").

## Assigning Bad Address and/or Bad Telephone Number Disposition Codes

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" 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 re-contact 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. It is permissible for survey vendors to request updated information about specific decedents/caregivers, rather than requesting a complete updated list. 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 by contacting the hospice
- 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 obtaining 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.

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

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

| Telephone Only Methodology<br>Assigning Final Survey Status/Disposition Codes 9, 10 and 11 | | |
|---|---|---|
| | 9 | 11 |

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

## Assigning Missing or Incomplete Caregiver Name Disposition Codes

Depending 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."

Caregivers with incomplete name information must not be administered the survey. Caregivers with incomplete name information that have been selected for the sample 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 does 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 applicable to all (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** = 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

**Percentage Complete** = (R/34) x 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 survey response rate formula below is included for informational purposes only; survey vendors are not required to perform this calculation.

$$\textbf{Response Rate} = \frac{\textbf{Total Number of Completed Surveys}}{\textbf{Total Number of Surveys Fielded – Total Number of Ineligible Surveys}}$$

- **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, 16, 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, 14, and 16

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 cahpshospicetechsupport@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" section 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 PGP standard compliant software 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.

Survey vendors may submit interim data any time during the quarter, with the exception of dates the Data Warehouse is closed, such as the week following each data submission deadline. However, fully corrected data files must be submitted by 11:59 PM Eastern Time on the required submission date. The data files 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 the survey vendors can submit data on their behalf. **A hospice's CAHPS Hospice Survey Vendor Authorization Form (see Appendix B) must be received at least 90 days prior to the submission of the hospice's data to the Data Warehouse.** The entire CAHPS Hospice Survey Vendor Authorization Form must be completed, including the calendar quarter the survey vendor will begin collecting and submitting data for the hospice.

Upon receipt of the CAHPS Hospice Survey Vendor Authorization Form, the CAHPS Hospice Survey Data Coordination Team will send a confirmation email to the authorizing hospice and will add the hospice to the list of hospices authorizing that survey vendor posted to the survey vendor's Data Warehouse folder.

If a survey vendor attempts to submit the hospice's survey data without authorization, the entire file containing the unauthorized CCN 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 resubmit the CAHPS Hospice Survey Vendor Authorization Form (see Appendix B) 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 entire CAHPS Hospice Survey Vendor Authorization Form must be completed, including the calendar quarter the hospice plans to switch to the new survey vendor.

**If a hospice is considering switching survey vendors, it must contact the CAHPS Hospice Survey Project Team right away.** Early contact with the CAHPS Hospice Survey Project Team will help make a successful transition to the new survey vendor. Be aware that in the past some hospices have suffered a two percent reduction in Medicare payments due to an unsuccessful transition to a new survey vendor.

Survey vendors or hospices can contact the CAHPS Hospice Survey Project Team at hospicecahpssurvey@hsag.com or 1-844-472-4621 for assistance with the process for switching survey vendors. The following items must be completed on the CAHPS Hospice Survey Vendor Authorization Form before a new survey vendor can be successfully authorized:

1. The Name of the Current CAHPS Hospice Survey Vendor that is being De-authorized.

2. The Name of the New CAHPS Hospice Survey Vendor with the start date, which corresponds to 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 a hospice wishes to change CAHPS Hospice Survey vendors, it may do so ONLY at the beginning of a calendar quarter. A quarter is based on the calendar year and corresponds to the month of patient death.

| Calendar Quarter | Corresponding to Patient Deaths | Caregivers are Surveyed | Vendor Authorization Form Deadline |
|---|---|---|---|
| Q1 2023 | January – March 2023 | April – June 2023 | April 2023 |
| Q2 2023 | April – June 2023 | July – September 2023 | July 2023 |
| Q3 2023 | July – September 2023 | October – December 2023 | October 2023 |
| Q4 2023 | October – December 2023 | January – April 2024 | January 2024 |

## 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. Survey vendors may also designate an optional third Data Administrator. The Data Administrators 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 Administrators 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 roles by submitting a new CAHPS Hospice Survey Data Warehouse Access Form for Vendors and Hospices. 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 up to three individuals 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 designees by submitting a new CAHPS Hospice Survey Data Warehouse Access Form for Vendors and Hospices. The new designee will be required to create a new password for the hospice's CAHPS Hospice Survey Data Warehouse account.

Survey vendors and hospices may designate their Data Administrators by completing the CAHPS Hospice Survey Data Warehouse Access Form for Vendors and Hospices (see Appendix C) and emailing or mailing 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 in the CAHPS Hospice Survey Data Warehouse (https://kiteworks.rand.org) 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.

## 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 the 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.060123.1.xml.pgp

Each file uploaded to the CAHPS Hospice Survey Data Warehouse must have a unique name, even if the prior file uploaded was rejected from the Warehouse for any reason. Any file uploaded with an identical file name to a prior file cannot be processed.

## 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 8 characters in length and contain at least one of each of the following classes of characters: uppercase letters, lowercase letters, numbers, and special characters).

## 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 will not 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 will not be able to see, locate, or access any survey vendor's or other hospice's folder. 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 the XML file format specifications and, as an additional security precaution, are required to encrypt survey data files using PGP public key encryption prior to submitting the files to the CAHPS Hospice Data Warehouse. PGP encryption is a widely used encryption standard (formerly PGP and still widely known as and referred to in this document as PGP) that provides cryptographic privacy and authentication for data communication. Each survey vendor is responsible for purchasing a PGP-compliant program if they don't already have one. The current version of Symantec File Share Encryption software meets this requirement, as do a number of other commercial or open-source products. Please note that software encryption standards are changing and becoming more restrictive in response to the increasing number and sophistication of cyber-attacks that threaten the security and privacy of all internet-based file transfers. For this reason, survey vendors are encouraged to periodically update their encryption software.

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 deleted. An email will be sent to the survey vendor's Data Administrators, informing them they have uploaded a file that does not comply with the established submission standards and that the file therefore will not be processed and will need to be resubmitted correctly.

## Instructions for Accessing the CAHPS Hospice Survey Data Warehouse

The process for survey vendors and hospices to access the CAHPS Hospice Survey Data Warehouse is as follows:

1. The Data Administrator must submit a Data Warehouse Access Form (see Appendix C) as an email attachment to CAHPShospicetechsupport@rand.org, by mail, or by FedEx.
2. 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 to the CAHPS Hospice Survey Data Warehouse (https://kiteworks.rand.org).
3. 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
4. On the first login only, the Data Administrator will be presented with a page to change his/her password
5. Once the password has been updated, the Data Administrator will be transferred to the "All files" tab of the CAHPS Hospice Survey Data Warehouse, where they will select the name of their organization
6. For vendors, selecting the "Upload" button within their organization's "Hospice" folder will allow the user to upload their organization's files.

*Note: 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 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 deleted. In such instances, an 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 submission 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.

Successfully submitted files will be put through a series of edit checks 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' and hospices' designated Data Administrators will receive an email indicating that the CAHPS Hospice Survey Data Submission Reports comprised from the edit checks listed above are available for viewing in their respective folders in the CAHPS Hospice Survey Data Warehouse. Vendor reports will be posted by 5 PM Eastern Time on the next business day after upload; hospice reports will be posted within two days 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 whose data were included in the data submission.

If a survey vendor submits data for a CCN in multiple data files in any quarter, the most recent submission for that CCN will completely overwrite any previous submission for that CCN, and only the CCN's data in the most recent submission will be stored in the CAHPS Hospice Survey Data Warehouse. If, for example, a survey vendor submits an XML file containing 10 CCNs, and later in the same quarter submits a new XML file containing one of those 10 CCNs, the CCN that appeared in both files will be overwritten by the later submission.

*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. The survey vendor is responsible for confirming that <u>all</u> of the submitted files have been accepted to the data warehouse.*

*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 Data Submission Detail Report (Part II) uploaded to the survey vendor's and hospice's CAHPS Hospice Survey 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

There are five possible CAHPS Hospice Survey Data Submission Reports that may be created for survey vendors. The reports will contain information related to each data submission as well as a summary of submissions for each hospice. The reports are as follows:

- **Hospices Not Authorized**: This report lists any CCNs included in the survey vendor's data submission that have not authorized the survey vendor for that quarter. If any CCNs are not authorized, **only** the Hospices Not Authorized and Data Submission Detail Report (Part I) will be created, and the file will not be accepted into the Data Warehouse.

- **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," the report will list all of the errors in the file, and the survey vendor 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 whether a Hospice Record was accepted, the sample size, the number of decedent/caregiver administrative records, the number of valid survey status codes, and the number of completed surveys for each hospice contained within the file. These are listed separately by month of death and overall.
- **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.

If the data file is able to be read, and does not contain any unauthorized CCNs, then the vendor's authorized hospices will receive the Data Submission Detail Reports (Part I & II), Survey Status Summary Report, and Review and Correction Report.

*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 and Attestation Statement 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 Quality Assurance Plan**
  The CAHPS Hospice Survey Quality Assurance Plan (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, subcontractors, and any other organizations, 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.
- **CAHPS Hospice Survey Materials**
  Materials relevant to CAHPS Hospice Survey administration, including mailing materials (i.e., questionnaires, cover letters, and outgoing/return envelopes) and/or telephone scripts, and interviewer CATI screenshots (including skip pattern logic), 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 subcontractors and any other organizations, 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.

- **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

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. Survey and data management system and quality controls
  4. Confidentiality, privacy, and security procedures
  5. Discussion of results of quality control activities
- 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 should be free of extraneous information and 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** (e.g., use Microsoft Word track changes). At a minimum, the updated QAP should specifically address the following items:

- Changes in survey administration processes, including any process changes due to revisions outlined in the CAHPS Hospice Survey *Quality Assurance Guidelines*
- A discussion of the results of the quality control checks performed in the prior year
- A discussion of the challenges faced by the survey vendor and/or client hospices in survey administration in the prior year, and how those challenges were addressed
- Changes in key staff
- Changes in resources

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 **<u>does not</u>** constitute or imply approval or endorsement of the survey vendor's CAHPS Hospice Survey administration processes.

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

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.

The CAHPS Hospice Survey Project Team works with the survey vendor in advance of the site visit to discuss agenda items that will be covered during the site visit. 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 may also review any additional information or facilities determined to be necessary to complete the site visit, including work performed by subcontractors and any other organizations, if applicable. **Survey vendors must make their subcontractors and any other organizations available to participate in the site visits and conference calls**.

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 compliance to protocols based on 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
- Communication with and training of staff, client hospices, subcontractors, and any other organizations
- 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 to include documentation of quality check activities conducted
- Specific and/or randomly selected records covering a time period to include the data in the most recent report period, or earlier

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 visit includes a review of sampling procedures. 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 participate during the site visit. If any CAHPS Hospice Survey processes are automated, then the programmer must be available during the site visit to review the programming. The site visit may also include interviews with key staff members and interactions with project staff, subcontractors, and any other organizations, if applicable. Any information observed or obtained during the site visit 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.

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 data and materials, and participation and cooperation in oversight activities, may result in sanctions being applied to a hospice or its survey vendor including:

- increased oversight activities
- loss of approved status to administer the CAHPS Hospice Survey
- application of the appropriate footnote(s) to CAHPS Hospice Survey results reported on the Care Compare tool
- suppression of publicly reported scores, as needed
- 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. Data Reporting

## Overview

This chapter describes the public reporting of the CAHPS Hospice Survey results on the Care Compare tool on Medicare.gov. All currently active hospices are reported on the Care Compare tool and in the accompanying downloadable database. CAHPS Hospice Survey measure scores are calculated across a rolling eight quarters and are published quarterly. The CAHPS Hospice Survey data submitted by each survey vendor is reviewed, cleaned, scored, and adjusted (including adjustments for case-mix and mode). Information describing the calculation of CAHPS Hospice Survey Top-, Middle-, and Bottom-Box scores and the case-mix adjustment methods for the CAHPS Hospice Survey measures is available on the Scoring and Analysis tab on the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org).

Please note that no data updates will be publicly reported for the November 2021 refresh; data from the November 2020 refresh will remain posted during this timeframe, and therefore, there will be no provider preview period for this quarter. The freeze has no impact on the requirement for hospices to report data to the data warehouse or for vendors to submit data to the data warehouse on a timely basis.

| Reporting Periods (Dates of Death) | Provider Preview Period | Compare Tool Refresh Dates |
|---|---|---|
| Q3 2019 – Q4 2019<br>Q3 2020 – Q4 2021 | August/September 2022 | November 2022 |
| Q4 2019<br>Q3 2020 – Q1 2022 | November/December 2022 | February 2023 |
| Q3 2020 – Q2 2022 | February/March 2023 | May 2023 |
| Q4 2020 – Q3 2022 | May/June 2023 | August 2023 |
| Q1 2021 – Q4 2022 | August/September 2023 | November 2023 |

## Publicly Reported CAHPS Hospice Survey Measures

The Care Compare tool reports "top-box" results for eight measures. There are six composite measures, which are comprised of multiple survey questions, and two single-item or global measures, which are the results of one survey question each. The eight measures are:

- Composite Measures
  1. Communication with Family (Q6, Q8, Q9, Q10, Q14, Q35)
  2. Getting Timely Help (Q5, Q7)
  3. Treating Patient with Respect (Q11, Q12)
  4. Emotional and Spiritual Support (Q36, Q37, Q38)
  5. Help for Pain and Symptoms (Q16, Q22, Q25, Q27)
  6. Training Family to Care for Patient (Q18, Q19, Q20, Q23, Q29)
- Global Measures
  1. Rating of this Hospice (Q39)
  2. Willingness to Recommend this Hospice (Q40)

## Scoring Overview

CMS calculates the "top-box," "middle-box," and "bottom-box" scores for the questions in the eight CAHPS Hospice Survey measures. If a survey respondent does not respond to a question for which he or she is eligible, a score is not calculated for that respondent for that question. With one exception, all responses to questions for which a respondent was eligible are used in the score calculation. The exception is the Training Family to Care for Patient measure; for this measure, the measure score is calculated only among those respondents who indicated that their family member received hospice care at home or in an assisted living facility.

For all questions, the "top-box" score for each response is calculated as a "100" if the most positive response category(ies) for that question is selected or a "0" otherwise. The "bottom-box" score for each response is calculated as a "100" if the least positive response category(ies) for that question is selected or a "0" otherwise.

Different questions have different response options. Responses are categorized as "top-box," "middle-box," or "bottom-box" as follows:

| Response Scale | Top-Box Response (most positive) | Middle-Box Response | Bottom-Box Response (least positive) |
|---|---|---|---|
| Never/Sometimes/Usually/Always | Always | Usually | Never; Sometimes |
| Never/Sometimes/Usually/Always (Question 10 only)* | Never | Sometimes | Always; Usually |
| No/Yes, Somewhat/Yes, Definitely | Yes, Definitely | Yes, Somewhat | No |
| Definitely No/Probably No/Probably Yes/Definitely Yes | Definitely Yes | Probably Yes | Probably No; Definitely No |
| Rating 0-10, where 10 is the most positive | 9 or 10 | 7 or 8 | 0-6 |
| Too Little/Right Amount/Too Much** | Right Amount | N/A*** | Too Little; Too Much / Too Little** |

* Question 10 is "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?"
**Prior to Q3 2018, the bottom box for this response scale was defined as 'too little' and 'too much.' Beginning with Q3 2018 decedent data, the bottom box was defined as 'too little;' responses of 'too much' were not included in scoring.
***The response options for this response scale are grouped into top- and bottom-box scores only.

The "**Top-box**" score is the proportion of respondents who gave the most positive response or responses to the question. For example, "Always" is generally the top-box response when a question's response options are Never, Sometimes, Usually, or Always.

The "**Middle-box**" score is the proportion of respondents who gave the intermediate response or responses to the question. For example, "Usually" is generally the middle-box response when a question's response options are Never, Sometimes, Usually, or Always. There is no middle box score when the response options are Too little, Right amount, or Too much.

The "**Bottom-box**" score is the proportion of respondents who gave the least positive response or responses. For example, "Sometimes" and "Never" are generally the bottom-box response when a question's response options are Never, Sometimes, Usually, or Always.

There are two special situations that have slightly different rules. First, the "Emotional and Spiritual Support" measure does not have a middle-box score; only top-box and bottom-box scores are reported. Additionally, the scoring is reversed for the question that asks, "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?" For this question, "Never" is the top-box response and "Always" and "Usually" are the bottom-box responses.

### Adjusting Results

CAHPS Hospice Survey results are adjusted for survey mode and case-mix prior to public reporting. Only adjusted results are publicly reported and considered the official CAHPS Hospice Survey results. The adjusted results may differ from the unadjusted results. Please see the Scoring and Analysis page of the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org) for more information on these data adjustments, as well as additional information regarding CAHPS Hospice Survey scores.

### Footnotes

Some hospices have footnotes displayed with their measure scores on the Care Compare tool on Medicare.gov. These footnotes are used to describe the reason a hospice does not have measure scores displayed, or any potential issues with the hospice's measure scores. There are six footnotes used for CAHPS Hospice Survey scores, shown below:

- Footnote 6 indicates that the number of cases is too small to report. This footnote is applied if there are fewer than 30 completed surveys for the hospice for the reporting period, or there were fewer than 11 answers for the measure.
- Footnote 7 indicates that results are based on a shorter time period than required
- Footnote 8 indicates that data were suppressed by CMS
- Footnote 9 indicates that there were discrepancies in the data collection process, as reported by survey vendors to CMS. Hospices should direct any questions regarding discrepancies to their survey vendors.
- Footnote 10 indicates that none of the required data were submitted for this reporting period
- Footnote 11 indicates that results are not available for this reporting period. This footnote is applied when the hospice is too new or too small to be required to participate in the CAHPS Hospice Survey, or when no cases meet the criteria for a measure for the reporting period.

## CAHPS Hospice Survey Provider Preview Reports

Prior to each quarterly release of data on the Care Compare tool, hospice providers are given the opportunity to review their CAHPS Hospice Survey results during a 30-day preview period using the CAHPS Hospice Survey Provider Preview Report. The purpose of these reports is to give providers the opportunity to preview their CAHPS Hospice Survey results on each measure, including their Star Ratings, prior to public display on the Care Compare tool on Medicare.gov. CAHPS Hospice Provider Preview Reports can be accessed via Certification and Survey Provider Enhanced Reports (CASPER) application, which is accessible from a Hospice's "Welcome to the CMS QIES Systems for Providers" page.

Providers will not be able to access their preview reports after 60 days from the report release date. CMS encourages providers to download and save their Hospice Provider Preview Reports for future reference as they will no longer be available in CASPER after this 60-day period.

*Note: Some hospices may not have their scores publicly reported. There are various reasons this could occur; for example, the hospice could be too small or too new to be required to participate in the CAHPS Hospice Survey, or there may be fewer than 30 completed surveys for the hospice over the 8-quarter reporting period. If a hospice's scores are not publicly reported, the Provider Preview Report will display "Not available," along with a footnote that explains why.*

### Thirty Day CAHPS Hospice Survey Preview Period

Hospices have 30 days to preview their CAHPS Hospice Survey measure results beginning on the date the reports are made available by CMS. If the hospice provider believes the data are inaccurate, a provider can request CMS review of the data contained within the CAHPS Hospice Provider Preview Report.

As noted above, the data presented in the CAHPS Hospice Provider Preview Report are adjusted for mode and case mix. This means the data may not match the data the hospice may have received from their survey vendor. A mismatch of this type does not imply the data in the Preview Report is inaccurate.

Requests for review of a hospice's CAHPS Hospice Survey results may be submitted via email to: hospicecahpssurvey@hsag.com. Please note, this is a different address than the one used for review requests involving HIS data. The procedure to request CMS' review of the CAHPS Hospice Survey data during the 30-day Preview Period can be found at https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Public-Reporting-CAHPS-Preview-Reports-and-Requests-for-CMS-Review-of-CAHPS-Data.html

All other questions related to the Hospice Quality Reporting Program should be directed to the Hospice Quality Help Desk at HospiceQualityQuestions@cms.hhs.gov. Technical questions about the CAHPS Hospice Survey should be directed to hospicecahpssurvey@hsag.com or call toll free at 1-844-472-4621.

## CAHPS Hospice Survey Star Ratings

In the FY 2022 Hospice Final Rule, CMS finalized public reporting of CAHPS Hospice Star Ratings no sooner than FY 2022. The intent of Star Ratings is to provide consumers with an easy-to-understand method for summarizing CAHPS Hospice Survey measure scores, and to make comparisons between hospices more straightforward. Hospices had an opportunity to review their Star Ratings during a dry run period in 2022. Beginning with the August 2022 refresh of Care Compare, a Family Caregiver Survey Rating Summary Star Rating will be publicly reported for all hospices with 75 or more completed surveys over the reporting period. Star Ratings will be updated every other quarter. Hospices will have the opportunity to see their CAHPS Hospice Survey Star Ratings in their official CMS Preview Report during the provider preview period prior to each update of Care Compare.

Methods for calculating Star Ratings are similar to those used for other CMS CAHPS initiatives. Stars range from one star (worst) to five stars (best), and are calculated based on "top-box" scores for each of the eight CAHPS Hospice Survey measures. Cut-points between stars are constructed using statistical clustering procedures that minimize score differences within a star category and maximize differences across star categories.

CMS uses a two-stage approach to calculate these cut-points. In the first stage, CMS determines initial cut-points by calculating the clustering algorithm among hospices with 30 or more completed surveys over 2 quarters (that is, 6 months); restricting these calculations to hospices that meet a minimum sample size promotes stability of cut-points. Depending on whether hospices that meet this minimum sample size have different score patterns than smaller hospices, the initial cut-points may be too high or too low. To ensure that cut-points reflect the full distribution of measure performance, in the second stage, CMS compares mean measure scores for the bigger hospices used in the first stage to all other hospices, and updates cut-points by adjusting the initial cut-points to reflect the normalized difference between bigger and smaller hospices. This two-stage approach allows for calculation of stable cut-points that reflect the full range of hospice performance.

An overall CAHPS Hospice Survey Star is calculated for each hospice by averaging the Star Ratings across the 8 measures, with a weight of ½ for Rating of the Hospice and Willingness to Recommend the Hospice, respectively, and a weight of one for each of the other measures. Only the overall Star Rating is publicly reported. Hospices must have a minimum of 75 completed surveys in order to be assigned a Star Rating.

Further details of the Star Ratings methodology are available on Star Ratings page of the CAHPS Hospice Survey Web site, www.hospicecahpssurvey.org.

# XIII. 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 and review requests for remote survey operations. The proposed alternative methodology(ies) or initiation of remote survey operations 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 or requests for remote survey operations, 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 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 unless otherwise specified
- Approved Exception Requests may only be implemented at the beginning of a quarter unless otherwise specified

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 thoroughly discuss how remote operations will be conducted to assure compliance with HIPAA, data security, and quality assurance requirements
- 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.
- A new Exception Request Form must be submitted for hospices not included in the original request

### Exception Request Category

Survey vendors must submit an Exception Request:

- to conduct any CAHPS Hospice Survey administration activities from a residence or virtual office
- for alternative strategies not identified in the CAHPS Hospice Survey *Quality Assurance Guidelines* manual
- for the use of survey materials that do not align with the examples provided in the CAHPS Hospice Survey Quality Assurance Guidelines V9.0

*Note: Survey vendors who were approved for remote operations during the public health emergency **must** resubmit an Exception Request for approval to conduct remote operations past December 31, 2022 (i.e., beginning January 1, 2023).*

*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. The review 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.

# XIV. 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 immediately 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.

## 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, survey administration begins late or does not occur for any month, sampled eligible decedent/caregiver found to be ineligible, or computer programming that caused an otherwise survey-eligible decedent/caregiver to be excluded from the sample frame.

- Survey vendors must complete and submit Discrepancy Report Forms on behalf of their client hospice(s)
- Survey vendors are required to complete and submit a Discrepancy Report Form 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.
  - The value "Unknown" is acceptable in an initial Discrepancy Report Form if the eligible and sample decedents/caregivers affected are not known at the time of submission but these values should be provided in an update
  - The patient month(s) of death that are affected must be clearly stated within the Discrepancy Report
- Survey vendors must notify all affected client hospices that a Discrepancy Report has been submitted

### Discrepancy Report Review Process

The Discrepancy Report will be thoroughly reviewed by the CAHPS Hospice Survey Project Team. 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. Email notification will be distributed to the organization submitting the Discrepancy Report Form once the outcome of the review has been determined. Hospices are encouraged to contact their survey vendor to inquire about the outcome of the review. In addition, a footnote may be applied to publicly reported CAHPS Hospice Survey results to indicate that these results are derived from data whose collection or processing deviated from established CAHPS Hospice Survey protocols. The footnote will be applied until the affected data are no longer included in publicly reported data.

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 Report Forms. 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.

# XV. 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. 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 for a minimum of three years. 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)
- Record general summary information such as total number of decedent/caregiver cases, survey-eligible size, decedent month, etc.
- 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. While the presence of such a change does not necessarily mean an error has occurred, it should prompt survey vendors to further evaluate the data in order to verify the difference(s). Listed below are suggested activities:

- Verify that data are associated with the correct hospice CCN
- Investigate data for notable changes in the counts of decedents/caregivers and eligible decedents/caregivers
- Prior to processing the decedents/caregivers list, run frequency/percentage tables for all administrative variables received from the hospice (e.g., sex, race, last location), and compare to same-variable tables from previous months.
    - Look for missing administrative data elements (e.g., decedent primary diagnosis, decedent date of birth), 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
  - 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

## Accuracy of Data Processing Activities

In order to ensure that CAHPS Hospice Survey data are valid and reliable, data processing activities must be conducted in accordance with required protocols. Data quality checks should be implemented to verify that the required protocols have been followed. Examples of data quality check activities include:

- Verify that every eligible decedent/caregiver has a chance of being sampled
- Evaluate the frequency of break-off surveys and/or unanswered questions, and investigate possible causes
- Review CAHPS Hospice Survey Data Submission Reports to confirm data submission activity is correct and as expected
- Review quarterly submission results from the Review and Correction Report to confirm a match with the frequency tables completed during previous quality check activities as described above

## Summary

This chapter highlights a number of possible activities to assist survey vendors in developing procedures for data quality checks. The information contained in this chapter is intended for instructional purposes and is not considered to be all-inclusive. The CAHPS Hospice Survey Project Team will conduct site visits to survey vendors that will include review of survey administration operations along with the documentation of quality checks that have been conducted.

# Appendix A

## Minimum Business Requirements

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# CAHPS Hospice Survey
# Minimum Business Requirements

A survey vendor must meet **ALL** of the Survey Vendor Minimum Business Requirements at the time the CAHPS®[1] Hospice Survey Participation Form is received (a subcontractor's or other organization's survey administration experience does not substitute for a survey vendor's). 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:**

| Criteria | Survey Vendor |
|---|---|
| **Current/Future Relationships with Hospices** | ➢ The following types of organizations are **not** eligible to administer the CAHPS Hospice Survey (as an approved CAHPS Hospice Survey vendor):<br>• 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;<br>• organizations that provide telehealth, monitoring of hospice patients, or teleprompting services for the hospice; and<br>• organizations that provide staffing to hospices for providing care to hospice patients, whether personal care aides or skilled services staff |

**Relevant Survey Experience:**
Demonstrated **recent** continuous experience in fielding patient-specific surveys in the requested mode(s) (i.e., Mail, Telephone, Mixed Mode [mail followed by telephone]).

| Criteria | Survey Vendor |
|---|---|
| **Number of Years in Business** | ➢ Minimum four years |
| **Number of Years Conducting Patient-Specific Surveys** | ➢ Minimum of three consecutive years Mail, and/or Telephone, and/or Mixed Mode (mail followed by telephone) patient-specific survey experience within the most recent three-year time period<br>➢ Prior experience in conducting surveys in English (required) and Spanish (preferred) |

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

| Criteria | Survey Vendor |
|---|---|
| **Sampling Experience** | ➢ Two years prior experience selecting a random sample based on specific eligibility criteria within the most recent two-year time period<br>➢ Work with contracted client(s) to obtain patient data for sampling via Health Insurance Portability and Accountability Act- (HIPAA) compliant electronic data transfer processes<br>➢ Adequately document sampling process<br>➢ Survey vendors are responsible for conducting the sampling process and must not subcontract this activity |

**Survey Capability and Capacity:**
Capability and capacity to handle a required volume of mail questionnaires and/or conduct standardized telephone and/or IVR interviewing in specified time frame.

| Criteria | Survey Vendor |
|---|---|
| **Personnel** | ➢ Designated CAHPS Hospice Survey personnel:<br>• Project Director with minimum two years prior experience conducting patient-specific surveys in the requested mode(s)<br>• Staff with minimum one year prior experience in sample frame development and sample selection<br>• 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<br>• Call Center/Mail Center Supervisor (subcontractor designee, if applicable) with minimum one year prior experience in role<br>➢ Have appropriate organizational back-up staff for coverage of key staff<br>➢ Volunteers are not permitted to be involved in any aspect of the CAHPS Hospice Survey administration process |
| **Physical Plant and System Resources** | ➢ Physical plant resources available to handle the volume of surveys being administered, including computer and technical equipment:<br>• A secure commercial work environment<br>• Home-based or virtual interviewers cannot be used to administer the CAHPS Hospice Survey, nor may they conduct any survey administration processes<br>• Physical facilities and electronic equipment and software to collect, process and report data securely<br>• If offering telephone surveys, must have the equipment, software and facilities to conduct computer-assisted telephone interviewing (CATI) and to monitor interviewers |

| Criteria | Survey Vendor |
|---|---|
| **Physical Plant and System Resources** | ➢ Electronic or alternative survey management system to:<br>• track fielded surveys throughout the protocol, avoiding respondent burden and losing respondents<br>• assign random, unique, de-identified identification number (Tracking ID) to track each sampled decedent/primary informal caregiver (i.e., family member or friend of the hospice patient)<br>➢ 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 or other organizations involved in survey administration.<br>➢ All System Resources are subject to oversight activities, including site visits to physical locations |
| **Sample Frame Creation** | ➢ A minimum of two years prior experience selecting a random sample based on specific eligibility criteria in the most recent two-year time period<br>➢ Generate the sample frame data file that contains all individuals who meet the eligible population criteria<br>➢ Draw random sample of individuals for the survey who meet the eligible population criteria |
| **Mail Administration** | ➢ Mail survey administration activities are not to be conducted from a residence, nor from a virtual office<br>➢ Obtain and update addresses of sampled caregivers of hospice decedents<br>➢ Produce and print professional quality survey instruments and materials according to guidelines; a sample of all mailing materials must be submitted for review<br>➢ Merge and print sample name and address on personalized mail survey cover letters and print unique Tracking ID on the survey questionnaire<br>➢ Mail out survey materials<br>➢ Receive and process (key-enter or scan) completed questionnaires<br>➢ Track and identify non-respondents for follow-up mailing<br>➢ Assign final survey status codes to describe the final result of work on each sampled record |
| **Telephone Administration** | ➢ Telephone interviews are not to be conducted from a residence, nor from a virtual office<br>➢ Obtain, verify and update telephone numbers<br>➢ Develop CATI system<br>➢ Collect telephone interview data for the survey using CATI system; a sample of the telephone script and interviewer screenshots must be submitted for review<br>➢ Identify non-respondents for follow-up telephone calls<br>➢ Schedule and conduct callbacks to non-respondents at varying times of the day and different days of the week<br>➢ Assign final survey status codes to reflect the final result of attempts to obtain a completed interview with each sampled record |

| Criteria | Survey Vendor |
|---|---|
| **Mixed Mode Administration (Mail with Telephone Follow-up)** | ➢ Mail survey administration and telephone interviews are not to be conducted from a residence, nor from a virtual office<br>➢ Adhere to all Mail Only and Telephone Only survey administration requirements (described above)<br>➢ Track cases from mail survey through telephone follow-up activities |
| **Data Submission** | ➢ Two years prior experience transmitting data via secure methods (HIPAA-compliant)<br>➢ Survey vendors are responsible for conducting data submission and must not subcontract this process<br>➢ Survey vendors must have the capacity to do the following actions to submit quarterly data files:<br>• Register as a user of the CAHPS Hospice Survey Data Warehouse<br>• Confirm contracted hospices have authorized survey vendor to submit data on behalf of the hospice<br>• Import scanned or key-entered data from completed mail surveys into a data file, if applicable<br>• Import (as necessary) data from CATI system into a data file, if applicable<br>• Develop data files and edit and clean data according to standard protocols<br>• Follow all data cleaning and data submission rules, including verifying that data files are de-identified and contain no duplicate cases<br>• 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<br>• Encrypt and submit data electronically in the specified format to the CAHPS Hospice Survey Data Warehouse<br>• Work with CMS' contractor to resolve data problems and data submission issues |
| **Data Security** | ➢ Survey vendors must have the capacity to do the following actions to secure electronic data:<br>• Use a firewall and/or other mechanisms for preventing unauthorized access to electronic files<br>• Implement access levels and security passwords so that only authorized users have access to sensitive data<br>• Implement daily data back-up procedures that adequately safeguard system data<br>• Test back-up files on a quarterly basis, at a minimum, to make sure the files are easily retrievable and working<br>• Perform frequent saves to media to minimize data losses in the event of power interruption |

| Criteria | Survey Vendor |
|---|---|
| **Data Security** | • Develop procedures for identifying and handling breaches of confidential data<br>• Develop a disaster recovery plan for conducting ongoing business operations in the event of a disaster |
| **Data Retention and Storage** | ➢ Survey vendors must have the capacity to do the following actions to securely store all data related to survey administration:<br>• Store CAHPS Hospice Survey-related data files, including decedents/caregivers lists and de-identified electronic data files (e.g., sample frame, XML files, etc.), for all applicable survey modes for a minimum of three years. Archived electronic data files must be easily retrievable.<br>• 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.<br>• Destroy CAHPS Hospice Survey related data files, including paper copies or scanned images of the questionnaires and electronic data files in a secure and environmentally safe location. Obtain a certificate of the destruction of data. |
| **Technical Assistance/ Customer Support** | ➢ Two years prior experience providing telephone customer support<br>➢ Provide toll-free customer support line:<br>• Offering customer support in all languages that the survey vendor administers the survey in<br>• Returning calls within 24-48 hours |
| **Organizational Confidentiality Requirements** | ➢ Survey vendors must have the capacity to do all of the following actions:<br>• Develop confidentiality agreements which include language related to HIPAA regulations and the protection of personal identifying information (PII) and obtain signatures from all personnel with access to survey information, including staff and all subcontractors or other organizations 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.<br>• Execute Business Associate Agreement(s) (BAA) in accordance with HIPAA regulations<br>• Confirm that staff and subcontractors or other organizations involved in survey administration are compliant with HIPAA regulations in regard to decedent/caregiver protected health information (PHI) and PII<br>• Establish protocols for secure file transmission. Emailing of PHI or PII via unsecure email is prohibited. |

**Participation in Quality Control Activities and Documentation Requirements:**
Personnel training and quality control mechanisms employed to collect valid, reliable survey data

| Criteria | Survey Vendor |
|---|---|
| **Demonstrated Quality Control Procedures** | ➢ Incorporate well-documented quality control procedures (as applicable) for:<br>• Training of in-house staff and subcontractors or other organizations involved in survey operations<br>• Printing, mailing and recording receipt of survey questionnaires, if applicable<br>• Telephone administration of survey, if applicable<br>• Coding and verifying of survey data and survey-related materials<br>• Scanning or keying-in survey data<br>• Preparation of final person-level data files for submission<br>• Submitting Discrepancy Reports immediately upon discovering a discrepancy in following CAHPS Hospice Survey protocols<br>• All other functions and processes that affect the administration of the CAHPS Hospice Survey<br>➢ Participate in any conference calls and site visits as part of overall quality monitoring activities:<br>• Provide documentation as requested for site visits and conference calls, including but not limited to: staff training records, telephone interviewer monitoring records and file construction documentation |
| **Documentation Requirements** | ➢ Keep electronic or hard copy files of staff training and training dates<br>➢ Maintain electronic documentation of telephone monitoring, if applicable<br>➢ Maintain documentation of mail production quality checks, if applicable<br>➢ Maintain documentation of all survey administration activities and related quality checks for review during site visits<br>➢ Develop a Quality Assurance Plan (QAP) for survey administration in accordance with CAHPS Hospice Survey *Quality Assurance Guidelines* and update the QAP at the time of process and/or key personnel changes as part of retaining participation status |

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

| Criteria | Survey Vendor |
|---|---|
| **Survey Training** | ➢ Attend the Introduction to CAHPS Hospice Survey Training session and all CAHPS Hospice Survey Update Training sessions (at a minimum, survey vendor's Project Manager and subcontractors or other organizations involved in survey administration assigned key roles must attend training)<br>➢ Successfully complete the post-training quiz measuring comprehension of CAHPS Hospice Survey protocols |
| **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)<br>➢ Fully comply with the CAHPS Hospice Survey oversight activities<br>➢ 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.<br>• 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<br>• 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<br>o If a survey vendor chooses to not re-apply at this time, then a 24-month wait period will be required before the organization is eligible to apply again<br>o If a CAHPS Hospice Survey vendor is approved for a second term and does not have any contracted hospice clients by the end of the second 24-month approved period, a 24-month wait period will be required before the organization is eligible to apply again |

# Appendix B

## Survey Vendor Authorization Form

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# 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 or switch to a new 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 by that vendor.** 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 2023 begins with January 2023 patient deaths (caregivers to be surveyed April 2023).*

The individual who completes this form for the hospice will be considered the CAHPS Hospice Survey Administrator for that hospice.

- This form must be signed and dated in the presence of a notary public, notarized and sent to the RAND Corporation.
- Hospices may also designate, on the form, an additional individual within the hospice organization to serve as the main point of contact with the CAHPS Hospice Survey Project Team.

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 applicable 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 and CCNs listed on the separate sheet.

Send the completed form to:

RAND Corporation
ATTN: Survey Research Group - Data Reduction
CAHPS Hospice Survey
1776 Main Street
Santa Monica, CA 90401
Phone: (310) 393-0411, 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. The RAND Corporation notifies vendors of hospices who have authorized them for data collection. Vendors cannot submit data for hospices that have not authorized them.*

# CAHPS Hospice Survey
# Survey Vendor Authorization Form

I, _____ acknowledge and accept the role
(print CAHPS Hospice Survey Administrator's name)

and all of the responsibilities of the CAHPS Hospice Survey Administrator for:

CCN _____ _____
(print CMS Certification Number or "see attached list of CCNs") (print name of hospice or "see attached list of hospices")

In this role I will be responsible for:

1) Authorizing a survey vendor to collect data for _____
(print name of hospice or "See attached list")
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 a new Vendor Authorization Form.
3) Designating an individual within the hospice organization to serve as the main point of contact with the CAHPS Hospice Survey Project Team.
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 submitting a new Vendor Authorization Form.

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 (if different from administrator): First and Last Name: _____

Phone Number: _____

Email: _____

If your hospice wishes to change your CAHPS Hospice Survey vendor, you may do so ONLY at the beginning of a calendar quarter.

| **Calendar Quarter** | Vendor Authorization Form Deadline: | Corresponding to Patient Deaths: | Caregivers are Surveyed: |
|---|---|---|---|
| **Q4 2022** | January 2023 | October – December 2022 | January – March 2023 |
| **Q1 2023** | April 2023 | January – March 2023 | April – June 2023 |
| **Q2 2023** | July 2023 | April – June 2023 | July – September 2023 |
| **Q3 2023** | October 2023 | July – September 2023 | October – December 2023 |
| **Q4 2023** | January 2024 | October – December 2023 | January – March 2024 |

Name of **Old Survey Vendor** (De-authorizing), or check box if no prior vendor:

_____

☐ No prior vendor.

**Last Calendar Quarter** for Old Survey Vendor (see above table): _____

☐ We have notified the old vendor of this change.
☐ We have scheduled stopping of the files submitted to the old vendor as of the above quarter.

Name of **New Survey Vendor** (Authorizing)*:

_____

**Start Calendar Quarter** for Vendor Authorizing (see above table):

_____

*Approved Survey Vendors may be located at: Approved-Vendor-List.

_____

Notary Public Signature: _____

Stamp: _____

Notary Public Date: _____

# Appendix C

## Data Warehouse Access Form

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# CAHPS Hospice Survey
## Data Warehouse Access Form for Vendors and Hospices

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 in the CAHPS Hospice Survey Data Warehouse. All hospices must also have a user account in order to monitor data submission activities.

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. **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.**

> *Please note: By submitting a new form, your organization is indicating a change to its Data Administrator and/or Back-up Data Administrator. Administrators listed on prior Data Warehouse Access Forms will no longer have access to the Data Warehouse.*

Date Form Submitted: _____

Your Organization's Name(s): _____

**For Hospices Only** Your Organization's CCN(s): _____

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

**Data Administrator**

First and Last Name: _____

Phone Number: _____

Email: _____

**Back-up Data Administrator**

First and Last Name: _____

Phone Number: _____

Email: _____

**Additional Data Administrator (Optional)**

First and Last Name: _____

Phone Number: _____

Email: _____

**Submit completed forms to the CAHPS Hospice Survey Data Coordination Team:**

As an email attachment to: cahpshospicetechsupport@rand.org

By mail or Fedex to: RAND Corporation, CAHPS Hospice Survey
ATTN: Survey Research Group - Data Reduction
1776 Main Street
Santa Monica, CA 90401

# Appendix D

## Sample File Layout

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# 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.

| Sample File Layout | | | |
|---|---|---|---|
| **Data Element** | **Length** | **Value Labels and Use** | **Required for Data Submission** |
| Provider Name | 100 | Name of the hospice | Yes |
| Provider ID | 10 | CMS Certification Number (CCN) [formerly known as Medicare Provider Number] | Yes |
| NPI | 10 | National Provider Identifier (NPI)<br>M = Missing | Yes |
| Facility Name[1] | 100 | Name of hospice, inpatient or nursing home facility, if applicable<br>N/A = Missing /Not Applicable | Yes |
| Number of Hospice Offices | 10 | 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. | Yes |
| Total Number of Live Discharges | 10 | Number of patients who were discharged alive during the month | Yes |
| Total Number of Decedents | 10 | Number of decedents during the month **for the hospice CCN only** (calculated as the number of records provided by hospice for the CCN plus the number of “no publicity” cases) | Yes |

[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 | | | |
|---|---|---|---|
| **Data Element** | **Length** | **Value Labels and Use** | **Required for Data Submission** |
| "No Publicity" Decedents/Caregivers | 10 | "No publicity" decedents/caregivers are those who initiate or voluntarily request at any time during their stay 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. | Yes |
| Hospice Decedent/Caregiver ID | 16 | Hospice-generated ID submitted to survey vendor | No |
| *Caregiver First Name* | 30 | Name information used to personalize materials to caregiver | No |
| *Caregiver Middle Initial* | 1 | | |
| *Caregiver Last Name* | 30 | | |
| *Caregiver Prefix Name* | 6 | | |
| *Caregiver Suffix Name* | 10 | | |
| *Decedent First Name* | 30 | | |
| *Decedent Middle Initial* | 1 | | |
| *Decedent Last Name* | 30 | | |
| *Decedent Prefix Name* | 6 | | |
| *Decedent Suffix Name* | 10 | | |
| Decedent Sex | 1 | 1 = Male<br>2 = Female<br>M = Missing | Yes |
| Decedent Hispanic | 1 | 1 = Hispanic<br>2 = Non-Hispanic<br>M = Missing | Yes |
| Decedent Race | 1 | 1 = White<br>2 = Black or African American<br>3 = Asian<br>4 = Native Hawaiian or Pacific Islander<br>5 = American Indian or Alaska Native<br>6 = More than one race<br>7 = Other<br>M = Missing | Yes |
| Decedent Date of Birth | 8 | MMDDYYYY<br>Used by survey vendor to calculate decedent age to confirm decedent meets eligibility criteria | Yes |

| Sample File Layout | | | |
|---|---|---|---|
| **Data Element** | **Length** | **Value Labels and Use** | **Required for Data Submission** |
| Decedent Date of Death | 8 | MMDDYYYY<br>Used by survey vendor to calculate decedent age to confirm decedent meets eligibility criteria | Yes |
| Decedent Hospice Admission Date | 8 | MMDDYYYY<br>Decedent admission date for his/her final episode of hospice care. Used by survey vendor to confirm decedent meets eligibility criteria. | Yes |
| Decedent Last Location/Setting of Care | 2 | 1 = Home (Do not include assisted living or any other facility)<br>2 = Assisted living<br>3 = Long-term care facility or non-skilled nursing facility<br>4 = Skilled nursing facility<br>5 = Inpatient hospital<br>6 = Inpatient hospice facility<br>7 = Long-term care facility (hospital)<br>8 = Inpatient psychiatric facility<br>9 = Location not otherwise specified<br>10 = Hospice facility<br>M = Missing<br><br>*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<br>2 = Medicaid<br>3 = Private<br>4 = Uninsured/No payer<br>5 = Program for All Inclusive Care for the Elderly (PACE)<br>6 = Other<br>M = Missing | Yes |

| Sample File Layout | | | |
|---|---|---|---|
| **Data Element** | **Length** | **Value Labels and Use** | **Required for Data Submission** |
| Decedent Payer Secondary | 1 | 1 = Medicare<br>2 = Medicaid<br>3 = Private<br>4 = Uninsured/No payer<br>5 = Program for All Inclusive Care for the Elderly (PACE)<br>6 = Other<br>7 = No Secondary Payer<br>M = Missing | Yes |
| Decedent Payer Other | 1 | 1 = Medicare<br>2 = Medicaid<br>3 = Private<br>4 = Uninsured/No payer<br>5 = Program for All Inclusive Care for the Elderly (PACE)<br>6 = Other<br>7 = No Other Payer<br>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.<br><br>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.<br><br>Examples of ICD-10 codes in the correct format are:<br>G20 – Parkinson’s disease<br>G30.9 – Alzheimer's disease, unspecified<br>I50.22 – Chronic systolic (congestive) heart failure<br>C7A.024 – Malignant carcinoid tumor of the descending colon<br>V00.818A – Other accident with wheelchair (powered): Initial encounter<br>MMMMMMMM = Missing | Yes |

| Sample File Layout | | | |
|---|---|---|---|
| **Data Element** | **Length** | **Value Labels and Use** | **Required for Data Submission** |
| *Caregiver Mailing Address 1* | 50 | Street address or post office box (address information used in protocols that have a mail mode of survey administration) | No |
| *Caregiver Mailing Address 2* | 50 | Mailing address 2nd line (if needed) | No |
| *Caregiver Mailing City* | 50 | Mailing city | No |
| *Caregiver Mailing State* | 2 | Two-character state abbreviation | No |
| *Caregiver Mailing Zip Code* | 9 | Nine-digit zip code; no hyphen, separators or de-limiters (i.e., 5-digit zip code followed by 4-digit extension) | No |
| *Caregiver Telephone Number 1* | 10 | 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) | No |
| *Caregiver Telephone Number 2* | 10 | 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) | No |
| *Caregiver Telephone Number 3* | 10 | 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) | No |
| *Caregiver Email Address* | 30 | Email address of caregiver | No |

| Sample File Layout | | | |
|---|---|---|---|
| **Data Element** | **Length** | **Value Labels and Use** | **Required for Data Submission** |
| Caregiver Relationship to the Decedent | 1 | 1 = Spouse/Partner<br>2 = Parent<br>3 = Child<br>4 = Other family member<br>5 = Friend<br>6 = Legal guardian (non-familial)<br>7 = Other<br>8 = No caregiver of record<br>9 = Paid caregiver (non-familial)<br>M = Missing | Yes |
| *Caregiver Language* | 1 | 1 = English<br>2 = Spanish<br>3 = Chinese<br>4 = Russian<br>5 = Portuguese<br>6 = Vietnamese<br>7 = Polish<br>8 = Korean<br>9 = Other<br>M = Missing | No |

# Appendix E

## XML File Specification
## Version 9.0

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# CAHPS Hospice Survey
# Sample XML File Layout Version 9.0


```xml
<?xml version="9.0"?>
<!-- CAHPS Hospice Survey XML File Specification Version 9.0 -->
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    <vendor-name>Vendor Business Name</vendor-name>
    <file-submission-yr>2023</file-submission-yr>
    <file-submission-month>1</file-submission-month>
    <file-submission-day>31</file-submission-day>
    <file-submission-number>1</file-submission-number>
    - <hospicedata>
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        <reference-month>1</reference-month>
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        <provider-id>123456</provider-id>
        <npi>1234567890</npi>
        <survey-mode>1</survey-mode>
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        <live-discharges>5</live-discharges>
        <no-publicity>1</no-publicity>
        <missing-dod>5</missing-dod>
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        <available-sample>139</available-sample>
        <sampled-cases>139</sampled-cases>
        <sample-size>136</sample-size>
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        <sample-type>1</sample-type>
        <number-offices>3</number-offices>
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            <birth-day>1</birth-day>
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```

```
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attempts-mail>
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count>
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    <location-assisted>0</location-assisted>
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    <location-hospital>0</location-hospital>
    <location-hospice-facility>0</location-hospice-
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    <location-other>0</location-other>
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    <gethelp>4</gethelp>
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    <helpasan>4</helpasan>
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    <h_confuse>4</h_confuse>
```

```
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```
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facility>
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```

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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-hospice-facility>0</location-hospice-
facility>
<location-other>0</location-other>
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<cemotion>1</cemotion>
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            islander>
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        <admission-month>1</admission-month>
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        <decedent-payer-secondary>2</decedent-payer-
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                islander>
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                <cAge>1</cAge>
                <cSex>1</cSex>
                <cEdu>4</cEdu>
                <cHomeLang>4</cHomeLang>
            </caregiverresponse>
        </decedentleveldata>
</vendordata>
```

# CAHPS Hospice Survey XML File Specification
# Version 9.0

This XML File Specification (Version 9.0) applies to **Q1 2023 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. There should be a Hospice Record for each month of the quarter for each CCN if the hospice was a client of the vendor for the month and sent a sample file (or confirmed zero decedents). 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.”

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **The following section defines the format of the Vendor Record.** | | | | | | |
| **<vendordata>**<br><br>Opening Tag, defines a submission by the survey vendor | 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 <> | | | | | |
| | None | N/A | N/A | NA | N/A | Yes |
| **<vendor-name>**<br><br>Sub-element of vendordata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This vendordata element should only occur once per file.<br>**Example: <vendor-name>Vendor Business Name</vendor-name>** | | | | | |
| | None | The name of the survey vendor. | Must be vendor's business name up to 100 alphanumeric characters. | Alphanumeric Character | 100 | Yes |
| **<file-submission-yr>**<br><br>Sub-element of vendordata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This vendordata element should only occur once per file.<br>**Example: <file-submission-yr>2023</file-submission-yr>** | | | | | |
| | None | The year in which the file is submitted. | YYYY<br>YYYY = (2023 or greater)<br>(cannot be 9999) | Numeric | 4 | Yes |
| **<file-submission-month>**<br><br>Sub-element of vendordata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This vendordata element should only occur once per file.<br>**Example: <file-submission-month>1</file-submission-month>** | | | | | |
| | None | The month in which the file is submitted. | MM<br>MM = (1 - 12)<br>(cannot be 00, 13 - 99) | Numeric | 2 | Yes |
| **<file-submission-day>**<br><br>Sub-element of vendordata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This vendordata element should only occur once per file.<br>**Example: <file-submission-day>31</file-submission-day>** | | | | | |
| | None | The day in which the file is submitted. | DD<br>DD = (1 - 31)<br>(cannot be 00, 32 - 99) | Numeric | 2 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<file-submission-number>**<br><br>Sub-element of vendordata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This vendordata element should only occur once per file.<br>**Example: <file-submission-number>1</file-submission-number>** | | | | | |
| | None | Ordinal number of the submission for the day. The submission count re-starts with every new day of the file submission. | 1 - 99 | Numeric | 2 | Yes |
| **The following section defines the format of the Hospice Record. There should be one hospicedata record for each month of the survey.** | | | | | | |
| **<hospicedata>**<br><br>Opening Tag, defines the hospice record of monthly sample data. There must be a separate hospicedata group for each month from which decedents/caregivers were sampled. | 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. | | | | | |
| | None | N/A | N/A | NA | N/A | Yes |
| **<reference-yr>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <reference-yr>2023</reference-yr>** | | | | | |
| | None | The year of death for the decedents included in this Hospice Record. | YYYY<br>YYYY = (2023 or greater)<br>(cannot be 9999) | Numeric | 4 | Yes |
| **<reference-month>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <reference-month>1</reference-month>** | | | | | |
| | None | The month of death for the decedents included in this Hospice Record. | MM<br>MM = (1 - 12)<br>(cannot be 00, 13 - 99) | Numeric | 2 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<provider-name>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <provider-name>Sample Hospice</provider-name>** | | | | | |
| | None | The name of the hospice represented by the survey. | N/A | Alphanumeric Character | 100 | Yes |
| **<provider-id>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <provider-id>123456</provider-id>** | | | | | |
| | None | The ID number (CCN) of the hospice represented by the survey. | Valid 6-digit CMS Certification Number (formerly known as Medicare Provider Number) | Alphanumeric Character | 10 | Yes |
| **<npi>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <npi>1234567890</npi>** | | | | | |
| | None | The National Provider Identifier (NPI) of the hospice represented by the survey. | Valid 10 digit National Provider Identifier<br>M = Missing | Alphanumeric Character | 10 | Yes |
| **<survey-mode>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <survey-mode>1</survey-mode>** | | | | | |
| | None | The mode of survey administration.<br>The survey mode must be the same for all three months within a quarter. | 1 - Mail Only<br>2 - Telephone Only<br>3 - Mixed Mode<br>8 - Not Applicable (no decedents in the sampled month) | Alphanumeric Character | 1 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<total-decedents>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <total-decedents>150</total-decedents>** | | | | | |
| | None | The total number of decedents in the hospice in the month including "no-publicity" decedents/caregivers. | M = Missing | Alphanumeric Character | 10 | Yes |
| **<live-discharges>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <live-discharges>5</live-discharges>** | | | | | |
| | None | The number of patients who were discharged alive during the month. | M = Missing | Alphanumeric Character | 10 | Yes |
| **<no-publicity>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <no-publicity>1</no-publicity>** | | | | | |
| | None | The number of "no publicity" decedents/caregivers during the month who initiated or voluntarily requested that they not be revealed as a patient and/or whose caregiver requested that they not be surveyed, and were excluded from the file. | M = Missing | Alphanumeric Character | 10 | Yes |
| **<missing-dod>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <missing-dod>5</missing-dod>** | | | | | |
| | None | 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. | N/A | Numeric | 10 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<ineligible-presample>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <ineligible-presample>5</ineligible-presample>** | | | | | |
| | None | The number of decedents/caregivers determined to be ineligible for the month prior to sampling, for any of the following reasons:<br>1. Decedent was under the age of 18<br>2. Decedent's death was less than 48 hours following last admission to hospice care<br>3. Decedent has no caregiver of record<br>4. Decedent's caregiver is a non-familial legal guardian or non-familial paid caregiver<br>5. Decedent's caregiver has an address outside the U.S. or U.S. Territories<br>This count should NOT include cases that are ineligible because of missing date of death. | N/A | Numeric | 10 | Yes |
| **<available-sample>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <available-sample>139</available-sample>** | | | | | |
| | None | 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>). | N/A | Numeric | 10 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<sampled-cases>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <sampled-cases>139</sampled-cases>** | | | | | |
| | None | 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. | N/A | Numeric | 10 | Yes |
| **<sample-size>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <sample-size>136</sample-size>** | | | | | |
| | None | The number of eligible decedents/caregivers drawn into the sample for the month, **not** including ineligible pre-sample (<ineligible-presample>) or ineligible post-sample (<ineligible-postsample>) cases. | N/A | Numeric | 10 | Yes |
| **<ineligible-postsample>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <ineligible-postsample>3</ineligible-postsample>** | | | | | |
| | None | Number of decedents/caregivers in the sample for the month with a "Final Survey Status" code 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," "14 – Institutionalized," or "16 - Sampling Error" | N/A | Numeric | 10 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<sample-type>**<br><br>Sub-element of hospicedata | 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.<br>**Example: <sample-type>1</sample-type>** | | | | | |
| | None | The type of sampling used for the month. | 1 - Simple Random Sample<br>2 - Census Sample | Numeric | 1 | Yes |
| | | | 8 - Not applicable (no decedents in the sampled month) | | | |
| **<number-offices>**<br><br>Sub-element of hospicedata | 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 provider in the file.<br>**Example: <number-offices>3</number-offices>** | | | | | |
| | None | 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. | N/A | Numeric | 10 | Yes |
| **</hospicedata>**<br><br>Closing tag for hospicedata | None | **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. | | | | |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **The following section defines the format of the Decedent/Caregiver Administrative Record.** | | | | | | |
| **<decedentleveldata>**<br><br>Opening Tag, defines the decedent level data record of monthly survey data | This is the opening element of the decedent/caregiver level data record. The closing tag for this element will be at the end of the decedent/caregiver level data record. **Note:** The <decedentleveldata> section includes the opening and closing <decedentleveldata> tags and all the tags between these two tags. The <decedentleveldata> section is required in the XML file, if at least one decedent/caregiver is being submitted. If the <sample-size> is 0, and no decedent/caregiver data is being submitted, the <decedentleveldata> section should not be included in the XML file. This decedent/caregiver level data element should only occur once per decedent/caregiver. | | | | | |
| | None | N/A | N/A | NA | N/A | Yes |
| **<provider-id>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata element also occurs in the previous hospicedata record, and will occur again as a data element in the caregiver response record.<br>**Example: <provider-id>123456</provider-id>** | | | | | |
| | None | The ID number (CCN) of the hospice represented by the survey. | Valid 6-digit CMS Certification Number (formerly known as Medicare Provider Number) | Alphanumeric Character | 10 | Yes |
| **<decedent-id>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata element will occur again as a data element in the caregiver response record.<br>**Example: <decedent-id>12345</decedent-id>** | | | | | |
| | None | The unique de-identified decedent/caregiver ID assigned by the survey vendor to uniquely identify the survey. | N/A | Alphanumeric Character | 16 | Yes |
| **<birth-yr>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <birth-yr>1999</birth-yr>** | | | | | |
| | None | The year the decedent was born as provided by the hospice. | YYYY<br>(cannot be 9999)<br>Use 8888 only if unable to obtain information by the data submission due date. | Numeric | 4 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<birth-month>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <birth-month>1</birth-month>** | | | | | |
| | None | The month the decedent was born as provided by the hospice. | MM<br>MM = (1 - 12)<br>(cannot be 00, 13 - 99)<br>Use 88 only if unable to obtain information by the data submission due date. | Numeric | 2 | Yes |
| **<birth-day>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <birth-day>1</birth-day>** | | | | | |
| | None | The day the decedent was born as provided by the hospice. | DD<br>DD = (1 - 31)<br>(cannot be 00, 32 - 99)<br>Use 88 only if unable to obtain information by the data submission due date. | Numeric | 2 | Yes |
| **<death-yr>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <death-yr>2023</death-yr>** | | | | | |
| | None | The year the decedent died as provided by the hospice. | YYYY<br>YYYY = (2023 or greater)<br>(cannot be 9999) | Numeric | 4 | Yes |
| **<death-month>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <death-month>1</death-month>** | | | | | |
| | None | The month the decedent died as provided by the hospice. | MM<br>MM = (1 - 12)<br>(cannot be 00, 13 - 99) | Numeric | 2 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<death-day>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <death-day>1</death-day>** | | | | | |
| | None | The day the decedent died as provided by the hospice. | DD<br>DD = (1 - 31)<br>(cannot be 00, 32 - 99) | Numeric | 2 | Yes |
| **<admission-yr>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <admission-yr>2021</admission-yr>** | | | | | |
| | None | The year the decedent was admitted for final episode of hospice care as provided by the hospice. | YYYY<br>YYYY = (2009 or later)<br>(cannot be 9999)<br>Use 8888 only if unable to obtain information by the data submission due date. | Numeric | 4 | Yes |
| **<admission-month>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <admission-month>1</admission-month>** | | | | | |
| | None | The month the decedent was admitted for final episode of hospice care as provided by the hospice. | MM<br>MM = (1 - 12)<br>(cannot be 00, 13 - 99)<br>Use 88 only if unable to obtain information by the data submission due date. | Numeric | 2 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<admission-day>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <admission-day>1</admission-day>** | | | | | |
| | None | The day the decedent was admitted for final episode of hospice care as provided by the hospice. | DD<br>DD = (1 - 31)<br>(cannot be 00, 32 - 99)<br>Use 88 only if unable to obtain information by the data submission due date. | Numeric | 2 | Yes |
| **<sex>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <sex>1</sex>** | | | | | |
| | None | The decedent's sex as provided by the hospice. | 1 - Male<br>2 - Female<br>M - Missing | Alphanumeric Character | 1 | Yes |
| **<decedent-hispanic>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <decedent-hispanic>2</decedent-hispanic>** | | | | | |
| | None | The indication whether on not decedent was Hispanic as provided by the hospice. | 1 - Hispanic<br>2 - Non-Hispanic<br>M - Missing | Alphanumeric Character | 1 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<decedent-race>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <decedent-race>1</decedent-race>** | | | | | |
| | None | The decedent's race as provided by the hospice. | 1 - White | Alphanumeric Character | 1 | Yes |
| | | | 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 | | | |
| **<caregiver-relationship>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <caregiver-relationship>1</caregiver-relationship>** | | | | | |
| | None | The caregiver relationship to the decedent as provided by the hospice. | 1 - Spouse/partner | Alphanumeric Character | 1 | Yes |
| | | | 2 - Parent | | | |
| | | | 3 - Child | | | |
| | | | 4 - Other family member | | | |
| | | | 5 - Friend | | | |
| | | | 6 - Legal guardian (non-familial) | | | |
| | | | 7 - Other | | | |
| | | | 8 - No caregiver of record | | | |
| | | | 9 - Paid caregiver (non-familial) | | | |
| | | | M - Missing | | | |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<decedent-payer-primary>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <decedent-payer-primary>1</decedent-payer-primary>** | | | | | |
| | None | The decedent's primary payer for healthcare services as provided by the hospice. | 1 - Medicare<br>2 - Medicaid<br>3 - Private<br>4 - Uninsured/no payer<br>5 - Program for All Inclusive Care for the Elderly (PACE)<br>6 - Other<br>M - Missing | Alphanumeric Character | 1 | Yes |
| **<decedent-payer-secondary>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <decedent-payer-secondary>2</decedent-payer-secondary>** | | | | | |
| | None | The decedent's secondary payer for healthcare services as provided by the hospice. | 1 - Medicare<br>2 - Medicaid<br>3 - Private<br>4 - Uninsured/no payer<br>5 - Program for All Inclusive Care for the Elderly (PACE)<br>6 - Other<br>7 - No Secondary Payer<br>M - Missing | Alphanumeric Character | 1 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<decedent-payer-other>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <decedent-payer-other>3</decedent-payer-other>** | | | | | |
| | None | The decedent's other payer for healthcare services as provided by the hospice. | 1 - Medicare<br>2 - Medicaid<br>3 - Private<br>4 - Uninsured/no payer<br>5 - Program for All Inclusive Care for the Elderly (PACE)<br>6 - Other<br>7 - No Other Payer<br>M - Missing | Alphanumeric Character | 1 | Yes |
| **<last-location>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <last-location>1</last-location>** | | | | | |
| | None | The decedent's last location/setting of hospice care as provided by the hospice. | 1 - Home<br>2 - Assisted living<br>3 - Long-term care facility or non-skilled nursing facility<br>4 - Skilled nursing facility<br>5 - Inpatient hospital<br>6 - Inpatient hospice facility<br>7 - Long-term care facility<br>8 - Inpatient psychiatric facility<br>9 - Location not otherwise specified<br>10 - Hospice facility<br>M - Missing | Alphanumeric Character | 2 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<facility-name>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This is an optional data element at this time but may be required in the future.<br>**Example: <facility-name>Facility</facility-name>** | | | | | |
| | None | The name of the assisted living facility, nursing home, hospital, or hospice facility/hospice house where the patient received care, if applicable (optional). | Facility name up to 100 alphanumeric characters.<br>N/A = Missing/Not Applicable | Alphanumeric Character | 100 | Yes |
| **<decedent-primary-diagnosis>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <decedent-primary-diagnosis>G30.9</decedent-primary-diagnosis>** | | | | | |
| | None | The decedent's primary diagnosis provided by the hospice. 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 character, though a small number have a third character that is alphabetic. 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. | ICD-10 code for the primary diagnosis of the decedent.<br>MMMMMMMM=Missing | Alphanumeric Character | 8 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<survey-status>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per caregiver/decedent.<br>**Example: <survey-status>1</survey-status>** | | | | | |
| | None | The disposition of the survey. For the final quarterly submission for each CCN, no cases should be coded 33 or M. | 1 - Completed Survey | Alphanumeric Character | 2 | Yes |
| | | | 2 - Ineligible: Deceased | | | |
| | | | 3 - Ineligible: Not in Eligible Population | | | |
| | | | 4 - Ineligible: Language Barrier | | | |
| | | | 5 - Ineligible: Mental/Physical Incapacity | | | |
| | | | 6 - Ineligible: Never Involved in Decedent Care | | | |
| | | | 7 - Non-response: Break-off | | | |
| | | | 8 - Non-response: Refusal | | | |
| | | | 9 - Non-response: Non-response after Maximum Attempts | | | |
| | | | 10 - Non-response: Bad/No Address | | | |
| | | | 11 - Non-response: Bad/No Telephone Number | | | |
| | | | 12 - Non-response: Incomplete Caregiver Name | | | |
| | | | 13 - Non-response: Incomplete Decedent Name | | | |
| | | | 14 - Ineligible: Institutionalized | | | |
| | | | 15 - Non-response: Hospice Disavowal | | | |
| | | | 16 - Sampling Error | | | |
| | | | 33 - No Response Collected (used only for interim data file submission) | | | |
| | | | M - Missing | | | |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<survey-completion-mode>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This tag is required if the survey mode is Mixed Mode and the "Final Survey Status" is "1 – Completed Survey," "6 – Ineligible: Never Involved in Decedent Care" or "7 – Non-response: Break-off." The values entered must match a value corresponding to the survey mode defined in the Hospice Record section of the XML file. If the XML Element <survey-mode> is other than Mixed Mode, this tag should not be included in the XML file.<br>**Example: <survey-completion-mode>88</survey-completion-mode>** | | | | | |
| | None | The survey mode used to complete a survey administered via the Mixed Mode. For Mail Only or Telephone Only, code 88. | 1 - Mixed Mode-mail<br>2 - Mixed Mode-phone<br>88 - Not Applicable | Numeric | 2 | 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." |
| **<number-survey-attempts-telephone>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This tag is required if the survey mode is Telephone Only or Mixed Mode. If the XML Element <survey-mode> is other than Telephone Only or Mixed Mode (phone), this tag does not need to be included in the XML file.<br>**Example: <number-survey-attempts-telephone>88</number-survey-attempts-telephone>** | | | | | |
| | None | The number of telephone contact attempts per survey with a survey mode of Telephone Only or Mixed Mode. For Mail Only or Mixed Mode (completed by mail), code 88. | 0 - No Attempts<br>1 - First Telephone Attempt<br>2 - Second Telephone Attempt<br>3 - Third Telephone Attempt<br>4 - Fourth Telephone Attempt<br>5 - Fifth Telephone Attempt<br>88 - Not Applicable | Numeric | 2 | No, conditionally required only if the survey mode is Telephone Only Mode or Mixed Mode. |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<number-survey-attempts-mail>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This tag is required if the survey mode is Mail Only. If the XML Element <survey-mode> is other than Mail Only, this tag does not need to be included in the XML file.<br>**Example: <number-survey-attempts-mail>1</number-survey-attempts-mail>** | | | | | |
| | None | The mail wave for which "Final Survey Status" code is determined per survey with a survey mode of Mail Only. For Telephone Only or Mixed Mode, code 88. | 1 - First Wave Mailing<br>2 - Second Wave Mailing<br>88 - Not Applicable | Numeric | 2 | No, conditionally required only if the survey mode is Mail Only. |
| **<language>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <language>1</language>** | | | | | |
| | None | The survey language in which the survey was administered (English, Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish, Korean). Only code 88 if survey not administered. | 1 - English<br>2 - Spanish<br>3 - Chinese<br>4 - Russian<br>5 - Portuguese<br>6 - Vietnamese<br>7 - Polish<br>8 - Korean<br>88 - Not Applicable | Numeric | 2 | Yes |
| **<lag-time>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver. **Note:** The Lag Time should not be coded as "Missing."<br>**Example: <lag-time>106</lag-time>** | | | | | |
| | None | The number of days between decedent date of death and the date that data collection activities ended for the decedent/caregiver. | 0 - 365<br>888 - Not Applicable (use only for interim data file submission) | Numeric | 3 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<supplemental-question-count>**<br><br>Sub-element of decedentleveldata | Each element must have a closing tag that is the same as the opening tag but with a forward slash. This decedentleveldata data element should only occur once per decedent/caregiver.<br>**Example: <supplemental-question-count>4</supplemental-question-count>** | | | | | |
| | None | A count of supplemental questions added to the questionnaire. | 0 - 15<br>M - Missing | Alphanumeric Character | 2 | No. Required only if “Final Survey Status” is “1 – Completed Survey,” “6 – Ineligible: Never Involved in Decedent Care” or “7 – Non-response: Break-off.” |
| **The following section defines the format of the Survey Results Record (caregiver response).**<br>**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.**<br>**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."** | | | | | | |
| **<caregiverresponse>**<br><br>Opening Tag, defines the decedent response data record within the caregiver level data record of monthly survey data | 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.<br>**Note:** There will be one <caregiverresponse> section for each caregiver if survey results are being submitted for the caregiver. The <caregiverresponse> section includes the opening and closing <caregiverresponse> tags and all the tags between these two tags. This <caregiverresponse> section is required in the XML file only if survey results are being submitted for the caregiver. If survey results are not being submitted for the caregiver the <caregiverresponse> section should not be submitted. This caregiver response element should only occur once per decedent. | | | | | |
| | None | N/A | N/A | NA | N/A | Yes |
| **<provider-id>**<br><br>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 caregiverresponse element also occurs in the previous hospicedata record and decedentleveldata record.<br>**Example: <provider-id>123456</provider-id>** | | | | | |
| | None | The ID number (CCN) of the hospice represented by the survey. | Valid 6-digit CMS Certification Number (formerly known as Medicare Provider Number). | Alphanumeric Character | 10 | Yes |

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

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

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

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<needhelp>**<br><br>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.<br>**Example: <needhelp>1</needhelp>** | | | | | |
| | None | Question 4: Need help. | 1 - Yes<br>2 - No<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<gethelp>**<br><br>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.<br>**Example: <gethelp>4</gethelp>** | | | | | |
| | None | Question 5: Get help. | 1 - Never<br>2 - Sometimes<br>3 - Usually<br>4 - Always<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<h_informtime>**<br><br>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.<br>**Example: <h_informtime>4</h_informtime>** | | | | | |
| | None | Question 6: Hospice inform. | 1 - Never<br>2 - Sometimes<br>3 - Usually<br>4 - Always<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<helpasan>**<br><br>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.<br>**Example: <helpasan>4</helpasan>** | | | | | |
| | None | Question 7: Help as soon as need. | 1 - Never | Alphanumeric Character | 2 | Yes |
| | | | 2 - Sometimes | | | |
| | | | 3 - Usually | | | |
| | | | 4 - Always | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<h_explain>**<br><br>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.<br>**Example: <h_explain>4</h_explain>** | | | | | |
| | None | Question 8: Hospice explain. | 1 - Never | Alphanumeric Character | 2 | Yes |
| | | | 2 - Sometimes | | | |
| | | | 3 - Usually | | | |
| | | | 4 - Always | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<h_inform>**<br><br>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.<br>**Example: <h_inform>4</h_inform>** | | | | | |
| | None | Question 9: Hospice inform. | 1 - Never | Alphanumeric Character | 2 | Yes |
| | | | 2 - Sometimes | | | |
| | | | 3 - Usually | | | |
| | | | 4 - Always | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<h_confuse>**<br><br>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.<br>**Example: <h_confuse>4</h_confuse>** | | | | | |
| | None | Question 10: Hospice confuse. | 1 - Never | Alphanumeric Character | 2 | Yes |
| | | | 2 - Sometimes | | | |
| | | | 3 - Usually | | | |
| | | | 4 - Always | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<h_dignity>**<br><br>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.<br>**Example: <h_dignity>4</h_dignity>** | | | | | |
| | None | Question 11: Hospice dignity. | 1 - Never | Alphanumeric Character | 2 | Yes |
| | | | 2 - Sometimes | | | |
| | | | 3 - Usually | | | |
| | | | 4 - Always | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<h_cared>**<br><br>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.<br>**Example: <h_cared>4</h_cared>** | | | | | |
| | None | Question 12: Hospice cared. | 1 - Never | Alphanumeric Character | 2 | Yes |
| | | | 2 - Sometimes | | | |
| | | | 3 - Usually | | | |
| | | | 4 - Always | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<h_talk>**<br><br>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.<br>**Example: <h_talk>1</h_talk>** | | | | | |
| | None | Question 13: Hospice talk. | 1 - Yes<br>2 - No<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<h_talklisten>**<br><br>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.<br>**Example: <h_talklisten>4</h_talklisten>** | | | | | |
| | None | Question 14: Hospice talk and listen. | 1 - Never<br>2 - Sometimes<br>3 - Usually<br>4 - Always<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<pain>**<br><br>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.<br>**Example: <pain>1</pain>** | | | | | |
| | None | Question 15: Pain. | 1 - Yes<br>2 - No<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<painhlp>**<br><br>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.<br>**Example: <painhlp>1</painhlp>** | | | | | |
| | None | Question 16: Pain help. | 1 - Yes, definitely<br>2 - Yes, somewhat<br>3 - No<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<painrx>**<br><br>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.<br>**Example: <painrx>1</painrx>** | | | | | |
| | None | Question 17: Pain medicine. | 1 - Yes<br>2 - No<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<painrxside>**<br><br>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.<br>**Example: <painrxside>1</painrxside>** | | | | | |
| | None | Question 18: Pain medication info. | 1 - Yes, definitely<br>2 - Yes, somewhat<br>3 - No<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<painrxwatch>**<br><br>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.<br>**Example: <painrxwatch>1</painrxwatch>** | | | | | |
| | None | Question 19: Pain medicine watch. | 1 - Yes, definitely<br>2 - Yes, somewhat<br>3 - No<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<painrxtrain>**<br><br>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.<br>**Example: <painrxtrain>4</painrxtrain>** | | | | | |
| | None | Question 20: Pain medicine train. | 1 - Yes, definitely | Alphanumeric Character | 2 | Yes |
| | | | 2 - Yes, somewhat | | | |
| | | | 3 - No | | | |
| | | | 4 - I did not need to give pain medicine to my family member | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<breath>**<br><br>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.<br>**Example: <breath>1</breath>** | | | | | |
| | None | Question 21: Breath. | 1 - Yes | Alphanumeric Character | 2 | Yes |
| | | | 2 - No | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<breathhlp>**<br><br>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.<br>**Example: <breathhlp>4</breathhlp>** | | | | | |
| | None | Question 22: Breath help. | 1 - Never | Alphanumeric Character | 2 | Yes |
| | | | 2 - Sometimes | | | |
| | | | 3 - Usually | | | |
| | | | 4 - Always | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<breathtrain>**<br><br>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.<br>**Example: <breathtrain>4</breathtrain>** | | | | | |
| | None | Question 23: Breath train. | 1 - Yes, definitely | Alphanumeric Character | 2 | Yes |
| | | | 2 - Yes, somewhat | | | |
| | | | 3 - No | | | |
| | | | 4 - I did not need to help my family member with trouble breathing | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<constip>**<br><br>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.<br>**Example: <constip>1</constip>** | | | | | |
| | None | Question 24: Constipation. | 1 - Yes | Alphanumeric Character | 2 | Yes |
| | | | 2 - No | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<constiphlp>**<br><br>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.<br>**Example: <constiphlp>4</constiphlp>** | | | | | |
| | None | Question 25: Constipation help. | 1 - Never | Alphanumeric Character | 2 | Yes |
| | | | 2 - Sometimes | | | |
| | | | 3 - Usually | | | |
| | | | 4 - Always | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<sad>**<br><br>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.<br>**Example: <sad>1</sad>** | | | | | |
| | None | Question 26: Sad. | 1 - Yes<br>2 - No<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<sadgethlp>**<br><br>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.<br>**Example: <sadgethlp>4</sadgethlp>** | | | | | |
| | None | Question 27: Sad get help. | 1 - Never<br>2 - Sometimes<br>3 - Usually<br>4 - Always<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<restless>**<br><br>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.<br>**Example: <restless>1</restless>** | | | | | |
| | None | Question 28: Restless. | 1 - Yes<br>2 - No<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<restlesstrain>**<br><br>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.<br>**Example: <restlesstrain>1</restlesstrain>** | | | | | |
| | None | Question 29: Restless train. | 1 - Yes, definitely<br>2 - Yes, somewhat<br>3 - No<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<movetrain>**<br><br>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.<br>**Example: <movetrain>4</movetrain>** | | | | | |
| | None | Question 30: Move train. | 1 - Yes, definitely | Alphanumeric Character | 2 | Yes |
| | | | 2 - Yes, somewhat | | | |
| | | | 3 - No | | | |
| | | | 4 - I did not need to move my family member | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<expectinfo>**<br><br>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.<br>**Example: <expectinfo>1</expectinfo>** | | | | | |
| | None | Question 31: Expect info. | 1 - Yes, definitely | Alphanumeric Character | 2 | Yes |
| | | | 2 - Yes, somewhat | | | |
| | | | 3 - No | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<receivednh>**<br><br>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.<br>**Example: <receivednh>1</receivednh>** | | | | | |
| | None | Question 32: Received nursing home. | 1 - Yes | Alphanumeric Character | 2 | Yes |
| | | | 2 - No | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<cooperatehnh>**<br><br>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.<br>**Example: <cooperatehnh>4</cooperatehnh>** | | | | | |
| | None | Question 33: Cooperate hospice and nursing home. | 1 - Never | Alphanumeric Character | 2 | Yes |
| | | | 2 - Sometimes | | | |
| | | | 3 - Usually | | | |
| | | | 4 - Always | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<differhnh>**<br><br>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.<br>**Example: <differhnh>4</differhnh>** | | | | | |
| | None | Question 34: Difference between hospice and nursing home. | 1 - Never | Alphanumeric Character | 2 | Yes |
| | | | 2 - Sometimes | | | |
| | | | 3 - Usually | | | |
| | | | 4 - Always | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<h_clisten>**<br><br>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.<br>**Example: <h_clisten>4</h_clisten>** | | | | | |
| | None | Question 35: Hospice listening carefully to caregiver. | 1 - Never | Alphanumeric Character | 2 | Yes |
| | | | 2 - Sometimes | | | |
| | | | 3 - Usually | | | |
| | | | 4 - Always | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<cbeliefrespect>**<br><br>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.<br>**Example: <cbeliefrespect>1</cbeliefrespect>** | | | | | |
| | None | Question 36: Caregiver beliefs respected. | 1 - Too little<br>2 - Right amount<br>3 - Too much<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<cemotion>**<br><br>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.<br>**Example: <cemotion>1</cemotion>** | | | | | |
| | None | Question 37: Caregiver emotion. | 1 - Too little<br>2 - Right amount<br>3 - Too much<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |
| **<cemotionafter>**<br><br>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.<br>**Example: <cemotionafter>1</cemotionafter>** | | | | | |
| | None | Question 38: Caregiver emotion after. | 1 - Too little<br>2 - Right amount<br>3 - Too much<br>88 - Not Applicable<br>M - Missing/Don't Know | Alphanumeric Character | 2 | Yes |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<ratehospice>**<br><br>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.<br>**Example: <ratehospice>8</ratehospice>** | | | | | |
| | None | Question 39: Rate hospice. | 0 - Worst hospice care possible | Alphanumeric Character | 2 | Yes |
| | | | 1 | | | |
| | | | 2 | | | |
| | | | 3 | | | |
| | | | 4 | | | |
| | | | 5 | | | |
| | | | 6 | | | |
| | | | 7 | | | |
| | | | 8 | | | |
| | | | 9 | | | |
| | | | 10 - Best hospice care possible | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |
| **<h_recommend>**<br><br>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.<br>**Example: <h_recommend>4</h_recommend>** | | | | | |
| | None | Question 40: Hospice recommended. | 1 - Definitely no | Alphanumeric Character | 2 | Yes |
| | | | 2 - Probably no | | | |
| | | | 3 - Probably yes | | | |
| | | | 4 - Definitely yes | | | |
| | | | 88 - Not Applicable | | | |
| | | | M - Missing/Don't Know | | | |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<pEdu>**<br><br>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.<br>**Example: <pEdu>4</pEdu>** | | | | | |
| | None | Question 41: Decedent education. | 1 - 8th grade or less | Alphanumeric Character | 1 | Yes |
| | | | 2 - Some high school but did not graduate | | | |
| | | | 3 - High school graduate or GED | | | |
| | | | 4 - Some college or 2-year degree | | | |
| | | | 5 - 4-year college graduate | | | |
| | | | 6 - More than 4-year college degree | | | |
| | | | 7- Don't Know | | | |
| | | | M - Missing/Don't Know | | | |
| **<pLatino>**<br><br>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.<br>**Example: <pLatino>1</pLatino>** | | | | | |
| | None | Question 42: Decedent Latino. | 1 - No, not Spanish/Hispanic/Latino | Alphanumeric Character | 1 | Yes |
| | | | 2 - Yes, Cuban | | | |
| | | | 3 - Yes, Mexican, Mexican American, Chicano/a | | | |
| | | | 4 - Yes, Puerto Rican | | | |
| | | | 5 - Yes, other Spanish/Hispanic/Latino | | | |
| | | | M - Missing/Don't Know | | | |

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

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

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<cAge>**<br><br>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.<br>**Example: <cAge>1</cAge>** | | | | | |
| | None | Question 44: Caregiver, age. | 1 - 18 to 24 | Alphanumeric Character | 1 | Yes |
| | | | 2 - 25 to 34 | | | |
| | | | 3 - 35 to 44 | | | |
| | | | 4 - 45 to 54 | | | |
| | | | 5 - 55 to 64 | | | |
| | | | 6 - 65 to 74 | | | |
| | | | 7 - 75 to 84 | | | |
| | | | 8 - 85 or older | | | |
| | | | M - Missing/Don't Know | | | |
| **<cSex>**<br><br>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.<br>**Example: <cSex>1</cSex>** | | | | | |
| | None | Question 45: Caregiver, sex. | 1 - Male | Alphanumeric Character | 1 | Yes |
| | | | 2 - Female | | | |
| | | | M - Missing/Don't Know | | | |
| **<cEdu>**<br><br>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.<br>**Example: <cEdu>4</cEdu>** | | | | | |
| | None | Question 46: Caregiver, education. | 1 - 8th grade or less | Alphanumeric Character | 1 | Yes |
| | | | 2 - Some high school but did not graduate | | | |
| | | | 3 - High school graduate or GED | | | |
| | | | 4 - Some college or 2-year degree | | | |
| | | | 5 - 4-year college graduate | | | |
| | | | 6 - More than 4-year college degree | | | |
| | | | M - Missing/Don't Know | | | |

| XML Element | Attributes | Description | Valid Values | Data Type | Max Field Size | Data Element Required |
|---|---|---|---|---|---|---|
| **<cHomeLang>**<br><br>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.<br>**Example: <cHomeLang>4</cHomeLang>** | | | | | |
| | None | Question 47: Language spoken at home. | 1 - English<br>2 - Spanish<br>3 - Chinese<br>4 - Russian<br>5 - Portuguese<br>6 - Vietnamese<br>7 - Polish<br>8 - Korean<br>9 - Some other language<br>M - Missing/Don't Know | Alphanumeric Character | 1 | Yes |
| **</caregiverresponse>**<br><br>Closing tag for 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>**<br><br>Closing tag for 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>**<br><br>Closing tag for 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. | | | | |

# Appendix F

## Interviewing Guidelines for Telephone Surveys

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# 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 <u>exactly</u> 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
  - During the course of the survey, use of neutral acknowledgement words such as the following is permitted:
    - Thank you
    - Alright
    - Okay
    - I understand, or I see
    - Yes, Ma'am
    - Yes, Sir
- read the script from the interviewer screens (reciting the survey from memory can lead to unnecessary errors and missed updates to the script)
- adjust the pace of the CAHPS Hospice Survey interview to be conducive to the needs of the caregiver
- 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.

- not leave messages on answering machines or with household members. Interviewers should attempt to re-contact the caregiver to complete the CAHPS Hospice Survey.
- tell the caregiver that there are no more questions and thank the caregiver for his or her time at the end of the survey. The interviewer may say, "Have a good (day/evening)." if appropriate.
- not administer the CAHPS Hospice Survey to any caregiver whom you know personally or professionally

## 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
  - The interviewer may use the pronoun appropriate to the decedent's gender ("he or she" or "him or her" if the caregiver mentions the decedent's gender
  - The interviewer may accept any alternative positive or negative response from the caregiver
- 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.
- request to speak with the sampled caregiver if calling the caregiver number and a business is reached. If the caregiver states they are at work and cannot speak, the interviewer should attempt to reschedule the call for a time that is more convenient for the caregiver, or obtain an alternate phone number at which to reach the caregiver.
- request to get in touch with the sampled caregiver if the interviewer reaches a healthcare facility staff member. Inform the healthcare facility staff member that the survey is part of a national initiative sponsored by the United States Department of Health and Human Services. The results of the survey will help hospices understand what they are doing well and what needs improvement.

  If the staff member indicates that the caregiver is unable to complete the survey (e.g., due to mental or physical incapacity), the interviewer should thank the staff member and code the attempt appropriately.

  *Note: Caregivers, if otherwise eligible, residing in healthcare facilities such as an assisted living facility, long-term care facility or nursing home are to be included in the CAHPS Hospice Survey sample frame and attempts to contact the caregiver to administer the survey must be made to those decedents/caregivers drawn into the sample.*

*Note: Healthcare facility telephone numbers cannot be placed on the survey vendor's do-not-call list, even if requested by the healthcare facility staff.*

## 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.
- Interviewers must clarify the caregiver response if accepting alternative positive and/or negative responses (Definitely yes, Probably yes, etc.)
- 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 <u>must</u> be read out loud
- Text in UPPERCASE letters <u>must not</u> be read out loud
  - However, YES and NO response options can be read, if appropriate
- 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 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 caregiver does not provide an answer to Question 4 of the CAHPS Hospice Survey and the interviewer selects “MISSING/DK” 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.

➢ There must be only one language (i.e., English, Spanish, or Russian) that appears on the electronic telephone interviewing system screen

# Appendix G

## Frequently Asked Questions for Customer Support

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# CAHPS Hospice Survey
## Frequently Asked Questions for Customer Support

## Overview

This document provides customer support guidance on responding to frequently asked questions (FAQ) from caregivers answering the CAHPS Hospice Survey. It should be used for all three modes of survey administration. The FAQ provide 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 caregivers 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 sponsored 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. The data are publicly reported on Care Compare (https://www.medicare.gov/care-compare/). 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 hospicecahpssurvey@hsag.com.

- **Are my answers confidential? Who will see my answers?**
  Your answers will be seen by the research staff, and may be shared with the hospice for purposes of quality improvement.

- **How long will this take?**
  The survey takes about 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].

- **Where can I find the results of the survey?**
  Official CAHPS Hospice Survey scores are publicly reported four times each year on the Care Compare Web site (https://www.medicare.gov/care-compare/). Scheduled refreshes for CAHPS Hospice Survey data occur in February, May, August, and November. Publicly reported CAHPS Hospice Survey results are calculated using eight quarters of survey data; A summary Star Rating based on CAHPS Hospice Survey results is updated twice a year.

## 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 concerned the survey might be a "scam," and if I answer with those response choices, it might be recorded and used for fraud against me.**
  You can use an alternative positive or negative response to answer the questions.

- **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.

- **The caregiver you have reached is in a healthcare facility.**
  This is [INTERVIEWER NAME] calling from [SURVEY VENDOR]. We are conducting a survey about hospice care. For this survey, we need to speak directly to [SAMPLED CAREGIVER NAME]. Is [SAMPLED CAREGIVER NAME] available?

  *[IF NECESSARY:]* We are doing a very important study that is part of a national initiative sponsored by the United States Department of Health and Human Services. The results of the survey will help hospices understand what they are doing well and what needs improvement.

  *NOTE: CAREGIVERS IN HEALTHCARE FACILITIES SUCH AS ASSISTED LIVIING FACILITIES, LONG-TERM CARE FACILITIES OR NURSING HOMES ARE ELIGIBLE FOR THE SURVEY.*

- **I would like to complete the survey online, is that an option?**
  No, the CAHPS Hospice Survey can only be completed by [DEPENDING ON MODE: mail / telephone / mail or telephone] at this time.

# Appendix H

## 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 QAP also serves as a key resource in the training of staff and subcontractors and any other organization responsible for performing CAHPS Hospice Survey administration functions.

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).

The QAP should be free of extraneous information and must provide sufficient detail 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. 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 <u>must</u> be followed in the survey vendor's QAP.**

### <u>Organizational Background and Structure</u>

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. Name and contact information for the person who heads the organization or the survey research portion of the organization.
    D. Physical location, if mailing address is different
    E. Web site address, if one is available
    F. Name of contact person, his or her direct telephone number and email address
    G. Name of backup contact person, his or her direct telephone number and email address
    H. Number of contracted client hospices per mode
    I. Survey vendor's approved survey mode(s)
    J. Date of the QAP

    ***Note: It is very important that the CAHPS Hospice Survey Project Team be able to reach your organization in case of problems with the data or other operational issues.***

***Survey vendors must update and resubmit their QAP at the time of process and/or key personnel changes as part of retaining participation status.***

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
      1. 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 these organizations, if applicable. Background and qualifications of all key personnel, subcontractors and any other organizations responsible for major functions of CAHPS Hospice Survey administration 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 any other organizations, if subcontractors and any 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 decedent or caregiver is personally or professionally known by the initial interviewer
      3. Describe how caregivers with multiple telephone numbers are handled, including how the telephone numbers are prioritized
   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. Provide a count of the maximum number of supplemental questions added to the CAHPS Hospice Survey. Identify where the supplemental questions are placed. List the transition statement(s) placed before the supplemental questions (include this information for each hospice, as applicable).

9. 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 vendor. 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. Describe the de-duplication process for multiple hospice stays and to verify that a decedent is provided only once in the decedents/caregivers list
G. If administering the survey in multiple languages, identify the languages and describe how the survey language to be administered to the eligible caregiver is chosen

10. 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.*

11. 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.

12. 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 CAHPS Hospice Survey "Final Survey Status" codes, if applicable

13. 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, including the estimated time to generate, review and submit the data before the data submission deadline

## Survey and Data Management System and Quality Controls

14. 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-identified numbers, generating sample frame, producing mail survey packets, telephone survey administration, XML file generation
    E. Address and telephone number updating resources

15. Describe the customer support telephone line and how it is 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 CAHPS Hospice 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 provides customer support in all languages that the survey vendor administers the survey in
    F. Describe how the survey vendor is ready to support calls from the deaf or the hearing impaired
    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

16. 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

17. Identify the specific timeline for incorporating the CAHPS Hospice Survey Quality Assurance Guidelines V8.0 changes into the survey vendor's survey administration processes.

**For items 18 – 23, 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**

18. Describe the process for monitoring on-site work and subcontractors' or any other organizations' work to ensure high quality results. Include monitoring of telephone interviewers, if applicable, and checks of printed mailing materials, if applicable.

19. 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)

20. 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.

21. 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.

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

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

## Confidentiality, Privacy and Security Procedures

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

25. 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.

26. Describe the process to destroy CAHPS Hospice Survey related data files, including paper copies or scanned images of the questionnaires and electronic data files in a secure and environmentally safe location, and maintaining certificate(s) of destruction.

27. Describe the disaster recovery plan for conducting ongoing business operations in the event of a disaster.

## QAP Update: Discussion of Results of Quality Control Activities

28. 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

29. Include any forms used in CAHPS Hospice Survey administration that may assist the CAHPS Hospice Survey Project Team in reviewing the survey vendor's processes (e.g., tracking logs, sample frame format, etc.).

    ***Note: These items should be templates only and must not contain any protected health information (PHI).***

# Appendix I

## Exception Request Form

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# CAHPS Hospice Survey
## Exception Request Form

The Exception Request Form must be completed and submitted online on the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org). The hospice(s) for which this Exception Request relates to must be listed in Section II along with each hospice's CMS Certification Number (CCN). All required fields are indicated with an asterisk (*).

***NOTE: This form does not accept any special characters or symbols in the text boxes. Use only alphanumeric characters when completing this form.***

### I. General Information

1a. Organization Name *

### II. Contact Person for this Exception Request

Confirmation email will be sent to the Contact Person.

2a. First Name *

2a. Middle Initial

2a. Last Name *

2b. Title *

2c. Degree (e.g. RN, MD, PhD)

2d. Mailing Address 1 *

2e. Mailing Address 2

2f. City *

2g. State *

2h. Zip Code *

2h. Telephone *

2i. Fax Number

2j. Email Address *

### III. Exception Request

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

1. Exception Request For (Check one in each box)

○ New Exception

○ Appeal of Exception Denial

Exception (specify):*

## 2. List of hospices applicable to this Exception Request

Total number of Affected Hospices *

0

Name of Hospice *

CCN *

Add

| Name Of Hospice | Ccn |
|---|---|

1 / 1 10 items per page

(click on a row in the grid to edit it)

## 3. Description of Exception Request

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

4000 characters remaining

3b. Rationale for Proposed Exception Requested *

4000 characters remaining

3c. Explanation of Implementation of Proposed Exception Requested *

4000 characters remaining

3d. Evidence that Exception Will Not Affect Results *

4000 characters remaining

40 + 5 = 8

Note: Please print completed Exception Report form before submitting.

Print Exception Report | Submit Form

# Appendix J

## Discrepancy Report Form

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# CAHPS Hospice Survey
## Discrepancy Report Form

The Discrepancy Report Form must be completed and submitted online on the CAHPS Hospice Survey Web site (www.hospicecahpssurvey.org). The requested information regarding the affected hospices must be provided in Section III in order to complete the CAHPS Hospice Survey Discrepancy Report. All required fields are indicated with an asterisk (*). If all of the information is not immediately available, survey vendors must submit an initial Discrepancy Report alerting CMS of the issue and subsequently update the Discrepancy Report with the remaining required information once available. When updating a Discrepancy Report, please note that the initial report is retained in its entirety; therefore, it is necessary only to provide the remaining required information pertaining to the original submission, referencing the Original Report Form ID.

***NOTE: This form does not accept any special characters or symbols in the text boxes. Use only alphanumeric characters when completing this form.***

Indicate whether this report is an Initial Discrepancy Report or an Updated Discrepancy Report.

- ◉ **Initial Discrepancy Report** * (Must be submitted within 24 hours after the discrepancy has been discovered.)
- ○ **Updated Discrepancy Report** * (If needed, must be submitted within two weeks of initial Discrepancy Report.)

**1. General Information**

| Unique Report ID | Submission Date | 1a. Name of Organization submitting the Discrepancy Report * |
|---|---|---|
| 8160 | | |

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

| 2a. First Name * | 2b. Last Name * | |
|---|---|---|
| 2c. Mailing Address 1 * | 2d. Mailing Address 2 | |
| 2e. City * | 2f. State * | 2g. Zip Code * |
| 2h. Telephone * | Extension | 2i. Fax Number |
| 2j. Email * | | |

## 3. Information about the Discrepancy

**3a. Description of the discrepancy** *

2000 characters remaining

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

2000 characters remaining

**3c. Description of the Corrective Action to fix the discrepancy, including estimated time for implementation** *

2000 characters remaining

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

2000 characters remaining

## 4. List of Hospices Applicable to this Discrepancy

**4a. Total Number of Affected Hospices** *

0

**4b. Add the information for the affected hospices by populating the following 10 fields. A hospice may be added more than once if there are multiple time frames for the hospice. It is important that the effects of the Discrepancy Report are quantified, however "unknown" will be accepted as a valid response.**

**Name of Hospice** *

**CCN** *

**Hospice Contact Name** *

**Email Address for the Hospice Contact** *

**Eligible Decedents/Caregivers Affected** *

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

**Sampled Decedents/Caregivers Affected** *

**Average Number of Surveys Administered per Month** *

**Time Frame Affected: Begin Date** *

**Time Frame Affected: End Date** *

Add

| Name Of Hospice | Ccn | Hospice Contact Person | Email Address | Eligible Decedents/Careg | Avg. Eligible Decedents/Careg Month | Sampled Decedents/Careg | Avg. Surveys Month | Begin Date | End Date |
|---|---|---|---|---|---|---|---|---|---|

1 / 1 10 items per page

(click on a row in the grid to edit it)

40 + 2 = ?

Note: Please print completed Discrepancy Report form before submitting.

Print Discrepancy Report Submit Form

# Appendix K

## Participation Exemption for Size Form

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# CAHPS Hospice Survey
## Participation Exemption for Size Form

The Participation Exemption for Size Form must be completed and submitted online on the CAHPS Hospice Survey Website (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 facilities.**

The Participation Exemption for Size Form has been successfully submitted once you are redirected to a "Thank you for your submission" page.

### I. General Information

1a. CCN Number *

Submission Date

1b. Organization Name *

### II. Contact Person at Hospice for this Exemption for Size Request

Confirmation email will be sent to the Contact Person.

2a. Name *

2b. Title *

2c. Mailing Address 1 *

2d. Mailing Address 2

2e. City *

2f. State *

2g. Zip Code *

2h. Telephone *

2i. Fax Number

2j. Email Address *

### 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, 2022 and December 31, 2022 (CY 2022) * 0

2. Enter the total number of patients during CY 2021 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 * 0

b. Enter the number of decedents:

i. who were under the age of 18 * 0

ii. who died within 48 hours of admission to hospice care * 0

iii. for whom there is no caregiver of record * 0

iv. for whom the caregiver is a non-familial legal guardian * 0

v. for whom the caregiver has a foreign (non-US or US Territory) home address * 0

vi. for whom the caregiver requested not to be contacted * 0

62 + 1 = ?

Note: Please print completed Exemption Report form before submitting.

Print Exemption Report | Submit Form

# Appendix L

## Attestation Statement

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# CAHPS Hospice Survey
## Attestation Statement

All of the data collected and submitted to the Centers for Medicare & Medicaid Services (CMS) for the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey by [*name of survey vendor*] and all our subcontractors and any other organizations (if applicable) engaged in survey activities are accurate and complete. This includes the following:

1. Meet and comply with the CAHPS Hospice Survey Minimum Business Requirements specified in the CAHPS Hospice Survey *Quality Assurance Guidelines*
2. Review and adhere to the CAHPS Hospice Survey *Quality Assurance Guidelines* and policy updates
3. Update annual CAHPS Hospice Survey Quality Assurance Plan to be complete, comprehensive and accurate
4. Attest to the accuracy of data collection activities
5. Comply with all requirements of the Health Insurance Portability and Accountability Act (HIPAA) Security and Privacy Rules in conducting all survey administration and data collection activities
6. Maintain confidentiality and security of all CAHPS Hospice Survey decedent/caregiver-related and survey-related data
7. Meet all CAHPS Hospice Survey due dates (including data submission)
8. Report any problems or discrepancies to CMS in a timely manner
9. Participate and cooperate (including subcontractors and any other organizations responsible for major functions of the CAHPS Hospice Survey) in all oversight activities conducted by the CAHPS Hospice Survey Project Team

The statements herein are true, complete and accurate to the best of my knowledge.

Survey Vendor Name: _____

Project Director or Authorized Representative Name: _____

Title: _____

Signature: _____

Date: _____

# Appendix M

## Examples of Additional Supplemental Questions for Survey Vendor Use

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# 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**[1]

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

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

## Personal Care Needs[2]

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, was 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.

# Appendix N

## Mail Survey Materials (English)

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# 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
Expires December 31, 2023

# 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 <u>hospice team</u> 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 <u>medicine</u>?**

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 <u>from the hospice team</u> 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

## 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

## YOUR OWN EXPERIENCE WITH HOSPICE

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

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

**36. Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?**

1☐ Too little
2☐ Right amount
3☐ Too much

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

1☐ Too little
2☐ Right amount
3☐ Too much

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

1☐ Too little
2☐ Right amount
3☐ Too much

## OVERALL RATING OF HOSPICE CARE

**39. Please answer the following questions about your family member's care from the hospice named on the survey cover. Do not include care from other hospices in your answers.**

**Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?**

- 0 ☐ 0 Worst hospice care possible
- 1 ☐ 1
- 2 ☐ 2
- 3 ☐ 3
- 4 ☐ 4
- 5 ☐ 5
- 6 ☐ 6
- 7 ☐ 7
- 8 ☐ 8
- 9 ☐ 9
- 10 ☐ 10 Best hospice care possible

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

- 1 ☐ Definitely no
- 2 ☐ Probably no
- 3 ☐ Probably yes
- 4 ☐ Definitely yes

## ABOUT YOUR FAMILY MEMBER

**41. What is the highest grade or level of school that <u>your family member</u> 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 <u>your family member</u> of Hispanic, Latino, or Spanish origin or descent?**

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

**43. What was <u>your family member's</u> race? Please choose one or more.**

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

## ABOUT YOU

**44. What is your age?**

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

**45. Are you male or female?**

1☐ Male
2☐ Female

**46. What is the highest grade or level of school that you have completed?**

1☐ 8th grade or less
2☐ Some high school but did not graduate
3☐ High school graduate or GED
4☐ Some college or 2-year degree
5☐ 4-year college graduate
6☐ More than 4-year college degree

**47. What language do you mainly speak at home?**

1☐ English
2☐ Spanish
3☐ Chinese
4☐ Russian
5☐ Portuguese
6☐ Vietnamese
7☐ Polish
8☐ Korean
9☐ 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
Expires December 31, 2023

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

  0 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***
  0 No

---

### THE HOSPICE PATIENT

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

[1]0 My spouse or partner
[2]0 My parent
[3]0 My mother-in-law or father-in-law
[4]0 My grandparent
[5]0 My aunt or uncle
[6]0 My sister or brother
[7]0 My child
[8]0 My friend
[9]0 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]0 Home
[2]0 Assisted living facility
[3]0 Nursing home
[4]0 Hospital
[5]0 Hospice facility/hospice house
[6]0 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]0 Never ➔ **If Never, go to Question 41**
[2]0 Sometimes
[3]0 Usually
[4]0 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 <u>hospice team</u> 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]0 Yes
[2]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]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 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]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 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]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 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]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 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]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 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]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 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]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 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]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 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]0 Yes
[2]0 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]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 Always

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

[1]0 Yes
[2]0 No ➔ **If No, go to Question 17**

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

[1]0 Yes, definitely
[2]0 Yes, somewhat
[3]0 No

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

[1]0 Yes
[2]0 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]0 Yes, definitely
[2]0 Yes, somewhat
[3]0 No

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

[1]0 Yes, definitely
[2]0 Yes, somewhat
[3]0 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]0 Yes, definitely
[2]0 Yes, somewhat
[3]0 No
[4]0 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]0 Yes
[2]0 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]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 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]0 Yes, definitely
[2]0 Yes, somewhat
[3]0 No
[4]0 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]0 Yes
[2]0 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]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 Always

**26. While your family member was in hospice care, did he or she show any feelings of anxiety or sadness?**

[1]0 Yes
[2]0 No ➔ **If No, go to Question 28**

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

- [1] 0 Never
- [2] 0 Sometimes
- [3] 0 Usually
- [4] 0 Always

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

- [1] 0 Yes
- [2] 0 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] 0 Yes, definitely
- [2] 0 Yes, somewhat
- [3] 0 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] 0 Yes, definitely
- [2] 0 Yes, somewhat
- [3] 0 No
- [4] 0 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] 0 Yes, definitely
- [2] 0 Yes, somewhat
- [3] 0 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] 0 Yes
- [2] 0 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] 0 Never
- [2] 0 Sometimes
- [3] 0 Usually
- [4] 0 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] 0 Never
- [2] 0 Sometimes
- [3] 0 Usually
- [4] 0 Always

## YOUR OWN EXPERIENCE WITH HOSPICE

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

[1]0 Never
[2]0 Sometimes
[3]0 Usually
[4]0 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]0 Too little
[2]0 Right amount
[3]0 Too much

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

[1]0 Too little
[2]0 Right amount
[3]0 Too much

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

[1]0 Too little
[2]0 Right amount
[3]0 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 0 Worst hospice care possible
[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 Best hospice care possible

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

[1]0 Definitely no
[2]0 Probably no
[3]0 Probably yes
[4]0 Definitely yes

## ABOUT YOUR FAMILY MEMBER

**41. What is the highest grade or level of school that <u>your family member</u> completed?**

- [1] 0 8th grade or less
- [2] 0 Some high school but did not graduate
- [3] 0 High school graduate or GED
- [4] 0 Some college or 2-year degree
- [5] 0 4-year college graduate
- [6] 0 More than 4-year college degree
- [7] 0 Don't know

**42. Was <u>your family member</u> of Hispanic, Latino, or Spanish origin or descent?**

- [1] 0 No, not Spanish/Hispanic/Latino
- [2] 0 Yes, Cuban
- [3] 0 Yes, Mexican, Mexican American, Chicano/a
- [4] 0 Yes, Puerto Rican
- [5] 0 Yes, Other Spanish/Hispanic/ Latino

**43. What was <u>your family member's</u> race? Please choose one or more.**

- [1] 0 American Indian or Alaska Native
- [2] 0 Asian
- [3] 0 Black or African American
- [4] 0 Native Hawaiian or other Pacific Islander
- [5] 0 White

## ABOUT YOU

**44. What is your age?**

- [1] 0 18 to 24
- [2] 0 25 to 34
- [3] 0 35 to 44
- [4] 0 45 to 54
- [5] 0 55 to 64
- [6] 0 65 to 74
- [7] 0 75 to 84
- [8] 0 85 or older

**45. Are you male or female?**

- [1] 0 Male
- [2] 0 Female

**46. What is the highest grade or level of school that you have completed?**

- 1 0 8th grade or less
- 2 0 Some high school but did not graduate
- 3 0 High school graduate or GED
- 4 0 Some college or 2-year degree
- 5 0 4-year college graduate
- 6 0 More than 4-year college degree

**47. What language do you <u>mainly</u> speak at home?**

- 1 0 English
- 2 0 Spanish
- 3 0 Chinese
- 4 0 Russian
- 5 0 Portuguese
- 6 0 Vietnamese
- 7 0 Polish
- 8 0 Korean
- 9 0 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
Expires December 31, 2023

# 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.
- 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?**

1O Never ➔ **If Never, go to Question 41**
2O Sometimes
3O Usually
4O 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 <u>hospice team</u> 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?**

1O Yes
2O 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?**

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

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

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

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

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

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

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

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

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

1O Yes
2O 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?**

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

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

1O Yes
2O No ➔ **If No, go to Question 17**

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

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

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

1O Yes
2O 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?**

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

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

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

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

1O Yes
2O No ➔ **If No, go to Question 24**

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

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

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

1O Yes
2O 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?**

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

**26. While your family member was in hospice care, did he or she show any feelings of anxiety or sadness?**

1O Yes
2O No ➔ **If No, go to Question 28**

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

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

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

1O Yes
2O 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?**

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

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

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

1O Yes
2O 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?**

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

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

## YOUR OWN EXPERIENCE WITH HOSPICE

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

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

1O Too little
2O Right amount
3O Too much

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

1O Too little
2O Right amount
3O Too much

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

1O Too little
2O Right amount
3O 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?**

0O 0 Worst hospice care possible
1O 1
2O 2
3O 3
4O 4
5O 5
6O 6
7O 7
8O 8
9O 9
10O 10 Best hospice care possible

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

1O Definitely no
2O Probably no
3O Probably yes
4O Definitely yes

## ABOUT YOUR FAMILY MEMBER

**41. What is the highest grade or level of school that <u>your family member</u> completed?**

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

**42. Was <u>your family member</u> of Hispanic, Latino, or Spanish origin or descent?**

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

**43. What was <u>your family member's</u> race? Please choose one or more.**

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

## ABOUT YOU

**44. What is your age?**

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

**45. Are you male or female?**

1O Male
2O Female

**46. What is the highest grade or level of school that you have completed?**

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

**47. What language do you <u>mainly</u> speak at home?**

1O English
2O Spanish
3O Chinese
4O Russian
5O Portuguese
6O Vietnamese
7O Polish
8O Korean
9O 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 [DECEDENT NAME]. We realize this may be a difficult time for you, but we hope that you will help us learn about the quality of care that you and your family member or friend received from the hospice.

Questions [NOTE THE QUESTION NUMBERS] in the enclosed survey are part of a national initiative sponsored by the United States Department of Health and Human Services (HHS) to measure the quality of care in hospices. The Centers for Medicare & Medicaid Services (CMS), which is part of HHS, is conducting this survey to improve hospice care. CMS pays for most of the hospice care in the U.S. It is CMS' 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. The Centers for Medicare & Medicaid Services (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 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.

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 (Expires December 31, 2023). 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."

**Reply-by Date (Optional)**

*The following two options are available for adding a reply-by date to the* ***follow-up cover letter****.*

*Placed above the salutation, such as:*

Please reply by: [DATE (mm/dd/yyyy)].

*In the fourth paragraph after the sentence, "After you have completed the survey, please return it in the enclosed pre-paid envelope." An example of allowable reply-by text includes:*

Please fill out the enclosed survey and mail it by [DATE (mm/dd/yyyy)] in the pre-paid envelope.

# Appendix O

## Mail Survey Materials (Spanish)

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# 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
Vence el 31 de diciembre, 2023

# CAHPS® Encuesta de Hospicio

## INSTRUCCIONES PARA LA ENCUESTA

- Por favor entréguele esta encuesta a la persona de su hogar que sepa más sobre los cuidados que recibió de este hospicio 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:

  ☐ 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**
  ☐ No

---

### EL PACIENTE DEL HOSPICIO

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

1☐ Es mi esposo/a o pareja
2☐ Es mi padre/madre
3☐ Es mi suegro/a
4☐ Es mi abuelo/a
5☐ Es mi tío/a
6☐ Es mi hermano/a
7☐ Es mi hijo/a
8☐ Es un/a amigo/a
9☐ Otro (por favor imprima):

_____

**2. Para esta encuesta, utilizaremos las palabras "su familiar" para referirnos a la persona cuyo nombre aparece en la carta de presentación de esta encuesta. ¿En qué lugar o lugares recibió su familiar los cuidados de este hospicio? Marque uno o más.**

1☐ En su casa
2☐ En un hogar de asistencia parcial
3☐ En una casa de ancianos y convalecencia
4☐ En un hospital
5☐ En un centro u hogar de hospicio
6☐ Otro (Por favor imprima):

_____

## SU PAPEL

**3. Mientras su familiar estuvo bajo los cuidados del hospicio, ¿con qué frecuencia supervisó usted o participó en dichos cuidados?**

1☐ Nunca ➔ **Si contestó Nunca, pase a la Pregunta 41**

2☐ A veces

3☐ La mayoría de las veces

4☐ Siempre

## LOS CUIDADOS QUE EL HOSPICIO PROPORCIONÓ A SU FAMILIAR

**Al responder el resto de las preguntas de esta encuesta, por favor piense sólo en la experiencia de su familiar con el hospicio nombrado en la portada de esta encuesta.**

**4. Para esta encuesta, el <u>equipo del hospicio</u> incluye a todos los doctores, enfermeras, trabajadores sociales, religiosos y demás personas que le proporcionaron cuidados paliativos a su familiar. Mientras su familiar estaba bajo los cuidados del hospicio, ¿tuvo usted que ponerse en contacto con el equipo del hospicio durante la noche, en fin de semana o en día festivo porque tenía alguna duda o necesitaba ayuda para el cuidado de su familiar?**

1☐ Sí

2☐ No ➔ **Si contestó No, pase a la Pregunta 6**

**5. ¿Con qué frecuencia obtuvo la ayuda que necesitaba del equipo del hospicio durante la noche, en fin de semana o en día festivo?**

1☐ Nunca

2☐ A veces

3☐ La mayoría de las veces

4☐ Siempre

**6. Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo de personal del hospicio lo mantuvo a usted informado de cuando iban a llegar a cuidar a su familiar?**

1☐ Nunca

2☐ A veces

3☐ La mayoría de las veces

4☐ Siempre

**7. Mientras su familiar estaba bajo los cuidados de este hospicio, cuando usted o un miembro de su familia le pedían ayuda al equipo del hospicio, ¿con qué frecuencia obtenían la ayuda tan pronto como la necesitaban?**

1☐ Nunca

2☐ A veces

3☐ La mayoría de las veces

4☐ Siempre

8. **Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio explicaba las cosas de un modo fácil de entender?**

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

9. **Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio lo mantenía a usted informado sobre el estado de su familiar?**

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

10. **Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia alguien del equipo del hospicio le dio a usted informes confusos o contradictorios sobre el estado o los cuidados de su familiar?**

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

11. **Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio 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 le 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 <u>medicamento</u> contra el dolor?**

1☐ Sí
2☐ No ➔ **Si contestó No, pase a la Pregunta 21**

**18. Entre los efectos secundarios de la medicina contra el dolor está la somnolencia. ¿Algún personal del equipo del hospicio habló con usted o su familiar sobre los efectos secundarios del medicamento contra el dolor?**

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

**19. ¿El equipo del hospicio le dio la capacitación que usted necesitaba para saber de qué efectos secundarios del medicamento contra el dolor tenía usted que estar pendiente?**

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

**20. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber si había que darle a su familiar más medicamento contra el dolor y, si sí, cuándo dárselo?**

1☐ Sí, definitivamente
2☐ Sí, más o menos
3☐ No
4☐ No tuve necesidad de dar medicamento para el dolor a mi familiar

**21. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿en algún momento tuvo su familiar dificultad para respirar o recibió tratamiento para su dificultad para respirar?**

1☐ Sí
2☐ No ➔ **Si contestó No, pase a la Pregunta 24**

**22. ¿Con qué frecuencia su familiar recibió la ayuda que necesitaba para su dificultad para respirar?**

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

**23. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber cómo ayudar a su familiar si él/ella tenía problemas para respirar?**

1☐ Sí, definitivamente
2☐ Sí, más o menos
3☐ No
4☐ No tuve que ayudar a mi familiar con problemas para respirar

**24. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿en algún momento tuvo su familiar problemas de estreñimiento?**

1☐ Sí
2☐ No ➔ **Si contestó No, pase a la Pregunta 26**

**25. ¿Con qué frecuencia su familiar recibió la ayuda que necesitaba para sus problemas de estreñimiento?**

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

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

1☐ Sí
2☐ No ➔ **Si contestó No, pase a la Pregunta 28**

**27. ¿Con qué frecuencia su familiar recibió <u>del equipo del hospicio</u> la ayuda que necesitaba para su ansiedad o tristeza?**

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

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

1☐ Sí
2☐ No ➔ **Si contestó No, pase a la Pregunta 30**

**29. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber qué hacer si su familiar se ponía inquieto o agitado?**

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

**30. Mover a su familiar incluye acciones como ayudarlo/a a darse la vuelta en la cama, o meterse y salir de la cama o sentarse y levantarse de una silla de ruedas. ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber cómo mover a su familiar de manera segura?**

1☐ Sí, definitivamente
2☐ Sí, más o menos
3☐ No
4☐ No tuve que mover a mi familiar

**31. ¿Le dio el equipo del hospicio tanta información como usted quería sobre qué acontecimientos esperar mientras su familiar estuviera muriéndose?**

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

## CUIDADOS DE HOSPICIO BRINDADOS EN UN HOGAR DE ANCIANOS Y CONVALECENCIA

**32. Algunas personas que viven en un hogar de ancianos o de convalecencia reciben allí mismo los cuidados de hospicio que necesitan. ¿Su familiar recibió cuidados paliativos de este hospicio cuando vivía en una casa de convalecencia?**

1☐ Sí
2☐ No ➔ **Si contestó No, pase a la Pregunta 35**

**33. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿con qué frecuencia el equipo del hospicio y el personal del hogar de ancianos y convalecencia se pusieron de acuerdo y acoplaron bien para proporcionarle los cuidados a su familiar?**

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

**34. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿con qué frecuencia los informes que el personal de la casa de convalecencia le daban sobre su familiar eran diferentes de los informes que le daba el equipo del hospicio?**

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

## SU PROPIA EXPERIENCIA CON EL CENTRO DE HOSPICIO

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

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

**36. Apoyo respecto a sus creencias religiosas o espirituales incluye hablar, rezar, momentos de recogimiento, u otras maneras de satisfacer sus necesidades religiosas o espirituales. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿cuánto apoyo recibió usted respecto a sus creencias religiosas y espirituales por parte del equipo del hospicio?**

1☐ Demasiado poco
2☐ Justo el necesario
3☐ Demasiado

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

1☐ Demasiado poco
2☐ Justo el necesario
3☐ Demasiado

**38. Durante las semanas posteriores a la muerte de su familiar, ¿recibió usted todo el apoyo emocional que usted quería por parte del equipo del hospicio?**

1☐ Demasiado poco
2☐ Justo el necesario
3☐ Demasiado

## CALIFICACIÓN GENERAL DE LOS CUIDADOS DEL HOSPICIO

**39. Por favor conteste las siguientes preguntas sobre los cuidados paliativos que recibió su familiar por parte del hospicio cuyo nombre aparece en la portada de esta encuesta. No incluya en sus respuestas cuidados proporcionados por otros.**

**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, cubano
3☐ Sí, mexicano, mexicano-americano, chicano
4☐ Sí, puertorriqueño
5☐ Sí, de otro origen hispano, latino o español

**43. ¿A qué raza pertenece su familiar? Marque una o más.**

1☐ Indígena americana o nativa de Alaska
2☐ Asiática
3☐ Negra o afroamericana
4☐ Nativa de Hawái u otras Islas del Pacífico
5☐ Blanca

## 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 <u>principalmente</u> en casa?**

1☐ Inglés
2☐ Español
3☐ Chino
4☐ Ruso
5☐ Portugués
6☐ Vietnamita
7☐ Polaco
8☐ Coreano
9☐ 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

Vence el 31 de diciembre, 2023

# CAHPS® Encuesta de Hospicio

## INSTRUCCIONES PARA LA ENCUESTA

- Por favor entréguele esta encuesta a la persona de su hogar que sepa más sobre los cuidados que recibió de este hospicio 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
  ● 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**
  0 No

---

### El PACIENTE DEL HOSPICIO

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

1 0 Es mi esposo/a o pareja
2 0 Es mi padre/madre
3 0 Es mi suegro/a
4 0 Es mi abuelo/a
5 0 Es mi tío/a
6 0 Es mi hermano/a
7 0 Es mi hijo/a
8 0 Es un/a amigo/a
9 0 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 0 En su casa
2 0 En un hogar de asistencia parcial
3 0 En una casa de ancianos y convalecencia
4 0 En un hospital
5 0 En un centro u hogar de hospicio
6 0 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]0 Nunca ➔ **Si contestó Nunca, pase a la Pregunta 41**

[2]0 A veces

[3]0 La mayoría de las veces

[4]0 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 <u>equipo del hospicio</u> 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]0 Sí

[2]0 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]0 Nunca

[2]0 A veces

[3]0 La mayoría de las veces

[4]0 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]0 Nunca

[2]0 A veces

[3]0 La mayoría de las veces

[4]0 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]0 Nunca

[2]0 A veces

[3]0 La mayoría de las veces

[4]0 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]0 Nunca
[2]0 A veces
[3]0 La mayoría de las veces
[4]0 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]0 Nunca
[2]0 A veces
[3]0 La mayoría de las veces
[4]0 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]0 Nunca
[2]0 A veces
[3]0 La mayoría de las veces
[4]0 Siempre

**11. Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio trataba a su familiar con dignidad y respeto?**

[1]0 Nunca
[2]0 A veces
[3]0 La mayoría de las veces
[4]0 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]0 Nunca
[2]0 A veces
[3]0 La mayoría de las veces
[4]0 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]0 Sí
[2]0 No ➔ **Si contestó No, pase a la Pregunta 15**

**14. ¿Con qué frecuencia el equipo del hospicio le escuchó con atención cuando usted les habló sobre problemas relacionados con los cuidados de su familiar?**

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

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

[1]0 Sí
[2]0 No ➔ **Si contestó No, pase a la Pregunta 17**

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

[1]0 Sí, definitivamente
[2]0 Sí, más o menos
[3]0 No

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

[1]0 Sí
[2]0 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]0 Sí, definitivamente
[2]0 Sí, más o menos
[3]0 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]0 Sí, definitivamente
[2]0 Sí, más o menos
[3]0 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]0 Sí, definitivamente
[2]0 Sí, más o menos
[3]0 No
[4]0 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 sitió ansiedad o tristeza?**

[1]0 Sí
[2]0 No ➔ **Si contestó No, pase a la Pregunta 28**

**27. ¿Con qué frecuencia su familiar recibió <u>del equipo del hospicio</u> 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]0 Sí, definitivamente
[2]0 Sí, más o menos
[3]0 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]0 Sí, definitivamente
[2]0 Sí, más o menos
[3]0 No
[4]0 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]0 Sí, definitivamente
[2]0 Sí, más o menos
[3]0 No

## CUIDADOS DE HOSPICIO BRINDADOS EN UN HOGAR DE ANCIANOS Y CONVALECENCIA

**32. Algunas personas que viven en un hogar de ancianos o de convalecencia reciben allí mismo los cuidados de hospicio que necesitan. ¿Su familiar recibió cuidados paliativos de este hospicio cuando vivía en una casa de convalecencia?**

[1]0 Sí
[2]0 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]0 Nunca
[2]0 A veces
[3]0 La mayoría de las veces
[4]0 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]0 Nunca
[2]0 A veces
[3]0 La mayoría de las veces
[4]0 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] 0 Nunca
- [2] 0 A veces
- [3] 0 La mayoría de las veces
- [4] 0 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] 0 Demasiado poco
- [2] 0 Justo el necesario
- [3] 0 Demasiado

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

- [1] 0 Demasiado poco
- [2] 0 Justo el necesario
- [3] 0 Demasiado

**38. Durante las semanas <u>posteriores</u> a la muerte de su familiar, ¿recibió usted todo el apoyo emocional que usted quería por parte del equipo del hospicio?**

- [1] 0 Demasiado poco
- [2] 0 Justo el necesario
- [3] 0 Demasiado

## CALIFICACIÓN GENERAL DE LOS CUIDADOS DEL HOSPICIO

**39. Por favor conteste las siguientes preguntas sobre los cuidados paliativos que recibió su familiar por parte del hospicio cuyo nombre aparece en la portada de esta encuesta. No incluya en sus respuestas cuidados proporcionados por otros.**

**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 0 Los peores cuidados posibles de un hospicio
- [1] 0 1
- [2] 0 2
- [3] 0 3
- [4] 0 4
- [5] 0 5
- [6] 0 6
- [7] 0 7
- [8] 0 8
- [9] 0 9
- [10] 0 10 Los mejores cuidados posibles de un hospicio

**40. ¿Le recomendaría este hospicio a sus amigos y familiares?**

- 1 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, cubano
- 3 Sí, mexicano, mexicano-americano, chicano
- 4 Sí, puertorriqueño
- 5 Sí, de otro origen hispano, latino o español

**43. ¿A qué raza pertenece su familiar? Marque una o más.**

- 1 Indígena americana o nativa de Alaska
- 2 Asiática
- 3 Negra o afroamericana
- 4 Nativa de Hawái u otras Islas del Pacífico
- 5 Blanca

## 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] 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 <u>principalmente</u> en casa?**

- [1] 0 Inglés
- [2] 0 Español
- [3] 0 Chino
- [4] 0 Ruso
- [5] 0 Portugués
- [6] 0 Vietnamita
- [7] 0 Polaco
- [8] 0 Coreano
- [9] 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

Vence el 31 de diciembre, 2023

# CAHPS® Encuesta de Hospicio

## INSTRUCCIONES PARA LA ENCUESTA

- Por favor entréguele esta encuesta a la persona de su hogar que sepa más sobre los cuidados que recibió de este hospicio 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.

  ○ 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**
  ○ 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 <u>equipo del hospicio</u> 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 hospicio 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 le 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 <u>medicamento</u> 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]O Sí, definitivamente
[2]O Sí, más o menos
[3]O 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]O Sí, definitivamente
[2]O Sí, más o menos
[3]O 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]O Sí, definitivamente
[2]O Sí, más o menos
[3]O No
[4]O 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]O Sí
[2]O 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]O Nunca
[2]O A veces
[3]O La mayoría de las veces
[4]O 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]O Sí, definitivamente
[2]O Sí, más o menos
[3]O No
[4]O 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]O Sí
[2]O 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 sitió ansiedad o tristeza?**

[1]O Sí
[2]O No ➔**Si contestó No, pase a la Pregunta 28**

**27. ¿Con qué frecuencia su familiar recibió <u>del equipo del hospicio</u> 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?**

[1]O Sí
[2]O 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]O Nunca
[2]O A veces
[3]O La mayoría de las veces
[4]O 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]O Nunca
[2]O A veces
[3]O La mayoría de las veces
[4]O 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]O Nunca
[2]O A veces
[3]O La mayoría de las veces
[4]O 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]O Demasiado poco
[2]O Justo el necesario
[3]O Demasiado

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

[1]O Demasiado poco
[2]O Justo el necesario
[3]O Demasiado

**38. Durante las semanas <u>posteriores</u> 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

## 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.**

**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]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

## SOBRE SU FAMILIAR

**41. ¿Cuál es el grado o nivel escolar más alto que ha completado <u>su familiar</u>?**

[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. ¿<u>Su familiar</u> es de origen hispano, latino o español?**

[1]O No, ni hispano, ni latino, ni español
[2]O Sí, cubano
[3]O Sí, mexicano, mexicano-americano, chicano
[4]O Sí, puertorriqueño
[5]O Sí, de otro origen hispano, latino o español

**43. ¿A qué raza pertenece su familiar? Marque una o más.**

[1]O Indígena americana o nativa de Alaska
[2]O Asiática
[3]O Negra o afroamericana
[4]O Nativa de Hawái u otras Islas del Pacífico
[5]O Blanca

## SOBRE USTED

**44. ¿Qué edad tiene usted?**

[1]O de 18 a 24 años
[2]O de 25 a 34 años
[3]O de 35 a 44 años
[4]O de 45 a 54 años
[5]O de 55 a 64 años
[6]O de 65 a 74 años
[7]O de 75 a 84 años
[8]O 85 años o más

**45. ¿Es usted hombre o mujer?**

[1]O Hombre
[2]O Mujer

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

[1]O 8 años de escuela o menos
[2]O Estudios de escuela secundario, 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

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

[1]O Inglés
[2]O Español
[3]O Chino
[4]O Ruso
[5]O Portugués
[6]O Vietnamita
[7]O Polaco
[8]O Coreano
[9]O 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 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]

# *Sample Follow-up Cover Letter for the CAHPS Hospice Survey*

[HOSPICE OR VENDOR LETTERHEAD]

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

Estimado/a [SAMPLED CAREGIVER NAME]:

Nuestros registros indican que recientemente usted fue una de las personas encargadas del cuidado de [DECEDENT NAME] en [NAME OF HOSPICE]. Hace aproximadamente tres semanas, le enviamos una encuesta sobre la atención que usted y su familiar o amigo recibieron en ese hospicio. Si ya nos devolvió la encuesta, por favor acepte nuestras disculpas y haga caso omiso de esta carta. Si no lo ha hecho ya, le agradeceríamos que se tomara el tiempo de contestar este importante cuestionario.

Esperamos que usted aproveche esta oportunidad para ayudarnos a saber qué calidad de atención recibió su familiar o amigo. Los resultados de esta encuesta se utilizarán para ayudar a garantizar que todos los estadounidenses reciban la más alta calidad de cuidados paliativos.

Las preguntas [NOTE THE QUESTION NUMBERS] del cuestionario adjunto son parte de una iniciativa nacional patrocinada por el Departamento de Salud y Servicios Humanos (HHS) de los Estados Unidos para evaluar la calidad de la atención de los hospicios. 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.

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 (Vence el 31 de diciembre, 2023). 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 iqual que las prequntas Sobre Sue Familiar 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."

**Reply-by Date (Optional)**

*The following two options are available for adding a reply-by date to the* ***follow-up cover letter****.*

*Placed above the salutation, such as:*

Por favor responda antes: de [DATE (dd/mm/yyyy)].

*In the fourth paragraph after the sentence, "After you have completed the survey, please return it in the enclosed pre-paid envelope." An example of allowable reply-by text includes:*

Por favor complete la encuesta adjunta y devuélvalo antes de [DATE (dd/mm/yyyy)] en el sobre porte prepago.

# Appendix P

## Mail Survey Materials (Traditional Chinese)

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# CAHPS® 安寧療護問卷調查

請根據患者從以下安寧療護機構所得到的服務回答下列調查問題:

[NAME OF HOSPICE]

在此問卷中所有的問題都與這個安寧療護機構的經驗有關.

如果您想知道更多有關此問卷的資訊，請打免費電話 [TOLL FREE NUMBER]. 所有打到這個號碼的電話都是免費的.

OMB# 0938-1257
2023 年 12 月 31 日到期

患者名字已列在問卷調查的首頁，請將此問卷交給您家中最瞭解患者所接受到安寧療護的人.

# 問卷調查填寫指南

- 此問卷需用深色的筆填寫.
- 請直接在選項前面的方框內畫“X”作為回答， 如下所示：

  ☒ 是

  ☐ 否

- 問卷中有時會指示您跳過一些問題，如以下情況，您會看到一個箭頭，旁邊的指示會告訴您接下來要回答哪一個問題，如下所示:

  ☒ 是➔如果選擇“是”，請跳至問題 **1**

  ☐ 否

---

## 安寧療護患者

**1. 您與問卷調查首頁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. 在此次問卷調查中, 詞語“家屬”是指在問卷調查的首頁中所列之患者. 您的家屬在什麼地方接受了該機構的安寧療護服務？ 請選擇一項或多項.**

1 ☐ 家

2 ☐ 輔助生活機構

3 ☐ 療養院

4 ☐ 醫院

5 ☐ 安寧療護機構/安養院

6 ☐ 其他（請用正楷填寫）：

_____

## 您的角色

**3.** 在您的家屬接受安寧療護期間，您多經常參與或監督他或她所接受的安寧療護？

1 ☐ 從未 ➔ 如果選擇“從未”，請跳至問題 **41**

2 ☐ 有時

3 ☐ 經常

4 ☐ 總是

## 您的家屬的安寧療護

在回答問卷中所有問題的時候，請只考慮您的家屬在本調查問卷附件中所列的安寧療護機構的經驗.

**4.** 在此問卷中，安寧療護小組包括所有護士、醫生、社工、靈性輔導師以及其他曾經向您的家屬提供安寧療護的人. 在您的家屬接受安寧療護期間您是否曾需要在夜間、週末或假日裏聯絡安寧療護小組，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.** 在夜間、週末或假日裏，您多常能從安寧療護小組那裏得到所需的幫助？

1 ☐ 從未

2 ☐ 有時

3 ☐ 經常

4 ☐ 總是

**6.** 在您的家屬接受安寧療護期間，安寧療護小組多常會通知您他們將何時到場來照料您的家屬？

1 ☐ 從未

2 ☐ 有時

3 ☐ 經常

4 ☐ 總是

**7.** 在您的家屬接受安寧療護期間，當您或者您的家屬向安寧療護小組求助的時候，多常能立即得到所需的幫助？

1 ☐ 從未

2 ☐ 有時

3 ☐ 經常

4 ☐ 總是

**8.** 在您的家屬接受安寧療護期間，安寧療護小組有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.** 在您的家屬接受安寧療護期間，安寧療護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.** 在您的家屬接受安寧療護期間，對於您家屬的狀況或護理情況，安寧療護小組的成員有多常提供您令人困惑或相互矛盾的資訊？

1 ☐ 從未
2 ☐ 有時
3 ☐ 經常
4 ☐ 總是

**11.** 在您的家屬接受安寧療護期間，安寧療護小組有多常以有尊嚴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.** 在您的家屬接受安寧療護期間，安寧療護小組有多常讓您感到他們真的關心您的家屬？

1 ☐ 從未
2 ☐ 有時
3 ☐ 經常
4 ☐ 總是

**13.** 在您的家屬接受安寧療護期間，您是否有跟安寧療護小組討論過任何在安寧療護中遇到的問題？

1 ☐ 是
2 ☐ 否 ➔ **如果選擇"否"，請跳至問題 15**

**14.** 在您與安寧療護小組討論家屬的安寧療護中出現的問題時，他們多經常會認真傾聽？

1 ☐ 從未
2 ☐ 有時
3 ☐ 經常
4 ☐ 總是

**15.** 在您的家屬接受安寧療護期間，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.** 您的家屬是否得到過所須的幫助以緩解他或她的疼痛？

1 ☐ 是的，當然是
2 ☐ 是的，某種程度上是
3 ☐ 否

**17.** 在您的家屬接受安寧療護期間，他或她是否服用了任何止痛的<u>藥物</u>？

1 ☐ 是
2 ☐ 否 ➔ **如果選擇"否"，請跳至問題 21**

**18.** 止痛藥物有副作用，其中包括嗜睡，安寧療護小組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，安寧療護小組是否提供您所需的訓練？

1 ☐ 是的，當然是

2 ☐ 是的，某種程度上是

3 ☐ 否

**20.** 關於是否與何時要給您的家屬服用 更多劑量的止痛藥物，安寧療護小組是否提供過您所需的訓練？

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.** 在您的家屬接受安寧療護期間， 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.** 關於在家屬呼吸困難時如何給予幫助，安寧療護小組是否提供過您所需的訓練？

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.** 在您的家屬接受安寧療護期間，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.** 遇到便秘問題的時候，您的家屬有多常得到所需的幫助？

1 ☐ 從未

2 ☐ 有時

3 ☐ 經常

4 ☐ 總是

**26.** 在您的家屬接受安寧療護期間， 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 28**

**27.** 在您的家屬感到焦慮或悲傷時，他或她有多常能從安寧療護小組處得到所需的幫助？

1 ☐ 從未

2 ☐ 有時

3 ☐ 經常

4 ☐ 總是

**28.** 在您的家屬接受安寧療護期間，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，安寧療護小組是否提供過您所需的訓練？

1 ☐ 是的，當然是

2 ☐ 是的，某種程度上是

3 ☐ 否

**30.** 搬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. 安寧療護小組是否提供過您所需的訓練來安全搬動您的家屬呢？

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會發生的事，安寧療護小組是否盡可能地向您提供了你所想要的相關資訊？

1 ☐ 是的，當然是

2 ☐ 是的，某種程度上是

3 ☐ 否

## 在療養院中得到的安寧療護

**32.** 有些人是在療養院中接受安寧療護服務的.您的家屬是否在他或她於療養院居住期間從該安寧療護醫院接受安寧療護服務？

1 ☐ 是

2 ☐ 否 ➔ **如果選擇“否”，請跳至問題 35**

**33.** 在您的家屬接受安寧療護期間，療養院工作人員和安寧療護小組多經常能協調一致來照顧您的家屬？

1 ☐ 從未

2 ☐ 有時

3 ☐ 經常

4 ☐ 總是

**34.** 在您的家屬接受安寧療護期間，療養院工作人員給您的資訊與安寧療護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

## 您自己的與安寧療護有關的經歷

**35.** 在您的家屬接受安寧療護期間，安寧療護小組多經常認真聽您說話？

1 ☐ 從未
2 ☐ 有時
3 ☐ 經常
4 ☐ 總是

**36.** 對宗教或靈性上的支援包括談話、 禱告、靈修或其他以滿足您宗教需要或靈性需求的方式.在您的家屬接受安寧療護期間，您從安寧療護小組得到了多少對宗教和靈性上的支持？

1 ☐ 太少
2 ☐ 適中
3 ☐ 太多

**37.** 在您的家屬接受安寧療護期間，您從安寧療護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，您從安寧療護小組得到了多少情感支持？

1 ☐ 太少
2 ☐ 適中
3 ☐ 太多

## 安寧療護整體評分

**39.** 根據您的家屬從問卷首頁所示的安寧療護得到的服務，回答以下問題.在回答時請不要將其他安寧療護的服務考慮在內.

請用 **0** 到 **10** 的數字表示，**0** 代表最差的安寧療護服務，**10** 則代表最好的安寧療護. 您會用哪個數字評價您家屬的安寧療護？

0 ☐ 0 最差的安寧療護
1 ☐ 1
2 ☐ 2
3 ☐ 3
4 ☐ 4
5 ☐ 5
6 ☐ 6
7 ☐ 7
8 ☐ 8
9 ☐ 9
10 ☐ 10 最好的安寧療護

**40.** 您會向您的朋友和家人推薦該安寧療護機構嗎？

1 ☐ 當然不會
2 ☐ 可能不會
3 ☐ 可能會
4 ☐ 當然會

## 有關您的家屬

**41.** 您的家屬已完成的最高學校年級或最高學歷是？

1 ☐ 國/初中 (8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
7 ☐ 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 ☐ 否，不是西班牙人/西班牙裔/拉丁裔
2 ☐ 是，是古巴人
3 ☐ 是，是墨西哥人、墨西哥裔美國人或奇卡諾人
4 ☐ 是，是波多黎各人
5 ☐ 是，是其他西班牙人/西班牙裔/拉丁裔人

**43.** 您的家屬的種族是？請選擇一項或多項.

1 ☐ 印第安人或阿拉斯加原住民
2 ☐ 亞洲人
3 ☐ 黑人或非裔美國人
4 ☐ 夏威夷島原住民或其他太平洋島民
5 ☐ 白人

## 關於您自己

**44.** 您的年齡是？

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.** 您的性別是？

1 ☐ 男
2 ☐ 女

**46.** 您已完成的最高學校年級或最高學歷是？

1 ☐ 國/初中 (8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 ☐ 波蘭文

8 ☐ 韓文

9 ☐ 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® 安寧療護問卷調查

請根據患者從以下安寧療護機構所得到的服務回答下列調查問題:

[NAME OF HOSPICE]

在此問卷中所有的問題都與這個安寧療護機構的經驗有關.

如果您想知道更多有關此問卷的資訊，請打免費電話 [TOLL FREE NUMBER]. 所有打到這個號碼的電話都是免費的.

OMB# 0938-1257
2023 年 12 月 31 日到期

患者名字已列在問卷調查的首頁，請將此問卷交給您家中最瞭解患者所接受到安寧療護的人.

## 問卷調查填寫指南

- 此問卷需用深色的筆填寫.
- 請直接在選項前面的**圓圈**內畫“X”作為回答，如下所示：

  ● 是

  ○ 否

- 問卷中有時會指示您跳過一些問題，如以下情況，您會看到一個箭頭，旁邊的指示會告訴您接下來要回答哪一個問題，如下所示：

  ● 是 ➔ **如果選擇“是”，請跳至問題 1**

  ○ 否

---

## 安寧療護患者

**1. 您與問卷調查首頁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. 在此次問卷調查中, 詞語“家屬”是指在問卷調查的首頁中所列之患者. 您的家屬在什麼地方接受了該機構的安寧療護服務？ 請選擇一項或多項.**

1○ 家

2○ 輔助生活機構

3○ 療養院

4○ 醫院

5○ 安寧療護機構/安養院

6○ 其他（請用正楷填寫）：

_____

## 您的角色

**3.** 在您的家屬接受安寧療護期間，您多經常參與或監督他或她所接受的安寧療護？

1O 從未 ➔ 如果選擇“從未”，請跳至問題 **41**

2O 有時

3O 經常

4O 總是

## 您的家屬的安寧療護

在回答問卷中所有問題的時候，請只考慮您的家屬在本調查問卷附件中所列的安寧療護機構的經驗.

**4.** 在此問卷中，安寧療護小組包括所有護士、醫生、社工、靈性輔導師以及其他曾經向您的家屬提供安寧療護的人. 在您的家屬接受安寧療護期間您是否曾需要在夜間、週末或假日裏聯絡安寧療護小組，對家屬的護理提出問題或者尋求幫助呢？

1O 是

2O 否 ➔ 如果選擇“否”，請跳至問題 **6**

**5.** 在夜間、週末或假日裏，您多常能從安寧療護小組那裏得到所需的幫助？

1O 從未

2O 有時

3O 經常

4O 總是

**6.** 在您的家屬接受安寧療護期間，安寧療護小組多常會通知您他們將何時到場來照料您的家屬？

1O 從未

2O 有時

3O 經常

4O 總是

**7.** 在您的家屬接受安寧療護期間，當您或者您的家屬向安寧療護小組求助的時候，多常能立即得到所需的幫助？

1O 從未

2O 有時

3O 經常

4O 總是

**8.** 在您的家屬接受安寧療護期間，安寧療護小組有多經常能用清晰易懂的方式向您解釋事情？

1O 從未

2O 有時

3O 經常

4O 總是

**9.** 在您的家屬接受安寧療護期間，安寧療護小組多經常會通知您讓您瞭解您家屬的情況？

1O 從未

2O 有時

3O 經常

4O 總是

**10.** 在您的家屬接受安寧療護期間，對於您家屬的狀況或護理情況，安寧療護小組的成員有多常提供您令人困惑或相互矛盾的資訊？

1 從未
2 有時
3 經常
4 總是

**11.** 在您的家屬接受安寧療護期間，安寧療護小組有多常以有尊嚴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.** 在您的家屬接受安寧療護期間，安寧療護小組有多常讓您感到他們真的關心您的家屬？

1 從未
2 有時
3 經常
4 總是

**13.** 在您的家屬接受安寧療護期間，您是否有跟安寧療護小組討論過任何在安寧療護中遇到的問題？

1 是
2 否 ➔ **如果選擇"否"，請跳至問題 15**

**14.** 在您與安寧療護小組討論家屬的安寧療護中出現的問題時，他們多經常會認真傾聽？

1 從未
2 有時
3 經常
4 總是

**15.** 在您的家屬接受安寧療護期間，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.** 您的家屬是否得到過所須的幫助以緩解他或她的疼痛？

1 是的，當然是
2 是的，某種程度上是
3 否

**17.** 在您的家屬接受安寧療護期間，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，其中包括嗜睡，安寧療護小組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，安寧療護小組是否提供您所需的訓練？

1 0 是的，當然是

2 0 是的，某種程度上是

3 0 否

**20.** 關於是否與何時要給您的家屬服用 更多劑量的止痛藥物，安寧療護小組是否提供過您所需的訓練？

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.** 在您的家屬接受安寧療護期間， 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.** 關於在家屬呼吸困難時如何給予幫助，安寧療護小組是否提供過您所需的訓練？

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.** 在您的家屬接受安寧療護期間，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.** 遇到便秘問題的時候，您的家屬有多常得到所需的幫助？

1 0 從未

2 0 有時

3 0 經常

4 0 總是

**26.** 在您的家屬接受安寧療護期間， 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 **28**

**27.** 在您的家屬感到焦慮或悲傷時，他或她有多常能從安寧療護小組處得到所需的幫助？

1 從未

2 有時

3 經常

4 總是

**28.** 在您的家屬接受安寧療護期間，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，安寧療護小組是否提供過您所需的訓練？

1 是的，當然是

2 是的，某種程度上是

3 否

**30.** 搬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. 安寧療護小組是否提供過您所需的訓練來安全搬動您的家屬呢？

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會發生的事，安寧療護小組是否盡可能地向您提供了你所想要的相關資訊？

1 是的，當然是

2 是的，某種程度上是

3 否

## 在療養院中得到的安寧療護

**32.** 有些人是在療養院中接受安寧療護服務的.您的家屬是否在他或她於療養院居住期間從該安寧療護醫院接受安寧療護服務？

1 是

2 否 ➔ **如果選擇“否”，請跳至問題 35**

**33.** 在您的家屬接受安寧療護期間，療養院工作人員和安寧療護小組多經常能協調一致來照顧您的家屬？

1 從未

2 有時

3 經常

4 總是

**34.** 在您的家屬接受安寧療護期間，療養院工作人員給您的資訊與安寧療護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

## 您自己的與安寧療護有關的經歷

**35.** 在您的家屬接受安寧療護期間，安寧療護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.** 對宗教或靈性上的支援包括談話、 禱告、靈修或其他以滿足您宗教需要或靈性需求的方式.在您的家屬接受安寧療護期間，您從安寧療護小組得到了多少對宗教和靈性上的支持？

1 O 太少
2 O 適中
3 O 太多

**37.** 在您的家屬接受安寧療護期間，您從安寧療護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，您從安寧療護小組得到了多少情感支持？

1 O 太少
2 O 適中
3 O 太多

## 安寧療護整體評分

**39.** 根據您的家屬從問卷首頁所示的安寧療護得到的服務，回答以下問題.在回答時請不要將其他安寧療護的服務考慮在內.

請用 **0** 到 **10** 的數字表示，**0** 代表最差的安寧療護服務，**10** 則代表最好的安寧療護. 您會用哪個數字評價您家屬的安寧療護？

0 O 0 最差的安寧療護
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 最好的安寧療護

**40.** 您會向您的朋友和家人推薦該安寧療護機構嗎？

1 O 當然不會
2 O 可能不會
3 O 可能會
4 O 當然會

## 有關您的家屬

**41.** 您的家屬已完成的最高學校年級或最高學歷是？

1 O 國/初中 (8年級) 或以下
2 O 上過高中，但是沒有畢業
3 O 高中畢業或高中同等學歷
4 O 上過大學或兩年制大學學位
5 O 四年制大學畢業
6 O 四年以上大學學位
7 O 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 O 否，不是西班牙人/西班牙裔/拉丁裔
2 O 是，是古巴人
3 O 是，是墨西哥人、墨西哥裔美國人或奇卡諾人
4 O 是， 是波多黎各人
5 O 是，是其他西班牙人/西班牙裔/拉丁裔人

**43.** 您的家屬的種族是？請選擇一項或多項.

1 O 印第安人或阿拉斯加原住民
2 O 亞洲人
3 O 黑人或非裔美國人
4 O 夏威夷島原住民或其他太平洋島民
5 O 白人

## 關於您自己

**44.** 您的年齡是？

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

**45.** 您的性別是？

1 O 男
2 O 女

**46.** 您已完成的最高學校年級或最高學歷是？

1 O 國/初中 (8年級) 或以下

2 O 上過高中，但是沒有畢業

3 O 高中畢業或高中同等學歷

4 O 上過大學或兩年制大學學位

5 O 四年制大學畢業

6 O 四年以上大學學位

**47.** 您在家裏主要講哪種語言？

1 O 英語

2 O 西班牙語

3 O 中文

4 O 俄語

5 O 葡萄牙語

6 O 越南語

7 O 波蘭文

8 O 韓文

9 O 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® 安寧療護問卷調查

請根據患者從以下安寧療護機構所得到的服務回答下列調查問題:

[NAME OF HOSPICE]

在此問卷中所有的問題都與這個安寧療護機構的經驗有關.

如果您想知道更多有關此問卷的資訊，請打免費電話 [TOLL FREE NUMBER]. 所有打到這個號碼的電話都是免費的.

OMB# 0938-1257
2023 年 12 月 31 日到期

患者名字已列在問卷調查的首頁，請將此問卷交給您家中最瞭解患者所接受到安寧療護的人.

# 問卷調查填寫指南

- 此問卷需用深色的筆填寫.
- 請直接在選項前面的圓圈內畫“X”作為回答， 如下所示：

  ● 是
  ○ 否

- 問卷中有時會指示您跳過一些問題，如以下情況，您會看到一個箭頭，旁邊的指示會告訴您接下來要回答哪一個問題，如下所示 :

  ● 是 ➔ **如果選擇“是”，請跳至問題 1**
  ○ 否

---

## 安寧療護患者

**1.** 您與問卷調查首頁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.** 在此次問卷調查中, 詞語“家屬”是指在問卷調查的首頁中所列之患者. 您的家屬在什麼地方接受了該機構的安寧療護服務？ 請選擇一項或多項.

[1]○ 家
[2]○ 輔助生活機構
[3]○ 療養院
[4]○ 醫院
[5]○ 安寧療護機構/安養院
[6]○ 其他（請用正楷填寫）：

_____

## 您的角色

**3.** 在您的家屬接受安寧療護期間，您多經常參與或監督他或她所接受的安寧療護？

[1]O 從未 ➔ 如果選擇“從未”，請跳至問題 **41**

[2]O 有時

[3]O 經常

[4]O 總是

## 您的家屬的安寧療護

在回答問卷中所有問題的時候，請只考慮您的家屬在本調查問卷附件中所列的安寧療護機構的經驗.

**4.** 在此問卷中，安寧療護小組包括所有護士、醫生、社工、靈性輔導師以及其他曾經向您的家屬提供安寧療護的人. 在您的家屬接受安寧療護期間您是否曾需要在夜間、週末或假日裏聯絡安寧療護小組，對家屬的護理提出問題或者尋求幫助呢？

[1]O 是

[2]O 否 ➔ 如果選擇“否”，請跳至問題 **6**

**5.** 在夜間、週末或假日裏，您多常能從安寧療護小組那裏得到所需的幫助？

[1]O 從未

[2]O 有時

[3]O 經常

[4]O 總是

**6.** 在您的家屬接受安寧療護期間，安寧療護小組多常會通知您他們將何時到場來照料您的家屬？

[1]O 從未

[2]O 有時

[3]O 經常

[4]O 總是

**7.** 在您的家屬接受安寧療護期間，當您或者您的家屬向安寧療護小組求助的時候，多常能立即得到所需的幫助？

[1]O 從未

[2]O 有時

[3]O 經常

[4]O 總是

**8.** 在您的家屬接受安寧療護期間，安寧療護小組有多經常能用清晰易懂的方式向您解釋事情？

[1]O 從未

[2]O 有時

[3]O 經常

[4]O 總是

**9.** 在您的家屬接受安寧療護期間，安寧療護小組多經常會通知您讓您瞭解您家屬的情況？

[1]O 從未

[2]O 有時

[3]O 經常

[4]O 總是

**10.** 在您的家屬接受安寧療護期間，對於您家屬的狀況或護理情況，安寧療護小組的成員有多常提供您令人困惑或相互矛盾的資訊？

[1]O 從未
[2]O 有時
[3]O 經常
[4]O 總是

**11.** 在您的家屬接受安寧療護期間，安寧療護小組有多常以有尊嚴和尊重的態度對待您的家屬？

[1]O 從未
[2]O 有時
[3]O 經常
[4]O 總是

**12.** 在您的家屬接受安寧療護期間，安寧療護小組有多常讓您感到他們真的關心您的家屬？

[1]O 從未
[2]O 有時
[3]O 經常
[4]O 總是

**13.** 在您的家屬接受安寧療護期間，您是否有跟安寧療護小組討論過任何在安寧療護中遇到的問題？

[1]O 是
[2]O 否 ➔ 如果選擇"否"，請跳至問題 **15**

**14.** 在您與安寧療護小組討論家屬的安寧療護中出現的問題時，他們多經常會認真傾聽？

[1]O 從未
[2]O 有時
[3]O 經常
[4]O 總是

**15.** 在您的家屬接受安寧療護期間，他或她是否有任何疼痛？

[1]O 是
[2]O 否 ➔ 如果選擇"否"，請跳至問題 **17**

**16.** 您的家屬是否得到過所須的幫助以緩解他或她的疼痛？

[1]O 是的，當然是
[2]O 是的，某種程度上是
[3]O 否

**17.** 在您的家屬接受安寧療護期間，他或她是否服用了任何止痛的藥物？

[1]O 是
[2]O 否 ➔ 如果選擇"否"，請跳至問題 **21**

**18.** 止痛藥物有副作用，其中包括嗜睡，安寧療護小組是否曾與您或者您的家屬討論過止痛藥物的副作用？

[1]O 是的，當然是
[2]O 是的，某種程度上是
[3]O 否

**19.** 關於使用止痛藥物時需要注意哪些副作用，安寧療護小組是否提供您所需的訓練？

[1]O 是的，當然是
[2]O 是的，某種程度上是
[3]O 否

**20.** 關於是否與何時要給您的家屬服用 更多劑量的止痛藥物，安寧療護小組是否提供過您所需的訓練？

[1]O 是的，當然是
[2]O 是的，某種程度上是
[3]O 否
[4]O 我不需要給我的家屬服用任何止痛藥物

**21.** 在您的家屬接受安寧療護期間， 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]O 是
[2]O 否➔ 如果選擇“否”，請跳至問題 **24**

**22.** 您的家屬多常能在呼吸困難的時候得到了他或她所需的幫助？

[1]O 從未
[2]O 有時
[3]O 經常
[4]O 總是

**23.** 關於在家屬呼吸困難時如何給予幫助，安寧療護小組是否提供過您所需的訓練？

[1]O 是的，當然是
[2]O 是的，某種程度上是
[3]O 否
[4]O 我不需要幫助我的家屬解決呼吸困難問題

**24.** 在您的家屬接受安寧療護期間，您的家屬是否曾有便秘問題？

[1]O 是
[2]O 否➔如果選擇“否”，請跳至問題 **26**

**25.** 遇到便秘問題的時候，您的家屬有多常得到所需的幫助？

[1]O 從未
[2]O 有時
[3]O 經常
[4]O 總是

**26.** 在您的家屬接受安寧療護期間， 他或她是否曾表現出焦慮或悲傷的跡象？

[1]O 是
[2]O 否 ➔如果選擇“否”，請跳至問 **28**

**27.** 在您的家屬感到焦慮或悲傷時，他或她有多常能從安寧療護小組處得到所需的幫助？

[1]O 從未
[2]O 有時
[3]O 經常
[4]O 總是

**28.** 在您的家屬接受安寧療護期間，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，安寧療護小組是否提供過您所需的訓練？

[1]O 是的，當然是
[2]O 是的，某種程度上是
[3]O 否

**30.** 搬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. 安寧療護小組是否提供過您所需的訓練來安全搬動您的家屬呢？

[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會發生的事，安寧療護小組是否盡可能地向您提供了你所想要的相關資訊？

[1]O 是的，當然是
[2]O 是的，某種程度上是
[3]O 否

## 在療養院中得到的安寧療護

**32.** 有些人是在療養院中接受安寧療護服務的.您的家屬是否在他或她於療養院居住期間從該安寧療護醫院接受安寧療護服務？

[1]O 是
[2]O 否➔ 如果選擇“否”，請跳至問題 **35**

**33.** 在您的家屬接受安寧療護期間，療養院工作人員和安寧療護小組多經常能協調一致來照顧您的家屬？

[1]O 從未
[2]O 有時
[3]O 經常
[4]O 總是

**34.** 在您的家屬接受安寧療護期間，療養院工作人員給您的資訊與安寧療護小組給您的資訊不一樣的情況多經常發生？

1O 從未
2O 有時
3O 經常
4O 總是

## 您自己的與安寧療護有關的經歷

**35.** 在您的家屬接受安寧療護期間，安寧療護小組多經常認真聽您說話？

1O 從未
2O 有時
3O 經常
4O 總是

**36.** 對宗教或靈性上的支援包括談話、 禱告、靈修或其他以滿足您宗教需要或靈性需求的方式.在您的家屬接受安寧療護期間，您從安寧療護小組得到了多少對宗教和靈性上的支持？

1O 太少
2O 適中
3O 太多

**37.** 在您的家屬接受安寧療護期間，您從安寧療護小組得到了多少的情感支持？

1O 太少
2O 適中
3O 太多

**38.** 在您的家屬去世後的幾周，您從安寧療護小組得到了多少情感支持？

1O 太少
2O 適中
3O 太多

## 安寧療護整體評分

**39.** 根據您的家屬從問卷首頁所示的安寧療護得到的服務，回答以下問題.在回答時請不要將其他安寧療護的服務考慮在內.

請用 **0** 到 **10** 的數字表示，**0** 代表最差的安寧療護服務，**10** 則代表最好的安寧療護. 您會用哪個數字評價您家屬的安寧療護？

0O 0 最差的安寧療護
1O 1
2O 2
3O 3
4O 4
5O 5
6O 6
7O 7
8O 8
9O 9
10O 10 最好的安寧療護

**40.** 您會向您的朋友和家人推薦該安寧療護機構嗎？

[1]O 當然不會
[2]O 可能不會
[3]O 可能會
[4]O 當然會

## 有關您的家屬

**41.** 您的家屬已完成的最高學校年級或最高學歷是？

[1]O國/初中 (8年級) 或以下
[2]O上過高中，但是沒有畢業
[3]O高中畢業或高中同等學歷
[4]O上過大學或兩年制大學學位
[5]O四年制大學畢業
[6]O四年以上大學學位
[7]O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]O否，不是西班牙人/西班牙裔/拉丁裔
[2]O是，是古巴人
[3]O是，是墨西哥人、墨西哥裔美國人或奇卡諾人
[4]O是， 是波多黎各人
[5]O是，是其他西班牙人/西班牙裔/拉丁裔人

**43.** 您的家屬的種族是？請選擇一項或多項.

[1]O印第安人或阿拉斯加原住民
[2]O亞洲人
[3]O黑人或非裔美國人
[4]O夏威夷島原住民或其他太平洋島民
[5]O白人

## 關於您自己

**44.** 您的年齡是？

[1]O 18 至 24
[2]O 25 至 34
[3]O 35 至 44
[4]O 45 至 54
[5]O 55 至 64
[6]O 65 至 74
[7]O 75 至 84
[8]O 85 及以上

**45.** 您的性別是？

[1]O 男
[2]O 女

**46.** 您已完成的最高學校年級或最高學歷是？

1O國/初中 (8年級) 或以下
2O上過高中，但是沒有畢業
3O高中畢業或高中同等學歷
4O上過大學或兩年制大學學位
5O四年制大學畢業
6O四年以上大學學位

**47.** 您在家裏主要講哪種語言？

1O英語
2O西班牙語
3O中文
4O俄語
5O葡萄牙語
6O越南語
7O波蘭文
8O韓文
9O 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安寧療護服務進行調查. 您被抽中參加此次調查，是因為您曾是[DECEDENT 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安寧療護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）為了衡量安寧療護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）開展，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有責任確保安寧療護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安寧療護護理情況. 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. 您的答案可能會與安寧療護機構分享，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安寧療護護理所提供的幫助.

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[DECEDENT 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安寧療護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）為了衡量安寧療護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）開展，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有責任確保安寧療護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安寧療護護理情況. 你的參與純屬自願，您的健康護理或福利不受任何影響.

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. 您的答案可能會與安寧療護機構分享，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安寧療護護理所提供的幫助.

敬啟
[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:*

## Traditional Chinese Version

"根據1995年《文書削減法》的規定，除非顯示有效的OMB管制編號，否則無人需要回應資訊收集。此次資訊收集的有效OMB管制編號為0938-1257（2023年12月31日到期）。完成此次資訊收集中1 – 40項問題"關於你的家人"及"關於你"部分所需時間估計為平均11分鐘，包括閱覽說明、搜索現有資料資源、收集所需資料，以及完成和審核收集到的資訊的時間。如果你對估計的時間準確性有任何意見，或對改善這份表格有任何建議，請寫信至: Centers for Medicare & Medicaid Services, 7500 Security Boulevard, Mail Stop C1-25-05, Baltimore, MD 21244-1850."

**Reply-by Date (Optional)**

*The following two options are available for adding a reply-by date to the* ***follow-up cover letter****.*

*Placed above the salutation, such as:*

請**最遲**於 [DATE (mm/dd/yyyy)]回覆。

*In the fourth paragraph after the sentence, "After you have completed the survey, please return it in the enclosed pre-paid envelope." An example of allowable reply-by text includes:*

請填寫隨附的調查問卷，並最遲於 [DATE (mm/dd/yyyy)]使用**已付郵費的**回郵信封寄回。

# Appendix Q

## Mail Survey Materials (Simplified Chinese)

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# CAHPS® 安宁疗护问卷调查

请根据患者从以下安宁疗护机构所得到的服务回答下列调查问题:

[NAME OF HOSPICE]

**在此问卷中所有的问题都与这个安宁疗护机构的经验有关.**

如果您想知道更多有关此问卷的信息, 请打免费电话 [TOLL FREE NUMBER]. 所有打到这个号码的电话都是免费的.

OMB# 0938-1257
将于 2023 年 12 月 31 日到期

患者名字已列在问卷调查的首页，请将此问卷交给您家中最了解患者所接受到安宁疗护的人

## 问卷填写指南

- 此问卷需用深色的笔填写.
- 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 1**

  ☐ 否

---

## 安宁疗护患者

**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☐ 我的岳母（婆婆）或岳父（公公）

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. 在此次问卷调查中,词语“家属”是指在问卷调查的首页中所列之患者.您的家属在什么地方接受了该机构的安宁疗护服务？ 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☐ 安宁疗护机构/赡养院

6☐ 其他（请用正楷填写）：

_____

## 您的角色

**3.** 在您的家属接受安宁疗护期间，您有多少机会参与或监督安宁疗护？

1☐ 从未 ➔ 如果选择“从未”，请跳至问题 **41**

2☐ 有时

3☐ 经常

4☐ 总是

## 您的家属的安宁疗护

在回答问卷中所有问题的时候，请只考虑您的家属在本调查问卷附件中所列的安宁疗护机构的经验.

**4.** 在此问卷中，安宁疗护小组 包括所有护士、医生、社工、灵性辅导师以及其他曾经向您的家属提供安宁疗护的人. 在您的家属接受安宁疗护期间您是否曾需要在夜间、周末或假日里联络安宁疗护小组，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.** 在夜间、周末或假日里，您多常能从安宁疗护小组那里得到所需的帮助？

1☐ 从未

2☐ 有时

3☐ 经常

4☐ 总是

**6.** 在您的家属接受安宁疗护期间，安宁疗护小组多常会通知您他们将何时到场来照料您的家属？

1☐ 从未

2☐ 有时

3☐ 经常

4☐ 总是

**7.** 在您的家属接受安宁疗护期间，当您或者您的家属向安宁疗护小组求助的时候，多常能立即得到所需的帮助？

1☐ 从未

2☐ 有时

3☐ 经常

4☐ 总是

**8.** 在您的家属接受安宁疗护期间，安宁疗护小组有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.** 在您的家属接受安宁疗护期间，安宁疗护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.** 在您的家属接受安宁疗护期间，对于您家属的状况或护理情况，安宁疗护小组的成员有多常提供您令人困惑或相互矛盾的信息？

1 ☐ 从未
2 ☐ 有时
3 ☐ 经常
4 ☐ 总是

**11.** 在您的家属接受安宁疗护期间，安宁疗护小组有多常以有尊严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.** 在您的家属接受安宁疗护期间，安宁疗护小组有多常让您感到他们真的关心您的家属？

1 ☐ 从未
2 ☐ 有时
3 ☐ 经常
4 ☐ 总是

**13.** 在您的家属接受安宁疗护期间，您是否有跟安宁疗护小组讨论过任何在安宁疗护中遇到的问题？

1 ☐ 是
2 ☐ 否➔ **如果选择“否”，请跳至问题 15**

**14.** 在您与安宁疗护小组讨论家属的安宁疗护中出现的问题时，他们多经常会认真倾听？

1 ☐ 从未
2 ☐ 有时
3 ☐ 经常
4 ☐ 总是

**15.** 在您的家属接受安宁疗护期间，他或她是否有任何疼痛？

1 ☐ 是
2 ☐ 否➔ **如果选择“否”，请跳至问题 17**

**16.** 您的家属是否得到过所须的帮助以缓解他或她的疼痛？

1 ☐ 是的，当然是
2 ☐ 是的，某种程度上是
3 ☐ 否

**17.** 在您的家属接受安宁疗护期间，他或她是否服用了任何止痛的 <u>药物</u>？

1 ☐ 是
2 ☐ 否➔ **如果选择“否”，请跳至问题 21**

**18.** 止痛药物有副作用，其中包括嗜睡，安宁疗护小组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，安宁疗护小组是否提供您所需的训练？

1☐ 是的，当然是

2☐ 是的，某种程度上是

3☐ 否

**20.** 关于是否与何时要给您的家属服用更多剂量的止痛药物，安宁疗护小组是否提供过您所需的训练？

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.** 在您的家属接受安宁疗护期间，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.** 关于在家属呼吸困难时如何给予帮助，安宁疗护小组是否提供过您所需的训练?？

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.** 在您的家属接受安宁疗护期间，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.** 在您的家属接受安宁疗护期间， 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，他或她有多常能 从安宁疗护小组处 得到所需的帮助？

1☐ 从未

2☐ 有时

3☐ 经常

4☐ 总是

**28.** 在您的家属接受安宁疗护期间，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.** 关于在家属变得不安或激动时应该如何处理，安宁疗护小组是否提供过您所需的训练？

1☐ 是的，当然是

2☐ 是的，某种程度上是

3☐ 否

**30.** 搬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。安宁疗护小组是否提供过您所需的训练来安全搬动您的家属呢？

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会发生的事，安宁疗护小组是否尽可能地向您提供了你所想要的相关信息？

1☐ 是的，当然是

2☐ 是的，某种程度上是

3☐ 否

## 在疗养院中得到的安宁疗护

**32.** 有些人是在疗养院中接受安宁疗护服务的.您的家属是否在他或她于疗养院居住期间从该安宁疗护医院接受安宁疗护服务？

1☐ 是

2☐ 否➔ **如果选择“否”，请跳至问题 35**

**33.** 在您的家属接受安宁疗护期间，疗养院工作人员和安宁疗护小组多经常能协调一致来照顾您的家属？

1☐ 从未

2☐ 有时

3☐ 经常

4☐ 总是

**34.** 在您的家属接受安宁疗护期间，疗养院工作人员给您的信息与安宁疗护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

## 您自己的与安宁疗护有关的经历

**35.** 在您的家属接受安宁疗护期间，安宁疗护小组多经常认真听您说话？

1 ☐ 从未
2 ☐ 有时
3 ☐ 经常
4 ☐ 总是

**36.** 对宗教或灵性上的支持包括谈话、 祷告、灵修或其他以满足您宗教需要或灵性需求的方式.在您的家属接受安宁疗护期间，您从安宁疗护小组得到了多少对宗教和灵性上的支持？

1 ☐ 太少
2 ☐ 适中
3 ☐ 太多

**37.** 在您的家属接受安宁疗护期间，您从安宁疗护小组得到了多少的 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，您从安宁疗护小组得到了多少情感支持？

1 ☐ 太少
2 ☐ 适中
3 ☐ 太多

## 安宁疗护整体评分

**39.** 根据您的家属从问卷首页所示的安宁疗护得到的服务，回答以下问题.在回答时请不要将其他安宁疗护的服务考虑在内.

请用 **0** 到 **10** 的数字表示，**0** 代表最差的安宁疗护服务，**10** 则代表最好的安宁疗护. 您会用哪个数字评价您家属的安宁疗护？

0 ☐ 0 最差的安宁疗护
1 ☐ 1
2 ☐ 2
3 ☐ 3
4 ☐ 4
5 ☐ 5
6 ☐ 6
7 ☐ 7
8 ☐ 8
9 ☐ 9
10 ☐ 10 最好的安宁疗护

**40.** 您会向您的朋友和家人推荐该安宁疗护机构吗？

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 ☐ 初中 (8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，是古巴人
3 ☐ 是 , 是墨西哥人 、 墨西哥裔美国 人或齐卡诺人
4 ☐ 是， 是波多黎各人
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 ☐ 印第安人或阿拉斯加原住民
2 ☐ 亚洲人
3 ☐ 黑人或非裔美国人
4 ☐ 夏威夷岛原住民或其他太平洋岛民
5 ☐ 白人

## 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 ☐ 初中 (8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 ☐ 越南語

7 ☐ 波兰文

8 ☐ 韩文

9 ☐ 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]**

# CAHPS® 安宁疗护问卷调查

请根据患者从以下安宁疗护机构所得到的服务回答下列调查问题:

[NAME OF HOSPICE]

**在此问卷中所有的问题都与这个安宁疗护机构的经验有关.**

如果您想知道更多有关此问卷的信息, 请打免费电话 [TOLL FREE NUMBER]. 所有打到这个号码的电话都是免费的.

OMB# 0938-1257
将于 2023 年 12 月 31 日到期

患者名字已列在问卷调查的首页，请将此问卷交给您家中最了解患者所接受到安宁疗护的人

## 问卷填写指南

- 此问卷需用深色的笔填写.
- 请直接在选项前面的圆圈内画“X”作为回答， 如下所示：

  ● 是
  O 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**
  O 否

---

## 安宁疗护患者

**1. 您与调查问卷附件中所列的患者是什么关系？**

1O 我的配偶或伴侣

2O 我的父母

3O 我的岳母（婆婆）或岳父（公公）

4O 我的（外）祖父/母

5O 我的姑姑（姨妈）或叔叔（舅舅）

6O 我的姐妹或兄弟

7O 我的孩子

8O 我的朋友

9O 其他（请用正楷填写）：

_____

**2. 在此次问卷调查中,词语“家属”是指在问卷调查的首页中所列之患者.您的家属在什么地方接受了该机构的安宁疗护服务？ 请选择一项或多项.**

1O 家

2O 辅助生活机构

3O 疗养院

4O 医院

5O 安宁疗护机构/赡养院

6O 其他（请用正楷填写）：

_____

## 您的角色

**3.** 在您的家属接受安宁疗护期间，您有多少机会参与或监督安宁疗护？

1O 从未 ➔ 如果选择“从未”，请跳至问题 **41**

2O 有时

3O 经常

4O 总是

## 您的家属的安宁疗护

在回答问卷中所有问题的时候，请只考虑您的家属在本调查问卷附件中所列的安宁疗护机构的经验.

**4.** 在此问卷中，安宁疗护小组 包括所有护士、医生、社工、灵性辅导师以及其他曾经向您的家属提供安宁疗护的人. 在您的家属接受安宁疗护期间您是否曾需要在夜间、周末或假日里联络安宁疗护小组，对家属的护理提出问题或者寻求帮助呢？

1O 是

2O 否➔ 如果选择“否”，请跳至问题 **6**

**5.** 在夜间、周末或假日里，您多常能从安宁疗护小组那里得到所需的帮助？

1O 从未

2O 有时

3O 经常

4O 总是

**6.** 在您的家属接受安宁疗护期间，安宁疗护小组多常会通知您他们将何时到场来照料您的家属？

1O 从未

2O 有时

3O 经常

4O 总是

**7.** 在您的家属接受安宁疗护期间，当您或者您的家属向安宁疗护小组求助的时候，多常能立即得到所需的帮助？

1O 从未

2O 有时

3O 经常

4O 总是

**8.** 在您的家属接受安宁疗护期间，安宁疗护小组有多经常能用清晰易懂的方式向您解释事情？

1O 从未

2O 有时

3O 经常

4O 总是

**9.** 在您的家属接受安宁疗护期间，安宁疗护小组多经常会通知您让您了解您家属的情况？

1O 从未

2O 有时

3O 经常

4O 总是

**10.** 在您的家属接受安宁疗护期间，对于您家属的状况或护理情况，安宁疗护小组的成员有多常提供您令人困惑或相互矛盾的信息？

1O 从未

2O 有时

3O 经常

4O 总是

**11.** 在您的家属接受安宁疗护期间，安宁疗护小组有多常以有尊严和尊重的态度对待您的家属？

1O 从未

2O 有时

3O 经常

4O 总是

**12.** 在您的家属接受安宁疗护期间，安宁疗护小组有多常让您感到他们真的关心您的家属？

1O 从未

2O 有时

3O 经常

4O 总是

**13.** 在您的家属接受安宁疗护期间，您是否有跟安宁疗护小组讨论过任何在安宁疗护中遇到的问题？

1O 是

2O 否➔ 如果选择“否”，请跳至问题 **15**

**14.** 在您与安宁疗护小组讨论家属的安宁疗护中出现的问题时，他们多经常会认真倾听？

1O 从未

2O 有时

3O 经常

4O 总是

**15.** 在您的家属接受安宁疗护期间，他或她是否有任何疼痛？

1O 是

2O 否➔ 如果选择“否”，请跳至问题 **17**

**16.** 您的家属是否得到过所须的帮助以缓解他或她的疼痛？

1O 是的，当然是

2O 是的，某种程度上是

3O 否

**17.** 在您的家属接受安宁疗护期间，他或她是否服用了任何止痛的 <u>药物</u>？

1O 是

2O 否➔ 如果选择“否”，请跳至问题 **21**

**18.** 止痛药物有副作用，其中包括嗜睡，安宁疗护小组是否曾与您或者您的家属讨论过止痛药物的副作用？

1O 是的，当然是

2O 是的，某种程度上是

3O 否

**19.** 关于使用止痛药物时需要注意哪些副作用，安宁疗护小组是否提供您所需的训练？

1 0 是的，当然是

2 0 是的，某种程度上是

3 0 否

**20.** 关于是否与何时要给您的家属服用更多剂量的止痛药物，安宁疗护小组是否提供过您所需的训练？

1 0 是的，当然是

2 0 是的，某种程度上是

3 0 否

4 0 我不需要给我的家属服用任何止痛药物

**21.** 在您的家属接受安宁疗护期间，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 0 是

2 0 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 0 从未

2 0 有时

3 0 经常

4 0 总是

**23.** 关于在家属呼吸困难时如何给予帮助，安宁疗护小组是否提供过您所需的训练??

1 0 是的，当然是

2 0 是的，某种程度上是

3 0 否

4 0 我不需要帮助我的家属解决呼吸困难问题

**24.** 在您的家属接受安宁疗护期间，您的家属是否曾有便秘问题？

1 0 是

2 0 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 0 从未

2 0 有时

3 0 经常

4 0 总是

**26.** 在您的家属接受安宁疗护期间， 他或她是否曾表现出焦虑或悲伤的迹象？

1 0 是

2 0 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，他或她有多常能 从安宁疗护小组处 得到所需的帮助？

1 从未

2 有时

3 经常

4 总是

**28.** 在您的家属接受安宁疗护期间，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.** 关于在家属变得不安或激动时应该如何处理，安宁疗护小组是否提供过您所需的训练？

1 是的，当然是

2 是的，某种程度上是

3 否

**30.** 搬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。安宁疗护小组是否提供过您所需的训练来安全搬动您的家属呢？

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会发生的事，安宁疗护小组是否尽可能地向您提供了你所想要的相关信息？

1 是的，当然是

2 是的，某种程度上是

3 否

## 在疗养院中得到的安宁疗护

**32.** 有些人是在疗养院中接受安宁疗护服务的.您的家属是否在他或她于疗养院居住期间从该安宁疗护医院接受安宁疗护服务？

1 是

2 否➔ 如果选择“否”，请跳至问题 **35**

**33.** 在您的家属接受安宁疗护期间，疗养院工作人员和安宁疗护小组多经常能协调一致来照顾您的家属？

1 从未

2 有时

3 经常

4 总是

**34.** 在您的家属接受安宁疗护期间，疗养院工作人员给您的信息与安宁疗护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

## 您自己的与安宁疗护有关的经历

**35.** 在您的家属接受安宁疗护期间，安宁疗护小组多经常认真听您说话？

1 O 从未

2 O 有时

3 O 经常

4 O 总是

**36.** 对宗教或灵性上的支持包括谈话、 祷告、灵修或其他以满足您宗教需要或灵性需求的方式.在您的家属接受安宁疗护期间，您从安宁疗护小组得到了多少对宗教和灵性上的支持？

1 O 太少

2 O 适中

3 O 太多

**37.** 在您的家属接受安宁疗护期间，您从安宁疗护小组得到了多少的 情感 支持？

1 O 太少

2 O 适中

3 O 太多

**38.** 在您的家属去世后的几周，您从安宁疗护小组得到了多少情感支持？

1 O 太少

2 O 适中

3 O 太多

## 安宁疗护整体评分

**39.** 根据您的家属从问卷首页所示的安宁疗护得到的服务，回答以下问题.在回答时请不要将其他安宁疗护的服务考虑在内.

请用 **0** 到 **10** 的数字表示，**0** 代表最差的安宁疗护服务，**10** 则代表最好的安宁疗护. 您会用哪个数字评价您家属的安宁疗护？

0 O 0 最差的安宁疗护

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 最好的安宁疗护

**40.** 您会向您的朋友和家人推荐该安宁疗护机构吗？

1 O 当然不会

2 O 可能不会

3 O 可能会

4 O 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？**

1O 初中 (8年级) 或以下

2O 上过高中，但是没有毕业

3O 高中毕业或高中同等学历

4O 上过大学或两年制大学学位

5O 四年制大学毕业

6O 四年以上大学学位

7O 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？**

1O 否，不是西班牙人/西班牙裔/拉丁裔

2O 是，是古巴人

3O 是 , 是墨西哥人 、 墨西哥裔美国人或齐卡诺人

4O 是， 是波多黎各人

5O 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.**

1O 印第安人或阿拉斯加原住民

2O 亚洲人

3O 黑人或非裔美国人

4O 夏威夷岛原住民或其他太平洋岛民

5O 白人

## 关于您自己

**44. 您的年龄是？**

1O 18 至 24

2O 25 至 34

3O 35 至 44

4O 45 至 54

5O 55 至 64

6O 65 至 74

7O 75 至 84

8O 85 及以上

**45. 您的性别是？**

1O 男

2O 女

**46.** 您已完成的最高学校年级或最高学历是？

1O 初中 (8年级) 或以下

2O 上过高中，但是没有毕业

3O 高中毕业或高中同等学历

4O 上过大学或两年制大学学位

5O 四年制大学毕业

6O 四年以上大学学位

**47.** 您在家里主要讲哪种语言？

1O 英语

2O 西班牙语

3O 中文

4O 俄语

5O 葡萄牙语

6O 越南語

7O 波兰文

8O 韩文

9O 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]**

# CAHPS® 安宁疗护问卷调查

请根据患者从以下安宁疗护机构所得到的服务回答下列调查问题:

[NAME OF HOSPICE]

**在此问卷中所有的问题都与这个安宁疗护机构的经验有关.**

如果您想知道更多有关此问卷的信息, 请打免费电话 [TOLL FREE NUMBER]. 所有打到这个号码的电话都是免费的.

OMB# 0938-1257
将于 2023 年 12 月 31 日到期*

患者名字已列在问卷调查的首页，请将此问卷交给您家中最了解患者所接受到安宁疗护的人

## 问卷填写指南

- ♦ 此问卷需用深色的笔填写.
- ♦ 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

---

## 安宁疗护患者

**1. 您与调查问卷附件中所列的患者是什么关系？**

1O 我的配偶或伴侣

2O 我的父母

3O 我的岳母（婆婆）或岳父（公公）

4O 我的（外）祖父/母

5O 我的姑姑（姨妈）或叔叔（舅舅）

6O 我的姐妹或兄弟

7O 我的孩子

8O 我的朋友

9O 其他（请用正楷填写）：

_____

**2. 在此次问卷调查中,词语“家属”是指在问卷调查的首页中所列之患者.您的家属在什么地方接受了该机构的安宁疗护服务？ 请选择一项或多项.**

1O 家

2O 辅助生活机构

3O 疗养院

4O 医院

5O 安宁疗护机构/赡养院

6O 其他（请用正楷填写）：

_____

## 您的角色

**3.** 在您的家属接受安宁疗护期间，您有多少机会参与或监督安宁疗护？

1O 从未 ➔ 如果选择“从未”，请跳至问题 **41**

2O 有时

3O 经常

4O 总是

## 您的家属的安宁疗护

在回答问卷中所有问题的时候，请只考虑您的家属在本调查问卷附件中所列的安宁疗护机构的经验.

**4.** 在此问卷中，安宁疗护小组 包括所有护士、医生、社工、灵性辅导师以及其他曾经向您的家属提供安宁疗护的人. 在您的家属接受安宁疗护期间您是否曾需要在夜间、周末或假日里联络安宁疗护小组，对家属的护理提出问题或者寻求帮助呢？

1O 是

2O 否➔ 如果选择“否”，请跳至问题 **6**

**5.** 在夜间、周末或假日里，您多常能从安宁疗护小组那里得到所需的帮助？

1O 从未

2O 有时

3O 经常

4O 总是

**6.** 在您的家属接受安宁疗护期间，安宁疗护小组多常会通知您他们将何时到场来照料您的家属？

1O 从未

2O 有时

3O 经常

4O 总是

**7.** 在您的家属接受安宁疗护期间，当您或者您的家属向安宁疗护小组求助的时候，多常能立即得到所需的帮助？

1O 从未

2O 有时

3O 经常

4O 总是

**8.** 在您的家属接受安宁疗护期间，安宁疗护小组有多经常能用清晰易懂的方式向您解释事情？

1O 从未

2O 有时

3O 经常

4O 总是

**9.** 在您的家属接受安宁疗护期间，安宁疗护小组多经常会通知您让您了解您家属的情况？

1O 从未

2O 有时

3O 经常

4O 总是

**10.** 在您的家属接受安宁疗护期间，对于您家属的状况或护理情况，安宁疗护小组的成员有多常提供您令人困惑或相互矛盾的信息？

1O 从未
2O 有时
3O 经常
4O 总是

**11.** 在您的家属接受安宁疗护期间，安宁疗护小组有多常以有尊严和尊重的态度对待您的家属？

1O 从未
2O 有时
3O 经常
4O 总是

**12.** 在您的家属接受安宁疗护期间，安宁疗护小组有多常让您感到他们真的关心您的家属？

1O 从未
2O 有时
3O 经常
4O 总是

**13.** 在您的家属接受安宁疗护期间，您是否有跟安宁疗护小组讨论过任何在安宁疗护中遇到的问题？

1O 是
2O 否➔ 如果选择“否”，请跳至问题 **15**

**14.** 在您与安宁疗护小组讨论家属的安宁疗护中出现的问题时，他们多经常会认真倾听？

1O 从未
2O 有时
3O 经常
4O 总是

**15.** 在您的家属接受安宁疗护期间，他或她是否有任何疼痛？

1O 是
2O 否➔ 如果选择“否”，请跳至问题 **17**

**16.** 您的家属是否得到过所须的帮助以缓解他或她的疼痛？

1O 是的，当然是
2O 是的，某种程度上是
3O 否

**17.** 在您的家属接受安宁疗护期间，他或她是否服用了任何止痛的 <u>药物</u>？

1O 是
2O 否➔ 如果选择“否”，请跳至问题 **21**

**18.** 止痛药物有副作用，其中包括嗜睡，安宁疗护小组是否曾与您或者您的家属讨论过止痛药物的副作用？

1O 是的，当然是
2O 是的，某种程度上是
3O 否

**19.** 关于使用止痛药物时需要注意哪些副作用，安宁疗护小组是否提供您所需的训练？

1O 是的，当然是
2O 是的，某种程度上是
3O 否

**20.** 关于是否与何时要给您的家属服用更多剂量的止痛药物，安宁疗护小组是否提供过您所需的训练？

1O 是的，当然是
2O 是的，某种程度上是
3O 否
4O 我不需要给我的家属服用任何止痛药物

**21.** 在您的家属接受安宁疗护期间，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？

1O 是
2O 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？

1O 从未
2O 有时
3O 经常
4O 总是

**23.** 关于在家属呼吸困难时如何给予帮助，安宁疗护小组是否提供过您所需的训练??

1O 是的，当然是
2O 是的，某种程度上是
3O 否
4O 我不需要帮助我的家属解决呼吸困难问题

**24.** 在您的家属接受安宁疗护期间，您的家属是否曾有便秘问题？

1O 是
2O 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？

1O 从未
2O 有时
3O 经常
4O 总是

**26.** 在您的家属接受安宁疗护期间， 他或她是否曾表现出焦虑或悲伤的迹象？

1O 是
2O 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，他或她有多常能 从安宁疗护小组处 得到所需的帮助？

1O 从未
2O 有时
3O 经常
4O 总是

**28.** 在您的家属接受安宁疗护期间，他或她是否曾变得不安或激动？

1O 是
2O 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，安宁疗护小组是否提供过您所需的训练？

1O 是的，当然是
2O 是的，某种程度上是
3O 否

**30.** 搬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。安宁疗护小组是否提供过您所需的训练来安全搬动您的家属呢？

1O 是的，当然是
2O 是的，某种程度上是
3O 否
4O 我不需要移动我的家属

**31.** 关于家属濒临死亡时会发生的事，安宁疗护小组是否尽可能地向您提供了你所想要的相关信息？

1O 是的，当然是
2O 是的，某种程度上是
3O 否

## 在疗养院中得到的安宁疗护

**32.** 有些人是在疗养院中接受安宁疗护服务的.您的家属是否在他或她于疗养院居住期间从该安宁疗护医院接受安宁疗护服务？

1O 是
2O 否➔ **如果选择“否”，请跳至问题 35**

**33.** 在您的家属接受安宁疗护期间，疗养院工作人员和安宁疗护小组多经常能协调一致来照顾您的家属？

1O 从未
2O 有时
3O 经常
4O 总是

**34.** 在您的家属接受安宁疗护期间，疗养院工作人员给您的信息与安宁疗护小组给您的信息不一样的情况多经常发生？

1O 从未
2O 有时
3O 经常
4O 总是

## 您自己的与安宁疗护有关的经历

**35.** 在您的家属接受安宁疗护期间，安宁疗护小组多经常认真听您说话？

1O 从未
2O 有时
3O 经常
4O 总是

**36.** 对宗教或灵性上的支持包括谈话、 祷告、灵修或其他以满足您宗教需要或灵性需求的方式.在您的家属接受安宁疗护期间，您从安宁疗护小组得到了多少对宗教和灵性上的支持？

1O 太少
2O 适中
3O 太多

**37.** 在您的家属接受安宁疗护期间，您从安宁疗护小组得到了多少的 情感 支持？

1O 太少
2O 适中
3O 太多

**38.** 在您的家属去世后的几周，您从安宁疗护小组得到了多少情感支持？

1O 太少
2O 适中
3O 太多

## 安宁疗护整体评分

**39.** 根据您的家属从问卷首页所示的安宁疗护得到的服务，回答以下问题.在回答时请不要将其他安宁疗护的服务考虑在内.

请用 **0** 到 **10** 的数字表示，**0** 代表最差的安宁疗护服务，**10** 则代表最好的安宁疗护. 您会用哪个数字评价您家属的安宁疗护？

0O 0 最差的安宁疗护
1O 1
2O 2
3O 3
4O 4
5O 5
6O 6
7O 7
8O 8
9O 9
10O 10 最好的安宁疗护

**40.** 您会向您的朋友和家人推荐该安宁疗护机构吗？

1O 当然不会
2O 可能不会
3O 可能会
4O 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？**

1O 初中 (8年级) 或以下
2O 上过高中，但是没有毕业
3O 高中毕业或高中同等学历
4O 上过大学或两年制大学学位
5O 四年制大学毕业
6O 四年以上大学学位
7O 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？**

1O 否，不是西班牙人/西班牙裔/拉丁裔
2O 是，是古巴人
3O 是 , 是墨西哥人 、 墨西哥裔美国人或齐卡诺人
4O 是， 是波多黎各人
5O 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.**

1O 印第安人或阿拉斯加原住民
2O 亚洲人
3O 黑人或非裔美国人
4O 夏威夷岛原住民或其他太平洋岛民
5O 白人

## 关于您自己

**44. 您的年龄是？**

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

**45. 您的性别是？**

1O 男
2O 女

**46.** 您已完成的最高学校年级或最高学历是？

1O 初中 (8年级) 或以下
2O 上过高中，但是没有毕业
3O 高中毕业或高中同等学历
4O 上过大学或两年制大学学位
5O 四年制大学毕业
6O 四年以上大学学位

**47.** 您在家里主要讲哪种语言？

1O 英语
2O 西班牙语
3O 中文
4O 俄语
5O 葡萄牙语
6O 越南語
7O 波兰文
8O 韩文
9O 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安宁疗护服务进行调查.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安宁疗护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）为了衡量安宁疗护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，目的是为了改善安宁疗护护理质量. 美国大部分安宁疗护护理都由CMS支付费用，CMS有责任确保安宁疗护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安宁疗护护理情况.你的参与纯属自愿，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.您的答案可能会与安宁疗护机构分享，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安宁疗护护理所提供的帮助.

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]：

我们的记录显示您最近在[HOSPICE NAME]为[DECEDENT NAME]提供了护理. 大约三周前，我们给您发送了一份有关您和您的家人或朋友在这件安宁疗护机构所接受的护理的调查. 如果您已经将调查寄回给我们，请接受我们的谢意，并忽略此信.但是如果您还没有寄出，如果您能花些时间完成这份重要的调查问卷，我们将不胜感激.

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安宁疗护护理服务.

所附的调查问题[NOTE THE QUESTION NUMBERS]是美国卫生及公共服务部（HHS）为了衡量安宁疗护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，目的是为了改善安宁疗护护理质量. 美国大部分安宁疗护护理都由CMS支付费用，CMS有责任确保安宁疗护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安宁疗护护理情况. 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.您的答案可能会与安宁疗护机构分享，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安宁疗护护理所提供的帮助.

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

"根据1995年削减公文法案(Paperwork Reduction Act), 除非资料收集文件附有正式的OMB号码，任何人都无须对此类文件作出回应。这份数据收集文件的正式OMB号码是0938-1257 (将于2023年12月31日到期)。完成这份数据收集中1 – 40项问题"关于你的家人"及"关于你"部分所需时间估计是平均11分钟，这包括阅读指示、查询现有数据来源、收集所需数据及完成并检查填写的数据。如果您对估计时间的准确性有任何指教或有改进本表格的建议，请写信到: Centers for Medicare & Medicaid Services, 7500 Security Boulevard, C1-25-05, Baltimore, MD 21244-1850."

**Reply-by Date (Optional)**

*The following two options are available for adding a reply-by date to the* ***follow-up cover letter****.*

*Placed above the salutation, such as:*

请于以下日期前回复：[DATE (yyyy/ mm/dd)]。

*In the fourth paragraph after the sentence, "After you have completed the survey, please return it in the enclosed pre-paid envelope." An example of allowable reply-by text includes:*

请填写随附的调查问卷，并于[DATE (yyyy /mm/dd)]前用已预付邮资的信封将其寄回。

# Appendix R

## Mail Survey Materials (Russian)

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# 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
Действует до 31 декабря 2023 г

**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.
- 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

## 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 ☐ 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 <u>хосписная команда</u> 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?**

1 ☐ Ни разу
2 ☐ Иногда
3 ☐ Как правило
4 ☐ 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 необходмую 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 <u>хосписной команды</u> 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, чего ожидать, когда умирал член Вашей семьи?**

1 ☐ Да, несомненно

2 ☐ Да, можно так сказать

3 ☐ Нет

## Хосписный уход в центре сестринского ухода

**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 <u>Вас</u>?**

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?**

1 ☐ Слишком мала

2 ☐ Достаточная

3 ☐ Чрезмерная

**37. Когда член Вашей семьи получал хосписный уход, насколько велика была <u>эмоциональная</u> поддержка со стороны хосписной команды?**

1 ☐ Слишком мала

2 ☐ Достаточная

3 ☐ Чрезмерная

**38. В ближайшие недели <u>после</u> смерти члена Вашей семьи, насколько велика была эмоциональная поддержка со стороны хосписной команды?**

1 ☐ Слишком мала

2 ☐ Достаточная

3 ☐ 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 0 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 Наихудшее качество хосписного ухода, которое только можно представить

1 ☐ 1

2 ☐ 2

3 ☐ 3

4 ☐ 4

5 ☐ 5

6 ☐ 6

7 ☐ 7

8 ☐ 8

9 ☐ 9

10 ☐ 10 Наилучшее качество хосписного ухода, которое только можно представить

**40. Порекомендовали ли бы Вы данный хоспис своим друзьям и семье?**

1 ☐ Точно 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 латино-американского происхождения?**

1 ☐ Нет, он не испанского/латино-американского происхождения

2 ☐ Да, он кубинец

3 ☐ Да, он мексиканец, мексикано-американец, американец мексиканского происхождения

4 ☐ Да, он пуэрториканец

5 ☐ Да, другого испанского/латино-американского происхождения

**43. К какой расовой группе принадлежал член Вашей семьи? Выберите, пожалуйста, один или несколько вариантов ответа.**

1 ☐ Американский индеец или уроженец Аляски

2 ☐ Азиат

3 ☐ Черная раса или афро-американец

4 ☐ Коренной гаваец или уроженец других островов Тихого океана

5 ☐ Белая раса

## ИНФОРМАЦИЯ О ВАС

**44. Сколько Вам лет?**

1 ☐ От 18 до 24 лет

2 ☐ От 25 до 34 лет

3 ☐ От 35 до 44 лет

4 ☐ От 45 до 54 лет

5 ☐ От 55 до 64 лет

6 ☐ От 65 до 74 лет

7 ☐ От 75 до 84 лет

8 ☐ 85 лет или старше

**45. Ваш пол?**

1 ☐ Мужской

2 ☐ Женский

**46. Какое образование Вы получили?**

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

**47. На каком языке Вы <u>в основном</u> общаетесь дома?**

1 ☐ Английский

2 ☐ Испанский

3 ☐ Китайский

4 ☐ Русский

5 ☐ Португальский

6 ☐ Вьетнамский

7 ☐ Польский

8 ☐ корейском

9 ☐ 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
Действует до 31 декабря 2023 г.

**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.
- Ответьте на все вопросы, закрашивая кружок, относящийся к нужному ответу.

  ● 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:

  ● 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 тесть/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 получал 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?**

1 0 Ни разу ➔ **Если ответ «ни разу», перейдите к вопросу 41**

2 0 Иногда

3 0 Как правило

4 0 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 <u>хосписная команда</u> 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 0 Да

2 0 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 0 Ни разу

2 0 Иногда

3 0 Как правило

4 0 Всегда

**6. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда информировала Вас о времени своего прибытия для оказания ему помощи?**

1 0 Ни разу

2 0 Иногда

3 0 Как правило

4 0 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 0 Ни разу

2 0 Иногда

3 0 Как правило

4 0 Всегда

**8. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда предоставляла объяснения в простой и доступной форме?**

1 0 Ни разу

2 0 Иногда

3 0 Как правило

4 0 Всегда

**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, получал ли он какие-то обезболивающие <u>препараты</u>?**

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 0 Да, несомненно

2 0 Да, можно так сказать

3 0 Нет

**19. Проводила ли с Вами хосписная команда необходимое обучение на тему побочных эффектов, за которыми необходимо следить при приеме обезболивающих препаратов?**

1 0 Да, несомненно

2 0 Да, можно так сказать

3 0 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 0 Да, несомненно

2 0 Да, можно так сказать

3 0 Нет

4 0 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 0 Да

2 0 Нет➔ **Если ответ «Нет», перейдите к Вопросу 24**

**22. Как часто член Вашей семьи получал всю необходимую помощь вследствие затрудненного дыхания?**

1 0 Ни разу

2 0 Иногда

3 0 Как правило

4 0 Всегда

**23. Проводила ли с Вами хосписная команда обучение по предоставлению помощи члену Вашей семьи, когда он испытывает проблемы с дыханием?**

1 0 Да, несомненно

2 0 Да, можно так сказать

3 0 Нет

4 0 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 0 Да

2 0 Нет➔ **Если ответ «Нет», перейдите к Вопросу 26**

**25. Как часто член Вашей семьи получал необходмую помощь вследствие запоров?**

1 0 Ни разу
2 0 Иногда
3 0 Как правило
4 0 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 <u>хосписной команды</u> 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

**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 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

## Хосписный уход в центре сестринского ухода

**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 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, предоставленных хосписной командой?**

1 0 Ни разу

2 0 Иногда

3 0 Как правило

4 0 Всегда

## Ваш Опыт с хосписом

**35. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда внимательно выслушивала <u>Вас</u>?**

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 <u>эмоциональная</u> поддержка со стороны хосписной команды?**

1 0 Слишком мала

2 0 Достаточная

3 0 Чрезмерная

**38. В ближайшие недели <u>после</u> смерти члена Вашей семьи, насколько велика была эмоциональная поддержка со стороны хосписной команды?**

1 0 Слишком мала
2 0 Достаточная
3 0 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 0 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 0 Наихудшее качество хосписного ухода, которое только можно представить
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 Наилучшее качество хосписного ухода, которое только можно представить

**40. Порекомендовали ли бы Вы данный хоспис своим друзьям и семье?**

1 0 Точно нет
2 0 Скорее всего, нет
3 0 Скорее всего, да
4 0 Да, несомненно

## Информация о члене Вашей семьи

**41. Какое образование получил <u>член Вашей семьи</u>?**

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
7 0 Не знаю

**42. <u>Был ли член Вашей семьи</u> испанского либо латино-американского происхождения?**

1 0 Нет, он не испанского/латино-американского происхождения
2 0 Да, он кубинец
3 0 Да, он мексиканец, мексикано-американец, американец мексиканского происхождения
4 0 Да, он пуэрториканец
5 0 Да, другого испанского/латино-американского происхождения

**43. К какой расовой группе принадлежал <u>член Вашей семьи</u>? Выберите, пожалуйста, один или несколько вариантов ответа.**

1 0 Американский индеец или уроженец Аляски
2 0 Азиат
3 0 Черная раса или афро-американец
4 0 Коренной гаваец или уроженец других островов Тихого океана
5 0 Белая раса

## 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 <u>в основном</u> общаетесь дома?**

1 0 Английский
2 0 Испанский
3 0 Китайский
4 0 Русский
5 0 Португальский
6 0 Вьетнамский
7 0 Польский
8 0 корейском
9 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]**

# 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
Действует до 31 декабря 2023 г.

**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.
- Ответьте на все вопросы, закрашивая кружок, относящийся к нужному ответу.

  ● Да

  O 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**

  O Нет

## ПАЦИЕНТ ХОСПИСА

**1. Какова Ваша степень родства с пациентом, указанным в сопроводительном письме к данной анкете?**

1 O Мой/моя супруг/а или партнер/ша

2 O Мой родитель

3 O Моя/мой теща/свекровь или тесть/свекр

4 O Мой/моя дедушка/бабушка

5 O Моя/мой тетя или дядя

6 O Моя/мой сестра или брат

7 O Мой ребенок

8 O Мой друг

9 O 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 O Дома

2 O В доме престарелых

3 O В центре сестринского ухода

4 O В больнице

5 O В хосписе

6 O 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 O Ни разу ➔ **Если ответ «ни разу», перейдите к вопросу 41**

2 O Иногда

3 O Как правило

4 O 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 <u>хосписная команда</u> 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 O Да

2 O 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 O Ни разу

2 O Иногда

3 O Как правило

4 O Всегда

**6. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда информировала Вас о времени своего прибытия для оказания ему помощи?**

1 O Ни разу

2 O Иногда

3 O Как правило

4 O 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 O Ни разу

2 O Иногда

3 O Как правило

4 O Всегда

**8. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда предоставляла объяснения в простой и доступной форме?**

1 O Ни разу

2 O Иногда

3 O Как правило

4 O Всегда

**9. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда информировала Вас о его состоянии?**

1 O Ни разу
2 O Иногда
3 O Как правило
4 O 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 O Ни разу
2 O Иногда
3 O Как правило
4 O Всегда

**11. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда относилась к нему с достоинством и уважением?**

1 O Ни разу
2 O Иногда
3 O Как правило
4 O Всегда

**12. Когда член Вашей семьи получал хосписный уход, как часто Вы испытывали ощущение, что хосписная команда действительно заботится о нем?**

1 O Ни разу
2 O Иногда
3 O Как правило
4 O 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 O Да
2 O 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 O Ни разу
2 O Иногда
3 O Как правило
4 O Всегда

**15. Когда член Вашей семьи получал хосписный уход, испытывал ли он боль?**

1 O Да
2 O Нет➔ **Если ответ «Нет», перейдите к Вопросу 17**

**16. Получал член Вашей семьи всю возможную необходимую ему помощь, когда испытывал боль?**

1 O Да, несомненно
2 O Да, можно так сказать
3 O Нет

**17. Когда член Вашей семьи получал хосписный уход, получал ли он какие-то обезболивающие <u>препараты</u>?**

1 O Да
2 O 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 O Да, несомненно
2 O Да, можно так сказать
3 O Нет

**19. Проводила ли с Вами хосписная команда необходимое обучение на тему побочных эффектов, за которыми необходимо следить при приеме обезболивающих препаратов?**

1 O Да, несомненно
2 O Да, можно так сказать
3 O 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 O Да, несомненно
2 O Да, можно так сказать
3 O Нет
4 O 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 O Да
2 O Нет➔ **Если ответ «Нет», перейдите к Вопросу 24**

**22. Как часто член Вашей семьи получал всю необходимую помощь вследствие затрудненного дыхания?**

1 O Ни разу
2 O Иногда
3 O Как правило
4 O Всегда

**23. Проводила ли с Вами хосписная команда обучение по предоставлению помощи члену Вашей семьи, когда он испытывает проблемы с дыханием?**

1 O Да, несомненно
2 O Да, можно так сказать
3 O Нет
4 O 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 O Да
2 O Нет➔ **Если ответ «Нет», перейдите к Вопросу 26**

**25. Как часто член Вашей семьи получал необходмую помощь вследствие запоров?**

1 O Ни разу
2 O Иногда
3 O Как правило
4 O Всегда

**26. Когда член Вашей семьи получал хосписный уход, испытывал ли он чувства тревоги или грусти?**

1 O Да
2 O 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 O Ни разу
2 O Иногда
3 O Как правило
4 O Всегда

**28. Когда член Вашей семьи получал хосписный уход, испытывал ли он ощущение беспокойства или возбуждения?**

1 O Да
2 O 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 O Да, несомненно
2 O Да, можно так сказать
3 O 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 O Да, несомненно
2 O Да, можно так сказать
3 O Нет
4 O 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 O Да, несомненно
2 O Да, можно так сказать
3 O Нет

## ХОСПИСНЫЙ УХОД В ЦЕНТРЕ СЕСТРИНСКОГО УХОДА

**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 O Да
2 O 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 O Ни разу
2 O Иногда
3 O Как правило
4 O 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 O Ни разу
2 O Иногда
3 O Как правило
4 O Всегда

## Ваш Опыт с хосписом

**35. Когда член Вашей семьи получал хосписный уход, как часто хосписная команда внимательно выслушивала Вас?**

1 O Ни разу
2 O Иногда
3 O Как правило
4 O 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 O Слишком мала
2 O Достаточная
3 O Чрезмерная

**37. Когда член Вашей семьи получал хосписный уход, насколько велика была эмоциональная поддержка со стороны хосписной команды?**

1 O Слишком мала
2 O Достаточная
3 O Чрезмерная

**38. В ближайшие недели после смерти члена Вашей семьи, насколько велика была эмоциональная поддержка со стороны хосписной команды?**

1 O Слишком мала
2 O Достаточная
3 O 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 0 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] O 0 Наихудшее качество хосписного ухода, которое только можно представить
- [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 Наилучшее качество хосписного ухода, которое только можно представить

**40. Порекомендовали ли бы Вы данный хоспис своим друзьям и семье?**

- [1] O Точно нет
- [2] O Скорее всего, нет
- [3] O Скорее всего, да
- [4] O Да, несомненно

## Информация о члене Вашей семьи

**41. Какое образование получил <u>член Вашей семьи</u>?**

- [1] O 8 классов и меньше
- [2] O Учился в старших классах, но не окончил школу
- [3] O Окончил среднюю школу
- [4] O Колледж или диплом о двухгодичном обучении
- [5] O Четырехгодичное законченное высшее образование
- [6] O Обучение свыше четырех лет высшего образования
- [7] O Не знаю

**42. <u>Был ли член Вашей семьи</u> испанского либо латино-американского происхождения?**

- [1] O Нет, он не испанского/латино-американского происхождения
- [2] O Да, он кубинец
- [3] O Да, он мексиканец, мексикано-американец, американец мексиканского происхождения
- [4] O Да, он пуэрториканец
- [5] O Да, другого испанского/латино-американского происхождения

**43. К какой расовой группе принадлежал <u>член Вашей семьи</u>? Выберите, пожалуйста, один или несколько вариантов ответа.**

1 O Американский индеец или уроженец Аляски
2 O Азиат
3 O Черная раса или афро-американец
4 O Коренной гаваец или уроженец других островов Тихого океана
5 O Белая раса

## ИНФОРМАЦИЯ О ВАС

**44. Сколько Вам лет?**

1 O От 18 до 24 лет
2 O От 25 до 34 лет
3 O От 35 до 44 лет
4 O От 45 до 54 лет
5 O От 55 до 64 лет
6 O От 65 до 74 лет
7 O От 75 до 84 лет
8 O 85 лет или старше

**45. Ваш пол?**

1 O Мужской
2 O Женский

**46. Какое образование Вы получили?**

1 O 8 классов и меньше
2 O Учился в старших классах, но не окончил школу
3 O Окончил среднюю школу
4 O Колледж или диплом о двухгодичном обучении
5 O Четырехгодичное законченное высшее образование
6 O Обучение свыше четырех лет высшего образования

**47. На каком языке Вы <u>в основном</u> общаетесь дома?**

1 O Английский
2 O Испанский
3 O Китайский
4 O Русский
5 O Португальский
6 O Вьетнамский
7 O Польский
8 O корейском
9 O 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 [DECEDENT NAME]. Мы понимаем, что это тяжелое для Вас время, но все же мы надеемся на то, что Вы поможете 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 «Медикэр» 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 обеспечение 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 приложенной анкете являются частью национальной инициативы оценки качества хосписного ухода, финансируемой Департаментом здравоохранения и социального обеспечения США. Центры обеспечения услуг по программам «Медикэр» 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 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

"В соответствии с Законом о Сокращении Бумажного Документооборота от 1995 года, не требуется, чтобы какое-либо лицо отвечало на просьбу о предоставлении информации, за исключением того случая, если на этой просьбе будет указан действительный контрольный номер OMB (Управления Менеджмента и Бюджета). Действительный контрольный номер Управления OMB для данного сбора информации следующий: № 0938- 1257 (Действует до 31 декабря 2023 г.). Расчётное время, требуемое для полного сбора данной информации, – в среднем 11 минут для ответа на с 1-го по 40-й вопросы анкеты – «О Члене Вашей Семьи» и «О Вас», включая время, необходимое для ознакомления с инструкциями, для поиска существующих источников информации, а также для сбора необходимых данных, заполнения и проверки собранной информации. Если у вас имеются какие-либо замечания по поводу точности оценки требуемого времени, или какие-либо рекомендации, просьба написать по следующему адресу: Centers for Medicare & Medicaid Services, 7500 Security Boulevard, C1-25-05, Baltimore, MD 21244-1850."

**Reply-by Date (Optional)**

*The following two options are available for adding a reply-by date to the* ***follow-up cover letter****.*

*Placed above the salutation, such as:*

Пожалуйста, ответьте до: [DATE (mm/dd/yyyy)].

*In the fourth paragraph after the sentence, "After you have completed the survey, please return it in the enclosed pre-paid envelope." An example of allowable reply-by text includes:*

Заполните прилагаемый опрос и отправьте его по почте до [DATE (mm/dd/yyyy)] в конверте с предоплатой.

# Appendix S

## Mail Survey Materials (Portuguese)

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# Inquérito CAHPS® Sobre Centros de Cuidados Paliativos

Responda às questões do inquérito sobre os cuidados que o doente recebeu neste centro de cuidados paliativos:

[NAME 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
Expira em 31 de dezembro de 2023

**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.
- 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 cônjugue 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 ☐ Nunca ➔ **Se Nunca, passe para a Questão 41**

2 ☐ Por vezes

3 ☐ Frequentemente

4 ☐ 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 <u>equipa do centro de cuidados paliativos</u> 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 ☐ Sim

2 ☐ 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 ☐ 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 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 <u>medicamento</u> 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?**

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 ☐ Sim

2 ☐ 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 ☐ Nunca

2 ☐ Por vezes

3 ☐ Frequentemente

4 ☐ Sempre

**26. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) mostrou sentimentos de ansiedade ou tristeza?**

1 ☐ Sim

2 ☐ Não➔ **Se Não, passe para a Questão 28**

**27. Com que frequência o seu familiar obteve a assistência necessária <u>por parte da equipa do centro de cuidados paliativos</u> para sentimentos de ansiedade ou tristeza?**

1 ☐ Nunca

2 ☐ Por vezes

3 ☐ Frequentemente

4 ☐ Sempre

**28. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) alguma vez ficou inquieto(a) ou agitado(a)?**

1 ☐ Sim

2 ☐ 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 ☐ 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

## CUIDADOS PALIATIVOS PRESTADOS EM CASA DE REPOUSO

**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 ☐ 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 <u>emocional</u> recebeu da equipa do centro de cuidados paliativos?**

1 ☐ Muito pouco

2 ☐ A quantidade certa

3 ☐ Demasiado

**38. Nas semanas <u>após</u> 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 PALIATIVOS

**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 <u>seu familiar</u> 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, Cubano
3 ☐ Sim, Mexicano, Mexicano Americano, Chicano
4 ☐ Sim, Porto Riquenho
5 ☐ Sim, Outro Espanhol/Hispânico/Latino

**43. Qual era a raça do seu familiar? Selecione um ou mais.**

1 ☐ Índio Americano ou Nativo do Alasca
2 ☐ Asiática
3 ☐ Negra ou Africano Americano
4 ☐ Nativo do Havai ou outra Ilha do Pacífico
5 ☐ Branca

## 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 <u>maioritariamente</u> em casa?**

1 ☐ Inglês

2 ☐ Espanhol

3 ☐ Chinês

4 ☐ Russo

5 ☐ Português

6 ☐ Vietnamita

7 ☐ Polonesa

8 ☐ Coreano

9 ☐ 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:

[NAME 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
Expira em 31 de dezembro de 2023

**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.
- Responda a todas as perguntas, preenchendo totalmente o círculo à esquerda da sua resposta.
  - ● 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 O Meu cônjugue ou parceiro
2 O Meu pai ou mãe
3 O Meu sogro ou sogra
4 O Meu avô ou avó
5 O Meu tio ou tia
6 O Meu irmão ou irmã
7 O Meu filho ou filha
8 O Meu amigo ou amiga
9 O 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 O Casa
2 O Unidades de residência assistida
3 O Casa de repouso
4 O Hospital
5 O Unidades de cuidados paliativos
6 O 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 <u>equipa do centro de cuidados paliativos</u> 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 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 O Sim, sem dúvida
2 O Sim, de certa forma
3 O Não

**17. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) tomou algum <u>medicamento</u> para as dores?**

1 O Sim
2 O 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 O Sim, sem dúvida
2 O Sim, de certa forma
3 O 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 O Sim, sem dúvida
2 O Sim, de certa forma
3 O 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 O Sim, sem dúvida
2 O Sim, de certa forma
3 O Não
4 O 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 O Sim
2 O 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 O Nunca
2 O Por vezes
3 O Frequentemente
4 O 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 O Sim, sem dúvida
2 O Sim, de certa forma
3 O Não
4 O 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 <u>por parte da equipa do centro de cuidados paliativos</u> 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

## CUIDADOS PALIATIVOS PRESTADOS EM CASA DE REPOUSO

**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] O Sim
[2] O 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] O Nunca
[2] O Por vezes
[3] O Frequentemente
[4] O 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] O Nunca
[2] O Por vezes
[3] O Frequentemente
[4] O 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] O Nunca
[2] O Por vezes
[3] O Frequentemente
[4] O 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] O Muito pouco
[2] O A quantidade certa
[3] O Demasiado

**37. Enquanto o seu familiar esteve no centro de cuidados paliativos, quanto apoio <u>emocional</u> recebeu da equipa do centro de cuidados paliativos?**

[1] O Muito pouco
[2] O A quantidade certa
[3] O 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 PALIATIVOS

**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, Cubano
3 O Sim, Mexicano, Mexicano Americano, Chicano
4 O Sim, Porto Riquenho
5 O Sim, Outro Espanhol/Hispânico/Latino

**43. Qual era a raça do seu familiar? Selecione um ou mais.**

1 O Índio Americano ou Nativo do Alasca
2 O Asiática
3 O Negra ou Africano Americano
4 O Nativo do Havai ou outra Ilha do Pacífico
5 O Branca

## SOBRE SI

**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 maioritariamente em casa?**

1 O Inglês
2 O Espanhol
3 O Chinês
4 O Russo
5 O Português
6 O Vietnamita
7 O Polonesa
8 O Coreano
9 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]**

# Inquérito CAHPS® Sobre Centros de Cuidados Paliativos

Responda às questões do inquérito sobre os cuidados que o doente recebeu neste centro de cuidados paliativos:

[NAME 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
Expira em 31 de dezembro de 2023

**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.
- Responda a todas as perguntas, preenchendo totalmente o círculo à esquerda da sua resposta.

  ● 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 O Meu cônjugue ou parceiro
2 O Meu pai ou mãe
3 O Meu sogro ou sogra
4 O Meu avô ou avó
5 O Meu tio ou tia
6 O Meu irmão ou irmã
7 O Meu filho ou filha
8 O Meu amigo ou amiga
9 O 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 O Casa
2 O Unidades de residência assistida
3 O Casa de repouso
4 O Hospital
5 O Unidades de cuidados paliativos
6 O 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 <u>equipa do centro de cuidados paliativos</u> 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 O Nunca
2 O Por vezes
3 O Frequentemente
4 O 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 O Nunca
2 O Por vezes
3 O Frequentemente
4 O 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 O Nunca
2 O Por vezes
3 O Frequentemente
4 O 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 O Nunca
2 O Por vezes
3 O Frequentemente
4 O 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 O Sim
2 O 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 O Nunca
2 O Por vezes
3 O Frequentemente
4 O Sempre

**15. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) sentiu qualquer dor?**

1 O Sim
2 O Não➔ **Se Não, passe para a Questão 17**

**16. O seu familiar recebeu a assistência para as dores que necessitava?**

1 O Sim, sem dúvida
2 O Sim, de certa forma
3 O Não

**17. Enquanto o seu familiar esteve no centro de cuidados paliativos, ele(a) tomou algum <u>medicamento</u> para as dores?**

1 O Sim
2 O 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 O Sim, sem dúvida
2 O Sim, de certa forma
3 O 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 O Sim, sem dúvida
2 O Sim, de certa forma
3 O 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 O Sim, sem dúvida
2 O Sim, de certa forma
3 O Não
4 O 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 O Sim
2 O 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 O Nunca
2 O Por vezes
3 O Frequentemente
4 O 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 O Sim, sem dúvida
2 O Sim, de certa forma
3 O Não
4 O 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 <u>por parte da equipa do centro de cuidados paliativos</u> 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

## CUIDADOS PALIATIVOS PRESTADOS EM CASA DE REPOUSO

**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 O Sim
2 O 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 O Nunca
2 O Por vezes
3 O Frequentemente
4 O 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 O Nunca
2 O Por vezes
3 O Frequentemente
4 O 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 O Nunca
2 O Por vezes
3 O Frequentemente
4 O 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 O Muito pouco
2 O A quantidade certa
3 O Demasiado

**37. Enquanto o seu familiar esteve no centro de cuidados paliativos, quanto apoio <u>emocional</u> recebeu da equipa do centro de cuidados paliativos?**

1 O Muito pouco
2 O A quantidade certa
3 O 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 PALIATIVOS

**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, Cubano
3 O Sim, Mexicano, Mexicano Americano, Chicano
4 O Sim, Porto Riquenho
5 O Sim, Outro Espanhol/Hispânico/Latino

**43. Qual era a raça do seu familiar? Selecione um ou mais.**

1 O Índio Americano ou Nativo do Alasca
2 O Asiática
3 O Negra ou Africano Americano
4 O Nativo do Havai ou outra Ilha do Pacífico
5 O Branca

## SOBRE SI

**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 maioritariamente em casa?**

1 O Inglês
2 O Espanhol
3 O Chinês
4 O Russo
5 O Português
6 O Vietnamita
7 O Polonesa
8 O Coreano
9 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 selecionado 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 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.

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 exibe um número de controle OMB válido. O número de controle OMB válido para esta recolha de informação é 0938-1257 (Expira em 31 de dezembro de 2023). 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."

**Reply-by Date (Optional)**

*The following two options are available for adding a reply-by date to the* ***follow-up cover letter****.*

*Placed above the salutation, such as:*

Responda até: [DATE (dd/mm/yyyy)].

*In the fourth paragraph after the sentence, "After you have completed the survey, please return it in the enclosed pre-paid envelope." An example of allowable reply-by text includes:*

Preencha o inquérito em anexo e envie-o pelo correio até [DATE (dd/mm/yyyy)] no envelope pré-pago.

# Appendix T

## Mail Survey Materials (Vietnamese)

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# 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:

[NAME 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
Hết hạn vào ngày 31/12/2023

# 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.

- 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?**

1 ☐ Vợ hoặc chồng của tôi
2 ☐ Cha/ mẹ của tôi
3 ☐ Cha/ mẹ vợ của tôi hoặc cha/ mẹ chồng của tôi
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):

_____

## 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 hỏi 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, <u>nhóm Hospice</u> 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 ☐ Có
2 ☐ Không →**Nếu không, trả lời tiếp câu hỏi 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 đươc 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 nhầm lẫn 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 ☐ Thưởng 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 cứ vấn đề về thành viên gia đình bạn với Hospice care?**

1 ☐ Có
2 ☐ Không → **Nếu không, trả lời tiếp câu hỏi 15**

**14. Nhóm Hospice có thường xuyên lắng nghe cẩn thận 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 <u>bất kỳ thuốc giảm</u> 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 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 cần lúc bị 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 hỏi 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 đươc 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 hỏi 28**

**27. Thành viên gia đình bạn có thường xuyên nhận được sự giúp đỡ hay họ cần <u>sự giúp đỡ từ nhóm Hospice</u> 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 hỏi 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

## NHẬN ĐƯỢC SỰ CHĂM 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 đươc 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 hỏi 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 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 thường
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 <u>nhiệt tình</u> 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 <u>sau khi</u> 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

**39. Vui lòng trả lời các câu hỏi dưới đây về sự chăm sóc thành viên gia đình bạn từ Hospice được đặt tên trên bìa khảo sát. Không bao gồm sự chăm sóc từ các Hospice khác trong câu trả lời của bạn.**

**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 <u>nhất của thành viên gia đình</u> 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 Khoá học 2 năm
- 5 ☐ Tốt nghiệp cao đẳng hệ 4 năm
- 6 ☐ Tốt nghiệp cao đẳng trên 4 năm học
- 7 ☐ Không biết

**42. <u>Thành viên gia đình</u> 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, Cuba
- 3 ☐ Phải, người Mễ Tây Cơ, người Mỹ gốc Mễ Tây Cơ, người Chicano (người gốc Mễ Tây Cơ sinh tại Mỹ)
- 4 ☐ Phải, Puerto Rican
- 5 ☐ Phải, người Tây Ban Nha, người gốc Nam Mỹ/ La Tinh

**43. Chủng tộc của <u>thành viên gia đình</u> bạn là gì? Vui lòng chọn một hoặc nhiều hơn.**

- 1 ☐ Người có nguồn gốc từ bất cứ sắc dân bản địa nào ở Bắc Mỹ và Nam Mỹ
- 2 ☐ Người Châu Á
- 3 ☐ Người da Đen hoặc người Mỹ gốc Phi
- 4 ☐ Người có nguồn gốc đảo Hawaii hay đảo khác ở Thái Bình Dương
- 5 ☐ Người da Trắng

## 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 khoá 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 <u>bạn sử dụng chính để</u> 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 ☐ Tiếng Ba Lan
8 ☐ Tiếng Hàn Quốc
9 ☐ 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:

[NAME 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
Hết hạn vào ngày 31/12/2023

# 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 → **Nếu có, trả lời tiếp câu hỏi 1**
  0 Không

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### BỆNH NHÂN CỦA HOSPICE

**1. Bạn có quan hệ như thế nào đối với người đã được liệt kê trong thư khảo sát?**

[1] 0 Vợ hoặc chồng của tôi
[2] 0 Cha/ mẹ của tôi
[3] 0 Cha/ mẹ vợ của tôi hoặc cha/ mẹ chồng của tôi
[4] 0 Ông bà nội/ngoại của tôi
[5] 0 Cô/chú của tôi
[6] 0 Anh/ chị/ em của tôi
[7] 0 Con của tôi
[8] 0 Bạn bè của tôi
[9] 0 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] 0 Nhà
[2] 0 Trung tâm trợ sinh
[3] 0 Viện dưỡng lão
[4] 0 Bệnh viện
[5] 0 Cơ sở/ viện tế bần
[6] 0 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:**

[1] 0 Không bao giờ →**Nếu không bao giờ, trả lời tiếp câu hỏi 41**
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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, <u>nhóm Hospice</u> 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] 0 Có
[2] 0 Không →**Nếu không, trả lời tiếp câu hỏi 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] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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 đươc sự giúp đỡ sớm nhất như bạn cần không?**

[1] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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 nhầm lẫn hoặc mâu thuẫn về tình trạng hay sự chăm sóc thành viên trong gia đình bạn hay không?**

[1] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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 với Hospice care?**

[1] 0 Có
[2] 0 Không→ **Nếu không, trả lời tiếp câu hỏi 15**

**14. Nhóm Hospice có thường xuyên lắng nghe cẩn thận khi bạn nói chuyện với họ về các vấn đề về thành viên của bạn khi đang ở Hospice care?**

[1] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 Luôn luôn

**15. Trong thời gian được Hospice chăm sóc, người thân của bạn có bất kỳ cơn đau nào không?**

[1] 0 Có
[2] 0 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] 0 Có, chắc chắn rồi
[2] 0 Có, một chút
[3] 0 Không

**17. Trong thời gian thành viên gia đình của bạn được Hospice chăm sóc, họ có nhận <u>bất kỳ thuốc giảm</u> đau nào không?**

[1] 0 Có
[2] 0 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] 0 Có, chắc chắn rồi
[2] 0 Có, một chút
[3] 0 Không

**19. Nhóm Hospice có dạy hoặc hướng dẫn cho bạn về những tác dụng phụ của thuốc giảm đau không?**

[1] 0 Có, chắc chắn rồi
[2] 0 Có, một chút
[3] 0 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] 0 Có, chắc chắn rồi
[2] 0 Có, một chút
[3] 0 Không
[4] 0 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] 0 Có
[2] 0 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 cần lúc bị khó thở hay không?**

[1] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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] 0 Có, chắc chắn rồi
[2] 0 Có, một chút
[3] 0 Không
[4] 0 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] 0 Có
[2] 0 Không→ **Nếu không, trả lời tiếp câu hỏi 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] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 Luôn luôn

**26. Trong thời gian thành viên gia đình bạn đươc Hospice chăm sóc, họ có thể hiện bất kỳ sự lo lắng hay buồn bã nào không?**

[1] 0 Có
[2] 0 Không→ **Nếu không, trả lời tiếp câu hỏi 28**

**27. Thành viên gia đình bạn có thường xuyên nhận được sự giúp đỡ hay họ cần <u>sự giúp đỡ từ nhóm Hospice</u> khi họ lo lắng hay khi họ buồn hay không?**

[1] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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] 0 Có
[2] 0 Không→ **Nếu không, trả lời tiếp câu hỏi 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] 0 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] 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

## NHẬN ĐƯỢC SỰ CHĂM 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 đươc 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 hỏi 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 cẩn thận không?**

[1] 0 Không bao giờ
[2] 0 Thỉnh thoảng
[3] 0 Thường thường
[4] 0 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] 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 <u>nhiệt tình</u> 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 <u>sau khi</u> 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

**39. Vui lòng trả lời các câu hỏi dưới đây về sự chăm sóc thành viên gia đình bạn từ Hospice được đặt tên trên bìa khảo sát. Không bao gồm sự chăm sóc từ các Hospice khác trong câu trả lời của bạn.**

**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?**

1 0 Lớp 8 hoặc thấp hơn
2 0 Trung học phổ thông, nhưng chưa tốt nghiệp phổ thông
3 0 Tốt nghiệp trung học phổ thông hoặc tương đương GED
4 0 Cao đẳng hoặc Khoá học 2 năm
5 0 Tốt nghiệp cao đẳng hệ 4 năm
6 0 Tốt nghiệp cao đẳng trên 4 năm học
7 0 Không biết

**42. Thành viên gia đình bạn là người Tây Ban Nha, La tinh/ hay có gốc Nam Mỹ không?**

1 0 Không, không phải người Tây Ban Nha/ gốc Nam Mỹ/ người La Tinh
2 0 Phải, Cuba
3 0 Phải, người Mễ Tây Cơ, người Mỹ gốc Mễ Tây Cơ, người Chicano (người gốc Mễ Tây Cơ sinh tại Mỹ)
4 0 Phải, Puerto Rican
5 0 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 0 Người có nguồn gốc từ bất cứ sắc dân bản địa nào ở Bắc Mỹ và Nam Mỹ
2 0 Người Châu Á
3 0 Người da Đen hoặc người Mỹ gốc Phi
4 0 Người có nguồn gốc đảo Hawaii hay đảo khác ở Thái Bình Dương
5 0 Người da Trắng

## THÔNG TIN VỀ BẠN

**44. Bạn bao nhiêu tuổi?**

1 0 18 đến 24
2 0 25 đến 34
3 0 35 đến 44
4 0 45 đến 54
5 0 55 đến 64
6 0 65 đến 74
7 0 75 đến 84
8 0 85 hoặc trên 85

**45. Bạn là nam hay nữ?**

1 0 Nam
2 0 Nữ

**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 <u>bạn sử dụng chính để</u> 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 Tiếng Ba Lan
8 0 Tiếng Hàn Quốc
9 0 Ngôn ngữ khác (vui lòng viết ra):

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***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:

[NAME 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
Hết hạn vào ngày 31/12/2023

# 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

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### BỆNH NHÂN CỦA HOSPICE

**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 Viện dưỡng lão
4 O Bệnh viện
5 O Cơ sở/ viện tế bần
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:**

1 O Không bao giờ → **Nếu không bao giờ, trả lời tiếp câu hỏi 41**
2 O Thỉnh thoảng
3 O Thường thường
4 O 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, <u>nhóm Hospice</u> 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 O Có
2 O Không → **Nếu không, trả lời tiếp câu hỏi 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 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O 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 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O 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 đươc sự giúp đỡ sớm nhất như bạn cần không?**

1 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O 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 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O 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 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O 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 nhầm lẫn hoặc mâu thuẫn 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 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 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 với Hospice care?**

1 O Có
2 O Không→ **Nếu không, trả lời tiếp câu hỏi 15**

**14. Nhóm Hospice có thường xuyên lắng nghe cẩn 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 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 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 <u>bất kỳ thuốc giảm</u> 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 O Có, chắc chắn rồi
2 O Có, một chút
3 O 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 O Có, chắc chắn rồi
2 O Có, một chút
3 O Không
4 O 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 O Có
2 O 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 cần lúc bị khó thở hay không?**

1 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O 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 O Có, chắc chắn rồi
2 O Có, một chút
3 O Không
4 O 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 O Có
2 O Không →**Nếu không, trả lời tiếp câu hỏi 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 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O Luôn luôn

**26. Trong thời gian thành viên gia đình bạn đươc Hospice chăm sóc, họ có thể hiện bất kỳ sự lo lắng hay buồn bã nào không?**

1 O Có
2 O Không →**Nếu không, trả lời tiếp câu hỏi 28**

**27. Thành viên gia đình bạn có thường xuyên nhận được sự giúp đỡ hay họ cần <u>sự giúp đỡ từ nhóm Hospice</u> khi họ lo lắng hay khi họ buồn hay không?**

1 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O 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 O Có
2 O Không →**Nếu không, trả lời tiếp câu hỏi 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 O Có, chắc chắn rồi
2 O Có, một chút
3 O 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 O Có, chắc chắn rồi
2 O Có, một chút
3 O Không
4 O 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 O Có, chắc chắn rồi
2 O Có, một chút
3 O Không

## NHẬN ĐƯỢC SỰ CHĂM 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 đươc chăm sóc từ Hospice này trong khi anh ấy/cô ấy đang sống ở viện dưỡng lão hay không?**

1 O Có
2 O Không →**Nếu không, trả lời tiếp câu hỏi 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 O Không bao giờ
2 O Thỉnh thoảng
3 O Thường thường
4 O 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] O Không bao giờ
[2] O Thỉnh thoảng
[3] O Thường thường
[4] O 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] O Không bao giờ
[2] O Thỉnh thoảng
[3] O Thường thường
[4] O 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] 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 <u>nhiệt tình</u> 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 <u>sau khi</u> 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

**39. Vui lòng trả lời các câu hỏi dưới đây về sự chăm sóc thành viên gia đình bạn từ Hospice được đặt tên trên bìa khảo sát. Không bao gồm sự chăm sóc từ các Hospice khác trong câu trả lời của bạn.**

**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] 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 <u>nhất của thành viên gia đình</u> bạn đã hoàn thành là gì?**

[1] O Lớp 8 hoặc thấp hơn
[2] O Trung học phổ thông, nhưng chưa tốt nghiệp phổ thông
[3] O Tốt nghiệp trung học phổ thông hoặc tương đương GED
[4] O Cao đẳng hoặc Khoá học 2 năm
[5] O Tốt nghiệp cao đẳng hệ 4 năm
[6] O Tốt nghiệp cao đẳng trên 4 năm học
[7] O Không biết

**42. <u>Thành viên gia đình</u> bạn là người Tây Ban Nha, La tinh/ hay có gốc Nam Mỹ không?**

[1] O Không, không phải người Tây Ban Nha/ gốc Nam Mỹ/ người La Tinh
[2] O Phải, Cuba
[3] O Phải, người Mễ Tây Cơ, người Mỹ gốc Mễ Tây Cơ, người Chicano (người gốc Mễ Tây Cơ sinh tại Mỹ)
[4] O Phải, Puerto Rican
[5] O Phải, người Tây Ban Nha, người gốc Nam Mỹ/ La Tinh

**43. Chủng tộc của <u>thành viên gia đình</u> bạn là gì? Vui lòng chọn một hoặc nhiều hơn.**

[1] O Người có nguồn gốc từ bất cứ sắc dân bản địa nào ở Bắc Mỹ và Nam Mỹ
[2] O Người Châu Á
[3] O Người da Đen hoặc người Mỹ gốc Phi
[4] O Người có nguồn gốc đảo Hawaii hay đảo khác ở Thái Bình Dương
[5] O Người da Trắng

## THÔNG TIN VỀ BẠN

**44. Bạn bao nhiêu tuổi?**

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

**45. Bạn là nam hay nữ?**

1 O Nam
2 O Nữ

**46. Trình độ học vấn cao nhất mà bạn đã hoàn thành là gì?**

1 O Lớp 8 hoặc thấp hơn
2 O Trung học phổ thông, nhưng chưa tốt nghiệp
3 O Tốt nghiệp trung học phổ thông hoặc GED
4 O Cao đẳng hoặc Khoá học 2 năm
5 O Tốt nghiệp cao đẳng hệ 4 năm học
6 O Tốt nghiệp cao đẳng hệ trên 4 năm học

**47. Ngôn ngữ <u>bạn sử dụng chính để</u> giao tiếp ở nhà là gì?**

1 O Tiếng Anh
2 O Tiếng Tây Ban Nha
3 O Tiếng Trung Quốc
4 O Tiếng Nga
5 O Tiếng Bồ Đào Nha
6 O Tiếng Việt
7 O Tiếng Ba Lan
8 O Tiếng Hàn Quốc
9 O 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]**

# *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 hospice 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 [DECEDENT 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.

Câu hỏi [NOTE THE QUESTION NUMBERS] trong cuộc khảo sát được đính kèm là một phần sáng kiến quốc gia được tài trợ bởi Bộ Y tế và Dịch vụ Nhân sinh Hoa Kỳ (HHS) để đo lường chất lượng chăm sóc của hospices. Dịch vụ Bảo hiểm Y tế Người già và Trợ giúp Bảo hiểm Y tế Người nghèo (CMS) – một phần của HHS – đang tiến hành cuộc khảo sát này để nâng cao dịch vụ chăm sóc. CMS chi cho hầu hết cho việc chăm sóc tại hospice care ở Hoa Kỳ. Đó là trach nhiêm của CMS để đảm bảo rằng, bệnh nhân của hospice và người thân hay bạn bè của họ có được sự chăm sóc với chất lượng cao nhất. 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 hospice 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 trả lại vào phong bì trả trước. Câu trả lời của bạn có thể được chia sẻ với 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]

# *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 hay hospice của chúng tôi. Nếu bạn đã gửi trả lại khảo sát đó cho chúng tôi, xin hãy vui lòng đón 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 hospice care.

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 hospices. Dịch vụ Bảo hiểm Y tế Người già và Trợ giúp Bảo hiểm Y tế Người nghèo (CMS) – một phần của HHS – đang tiến hành cuộc khảo sát này để nâng cao dịch vụ chăm sóc. CMS chi cho hầu hết cho việc chăm sóc tại hospice care ở Hoa Kỳ. Đó là trach nhiêm của CMS để đảm bảo rằng, bệnh nhân của hospice và người thân hay bạn bè của họ có được sự chăm sóc với chất lượng cao nhất. 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 hospice care mà người thân hay gia đình bạn nhận được.

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]

# 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:*

## Vietnamese Version

"Thể theo Đạo luật Giảm thiểu Thủ tục Giấy tờ năm 1995, không một ai bị bắt buộc phải trả lời và cung cấp thông tin trừ khi trên bản câu hỏi có ghi rõ số kiểm soát OMB có hiệu lực. Số kiểm soát OMB có hiệu lực cho bản thu thập thông tin này là 0938-1257 (Hết hạn vào ngày 31/12/2023). Thời gian cần thiết để hoàn thành bản thu thập thông tin này được ước tính trung bình 11 phút cho các câu hỏi từ 1 – 40, những câu hỏi "Giới thiệu Thành viên Gia đình Bạn" và những câu hỏi "Thông tin về Bạn" trong cuộc khảo sát, bao gồm thời gian để xem xét hướng dẫn, tìm kiếm các nguồn dữ liệu hiện có, thu thập các dữ liệu cần thiết, hoàn thành và xem xét lại việc thu thập thông tin. Nếu quý vị có ý kiến gì về mức chính xác của thời gian ước tính hoặc đề nghị gì trong việc đơn giản hóa bản thăm dò ý kiến này, vui lòng gửi thư về: Centers for Medicare & Medicaid Services, 7500 Security Boulevard, C1-25-05, Baltimore, MD 21244-1850."

**Reply-by Date (Optional)**

*The following two options are available for adding a reply-by date to the* ***follow-up cover letter****.*

*Placed above the salutation, such as:*

Vui lòng trả lời trước: [DATE (dd/mm/yyyy)].

*In the fourth paragraph after the sentence, "After you have completed the survey, please return it in the enclosed pre-paid envelope." An example of allowable reply-by text includes:*

Vui lòng điền vào bản khảo sát kèm theo và gửi nó qua đường bưu điện trước [DATE (dd / mm / yyyy)] trong phong bì trả trước.

# Appendix U

## Mail Survey Materials (Polish)

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# CAHPS® Ankieta na temat usług hospicjum

Proszę odpowiedzieć na pytania ankiety dotyczące opieki, jaką pacjent uzyskał we wskazanym poniżej hospicjum:

[NAME OF HOSPICE]

**Wszystkie pytania tej ankiety będą dotyczyć doświadczeń związanych z wyżej wymienionym hospicjum.**

Aby dowiedzieć się więcej na temat tej ankiety, proszę zadzwonić pod [TOLL FREE NUMBER]. Wszystkie połączenia z tym numerem są bezpłatne.

OMB#0938-1257
Traci ważność dnia 31.12.2023

# CAHPS® Ankieta na temat usług hospicjum

## WSKAZÓWKI DO ANKIETY

- Proszę przekazać tę ankietę domownikowi, który wie najwięcej o opiece hospicyjnej, zapewnianej osobie wymienionej w liście przewodnim dołączonym do tej ankiety.
- Proszę wypełnić ankietę ciemnym długopisem.
- Proszę postawić X wewnątrz kratki przy wybranej odpowiedzi, jak w poniższym przykładzie.
  - ☐ Tak
  - ☒ Nie
- Czasami prosimy o opuszczenie niektórych pytań ankiety. W takim przypadku widoczna będzie strzałka z informacją, do którego pytania należy przejść, na przykład:
  - ☒ Tak ➔ ***Jeżeli Tak, proszę przejść do Pytania 1***
  - ☐ Nie

---

### PACJENT HOSPICJUM

**1. Kim jest dla Pana/Pani osoba wymieniona w liście towarzyszącym tej ankiecie?**

1☐ Mój współmałżonek/ka lub partner/ka
2☐ Mój rodzic
3☐ Moja teściowa lub teść
4☐ Moja babcia lub dziadek
5☐ Moja ciotka lub wujek
6☐ Moja siostra lub brat
7☐ Moje dziecko
8☐ Moja przyjaciółka lub przyjaciel
9☐ Inne (proszę wpisać drukowanymi literami):

_____

**2. W tej ankiecie zwrot „członek rodziny" oznacza osobę wymienioną w liście przewodnim dołączonym do tej ankiety. W jakich lokalizacjach członek rodziny korzystał z opieki tego hospicjum? Proszę wybrać jedną lub więcej odpowiedzi:**

1☐ Dom
2☐ Ośrodek opieki z zamieszkaniem (*Assisted living facility*)
3☐ Dom opieki pielęgniarskiej (*Nursing home*)
4☐ Szpital
5☐ Ośrodek / dom hospicjum
6☐ Inne (proszę wpisać drukowanymi literami):

_____

## PANA/PANI ROLA

**3. Kiedy członek rodziny był pod opieką hospicjum, jak często uczestniczył/a Pan/Pani w tej opiece lub nadzorował/a ją?**

1☐ Nigdy ➔**Jeżeli Nigdy, proszę przejść do Pytania 41**
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

## OPIEKA HOSPICJUM NAD CZŁONKIEM RODZINY

**Odpowiadając na pozostałe pytania tej ankiety, prosimy wziąć pod uwagę tylko doświadczenia członka rodziny związane z hospicjum, którego nazwa podana jest na stronie tytułowej ankiety.**

**4. W tej ankiecie <u>personel hospicjum</u> oznacza wszystkie pielęgniarki, wszystkich lekarzy, pracowników socjalnych, kapelanów i inne osoby, które zapewniały opiekę hospicyjną członkowi Pana/Pani rodziny. Kiedy członek rodziny był pod opieką hospicjum, czy musiał/a Pan/Pani kontaktować się z personelem hospicjum wieczorami, w weekendy, albo w święta w sprawie pytań lub pomocy w opiece nad członkiem rodziny?**

1☐ Tak
2☐ Nie ➔**Jeżeli Nie, proszę przejść do Pytania 6**

**5. Jak często uzyskiwał/a Pan/Pani potrzebną pomoc personelu hospicjum wieczorami, w weekendy, albo w święta?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**6. Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum informował Pana/Panią, kiedy ktoś przyjdzie, aby zaopiekować się członkiem rodziny?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**7. Kiedy członek rodziny był pod opieką hospicjum i Pan/Pani albo członek rodziny prosił personel hospicjum o pomoc, jak często zapewniana ona była tak szybko, jak była potrzebna?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**8. Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum wyjaśniał różne informacje w przystępny sposób?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**9. Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum przekazywał Panu/Pani informacje na temat stanu członka rodziny?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**10. Kiedy członek rodziny był pod opieką hospicjum, jak często ktoś z personelu hospicjum przekazywał Panu/Pani mylące lub sprzeczne informacje na temat stanu członka rodziny lub opieki nad nim?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**11. Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum traktował członka rodziny z szacunkiem i godnością?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**12. Kiedy członek rodziny był pod opieką hospicjum, jak często miał/a Pan/Pani wrażenie, że zespół hospicjum naprawdę troszczy się o członka rodziny?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**13. Kiedy członek rodziny był pod opieką hospicjum, czy rozmawiał/a Pan/Pani z zespołem hospicjum na temat problemów związanych z opieką hospicjum nad członkiem rodziny?**

1☐ Tak
2☐ Nie ➔**Jeżeli Nie, proszę przejść do Pytania 15**

**14. Jak często personel hospicjum słuchał Pana/Pani uważnie, kiedy mówił/a Pan/Pani o problemach związanych z opieką hospicjum nad członkiem rodziny?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**15. Czy członek rodziny odczuwał jakikolwiek ból, kiedy był pod opieką hospicjum?**

1☐ Tak
2☐ Nie ➔**Jeżeli Nie, proszę przejść do Pytania 17**

**16. Czy członek rodziny otrzymywał tyle pomocy w opanowaniu bólu, ile potrzebował?**

1☐ Zdecydowanie tak
2☐ W pewnym stopniu tak
3☐ Nie

**17. Czy członek rodziny otrzymywał jakiś lek przeciwbólowy, kiedy był pod opieką hospicjum?**

1☐ Tak
2☐ Nie ➔**Jeżeli Nie, proszę przejść do Pytania 21**

**18. Skutki uboczne leków przeciwbólowych obejmują np. senność. Czy ktoś z personelu hospicjum rozmawiał z Panem/Panią lub członkiem rodziny o skutkach ubocznych leków przeciwbólowych?**

1☐ Zdecydowanie tak
2☐ W pewnym stopniu tak
3☐ Nie

**19. Czy personel hospicjum przeszkolił Pana/Panią w zakresie skutków ubocznych leków przeciwbólowych, na które trzeba uważać?**

1☐ Zdecydowanie tak
2☐ W pewnym stopniu tak
3☐ Nie

**20. Czy personel hospicjum przeszkolił Pana/Panią na temat okoliczności, w których należy podawać członkowi rodziny więcej leków przeciwbólowych?**

1☐ Zdecydowanie tak
2☐ W pewnym stopniu tak
3☐ Nie
4☐ Nie potrzebowałem/am podawać leków przeciwbólowych członkowi rodziny

**21. Czy członek rodziny miał trudności z oddychaniem lub był leczony z powodu trudności z oddychaniem, kiedy był pod opieką hospicjum?**

1☐ Tak
2☐ Nie ➔**Jeżeli Nie, proszę przejść do Pytania 24**

**22. Jak często członek rodziny otrzymywał potrzebną pomoc z powodu trudności z oddychaniem?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**23. Czy personel hospicjum przeszkolił Pana/Panią na temat sposobów udzielania pomocy członkowi rodziny w przypadku trudności z oddychaniem?**

1☐ Zdecydowanie tak
2☐ W pewnym stopniu tak
3☐ Nie
4☐ Nie potrzebowałem/am udzielać pomocy członkowi rodziny z powodu trudności z oddychaniem

**24. Czy członkowi rodziny dokuczały kiedykolwiek zaparcia, kiedy był pod opieką hospicjum?**

1☐ Tak
2☐ Nie ➔**Jeżeli Nie, proszę przejść do Pytania 26**

**25. Jak często członek rodziny otrzymywał potrzebną pomoc w związku z zaparciami?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**26. Czy członek rodziny okazywał kiedykolwiek lęk lub smutek, kiedy był pod opieką hospicjum?**

1☐ Tak
2☐ Nie ➔**Jeżeli Nie, proszę przejść do Pytania 28**

**27. Jak często członek rodziny otrzymywał <u>od personelu hospicjum</u> potrzebną pomoc w związku z odczuwanym lękiem lub smutkiem?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**28. Czy członek rodziny wykazywał kiedykolwiek niepokój ruchowy lub pobudzenie, kiedy był pod opieką hospicjum?**

1☐ Tak
2☐ Nie ➔**Jeżeli Nie, proszę przejść do Pytania 30**

**29. Czy personel hospicjum przeszkolił Pana/Panią na temat sposobów udzielania pomocy członkowi rodziny w przypadku niepokoju ruchowego lub pobudzenia?**

1☐ Zdecydowanie tak
2☐ W pewnym stopniu tak
3☐ Nie

**30. Pomoc członkowi rodziny w poruszaniu się obejmuje takie czynności jak pomoc przy obracaniu się na łóżku, wstawaniu z łóżka lub wózka inwalidzkiego. Czy personel hospicjum zapewnił Panu/Pani szkolenie na temat tego, jak bezpiecznie pomagać członkowi rodziny w poruszaniu się?**

1☐ Zdecydowanie tak
2☐ W pewnym stopniu tak
3☐ Nie
4☐ Nie potrzebowałem/am pomagać członkowi rodziny w poruszaniu się

**31. Czy personel hospicjum przekazał Panu/Pani wszystkie informacje, jakie chciał/a Pan/Pani uzyskać na temat tego, czego należy oczekiwać w czasie, kiedy członek rodziny umiera?**

1☐ Zdecydowanie tak
2☐ W pewnym stopniu tak
3☐ Nie

## OPIEKA HOSPICJUM ŚWIADCZONA W DOMU OPIEKI PIELĘGNIARSKIEJ

**32. Niektórzy pacjenci mają zapewnianą opiekę hospicyjną, kiedy przebywają w domu opieki pielęgniarskiej. Czy członek rodziny miał zapewnioną opiekę tego hospicjum, kiedy przebywał w domu opieki pielęgniarskiej?**

1☐ Tak
2☐ Nie ➔**Jeżeli Nie, proszę przejść do Pytania 35**

**33. Kiedy członek rodziny był pod opieką hospicjum, jak często personel domu opieki pielęgniarskiej współpracował z personelem hospicjum w zapewnianiu mu opieki?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**34. Kiedy członek rodziny był pod opieką hospicjum, jak często informacje na temat członka rodziny przekazywane przez personel domu opieki pielęgniarskiej różniły się od tych, które przekazywał personel hospicjum?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

## PANA/PANI WŁASNE DOŚWIADCZENIA ZWIĄZANE Z HOSPICJUM

**35. Jak często personel hospicjum słuchał Pana/Pani uważnie, kiedy członek rodziny był pod opieką hospicjum?**

1☐ Nigdy
2☐ Czasami
3☐ Zazwyczaj
4☐ Zawsze

**36. Wsparcie dla wierzeń religijnych czy innych form duchowości obejmuje rozmowy, modlitwę, czas spędzany w ciszy i inne sposoby zaspakajania potrzeb religijnych lub duchowych. Kiedy członek rodziny był pod opieką hospicjum, jak wiele wsparcia dla Pana/Pani wierzeń religijnych czy innych form duchowości otrzymał/a Pan/Pani od personelu hospicjum?**

1☐ Za mało
2☐ Wystarczająco
3☐ Za dużo

**37. Jak wiele wsparcia <u>emocjonalnego</u> dostarczał Panu/Pani personel hospicjum, kiedy członek rodziny był pod opieką hospicjum?**

1☐ Za mało
2☐ Wystarczająco
3☐ Za dużo

**38. Jak wiele wsparcia emocjonalnego otrzymała/a Pan/Pani od personelu hospicjum w tygodniach <u>po śmierci</u> członka Pana/Pani rodziny?**

1☐ Za mało
2☐ Wystarczająco
3☐ Za dużo

## OGÓLNA OCENA OPIEKI HOSPICJUM

**39. Odpowiadając na kolejne pytania ankiety, prosimy wziąć pod uwagę opiekę, jaką członek rodziny otrzymał ze strony hospicjum, którego nazwa podana jest na stronie tytułowej ankiety. Prosimy nie uwzględniać w odpowiedziach opieki świadczonej przez inne hospicja.**

**Posługując się skalą od 0 do 10, na której 0 oznacza najgorszą możliwą opiekę hospicjum, a 10 oznacza najlepszą możliwą opiekę hospicjum, jak ocenił/a/by Pan/Pani opiekę hospicjum, jaką otrzymał członek Pana/Pani rodziny?**

0☐ 0 Najgorsza możliwa opieka hospicjum
1☐ 1
2☐ 2
3☐ 3
4☐ 4
5☐ 5
6☐ 6
7☐ 7
8☐ 8
9☐ 9
10☐ 10 Najlepsza możliwa opieka hospicjum

**40. Czy polecił/a/by Pan/Pani to hospicjum znajomym i rodzinie?**

1☐ Na pewno nie
2☐ Chyba nie
3☐ Chyba tak
4☐ Na pewno tak

## INFORMACJE O CZŁONKU RODZINY

**41. Jaki najwyższy poziom wykształcenia lub ile klas szkoły ukończył <u>członek rodziny</u>?**

1☐ 8 klas lub mniej
2☐ Rozpoczęta, ale nie ukończona szkoła średnia
3☐ Ukończona szkoła średnia lub zdany egzamin GED
4☐ Niepełne studia lub dyplom po studium 2-letnim
5☐ Skończone studia 4-letnie
6☐ Więcej niż skończone studia 4-letnie
7☐ Nie wiem

**42. Czy <u>członek Pana/Pani rodziny</u> był Latynosem/pochodzenia iberyjskiego lub miał przodków pochodzenia latynoskiego/ iberyjskiego?**

1☐ Nie, nie był Latynosem/ pochodzenia iberyjskiego
2☐ Tak, Kubańczyk
3☐ Tak, Meksykanin, Amerykanin pochodzenia meksykańskiego (Chicano)
4☐ Tak, Portorykańczyk
5☐ Tak, innego pochodzenia latynoskiego/ iberyjskiego

**43. Jakiej rasy był <u>członek Pana/Pani rodziny</u>? Proszę wybrać co najmniej jedną odpowiedź.**

1☐ Rodowity Indianin lub Alaskańczyk
2☐ Rasa azjatycka
3☐ Rasa czarna - Afroamerykanin
4☐ Rodowity mieszkaniec Hawajów lub innych wysp Pacyfiku
5☐ Rasa biała

## INFORMACJE O PANU/PANI

**44. Proszę podać swój wiek:**

1☐ 18 do 24 lat
2☐ 25 do 34 lat
3☐ 35 do 44 lat
4☐ 45 do 54 lat
5☐ 55 do 64 lat
6☐ 65 do 74 lat
7☐ 75 do 84 lat
8☐ 85 lat lub więcej

**45. Proszę podać swoją płeć:**

1☐ Mężczyzna
2☐ Kobieta

**46. Jaki jest najwyższy poziom Pana/Pani wykształcenia lub liczba ukończonych klas?**

1☐ 8 klas lub mniej
2☐ Rozpoczęta, ale nie ukończona szkoła średnia
3☐ Ukończona szkoła średnia lub zdany GED
4☐ Niepełne studia lub dyplom po studium 2-letnim
5☐ Skończone studia 4-letnie
6☐ Więcej niż skończone studia 4-letnie

**47. Jakim językiem <u>głównie</u> mówi Pan/Pani w domu?**

1☐ Angielski
2☐ Hiszpański
3☐ Chiński
4☐ Rosyjski
5☐ Portugalski
6☐ Wietnamski
7☐ Polski
8☐ Koreański
9☐ Inny język (proszę wpisać drukowanymi literami):

_____

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***DZIĘKUJEMY***

**Prosimy odesłać wypełnioną ankietę w załączonej kopercie z opłaconymi kosztami przesyłki zwrotnej.**

**[NAME OF SURVEY VENDOR]**

**[RETURN ADDRESS OF SURVEY VENDOR]**

# CAHPS® Ankieta na temat usług hospicjum

Proszę odpowiedzieć na pytania ankiety dotyczące opieki, jaką pacjent uzyskał we wskazanym poniżej hospicjum:

[NAME OF HOSPICE]

**Wszystkie pytania tej ankiety będą dotyczyć doświadczeń związanych z wyżej wymienionym hospicjum.**

Aby dowiedzieć się więcej na temat tej ankiety, proszę zadzwonić pod [TOLL FREE NUMBER]. Wszystkie połączenia z tym numerem są bezpłatne.

OMB#0938-1257
Traci ważność dnia 31.12.2023

# CAHPS® Ankieta na temat usług hospicjum

## WSKAZÓWKI DO ANKIETY

- Proszę przekazać tę ankietę domownikowi, który wie najwięcej o opiece hospicyjnej, zapewnianej osobie wymienionej w liście przewodnim dołączonym do tej ankiety.
- Proszę wypełnić ankietę ciemnym długopisem.
- Odpowiedz na wszystkie pytania, wypełniając całkowicie kółko znajdujące się z lewej strony wybranej odpowiedzi.

  0 Tak

  ● Nie

- Czasami prosimy o opuszczenie niektórych pytań ankiety. W takim przypadku widoczna będzie strzałka z informacją, do którego pytania należy przejść, na przykład:

  ● Tak ➔ ***Jeżeli Tak, proszę przejść do Pytania 1***

  0 Nie

---

### PACJENT HOSPICJUM

**1. Kim jest dla Pana/Pani osoba wymieniona w liście towarzyszącym tej ankiecie?**

[1]0 Mój współmałżonek/ka lub partner/ka

[2]0 Mój rodzic

[3]0 Moja teściowa lub teść

[4]0 Moja babcia lub dziadek

[5]0 Moja ciotka lub wujek

[6]0 Moja siostra lub brat

[7]0 Moje dziecko

[8]0 Moja przyjaciółka lub przyjaciel

[9]0 Inne (proszę wpisać drukowanymi literami):

_____

**2. W tej ankiecie zwrot „członek rodziny" oznacza osobę wymienioną w liście przewodnim dołączonym do tej ankiety. W jakich lokalizacjach członek rodziny korzystał z opieki tego hospicjum? Proszę wybrać jedną lub więcej odpowiedzi:**

[1]0 Dom

[2]0 Ośrodek opieki z zamieszkaniem (*Assisted living facility*)

[3]0 Dom opieki pielęgniarskiej (*Nursing home*)

[4]0 Szpital

[5]0 Ośrodek / dom hospicjum

[6]0 Inne (proszę wpisać drukowanymi literami):

_____

## PANA/PANI ROLA

**3. Kiedy członek rodziny był pod opieką hospicjum, jak często uczestniczył/a Pan/Pani w tej opiece lub nadzorował/a ją?**

[1]0 Nigdy ➔**Jeżeli Nigdy, proszę przejść do Pytania 41**

[2]0 Czasami

[3]0 Zazwyczaj

[4]0 Zawsze

## OPIEKA HOSPICJUM NAD CZŁONKIEM RODZINY

**Odpowiadając na pozostałe pytania tej ankiety, prosimy wziąć pod uwagę tylko doświadczenia członka rodziny związane z hospicjum, którego nazwa podana jest na stronie tytułowej ankiety.**

**4. W tej ankiecie <u>personel hospicjum</u> oznacza wszystkie pielęgniarki, wszystkich lekarzy, pracowników socjalnych, kapelanów i inne osoby, które zapewniały opiekę hospicyjną członkowi Pana/Pani rodziny. Kiedy członek rodziny był pod opieką hospicjum, czy musiał/a Pan/Pani kontaktować się z personelem hospicjum wieczorami, w weekendy, albo w święta w sprawie pytań lub pomocy w opiece nad członkiem rodziny?**

[1]0 Tak

[2]0 Nie ➔**Jeżeli Nie, proszę przejść do Pytania 6**

**5. Jak często uzyskiwał/a Pan/Pani potrzebną pomoc personelu hospicjum wieczorami, w weekendy, albo w święta?**

[1]0 Nigdy

[2]0 Czasami

[3]0 Zazwyczaj

[4]0 Zawsze

**6. Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum informował Pana/Panią, kiedy ktoś przyjdzie, aby zaopiekować się członkiem rodziny?**

[1]0 Nigdy

[2]0 Czasami

[3]0 Zazwyczaj

[4]0 Zawsze

**7. Kiedy członek rodziny był pod opieką hospicjum i Pan/Pani albo członek rodziny prosił personel hospicjum o pomoc, jak często zapewniana ona była tak szybko, jak była potrzebna?**

[1]0 Nigdy

[2]0 Czasami

[3]0 Zazwyczaj

[4]0 Zawsze

8. **Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum wyjaśniał różne informacje w przystępny sposób?**

   [1]0 Nigdy
   [2]0 Czasami
   [3]0 Zazwyczaj
   [4]0 Zawsze

9. **Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum przekazywał Panu/Pani informacje na temat stanu członka rodziny?**

   [1]0 Nigdy
   [2]0 Czasami
   [3]0 Zazwyczaj
   [4]0 Zawsze

10. **Kiedy członek rodziny był pod opieką hospicjum, jak często ktoś z personelu hospicjum przekazywał Panu/Pani mylące lub sprzeczne informacje na temat stanu członka rodziny lub opieki nad nim?**

    [1]0 Nigdy
    [2]0 Czasami
    [3]0 Zazwyczaj
    [4]0 Zawsze

11. **Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum traktował członka rodziny z szacunkiem i godnością?**

    [1]0 Nigdy
    [2]0 Czasami
    [3]0 Zazwyczaj
    [4]0 Zawsze

12. **Kiedy członek rodziny był pod opieką hospicjum, jak często miał/a Pan/Pani wrażenie, że zespół hospicjum naprawdę troszczy się o członka rodziny?**

    [1]0 Nigdy
    [2]0 Czasami
    [3]0 Zazwyczaj
    [4]0 Zawsze

13. **Kiedy członek rodziny był pod opieką hospicjum, czy rozmawiał/a Pan/Pani z zespołem hospicjum na temat problemów związanych z opieką hospicjum nad członkiem rodziny?**

    [1]0 Tak
    [2]0 Nie ➔**Jeżeli Nie, proszę przejść do Pytania 15**

14. **Jak często personel hospicjum słuchał Pana/Pani uważnie, kiedy mówił/a Pan/Pani o problemach związanych z opieką hospicjum nad członkiem rodziny?**

    [1]0 Nigdy
    [2]0 Czasami
    [3]0 Zazwyczaj
    [4]0 Zawsze

**15. Czy członek rodziny odczuwał jakikolwiek ból, kiedy był pod opieką hospicjum?**

[1]0 Tak

[2]0 Nie ➔**Jeżeli Nie, proszę przejść do Pytania 17**

**16. Czy członek rodziny otrzymywał tyle pomocy w opanowaniu bólu, ile potrzebował?**

[1]0 Zdecydowanie tak

[2]0 W pewnym stopniu tak

[3]0 Nie

**17. Czy członek rodziny otrzymywał jakiś lek przeciwbólowy, kiedy był pod opieką hospicjum?**

[1]0 Tak

[2]0 Nie ➔**Jeżeli Nie, proszę przejść do Pytania 21**

**18. Skutki uboczne leków przeciwbólowych obejmują np. senność. Czy ktoś z personelu hospicjum rozmawiał z Panem/Panią lub członkiem rodziny o skutkach ubocznych leków przeciwbólowych?**

[1]0 Zdecydowanie tak

[2]0 W pewnym stopniu tak

[3]0 Nie

**19. Czy personel hospicjum przeszkolił Pana/Panią w zakresie skutków ubocznych leków przeciwbólowych, na które trzeba uważać?**

[1]0 Zdecydowanie tak

[2]0 W pewnym stopniu tak

[3]0 Nie

**20. Czy personel hospicjum przeszkolił Pana/Panią na temat okoliczności, w których należy podawać członkowi rodziny więcej leków przeciwbólowych?**

[1]0 Zdecydowanie tak

[2]0 W pewnym stopniu tak

[3]0 Nie

[4]0 Nie potrzebowałem/am podawać leków przeciwbólowych członkowi rodziny

**21. Czy członek rodziny miał trudności z oddychaniem lub był leczony z powodu trudności z oddychaniem, kiedy był pod opieką hospicjum?**

[1]0 Tak

[2]0 Nie ➔**Jeżeli Nie, proszę przejść do Pytania 24**

**22. Jak często członek rodziny otrzymywał potrzebną pomoc z powodu trudności z oddychaniem?**

[1]0 Nigdy

[2]0 Czasami

[3]0 Zazwyczaj

[4]0 Zawsze

**23. Czy personel hospicjum przeszkolił Pana/Panią na temat sposobów udzielania pomocy członkowi rodziny w przypadku trudności z oddychaniem?**

[1]0 Zdecydowanie tak

[2]0 W pewnym stopniu tak

[3]0 Nie

[4]0 Nie potrzebowałem/am udzielać pomocy członkowi rodziny z powodu trudności z oddychaniem

**24. Czy członkowi rodziny dokuczały kiedykolwiek zaparcia, kiedy był pod opieką hospicjum?**

[1]0 Tak

[2]0 Nie ➔**Jeżeli Nie, proszę przejść do Pytania 26**

**25. Jak często członek rodziny otrzymywał potrzebną pomoc w związku z zaparciami?**

[1]0 Nigdy

[2]0 Czasami

[3]0 Zazwyczaj

[4]0 Zawsze

**26. Czy członek rodziny okazywał kiedykolwiek lęk lub smutek, kiedy był pod opieką hospicjum?**

[1]0 Tak

[2]0 Nie ➔**Jeżeli Nie, proszę przejść do Pytania 28**

**27. Jak często członek rodziny otrzymywał <u>od personelu hospicjum</u> potrzebną pomoc w związku z odczuwanym lękiem lub smutkiem?**

[1]0 Nigdy

[2]0 Czasami

[3]0 Zazwyczaj

[4]0 Zawsze

**28. Czy członek rodziny wykazywał kiedykolwiek niepokój ruchowy lub pobudzenie, kiedy był pod opieką hospicjum?**

[1]0 Tak

[2]0 Nie ➔**Jeżeli Nie, proszę przejść do Pytania 30**

**29. Czy personel hospicjum przeszkolił Pana/Panią na temat sposobów udzielania pomocy członkowi rodziny w przypadku niepokoju ruchowego lub pobudzenia?**

[1]0 Zdecydowanie tak

[2]0 W pewnym stopniu tak

[3]0 Nie

**30. Pomoc członkowi rodziny w poruszaniu się obejmuje takie czynności jak pomoc przy obracaniu się na łóżku, wstawaniu z łóżka lub wózka inwalidzkiego. Czy personel hospicjum zapewnił Panu/Pani szkolenie na temat tego, jak bezpiecznie pomagać członkowi rodziny w poruszaniu się?**

[1]0 Zdecydowanie tak
[2]0 W pewnym stopniu tak
[3]0 Nie
[4]0 Nie potrzebowałem/am pomagać członkowi rodziny w poruszaniu się

**31. Czy personel hospicjum przekazał Panu/Pani wszystkie informacje, jakie chciał/a Pan/Pani uzyskać na temat tego, czego należy oczekiwać w czasie, kiedy członek rodziny umiera?**

[1]0 Zdecydowanie tak
[2]0 W pewnym stopniu tak
[3]0 Nie

## OPIEKA HOSPICJUM ŚWIADCZONA W DOMU OPIEKI PIELĘGNIARSKIEJ

**32. Niektórzy pacjenci mają zapewnianą opiekę hospicyjną, kiedy przebywają w domu opieki pielęgniarskiej. Czy członek rodziny miał zapewnioną opiekę tego hospicjum, kiedy przebywał w domu opieki pielęgniarskiej?**

[1]0 Tak
[2]0 Nie ➔**Jeżeli Nie, proszę przejść do Pytania 35**

**33. Kiedy członek rodziny był pod opieką hospicjum, jak często personel domu opieki pielęgniarskiej współpracował z personelem hospicjum w zapewnianiu mu opieki?**

[1]0 Nigdy
[2]0 Czasami
[3]0 Zazwyczaj
[4]0 Zawsze

**34. Kiedy członek rodziny był pod opieką hospicjum, jak często informacje na temat członka rodziny przekazywane przez personel domu opieki pielęgniarskiej różniły się od tych, które przekazywał personel hospicjum?**

[1]0 Nigdy
[2]0 Czasami
[3]0 Zazwyczaj
[4]0 Zawsze

## PANA/PANI WŁASNE DOŚWIADCZENIA ZWIĄZANE Z HOSPICJUM

**35. Jak często personel hospicjum słuchał Pana/Pani uważnie, kiedy członek rodziny był pod opieką hospicjum?**

[1]0 Nigdy
[2]0 Czasami
[3]0 Zazwyczaj
[4]0 Zawsze

**36. Wsparcie dla wierzeń religijnych czy innych form duchowości obejmuje rozmowy, modlitwę, czas spędzany w ciszy i inne sposoby zaspakajania potrzeb religijnych lub duchowych. Kiedy członek rodziny był pod opieką hospicjum, jak wiele wsparcia dla Pana/Pani wierzeń religijnych czy innych form duchowości otrzymał/a Pan/Pani od personelu hospicjum?**

[1]0 Za mało
[2]0 Wystarczająco
[3]0 Za dużo

**37. Jak wiele wsparcia <u>emocjonalnego</u> dostarczał Panu/Pani personel hospicjum, kiedy członek rodziny był pod opieką hospicjum?**

[1]0 Za mało
[2]0 Wystarczająco
[3]0 Za dużo

**38. Jak wiele wsparcia emocjonalnego otrzymała/a Pan/Pani od personelu hospicjum w tygodniach <u>po śmierci</u> członka Pana/Pani rodziny?**

[1]0 Za mało
[2]0 Wystarczająco
[3]0 Za dużo

## OGÓLNA OCENA OPIEKI HOSPICJUM

**39. Odpowiadając na kolejne pytania ankiety, prosimy wziąć pod uwagę opiekę, jaką członek rodziny otrzymał ze strony hospicjum, którego nazwa podana jest na stronie tytułowej ankiety. Prosimy nie uwzględniać w odpowiedziach opieki świadczonej przez inne hospicja.**

**Posługując się skalą od 0 do 10, na której 0 oznacza najgorszą możliwą opiekę hospicjum, a 10 oznacza najlepszą możliwą opiekę hospicjum, jak ocenił/a/by Pan/Pani opiekę hospicjum, jaką otrzymał członek Pana/Pani rodziny?**

[0]0 0 Najgorsza możliwa opieka hospicjum
[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 Najlepsza możliwa opieka hospicjum

**40. Czy polecił/a/by Pan/Pani to hospicjum znajomym i rodzinie?**

[1]0 Na pewno nie
[2]0 Chyba nie
[3]0 Chyba tak
[4]0 Na pewno tak

## INFORMACJE O CZŁONKU RODZINY

**41. Jaki najwyższy poziom wykształcenia lub ile klas szkoły ukończył członek rodziny?**

- [1] 8 klas lub mniej
- [2] Rozpoczęta, ale nie ukończona szkoła średnia
- [3] Ukończona szkoła średnia lub zdany egzamin GED
- [4] Niepełne studia lub dyplom po studium 2-letnim
- [5] Skończone studia 4-letnie
- [6] Więcej niż skończone studia 4-letnie
- [7] Nie wiem

**42. Czy członek Pana/Pani rodziny był Latynosem/pochodzenia iberyjskiego lub miał przodków pochodzenia latynoskiego/ iberyjskiego?**

- [1] Nie, nie był Latynosem/ pochodzenia iberyjskiego
- [2] Tak, Kubańczyk
- [3] Tak, Meksykanin, Amerykanin pochodzenia meksykańskiego (Chicano)
- [4] Tak, Portorykańczyk
- [5] Tak, innego pochodzenia latynoskiego/ iberyjskiego

**43. Jakiej rasy był członek Pana/Pani rodziny? Proszę wybrać co najmniej jedną odpowiedź.**

- [1] Rodowity Indianin lub Alaskańczyk
- [2] Rasa azjatycka
- [3] Rasa czarna - Afroamerykanin
- [4] Rodowity mieszkaniec Hawajów lub innych wysp Pacyfiku
- [5] Rasa biała

## INFORMACJE O PANU/PANI

**44. Proszę podać swój wiek:**

- [1] 18 do 24 lat
- [2] 25 do 34 lat
- [3] 35 do 44 lat
- [4] 45 do 54 lat
- [5] 55 do 64 lat
- [6] 65 do 74 lat
- [7] 75 do 84 lat
- [8] 85 lat lub więcej

**45. Proszę podać swoją płeć:**

- [1] Mężczyzna
- [2] Kobieta

**46. Jaki jest najwyższy poziom Pana/Pani wykształcenia lub liczba ukończonych klas?**

- [1] 8 klas lub mniej
- [2] Rozpoczęta, ale nie ukończona szkoła średnia
- [3] Ukończona szkoła średnia lub zdany GED
- [4] Niepełne studia lub dyplom po studium 2-letnim
- [5] Skończone studia 4-letnie
- [6] Więcej niż skończone studia 4-letnie

**47. Jakim językiem <u>głównie</u> mówi Pan/Pani w domu?**

- [1] Angielski
- [2] Hiszpański
- [3] Chiński
- [4] Rosyjski
- [5] Portugalski
- [6] Wietnamski
- [7] Polski
- [8] Koreański
- [9] Inny język (proszę wpisać drukowanymi literami): _____

***DZIĘKUJEMY***

**Prosimy odesłać wypełnioną ankietę w załączonej kopercie z opłaconymi kosztami przesyłki zwrotnej.**

**[NAME OF SURVEY VENDOR]**

**[RETURN ADDRESS OF SURVEY VENDOR]**

# CAHPS® Ankieta na temat usług hospicjum

Proszę odpowiedzieć na pytania ankiety dotyczące opieki, jaką pacjent uzyskał we wskazanym poniżej hospicjum:

[NAME OF HOSPICE]

**Wszystkie pytania tej ankiety będą dotyczyć doświadczeń związanych z wyżej wymienionym hospicjum.**

Aby dowiedzieć się więcej na temat tej ankiety, proszę zadzwonić pod [TOLL FREE NUMBER]. Wszystkie połączenia z tym numerem są bezpłatne.

OMB#0938-1257
Traci ważność dnia 31.12.2023

# CAHPS® Ankieta na temat usług hospicjum

## WSKAZÓWKI DO ANKIETY

- Proszę przekazać tę ankietę domownikowi, który wie najwięcej o opiece hospicyjnej, zapewnianej osobie wymienionej w liście przewodnim dołączonym do tej ankiety.
- Proszę wypełnić ankietę ciemnym długopisem.
- Odpowiedz na wszystkie pytania, wypełniając całkowicie kółko znajdujące się z lewej strony wybranej odpowiedzi.
  - ○ Tak
  - ● Nie
- Czasami prosimy o opuszczenie niektórych pytań ankiety. W takim przypadku widoczna będzie strzałka z informacją, do którego pytania należy przejść, na przykład:
  - ● Tak ➔ ***Jeżeli Tak, proszę przejść do Pytania 1***
  - ○ Nie

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### PACJENT HOSPICJUM

**1. Kim jest dla Pana/Pani osoba wymieniona w liście towarzyszącym tej ankiecie?**

- 1○ Mój współmałżonek/ka lub partner/ka
- 2○ Mój rodzic
- 3○ Moja teściowa lub teść
- 4○ Moja babcia lub dziadek
- 5○ Moja ciotka lub wujek
- 6○ Moja siostra lub brat
- 7○ Moje dziecko
- 8○ Moja przyjaciółka lub przyjaciel
- 9○ Inne (proszę wpisać drukowanymi literami): _____

**2. W tej ankiecie zwrot „członek rodziny" oznacza osobę wymienioną w liście przewodnim dołączonym do tej ankiety. W jakich lokalizacjach członek rodziny korzystał z opieki tego hospicjum? Proszę wybrać jedną lub więcej odpowiedzi:**

- 1○ Dom
- 2○ Ośrodek opieki z zamieszkaniem (*Assisted living facility*)
- 3○ Dom opieki pielęgniarskiej (*Nursing home*)
- 4○ Szpital
- 5○ Ośrodek / dom hospicjum
- 6○ Inne (proszę wpisać drukowanymi literami): _____

## PANA/PANI ROLA

**3. Kiedy członek rodziny był pod opieką hospicjum, jak często uczestniczył/a Pan/Pani w tej opiece lub nadzorował/a ją?**

1O Nigdy ➔**Jeżeli Nigdy, proszę przejść do Pytania 41**

2O Czasami

3O Zazwyczaj

4O Zawsze

## OPIEKA HOSPICJUM NAD CZŁONKIEM RODZINY

**Odpowiadając na pozostałe pytania tej ankiety, prosimy wziąć pod uwagę tylko doświadczenia członka rodziny związane z hospicjum, którego nazwa podana jest na stronie tytułowej ankiety.**

**4. W tej ankiecie <u>personel hospicjum</u> oznacza wszystkie pielęgniarki, wszystkich lekarzy, pracowników socjalnych, kapelanów i inne osoby, które zapewniały opiekę hospicyjną członkowi Pana/Pani rodziny. Kiedy członek rodziny był pod opieką hospicjum, czy musiał/a Pan/Pani kontaktować się z personelem hospicjum wieczorami, w weekendy, albo w święta w sprawie pytań lub pomocy w opiece nad członkiem rodziny?**

1O Tak

2O Nie ➔**Jeżeli Nie, proszę przejść do Pytania 6**

**5. Jak często uzyskiwał/a Pan/Pani potrzebną pomoc personelu hospicjum wieczorami, w weekendy, albo w święta?**

1O Nigdy

2O Czasami

3O Zazwyczaj

4O Zawsze

**6. Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum informował Pana/Panią, kiedy ktoś przyjdzie, aby zaopiekować się członkiem rodziny?**

1O Nigdy

2O Czasami

3O Zazwyczaj

4O Zawsze

**7. Kiedy członek rodziny był pod opieką hospicjum i Pan/Pani albo członek rodziny prosił personel hospicjum o pomoc, jak często zapewniana ona była tak szybko, jak była potrzebna?**

1O Nigdy

2O Czasami

3O Zazwyczaj

4O Zawsze

8. **Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum wyjaśniał różne informacje w przystępny sposób?**

   1O Nigdy
   2O Czasami
   3O Zazwyczaj
   4O Zawsze

9. **Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum przekazywał Panu/Pani informacje na temat stanu członka rodziny?**

   1O Nigdy
   2O Czasami
   3O Zazwyczaj
   4O Zawsze

10. **Kiedy członek rodziny był pod opieką hospicjum, jak często ktoś z personelu hospicjum przekazywał Panu/Pani mylące lub sprzeczne informacje na temat stanu członka rodziny lub opieki nad nim?**

    1O Nigdy
    2O Czasami
    3O Zazwyczaj
    4O Zawsze

11. **Kiedy członek rodziny był pod opieką hospicjum, jak często personel hospicjum traktował członka rodziny z szacunkiem i godnością?**

    1O Nigdy
    2O Czasami
    3O Zazwyczaj
    4O Zawsze

12. **Kiedy członek rodziny był pod opieką hospicjum, jak często miał/a Pan/Pani wrażenie, że zespół hospicjum naprawdę troszczy się o członka rodziny?**

    1O Nigdy
    2O Czasami
    3O Zazwyczaj
    4O Zawsze

13. **Kiedy członek rodziny był pod opieką hospicjum, czy rozmawiał/a Pan/Pani z zespołem hospicjum na temat problemów związanych z opieką hospicjum nad członkiem rodziny?**

    1O Tak
    2O Nie ➔**Jeżeli Nie, proszę przejść do Pytania 15**

14. **Jak często personel hospicjum słuchał Pana/Pani uważnie, kiedy mówił/a Pan/Pani o problemach związanych z opieką hospicjum nad członkiem rodziny?**

    1O Nigdy
    2O Czasami
    3O Zazwyczaj
    4O Zawsze

**15. Czy członek rodziny odczuwał jakikolwiek ból, kiedy był pod opieką hospicjum?**

1O Tak

2O Nie ➔**Jeżeli Nie, proszę przejść do Pytania 17**

**16. Czy członek rodziny otrzymywał tyle pomocy w opanowaniu bólu, ile potrzebował?**

1O Zdecydowanie tak

2O W pewnym stopniu tak

3O Nie

**17. Czy członek rodziny otrzymywał jakiś lek przeciwbólowy, kiedy był pod opieką hospicjum?**

1O Tak

2O Nie ➔**Jeżeli Nie, proszę przejść do Pytania 21**

**18. Skutki uboczne leków przeciwbólowych obejmują np. senność. Czy ktoś z personelu hospicjum rozmawiał z Panem/Panią lub członkiem rodziny o skutkach ubocznych leków przeciwbólowych?**

1O Zdecydowanie tak

2O W pewnym stopniu tak

3O Nie

**19. Czy personel hospicjum przeszkolił Pana/Panią w zakresie skutków ubocznych leków przeciwbólowych, na które trzeba uważać?**

1O Zdecydowanie tak

2O W pewnym stopniu tak

3O Nie

**20. Czy personel hospicjum przeszkolił Pana/Panią na temat okoliczności, w których należy podawać członkowi rodziny więcej leków przeciwbólowych?**

1O Zdecydowanie tak

2O W pewnym stopniu tak

3O Nie

4O Nie potrzebowałem/am podawać leków przeciwbólowych członkowi rodziny

**21. Czy członek rodziny miał trudności z oddychaniem lub był leczony z powodu trudności z oddychaniem, kiedy był pod opieką hospicjum?**

1O Tak

2O Nie ➔**Jeżeli Nie, proszę przejść do Pytania 24**

**22. Jak często członek rodziny otrzymywał potrzebną pomoc z powodu trudności z oddychaniem?**

1O Nigdy

2O Czasami

3O Zazwyczaj

4O Zawsze

**23. Czy personel hospicjum przeszkolił Pana/Panią na temat sposobów udzielania pomocy członkowi rodziny w przypadku trudności z oddychaniem?**

1O Zdecydowanie tak
2O W pewnym stopniu tak
3O Nie
4O Nie potrzebowałem/am udzielać pomocy członkowi rodziny z powodu trudności z oddychaniem

**24. Czy członkowi rodziny dokuczały kiedykolwiek zaparcia, kiedy był pod opieką hospicjum?**

1O Tak
2O Nie ➔**Jeżeli Nie, proszę przejść do Pytania 26**

**25. Jak często członek rodziny otrzymywał potrzebną pomoc w związku z zaparciami?**

1O Nigdy
2O Czasami
3O Zazwyczaj
4O Zawsze

**26. Czy członek rodziny okazywał kiedykolwiek lęk lub smutek, kiedy był pod opieką hospicjum?**

1O Tak
2O Nie ➔**Jeżeli Nie, proszę przejść do Pytania 28**

**27. Jak często członek rodziny otrzymywał <u>od personelu hospicjum</u> potrzebną pomoc w związku z odczuwanym lękiem lub smutkiem?**

1O Nigdy
2O Czasami
3O Zazwyczaj
4O Zawsze

**28. Czy członek rodziny wykazywał kiedykolwiek niepokój ruchowy lub pobudzenie, kiedy był pod opieką hospicjum?**

1O Tak
2O Nie ➔**Jeżeli Nie, proszę przejść do Pytania 30**

**29. Czy personel hospicjum przeszkolił Pana/Panią na temat sposobów udzielania pomocy członkowi rodziny w przypadku niepokoju ruchowego lub pobudzenia?**

1O Zdecydowanie tak
2O W pewnym stopniu tak
3O Nie

**30. Pomoc członkowi rodziny w poruszaniu się obejmuje takie czynności jak pomoc przy obracaniu się na łóżku, wstawaniu z łóżka lub wózka inwalidzkiego. Czy personel hospicjum zapewnił Panu/Pani szkolenie na temat tego, jak bezpiecznie pomagać członkowi rodziny w poruszaniu się?**

1O Zdecydowanie tak
2O W pewnym stopniu tak
3O Nie
4O Nie potrzebowałem/am pomagać członkowi rodziny w poruszaniu się

**31. Czy personel hospicjum przekazał Panu/Pani wszystkie informacje, jakie chciał/a Pan/Pani uzyskać na temat tego, czego należy oczekiwać w czasie, kiedy członek rodziny umiera?**

1O Zdecydowanie tak
2O W pewnym stopniu tak
3O Nie

## OPIEKA HOSPICJUM ŚWIADCZONA W DOMU OPIEKI PIELĘGNIARSKIEJ

**32. Niektórzy pacjenci mają zapewnianą opiekę hospicyjną, kiedy przebywają w domu opieki pielęgniarskiej. Czy członek rodziny miał zapewnioną opiekę tego hospicjum, kiedy przebywał w domu opieki pielęgniarskiej?**

1O Tak
2O Nie ➔**Jeżeli Nie, proszę przejść do Pytania 35**

**33. Kiedy członek rodziny był pod opieką hospicjum, jak często personel domu opieki pielęgniarskiej współpracował z personelem hospicjum w zapewnianiu mu opieki?**

1O Nigdy
2O Czasami
3O Zazwyczaj
4O Zawsze

**34. Kiedy członek rodziny był pod opieką hospicjum, jak często informacje na temat członka rodziny przekazywane przez personel domu opieki pielęgniarskiej różniły się od tych, które przekazywał personel hospicjum?**

1O Nigdy
2O Czasami
3O Zazwyczaj
4O Zawsze

## PANA/PANI WŁASNE DOŚWIADCZENIA ZWIĄZANE Z HOSPICJUM

**35. Jak często personel hospicjum słuchał Pana/Pani uważnie, kiedy członek rodziny był pod opieką hospicjum?**

1O Nigdy
2O Czasami
3O Zazwyczaj
4O Zawsze

**36. Wsparcie dla wierzeń religijnych czy innych form duchowości obejmuje rozmowy, modlitwę, czas spędzany w ciszy i inne sposoby zaspakajania potrzeb religijnych lub duchowych. Kiedy członek rodziny był pod opieką hospicjum, jak wiele wsparcia dla Pana/Pani wierzeń religijnych czy innych form duchowości otrzymał/a Pan/Pani od personelu hospicjum?**

1O Za mało
2O Wystarczająco
3O Za dużo

**37. Jak wiele wsparcia <u>emocjonalnego</u> dostarczał Panu/Pani personel hospicjum, kiedy członek rodziny był pod opieką hospicjum?**

1O Za mało
2O Wystarczająco
3O Za dużo

**38. Jak wiele wsparcia emocjonalnego otrzymała/a Pan/Pani od personelu hospicjum w tygodniach <u>po śmierci</u> członka Pana/Pani rodziny?**

1O Za mało
2O Wystarczająco
3O Za dużo

## OGÓLNA OCENA OPIEKI HOSPICJUM

**39. Odpowiadając na kolejne pytania ankiety, prosimy wziąć pod uwagę opiekę, jaką członek rodziny otrzymał ze strony hospicjum, którego nazwa podana jest na stronie tytułowej ankiety. Prosimy nie uwzględniać w odpowiedziach opieki świadczonej przez inne hospicja.**

**Posługując się skalą od 0 do 10, na której 0 oznacza najgorszą możliwą opiekę hospicjum, a 10 oznacza najlepszą możliwą opiekę hospicjum, jak ocenił/a/by Pan/Pani opiekę hospicjum, jaką otrzymał członek Pana/Pani rodziny?**

0O 0 Najgorsza możliwa opieka hospicjum
1O 1
2O 2
3O 3
4O 4
5O 5
6O 6
7O 7
8O 8
9O 9
10O 10 Najlepsza możliwa opieka hospicjum

**40. Czy polecił/a/by Pan/Pani to hospicjum znajomym i rodzinie?**

1O Na pewno nie
2O Chyba nie
3O Chyba tak
4O Na pewno tak

## INFORMACJE O CZŁONKU RODZINY

**41. Jaki najwyższy poziom wykształcenia lub ile klas szkoły ukończył członek rodziny?**

1O 8 klas lub mniej
2O Rozpoczęta, ale nie ukończona szkoła średnia
3O Ukończona szkoła średnia lub zdany egzamin GED
4O Niepełne studia lub dyplom po studium 2-letnim
5O Skończone studia 4-letnie
6O Więcej niż skończone studia 4-letnie
7O Nie wiem

**42. Czy członek Pana/Pani rodziny był Latynosem/pochodzenia iberyjskiego lub miał przodków pochodzenia latynoskiego/ iberyjskiego?**

1O Nie, nie był Latynosem/ pochodzenia iberyjskiego
2O Tak, Kubańczyk
3O Tak, Meksykanin, Amerykanin pochodzenia meksykańskiego (Chicano)
4O Tak, Portorykańczyk
5O Tak, innego pochodzenia latynoskiego/ iberyjskiego

**43. Jakiej rasy był członek Pana/Pani rodziny? Proszę wybrać co najmniej jedną odpowiedź.**

1O Rodowity Indianin lub Alaskańczyk
2O Rasa azjatycka
3O Rasa czarna - Afroamerykanin
4O Rodowity mieszkaniec Hawajów lub innych wysp Pacyfiku
5O Rasa biała

## INFORMACJE O PANU/PANI

**44. Proszę podać swój wiek:**

1O 18 do 24 lat
2O 25 do 34 lat
3O 35 do 44 lat
4O 45 do 54 lat
5O 55 do 64 lat
6O 65 do 74 lat
7O 75 do 84 lat
8O 85 lat lub więcej

**45. Proszę podać swoją płeć:**

1O Mężczyzna
2O Kobieta

**46. Jaki jest najwyższy poziom Pana/Pani wykształcenia lub liczba ukończonych klas?**

1O 8 klas lub mniej
2O Rozpoczęta, ale nie ukończona szkoła średnia
3O Ukończona szkoła średnia lub zdany GED
4O Niepełne studia lub dyplom po studium 2-letnim
5O Skończone studia 4-letnie
6O Więcej niż skończone studia 4-letnie

**47. Jakim językiem <u>głównie</u> mówi Pan/Pani w domu?**

1O Angielski
2O Hiszpański
3O Chiński
4O Rosyjski
5O Portugalski
6O Wietnamski
7O Polski
8O Koreański
9O Inny język (proszę wpisać drukowanymi literami):

_____

***DZIĘKUJEMY***

**Prosimy odesłać wypełnioną ankietę w załączonej kopercie z opłaconymi kosztami przesyłki zwrotnej.**

**[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]

Szanowny Panie/ Szanowna Pani,

[HOSPICE NAME] prowadzi ankietę na temat usług świadczonych przez hospicjum na rzecz pacjentów i ich rodzin. Wybrano Pana/Panią do tej ankiety, ponieważ ustaliliśmy, że był/a Pan/Pani opiekunem/opiekunką [DECEDENT NAME] Zdajemy sobie sprawę, że może to być dla Pana/Pani trudny okres, mamy jednak nadzieję, że pomoże nam Pan/Pani uzyskać informacje na temat jakości opieki, jaką członek Pana/Pani rodziny lub przyjaciel otrzymał ze strony hospicjum.

Pytania [NOTE THE QUESTION NUMBERS] w załączonej ankiecie są częścią ogólnokrajowej inicjatywy sponsorowanej przez federalny Departament Zdrowia i Usług dla Ludności (Department of Health and Human Services, HHS), którego celem jest określenie jakości opieki świadczonej przez hospicja. Ośrodki Centers for Medicare & Medicaid Services (CMS), będące częścią HHS, prowadzą tę ankietę w celu poprawy jakości opieki w hospicjach. CMS pokrywa koszty większości opieki w hospicjach w USA. CMS ma również obowiązek zapewnić, że pacjenci hospicjów, członkowie ich rodzin i przyjaciele otrzymują opiekę wysokiej jakości. Jednym ze sposobów wywiązywania się z tego obowiązku jest uzyskanie informacji bezpośrednio od Pana/Pani na temat opieki hospicyjnej, jaką otrzymał członek Pana/Pani rodziny lub przyjaciel. Udział w ankiecie jest dobrowolny i nie będzie miał wpływu na Pana/Pani opiekę zdrowotną ani świadczenia.

Mamy nadzieję, że znajdzie Pan/Pani czas na wypełnienie tej ankiety. Po wypełnieniu ankiety prosimy zwrócić ją w dołączonej kopercie z opłaconymi kosztami przesyłki. Pana/Pani odpowiedzi mogą być udostępnione hospicjum w celu poprawy jakości świadczonych usług. [OPTIONAL: Być może zauważy Pan/Pani numer podany na ankiecie. Numer ten służy do powiadomienia nas, że odesłał/a Pan/Pani swoją ankietę, co oznacza, że nie musimy wysyłać upomnień].

W razie jakichkolwiek pytań na temat załączonej ankiety, prosimy zadzwonić pod bezpłatny numer 1-800-xxx-xxxx. Dziękujemy za przyczynienie się do poprawy opieki hospicjów nad wszystkimi pacjentami.

Z poważaniem,
[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]

Szanowny Panie/ Szanowna Pani,

Nasze dane wskazują, że niedawno opiekował/a się Pan/Pani [DECEDENT NAME] w [NAME OF HOSPICE]. Mniej więcej trzy tygodnie temu wysłaliśmy do Pana/Pani ankietę na temat jakości opieki, jaką Pan/Pani i członek Pana/Pani rodziny lub przyjaciel otrzymał ze strony hospicjum. Jeżeli już odesłał/a Pan/Pani do nas ankietę, bardzo za to dziękujemy i prosimy zignorować to przypomnienie. Jeżeli jednak jeszcze Pan/Pani tego nie zrobił/a, bylibyśmy zobowiązani, gdyby znalazł/a Pan/Pani chwilę na wypełnienie tej ważnej ankiety.

Mamy nadzieję, że skorzysta Pan/Pani z tej możliwości, aby pomóc nam uzyskać informacje na temat jakości opieki, jaką otrzymał Pan/Pani i członek Pana/Pani rodziny lub przyjaciel. Wyniki ankiety przyczynią się do zapewnienia najwyższej jakości opieki hospicyjnej wszystkim Amerykanom.

Pytania [NOTE THE QUESTION NUMBERS] w załączonej ankiecie są częścią ogólnokrajowej inicjatywy sponsorowanej przez federalny Departament Zdrowia i Usług dla Ludności (Department of Health and Human Services, HHS), którego celem jest określenie jakości opieki świadczonej przez hospicja. Ośrodki Centers for Medicare & Medicaid Services (CMS), będące częścią HHS, prowadzą tę ankietę w celu poprawy jakości opieki w hospicjach. CMS pokrywa koszty większości opieki w hospicjach w USA. CMS ma również obowiązek zapewnić, że pacjenci hospicjów, członkowie ich rodzin i przyjaciele otrzymują opiekę wysokiej jakości. Jednym ze sposobów wywiązywania się z tego obowiązku jest uzyskanie informacji bezpośrednio od Pana/Pani na temat opieki hospicyjnej, jaką otrzymał członek Pana/Pani rodziny lub przyjaciel. Udział w ankiecie jest dobrowolny i nie będzie miał wpływu na Pana/Pani opiekę zdrowotną ani świadczenia.

Prosimy o znalezienie kilku minut na wypełnienie załączonej ankiety. Po wypełnieniu ankiety prosimy zwrócić ją w dołączonej kopercie z opłaconymi kosztami przesyłki. Pana/Pani odpowiedzi mogą być udostępnione hospicjum w celu poprawy jakości świadczonych usług. [OPTIONAL: Być może zauważy Pan/Pani numer podany na tej ankiecie. Ten numer służy do powiadomienia nas, że odesłał/a Pan/Pani swoją ankietę, co oznacza, że nie musimy wysyłać upomnień].

W razie jakichkolwiek pytań na temat załączonej ankiety, prosimy zadzwonić pod bezpłatny numer 1-800-xxx-xxxx. Dziękujemy za przyczynienie się do poprawy opieki hospicjów nad wszystkimi pacjentami.

Z poważaniem,
[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:*

## Polish Version

Zgodnie z Ustawą o ograniczeniu dokumentacji z roku 1995, nie ma obowiązku odpowiadania na wnioski o informacje, jeżeli wniosek nie zawiera ważnego numeru kontrolnego OMB. Ważny numer kontrolny OMB dotyczący tego wniosku o informacje to 0938-1257 (traci ważność dnia 31.12.2023). Szacuje się, że czas wymagany do wypełnienia tego wniosku o informacje to ok. 11 minut dla pytań 1 – 40, pytań z części „Informacje o członku rodziny" i „Informacje o Panu/Pani", co obejmuje czas na zapoznanie się z instrukcją, przeszukanie istniejących źródeł danych, zgromadzenie potrzebnych danych, wypełnienie i przegląd formularza użytego do gromadzenia informacji. Wszelkie uwagi na temat dokładności wyznaczonego szacunkowo czasu wypełnienia ankiety i sugestie odnośnie ulepszenia formularza należy kierować na adres: Centers for Medicare & Medicaid Services, 7500 Security Boulevard, C1-25-05, Baltimore, MD 21244-1850.

**Reply-by Date (Optional)**

*The following two options are available for adding a reply-by date to the* ***follow-up cover letter****.*

*Placed above the salutation, such as:*

Prosimy odpowiedzieć do: [DATE (mm/dd/yyyy)].

*In the fourth paragraph after the sentence, "After you have completed the survey, please return it in the enclosed pre-paid envelope." An example of allowable reply-by text includes:*

Prosimy wypełnić załączoną ankietę i wysłać ją do [DATE (mm/dd/yyyy)] w opłaconej kopercie zwrotnej.

# Appendix V

## Mail Survey Materials (Korean)

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# CAHPS® 호스피스 설문 조사

이 호스피스로부터 환자가 받은 케어에 관해서 설문지에 답변해 주시기 바랍니다.

[NAME OF HOSPICE]

**이 설문지의 모든 질문들은 이 호스피스와의 경험에 관한 것입니다.**

본 설문지에 관해서 더 자세히 알고 싶으시면, [TOLL FREE NUMBER] 로 연락을 주시기 바랍니다. 이 번호로의 통화는 무료로 이용하실 수 있습니다.

OMB#0938-1257
2023 년 12 월 31 에 만료됨

# CAHPS® 호스피스 설문 조사

## 설문 조사 지시 사항

- 본 설문지는 설문지 커버레터에 적혀있는 사람이 받은 호스피스 케어에 관하여 가장 잘 알고 있는 귀하의 가족 구성원에게 주시기 바랍니다.
- 설문지를 작성하실 때 어두운 색깔의 펜을 사용하여 주십시오.
- 답변은 해당하는 네모 안에 X 를 직접 적어주세요, 밑에 견본이 있습니다.
  - ☐ 예
  - ☒ 아니요
- 이 설문지에서 몇 개의 질문들은 건너 뛰라고 할 수도 있습니다. 이런 경우, 여기에 나온 것처럼 다음에 답변할 질문이 무엇인지를 말하는 안내와 함께 화살표가 표시되어 있습니다.
  - ☒ 예 ➔ *응답이 '예'면 **1** 번으로 가세요.*
  - ☐ 아니요

---

### 호스피스 환자

**1. 귀하는 설문지 커버 레터에 나와 있는 사람과 어떤 관계 입니까?**

1☐ 배우자나 파트너
2☐ 부모
3☐ 시어머니(장모) 또는 시아버지(장인)
4☐ 조부모
5☐ 고모(이모) 또는 삼촌(외삼촌)
6☐ 자매 또는 형제
7☐ 자녀
8☐ 친구
9☐ 이외(정자체로 써주세요).

_____

**2. 이 설문지에서, "가족"은 설문지 커버 레터에 나와 있는 사람을 말합니다. 귀하의 가족이 이 호스피스로부터 케어를 받은 장소가 어디입니까? 한가지 이상 선택하십시오.**

1☐ 집
2☐ 노인 원호 생활 시설
3☐ 양로원
4☐ 병원
5☐ 호스피스 시설/ 호스피스 집
6☐ 이외(정자체로 써주세요).

_____

## 귀하의 역할

**3.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 케어 받는 가족을 돌보는 데 참여하고 감독을 했습니까?

1☐ 전혀 ➔ 응답이 '전혀'이면, **41** 번으로 가세요.
2☐ 때때로
3☐ 보통
4☐ 항상

## 가족의 호스피스 케어

이 설문지의 나머지 질문에 답변하실 때, 설문지 커버에 나와 있는 이름의 호스피스에 대한 귀하의 가족의 경험만을 생각해 주십시오.

**4.** 이 설문지에서, 호스피스 팀은 귀하의 가족에게 호스피스 케어를 제공했던 모든 간호사, 의사, 사회 복지사, 목사님 그리고 다른 사람들을 포함합니다. 귀하의 가족이 호스피스 케어를 받는 동안, 질문이 있거나 귀하의 가족을 케어하는 데 도움을 받기 위해 호스피스 팀에게 저녁, 주말, 휴일에 연락을 해야 했습니까?

1☐ 예
2☐ 아니요 ➔ 응답이 '아니요'면, **6** 번으로 가세요.

**5.** 귀하는 얼마나 자주 호스피스 팀으로부터 저녁, 주말, 휴일에 필요한 도움을 받으셨습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**6.** 귀하의 가족이 호스피스의 케어를 받는 동안, 호스피스 팀은 귀하의 가족에게 케어를 위한 방문의 도착 시간을 얼마나 자주 알려 주었습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**7.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하 또는 귀하의 가족이 호스피스 팀에게 도움을 요청 했을 때, 도움을 얼마나 즉시 자주 받았습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**8.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 이해하기 쉽게 설명을 해 주었습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**9.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 귀하의 가족의 상태에 관해서 알려 주었습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**10.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀원이 귀하에게 귀하의 가족의 상태나 케어에 관해서 혼란스럽거나 모순되는 정보를 주었습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**11.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 귀하의 가족을 존중하면서 대하였습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**12.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 귀하의 가족을 보살핀다고 느끼셨습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**13.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하의 가족의 호스피스 케어에 관한 문제에 대해서 호스피스 팀과 이야기를 나누셨습니까?

1☐ 예
2☐ 아니요 ➔응답이 '아니요'면, **15** 번으로 가세요.

**14.** 귀하께서 귀하의 가족의 호스피스 케어에 대해서 호스피스 팀과 이야기 할 때 얼마나 자주 호스피스 팀이 주의 깊게 경청해 주었나요?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**15.** 귀하의 가족이 호스피스 케어를 받는 동안 통증이 있었던 적이 있습니까?

1☐ 예
2☐ 아니요 ➔응답이 '아니요'면, **17** 번으로 가세요.

**16.** 귀하의 가족이 통증에 따라 필요한 만큼 도움을 받았습니까?

1☐ 예, 확실히
2☐ 예, 다소
3☐ 아니요

**17.** 귀하의 가족이 호스피스 케어를 받는 동안, 가족 분이 통증 약을 받으셨습니까?

1☐ 예
2☐ 아니요 ➔응답이 '아니요'면, **21** 번으로 가세요.

**18.** 통증 약의 부작용엔 졸림 증상과 같은 것이 있습니다. 호스피스 팀 중 누군가가 귀하 또는 귀하의 가족에게 통증약의 부작용에 대해서 설명했습니까?

1☐ 예, 확실히
2☐ 예, 다소
3☐ 아니

**19.** 호스피스팀이 귀하께 통증약의 주의 해야할 부작용에 관해서 필요한 안내를 해드렸습니까?

1☐ 예, 확실히
2☐ 예, 다소
3☐ 아니요

**20.** 호스피스 팀이 귀하께 언제 귀하의 가족에게 통증 약을 더 드려야 되는지 여부와 시기에 관해서 필요한 안내를 해 드렸습니까?

1☐ 예, 확실히
2☐ 예, 다소
3☐ 아니요
4☐ 가족에게 통증 약을 줄 필요가 없었다

**21.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하의 가족께서 호흡곤란이 있었거나 호흡곤란에 대한 치료를 받으신 적이 있습니까?

1☐ 예
2☐ 아니요 ➔응답이 '아니요'면, **24** 번으로 가세요.

**22.** 귀하의 가족이 호흡 곤란에 관해서 얼마나 자주 필요한 도움을 받았습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**23.** 호스피스 팀이 귀하께 귀하의 가족이 호흡 곤란을 느낄때 어떻게 도와야 하는지에 관한 필요한 안내를 해드렸습니까?

1☐ 예, 확실히
2☐ 예, 다소
3☐ 아니요
4☐ 가족의 호흡 곤란을 도울 필요가 없었다

**24.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하의 가족이 변비로 고생하신 적이 있습니까?

1☐ 예
2☐ 아니요 ➔응답이 '아니요'면 **26** 번으로 가세요

**25.** 귀하의 가족이 변비에 관해 얼마나 자주 필요한 도움을 받았습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**26.** 귀하의 가족이 호스피스 케어를 받는 중에, 불안이나 슬픔을 보인 적이 있습니까?

1☐ 예
2☐ 아니요 ➔응답이 '아니요'면 **28** 번으로 가세요.

**27.** 얼마나 자주 귀하의 가족이 <u>호스피스 팀으로부터</u> 불안이나 슬픈 감정에 도움을 받은 적이 있습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**28.** 귀하의 가족이 호스피스 케어를 받는 동안, 안절부절 하거나 불안해 한 적이 있으십니까?

1☐ 예
2☐ 아니요 ➔응답이 '아니요'면 **30** 번으로 가세요.

**29.** 호스피스 팀이 귀하께 귀하의 가족이 안절부절 하거나 불안해 할 때 어떻게 해야 되는지에 관해 설명을 해 드렸습니까?

1☐ 예, 확실히
2☐ 예, 다소
3☐ 아니요

**30.** 귀하의 가족을 움직이게 하는 것에는 침대에서 방향을 바꾸는 것 또는 휠체어에 앉거나 일어나는 것, 또는 침대에 눕거나 일어나는 것이 포함됩니다. 호스피스 팀이 귀하께 어떻게 가족을 안전하게 움직일 수 있는지 필요한 안내를 해 드렸습니까?

1☐ 예, 확실히
2☐ 예, 다소
3☐ 아니요
4☐ 가족을 움직일 필요가 없었다.

**31.** 귀하의 가족께서 돌아가실 때, 호스피스팀이 귀하께서 무엇을 예상하셔야 되는지 원하시는 만큼의 정보를 드렸습니까?

1☐ 예, 확실히
2☐ 예, 다소
3☐ 아니요

## 호스피스 케어를 양로원에서 받은 경우

**32.** 어떤 분들은 양로원에 사시면서 호스피스 케어를 받으십니다. 귀하의 가족께서 양로원에 사시면서 호스피스 케어를 받으셨습니까?

1☐ 예
2☐ 아니요 ➔응답이 '아니요'면, **35** 번으로 가세요.

**33.** 귀하의 가족이 호스피스 케어를 받는 동안, 양로원 직원과 호스피스 팀이 얼마나 자주 귀하의 가족을 보살피기 위해서 함께 잘 일했습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**34.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주, 양로원 직원으로부터 귀하의 가족에 관해 받은 정보와 호스피스 팀으로부터 받은 정보가 달랐습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

## 호스피스에 관한 귀하의 경험

**35.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 주의 깊게 귀하께 경청 하였습니까?

1☐ 전혀
2☐ 때때로
3☐ 보통
4☐ 항상

**36.** 종교적이거나 영적인 믿음에 관한 지원은 대화, 기도, 묵상 또는 어떠한 방식으로든 종교적이거나 영적으로 필요한 것을 충족시키는 것을 포함합니다. 귀하의 가족이 호스피스 케어를 받는 동안, 귀하는 호스피스 팀으로부터 얼마나 종교적 그리고 영적인 믿음에 관한 지원을 받으셨습니까?

1☐ 너무 적게
2☐ 적당하게
3☐ 너무 많이

**37.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하는 호스피스 팀으로부터 얼마나 정서적인 지원을 받았습니까?

1☐ 너무 적게
2☐ 적당하게
3☐ 너무 많이

**38.** 귀하의 가족이 돌아가신 후 몇 주 동안, 귀하는 호스피스 팀으로부터 얼마나 정서적인 지원을 받으셨습니까?

1☐ 너무 적게
2☐ 적당하게
3☐ 너무 많이

## 호스피스 케어의 전체적인 점수

**39.** 설문지 겉 표지에 나와 있는 호스피스에게 귀하의 가족이 받은 케어에 관해서 다음의 질문들에 답변해 주시기 바랍니다. 귀하의 답변에 다른 호스피스로부터 받은 케어는 포함시키지 마십시오.

**0** 은 최악의 호스피스 케어이고 **10** 이 최고의 호스피스 케어라고 할 때 **0** 부터 **10** 까지의 숫자를 사용해서, 귀하의 가족이 받은 호스피스 케어에 대해 몇 점을 주시겠습니까?

0☐ 0 최악의 호스피스 케어
1☐ 1
2☐ 2
3☐ 3
4☐ 4
5☐ 5
6☐ 6
7☐ 7
8☐ 8
9☐ 9
10☐ 10 최고의 호스피스 케어

**40.** 이 호스피스를 귀하의 친구나 가족에게 추천 하시겠습니까?

1☐ 절대 안 함
2☐ 안 할 것 같음
3☐ 할 것 같음
4☐ 확실히 할 것임

## 귀하의 가족에 관해서

**41. 귀하의 가족의 최종 학력이 어떻게 되시나요?**

1☐ 중졸 이하
2☐ 고교 중퇴
3☐ 고졸 또는 검정고시(GED)
4☐ 대학 중퇴 또는 2 년제 대학 학위
5☐ 4 년제 대학 졸업
6☐ 대학원 이상
7☐ 모름

**42. 귀하의 가족이 히스패닉, 라티노 또는 스페인계 출신인가요?**

1☐ 아니요, 히스패닉, 라티노, 스페인계 아님
2☐ 예, 쿠바 사람
3☐ 예, 멕시코 사람, 멕시코계 미국인, 치카노 사람
4☐ 예, 푸에르토리칸
5☐ 예, 다른 스페인계/히스패닉/라티노

**43. 귀하의 가족의 인종이 무엇입니까? 한 개 또는 한 개 이상을 고를 수 있습니다.**

1☐ 미국 인디안 또는 알래스카 원주민
2☐ 아시아인
3☐ 흑인 또는 아프리카계 미국인
4☐ 하와이 원주민 혹은 다른 태평양 제도인
5☐ 백인

## 귀하에 관해서

**44. 귀하의 연세가 어떻게 되십니까?**

1☐ 18 ~ 24 세
2☐ 25 ~ 34 세
3☐ 35 ~ 44 세
4☐ 45 ~ 54 세
5☐ 55 ~ 64 세
6☐ 65 ~ 74 세
7☐ 75 ~ 84 세
8☐ 85 세 이상

**45. 귀하는 남성입니까, 아니면 여성입니까?**

1☐ 남성
2☐ 여성

**46. 귀하의 학력이 어떻게 되십니까?**

1☐ 중졸 이하
2☐ 고교 중퇴
3☐ 고졸 또는 검정고시(GED)
4☐ 대학 중퇴 또는 2 년제 대학 학위
5☐ 4 년제 대학 졸업
6☐ 대학원 이상

**47. 댁에서 사용하시는 주요 언어가 무엇입니까?**

1☐ 영어
2☐ 스페인어
3☐ 중국어
4☐ 러시아어
5☐ 포르투갈어
6☐ 베트남어
7☐ 폴란드어
8☐ 한국어
9☐ 다른 언어(정자체로 써주세요).

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*감사합니다*

**작성하신 설문지를 우편요금 선납 반송용 우편 봉투에 넣어서 보내주세요.**

**[NAME OF SURVEY VENDOR]**

**[RETURN ADDRESS OF SURVEY VENDOR]**

# CAHPS® 호스피스 설문 조사

이 호스피스로부터 환자가 받은 케어에 관해서 설문지에 답변해 주시기 바랍니다.

[NAME OF HOSPICE]

**이 설문지의 모든 질문들은 이 호스피스와의 경험에 관한 것입니다.**

본 설문지에 관해서 더 자세히 알고 싶으시면, [TOLL FREE NUMBER] 로 연락을 주시기 바랍니다. 이 번호로의 통화는 무료로 이용하실 수 있습니다.

OMB#0938-1257
2023 년 12 월 31 에 만료됨

# CAHPS® 호스피스 설문 조사

## 설문 조사 지시 사항

- 본 설문지는 설문지 커버레터에 적혀있는 사람이 받은 호스피스 케어에 관하여 가장 잘 알고 있는 귀하의 가족 구성원에게 주시기 바랍니다.
- 설문지를 작성하실 때 어두운 색깔의 펜을 사용하여 주십시오.
- 질문의 왼쪽에 있는 원을 완전히 채워서 모든 질문에 답변을 해주십시오.
  - 0 예
  - ● 아니요
- 이 설문지에서 몇 개의 질문들은 건너 뛰라고 할 수도 있습니다. 이런 경우, 여기에 나온 것처럼 다음에 답변할 질문이 무엇인지를 말하는 안내와 함께 화살표가 표시되어 있습니다.
  - ● 예 ➔ *응답이 '예'면 1 번으로 가세요.*
  - 0 아니요

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### 호스피스 환자

**1. 귀하는 설문지 커버 레터에 나와 있는 사람과 어떤 관계 입니까?**

- [1]0 배우자나 파트너
- [2]0 부모
- [3]0 시어머니(장모) 또는 시아버지(장인)
- [4]0 조부모
- [5]0 고모(이모) 또는 삼촌(외삼촌)
- [6]0 자매 또는 형제
- [7]0 자녀
- [8]0 친구
- [9]0 이외(정자체로 써주세요).

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**2. 이 설문지에서, "가족"은 설문지 커버 레터에 나와 있는 사람을 말합니다. 귀하의 가족이 이 호스피스로부터 케어를 받은 장소가 어디입니까? 한가지 이상 선택하십시오.**

- [1]0 집
- [2]0 노인 원호 생활 시설
- [3]0 양로원
- [4]0 병원
- [5]0 호스피스 시설/ 호스피스 집
- [6]0 이외(정자체로 써주세요).

_____

## 귀하의 역할

**3.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 케어 받는 가족을 돌보는 데 참여하고 감독을 했습니까?

[1]O 전혀 ➔ 응답이 '전혀'이면, **41** 번으로 가세요.
[2]O 때때로
[3]O 보통
[4]O 항상

## 가족의 호스피스 케어

이 설문지의 나머지 질문에 답변하실 때, 설문지 커버에 나와 있는 이름의 호스피스에 대한 귀하의 가족의 경험만을 생각해 주십시오.

**4.** 이 설문지에서, 호스피스 팀은 귀하의 가족에게 호스피스 케어를 제공했던 모든 간호사, 의사, 사회복지사, 목사님 그리고 다른 사람들을 포함합니다. 귀하의 가족이 호스피스 케어를 받는 동안, 질문이 있거나 귀하의 가족을 케어하는 데 도움을 받기 위해 호스피스 팀에게 저녁, 주말, 휴일에 연락을 해야 했습니까?

[1]O 예
[2]O 아니요 ➔ 응답이 '아니요'면, **6** 번으로 가세요.

**5.** 귀하는 얼마나 자주 호스피스 팀으로부터 저녁, 주말, 휴일에 필요한 도움을 받으셨습니까?

[1]O 전혀
[2]O 때때로
[3]O 보통
[4]O 항상

**6.** 귀하의 가족이 호스피스의 케어를 받는 동안, 호스피스 팀은 귀하의 가족에게 케어를 위한 방문의 도착 시간을 얼마나 자주 알려 주었습니까?

[1]O 전혀
[2]O 때때로
[3]O 보통
[4]O 항상

**7.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하 또는 귀하의 가족이 호스피스 팀에게 도움을 요청 했을 때, 도움을 얼마나 즉시 자주 받았습니까?

[1]O 전혀
[2]O 때때로
[3]O 보통
[4]O 항상

**8.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 이해하기 쉽게 설명을 해 주었습니까?

[1]O 전혀
[2]O 때때로
[3]O 보통
[4]O 항상

**9.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 귀하의 가족의 상태에 관해서 알려 주었습니까?

[1]O 전혀
[2]O 때때로
[3]O 보통
[4]O 항상

**10.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀원이 귀하에게 귀하의 가족의 상태나 케어에 관해서 혼란스럽거나 모순되는 정보를 주었습니까?

[1]O 전혀
[2]O 때때로
[3]O 보통
[4]O 항상

**11.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 귀하의 가족을 존중하면서 대하였습니까?

[1]O 전혀
[2]O 때때로
[3]O 보통
[4]O 항상

**12.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 귀하의 가족을 보살핀다고 느끼셨습니까?

[1]O 전혀
[2]O 때때로
[3]O 보통
[4]O 항상

**13.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하의 가족의 호스피스 케어에 관한 문제에 대해서 호스피스 팀과 이야기를 나누셨습니까?

[1]O 예
[2]O 아니요 ➔응답이 '아니요'면, **15** 번으로 가세요.

**14.** 귀하께서 귀하의 가족의 호스피스 케어에 대해서 호스피스 팀과 이야기 할 때 얼마나 자주 호스피스 팀이 주의 깊게 경청해 주었나요?

[1]O 전혀
[2]O 때때로
[3]O 보통
[4]O 항상

**15.** 귀하의 가족이 호스피스 케어를 받는 동안 통증이 있었던 적이 있습니까?

[1]O 예
[2]O 아니요 ➔응답이 '아니요'면, **17** 번으로 가세요.

**16.** 귀하의 가족이 통증에 따라 필요한 만큼 도움을 받았습니까?

[1]O 예, 확실히
[2]O 예, 다소
[3]O 아니요

**17.** 귀하의 가족이 호스피스 케어를 받는 동안, 가족 분이 통증 약을 받으셨습니까?

[1]O 예
[2]O 아니요 ➔응답이 '아니요'면, **21** 번으로 가세요.

**18.** 통증 약의 부작용엔 졸림 증상과 같은 것이 있습니다. 호스피스 팀 중 누군가가 귀하 또는 귀하의 가족에게 통증약의 부작용에 대해서 설명했습니까?

[1]O 예, 확실히
[2]O 예, 다소
[3]O 아니

**19.** 호스피스팀이 귀하께 통증약의 주의 해야할 부작용에 관해서 필요한 안내를 해드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요

**20.** 호스피스 팀이 귀하께 언제 귀하의 가족에게 통증 약을 더 드려야 되는지 여부와 시기에 관해서 필요한 안내를 해 드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요
4O 가족에게 통증 약을 줄 필요가 없었다

**21.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하의 가족께서 호흡곤란이 있었거나 호흡곤란에 대한 치료를 받으신 적이 있습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면, **24** 번으로 가세요.

**22.** 귀하의 가족이 호흡 곤란에 관해서 얼마나 자주 필요한 도움을 받았습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**23.** 호스피스 팀이 귀하께 귀하의 가족이 호흡 곤란을 느낄때 어떻게 도와야 하는지에 관한 필요한 안내를 해드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요
4O 가족의 호흡 곤란을 도울 필요가 없었다

**24.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하의 가족이 변비로 고생하신 적이 있습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면 **26** 번으로 가세요

**25.** 귀하의 가족이 변비에 관해 얼마나 자주 필요한 도움을 받았습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**26.** 귀하의 가족이 호스피스 케어를 받는 중에, 불안이나 슬픔을 보인 적이 있습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면 **28** 번으로 가세요.

**27.** 얼마나 자주 귀하의 가족이 호스피스 팀으로부터 불안이나 슬픈 감정에 도움을 받은 적이 있습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**28.** 귀하의 가족이 호스피스 케어를 받는 동안, 안절부절 하거나 불안해 한 적이 있으십니까?

1O 예
2O 아니요 ➔응답이 '아니요'면 **30** 번으로 가세요.

**29.** 호스피스 팀이 귀하께 귀하의 가족이 안절부절 하거나 불안해 할 때 어떻게 해야 되는지에 관해 설명을 해 드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요

**30.** 귀하의 가족을 움직이게 하는 것에는 침대에서 방향을 바꾸는 것 또는 휠체어에 앉거나 일어나는 것, 또는 침대에 눕거나 일어나는 것이 포함됩니다. 호스피스 팀이 귀하께 어떻게 가족을 안전하게 움직일 수 있는지 필요한 안내를 해 드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요
4O 가족을 움직일 필요가 없었다.

**31.** 귀하의 가족께서 돌아가실 때, 호스피스팀이 귀하께서 무엇을 예상하셔야 되는지 원하시는 만큼의 정보를 드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요

## 호스피스 케어를 양로원에서 받은 경우

**32.** 어떤 분들은 양로원에 사시면서 호스피스 케어를 받으십니다. 귀하의 가족께서 양로원에 사시면서 호스피스 케어를 받으셨습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면, **35** 번으로 가세요.

**33.** 귀하의 가족이 호스피스 케어를 받는 동안, 양로원 직원과 호스피스 팀이 얼마나 자주 귀하의 가족을 보살피기 위해서 함께 잘 일했습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**34.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주, 양로원 직원으로부터 귀하의 가족에 관해 받은 정보와 호스피스 팀으로부터 받은 정보가 달랐습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

## 호스피스에 관한 귀하의 경험

**35.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 주의 깊게 귀하께 경청 하였습니까?

1 O 전혀
2 O 때때로
3 O 보통
4 O 항상

**36.** 종교적이거나 영적인 믿음에 관한 지원은 대화, 기도, 묵상 또는 어떠한 방식으로든 종교적이거나 영적으로 필요한 것을 충족시키는 것을 포함합니다. 귀하의 가족이 호스피스 케어를 받는 동안, 귀하는 호스피스 팀으로부터 얼마나 종교적 그리고 영적인 믿음에 관한 지원을 받으셨습니까?

1 O 너무 적게
2 O 적당하게
3 O 너무 많이

**37.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하는 호스피스 팀으로부터 얼마나 정서적인 지원을 받았습니까?

1 O 너무 적게
2 O 적당하게
3 O 너무 많이

**38.** 귀하의 가족이 돌아가신 후 몇 주 동안, 귀하는 호스피스 팀으로부터 얼마나 정서적인 지원을 받으셨습니까?

1 O 너무 적게
2 O 적당하게
3 O 너무 많이

## 호스피스 케어의 전체적인 점수

**39.** 설문지 겉 표지에 나와 있는 호스피스에게 귀하의 가족이 받은 케어에 관해서 다음의 질문들에 답변해 주시기 바랍니다. 귀하의 답변에 다른 호스피스로부터 받은 케어는 포함시키지 마십시오.

**0** 은 최악의 호스피스 케어이고 **10** 이 최고의 호스피스 케어라고 할 때 **0** 부터 **10** 까지의 숫자를 사용해서, 귀하의 가족이 받은 호스피스 케어에 대해 몇 점을 주시겠습니까?

0 O 0 최악의 호스피스 케어
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 최고의 호스피스 케어

**40. 이 호스피스를 귀하의 친구나 가족에게 추천 하시겠습니까?**

1O 절대 안 함
2O 안 할 것 같음
3O 할 것 같음
4O 확실히 할 것임

## 귀하의 가족에 관해서

**41. 귀하의 가족의 최종 학력이 어떻게 되시나요?**

1O 중졸 이하
2O 고교 중퇴
3O 고졸 또는 검정고시(GED)
4O 대학 중퇴 또는 2 년제 대학 학위
5O 4 년제 대학 졸업
6O 대학원 이상
7O 모름

**42. 귀하의 가족이 히스패닉, 라티노 또는 스페인계 출신인가요?**

1O 아니요, 히스패닉, 라티노, 스페인계 아님
2O 예, 쿠바 사람
3O 예, 멕시코 사람, 멕시코계 미국인, 치카노 사람
4O 예, 푸에르토리칸
5O 예, 다른 스페인계/히스패닉/라티노

**43. 귀하의 가족의 인종이 무엇입니까? 한 개 또는 한 개 이상을 고를 수 있습니다.**

1O 미국 인디안 또는 알래스카 원주민
2O 아시아인
3O 흑인 또는 아프리카계 미국인
4O 하와이 원주민 혹은 다른 태평양 제도인
5O 백인

## 귀하에 관해서

**44. 귀하의 연세가 어떻게 되십니까?**

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

**45. 귀하는 남성입니까, 아니면 여성입니까?**

1O 남성
2O 여성

**46. 귀하의 학력이 어떻게 되십니까?**

1 O 중졸 이하
2 O 고교 중퇴
3 O 고졸 또는 검정고시(GED)
4 O 대학 중퇴 또는 2 년제 대학 학위
5 O 4 년제 대학 졸업
6 O 대학원 이상

**47. 댁에서 사용하시는 주요 언어가 무엇입니까?**

1 O 영어
2 O 스페인어
3 O 중국어
4 O 러시아어
5 O 포르투갈어
6 O 베트남어
7 O 폴란드어
8 O 한국어
9 O 다른 언어(정자체로 써주세요)

_____

*감사합니다*

**작성하신 설문지를 우편요금 선납 반송용 우편 봉투에 넣어서 보내주세요.**

**[NAME OF SURVEY VENDOR]**

**[RETURN ADDRESS OF SURVEY VENDOR]**

# CAHPS® 호스피스 설문 조사

이 호스피스로부터 환자가 받은 케어에 관해서 설문지에 답변해 주시기 바랍니다.

[NAME OF HOSPICE]

**이 설문지의 모든 질문들은 이 호스피스와의 경험에 관한 것입니다.**

본 설문지에 관해서 더 자세히 알고 싶으시면, [TOLL FREE NUMBER] 로 연락을 주시기 바랍니다. 이 번호로의 통화는 무료로 이용하실 수 있습니다.

OMB#0938-1257
2023 년 12 월 31 에 만료됨

# CAHPS® 호스피스 설문 조사

## 설문 조사 지시 사항

- 본 설문지는 설문지 커버레터에 적혀있는 사람이 받은 호스피스 케어에 관하여 가장 잘 알고 있는 귀하의 가족 구성원에게 주시기 바랍니다.
- 설문지를 작성하실 때 어두운 색깔의 펜을 사용하여 주십시오.
- 질문의 왼쪽에 있는 원을 완전히 채워서 모든 질문에 답변을 해주십시오.
  - ○ 예
  - ● 아니요
- 이 설문지에서 몇 개의 질문들은 건너 뛰라고 할 수도 있습니다. 이런 경우, 여기에 나온 것처럼 다음에 답변할 질문이 무엇인지를 말하는 안내와 함께 화살표가 표시되어 있습니다.
  - ● 예 ➔ *응답이 '예'면 **1** 번으로 가세요.*
  - ○ 아니요

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### 호스피스 환자

**1. 귀하는 설문지 커버 레터에 나와 있는 사람과 어떤 관계 입니까?**

1○ 배우자나 파트너
2○ 부모
3○ 시어머니(장모) 또는 시아버지(장인)
4○ 조부모
5○ 고모(이모) 또는 삼촌(외삼촌)
6○ 자매 또는 형제
7○ 자녀
8○ 친구
9○ 이외(정자체로 써주세요).

_____

**2. 이 설문지에서, "가족"은 설문지 커버 레터에 나와 있는 사람을 말합니다. 귀하의 가족이 이 호스피스로부터 케어를 받은 장소가 어디입니까? 한가지 이상 선택하십시오.**

1○ 집
2○ 노인 원호 생활 시설
3○ 양로원
4○ 병원
5○ 호스피스 시설/ 호스피스 집
6○ 이외(정자체로 써주세요).

_____

## 귀하의 역할

**3.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 케어 받는 가족을 돌보는 데 참여하고 감독을 했습니까?

1O 전혀 ➔ 응답이 '전혀'이면, **41** 번으로 가세요.
2O 때때로
3O 보통
4O 항상

## 가족의 호스피스 케어

이 설문지의 나머지 질문에 답변하실 때, 설문지 커버에 나와 있는 이름의 호스피스에 대한 귀하의 가족의 경험만을 생각해 주십시오.

**4.** 이 설문지에서, 호스피스 팀은 귀하의 가족에게 호스피스 케어를 제공했던 모든 간호사, 의사, 사회 복지사, 목사님 그리고 다른 사람들을 포함합니다. 귀하의 가족이 호스피스 케어를 받는 동안, 질문이 있거나 귀하의 가족을 케어하는 데 도움을 받기 위해 호스피스 팀에게 저녁, 주말, 휴일에 연락을 해야 했습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면, **6** 번으로 가세요.

**5.** 귀하는 얼마나 자주 호스피스 팀으로부터 저녁, 주말, 휴일에 필요한 도움을 받으셨습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**6.** 귀하의 가족이 호스피스의 케어를 받는 동안, 호스피스 팀은 귀하의 가족에게 케어를 위한 방문의 도착 시간을 얼마나 자주 알려 주었습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**7.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하 또는 귀하의 가족이 호스피스 팀에게 도움을 요청 했을 때, 도움을 얼마나 즉시 자주 받았습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**8.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 이해하기 쉽게 설명을 해 주었습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**9.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 귀하의 가족의 상태에 관해서 알려 주었습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**10.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀원이 귀하에게 귀하의 가족의 상태나 케어에 관해서 혼란스럽거나 모순되는 정보를 주었습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**11.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 귀하의 가족을 존중하면서 대하였습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**12.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 귀하의 가족을 보살핀다고 느끼셨습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**13.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하의 가족의 호스피스 케어에 관한 문제에 대해서 호스피스 팀과 이야기를 나누셨습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면, **15** 번으로 가세요.

**14.** 귀하께서 귀하의 가족의 호스피스 케어에 대해서 호스피스 팀과 이야기 할 때 얼마나 자주 호스피스 팀이 주의 깊게 경청해 주었나요?

1O 전혀
2O 때때로
3O 보통
4O 항상

**15.** 귀하의 가족이 호스피스 케어를 받는 동안 통증이 있었던 적이 있습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면, **17** 번으로 가세요.

**16.** 귀하의 가족이 통증에 따라 필요한 만큼 도움을 받았습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요

**17.** 귀하의 가족이 호스피스 케어를 받는 동안, 가족 분이 통증 약을 받으셨습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면, **21** 번으로 가세요.

**18.** 통증 약의 부작용엔 졸림 증상과 같은 것이 있습니다. 호스피스 팀 중 누군가가 귀하 또는 귀하의 가족에게 통증약의 부작용에 대해서 설명했습니까?

1O 예, 확실히
2O 예, 다소
3O 아니

**19.** 호스피스팀이 귀하께 통증약의 주의 해야할 부작용에 관해서 필요한 안내를 해드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요

**20.** 호스피스 팀이 귀하께 언제 귀하의 가족에게 통증 약을 더 드려야 되는지 여부와 시기에 관해서 필요한 안내를 해 드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요
4O 가족에게 통증 약을 줄 필요가 없었다.

**21.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하의 가족께서 호흡곤란이 있었거나 호흡곤란에 대한 치료를 받으신 적이 있습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면, **24** 번으로 가세요.

**22.** 귀하의 가족이 호흡 곤란에 관해서 얼마나 자주 필요한 도움을 받았습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**23.** 호스피스 팀이 귀하께 귀하의 가족이 호흡 곤란을 느낄때 어떻게 도와야 하는지에 관한 필요한 안내를 해드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요
4O 가족의 호흡 곤란을 도울 필요가 없었다.

**24.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하의 가족이 변비로 고생하신 적이 있습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면 **26** 번으로 가세요

**25.** 귀하의 가족이 변비에 관해 얼마나 자주 필요한 도움을 받았습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**26.** 귀하의 가족이 호스피스 케어를 받는 중에, 불안이나 슬픔을 보인 적이 있습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면 **28** 번으로 가세요.

**27.** 얼마나 자주 귀하의 가족이 호스피스 팀으로부터 불안이나 슬픈 감정에 도움을 받은 적이 있습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**28.** 귀하의 가족이 호스피스 케어를 받는 동안, 안절부절 하거나 불안해 한 적이 있으십니까?

1O 예
2O 아니요 ➔응답이 '아니요'면 **30** 번으로 가세요.

**29.** 호스피스 팀이 귀하께 귀하의 가족이 안절부절 하거나 불안해 할 때 어떻게 해야 되는지에 관해 설명을 해 드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요

**30.** 귀하의 가족을 움직이게 하는 것에는 침대에서 방향을 바꾸는 것 또는 휠체어에 앉거나 일어나는 것, 또는 침대에 눕거나 일어나는 것이 포함됩니다. 호스피스 팀이 귀하께 어떻게 가족을 안전하게 움직일 수 있는지 필요한 안내를 해 드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요
4O 가족을 움직일 필요가 없었다.

**31.** 귀하의 가족께서 돌아가실 때, 호스피스팀이 귀하께서 무엇을 예상하셔야 되는지 원하시는 만큼의 정보를 드렸습니까?

1O 예, 확실히
2O 예, 다소
3O 아니요

## 호스피스 케어를 양로원에서 받은 경우

**32.** 어떤 분들은 양로원에 사시면서 호스피스 케어를 받으십니다. 귀하의 가족께서 양로원에 사시면서 호스피스 케어를 받으셨습니까?

1O 예
2O 아니요 ➔응답이 '아니요'면, **35** 번으로 가세요.

**33.** 귀하의 가족이 호스피스 케어를 받는 동안, 양로원 직원과 호스피스 팀이 얼마나 자주 귀하의 가족을 보살피기 위해서 함께 잘 일했습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**34.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주, 양로원 직원으로부터 귀하의 가족에 관해 받은 정보와 호스피스 팀으로부터 받은 정보가 달랐습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

## 호스피스에 관한 귀하의 경험

**35.** 귀하의 가족이 호스피스 케어를 받는 동안, 얼마나 자주 호스피스 팀이 주의 깊게 귀하께 경청 하였습니까?

1O 전혀
2O 때때로
3O 보통
4O 항상

**36.** 종교적이거나 영적인 믿음에 관한 지원은 대화, 기도, 묵상 또는 어떠한 방식으로든 종교적이거나 영적으로 필요한 것을 충족시키는 것을 포함합니다. 귀하의 가족이 호스피스 케어를 받는 동안, 귀하는 호스피스 팀으로부터 얼마나 종교적 그리고 영적인 믿음에 관한 지원을 받으셨습니까?

1O 너무 적게
2O 적당하게
3O 너무 많이

**37.** 귀하의 가족이 호스피스 케어를 받는 동안, 귀하는 호스피스 팀으로부터 얼마나 정서적인 지원을 받았습니까?

1O 너무 적게
2O 적당하게
3O 너무 많이

**38.** 귀하의 가족이 돌아가신 후 몇 주 동안, 귀하는 호스피스 팀으로부터 얼마나 정서적인 지원을 받으셨습니까?

1O 너무 적게
2O 적당하게
3O 너무 많이

## 호스피스 케어의 전체적인 점수

**39.** 설문지 겉 표지에 나와 있는 호스피스에게 귀하의 가족이 받은 케어에 관해서 다음의 질문들에 답변해 주시기 바랍니다. 귀하의 답변에 다른 호스피스로부터 받은 케어는 포함시키지 마십시오.

**0** 은 최악의 호스피스 케어이고 **10** 이 최고의 호스피스 케어라고 할 때 **0** 부터 **10** 까지의 숫자를 사용해서, 귀하의 가족이 받은 호스피스 케어에 대해 몇 점을 주시겠습니까?

0O 0 최악의 호스피스 케어
1O 1
2O 2
3O 3
4O 4
5O 5
6O 6
7O 7
8O 8
9O 9
10O 10 최고의 호스피스 케어

**40. 이 호스피스를 귀하의 친구나 가족에게 추천 하시겠습니까?**

1O 절대 안 함
2O 안 할 것 같음
3O 할 것 같음
4O 확실히 할 것임

## 귀하의 가족에 관해서

**41. 귀하의 가족의 최종 학력이 어떻게 되시나요?**

1O 중졸 이하
2O 고교 중퇴
3O 고졸 또는 검정고시(GED)
4O 대학 중퇴 또는 2 년제 대학 학위
5O 4 년제 대학 졸업
6O 대학원 이상
7O 모름

**42. 귀하의 가족이 히스패닉, 라티노 또는 스페인계 출신인가요?**

1O 아니요, 히스패닉, 라티노, 스페인계 아님
2O 예, 쿠바 사람
3O 예, 멕시코 사람, 멕시코계 미국인, 치카노 사람
4O 예, 푸에르토리칸
5O 예, 다른 스페인계/히스패닉/라티노

**43. 귀하의 가족의 인종이 무엇입니까? 한 개 또는 한 개 이상을 고를 수 있습니다.**

1O 미국 인디안 또는 알래스카 원주민
2O 아시아인
3O 흑인 또는 아프리카계 미국인
4O 하와이 원주민 혹은 다른 태평양 제도인
5O 백인

## 귀하에 관해서

**44. 귀하의 연세가 어떻게 되십니까?**

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

**45. 귀하는 남성입니까, 아니면 여성입니까?**

1O 남성
2O 여성

**46. 귀하의 학력이 어떻게 되십니까?**

1O 중졸 이하
2O 고교 중퇴
3O 고졸 또는 검정고시(GED)
4O 대학 중퇴 또는 2 년제 대학 학위
5O 4 년제 대학 졸업
6O 대학원 이상

**47. 댁에서 사용하시는 주요 언어가 무엇입니까?**

1O 영어
2O 스페인어
3O 중국어
4O 러시아어
5O 포르투갈어
6O 베트남어
7O 폴란드어
8O 한국어
9O 다른 언어(정자체로 써주세요)

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*감사합니다*

**작성하신 설문지를 우편요금 선납 반송용 우편 봉투에 넣어서 보내주세요.**

**[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]

[SAMPLED CAREGIVER NAME] 께:

[HOSPICE NAME]은(는) 환자와 가족이 받은 호스피스 서비스에 관해서 설문조사를 실시하고 있습니다. 귀하는 [DECEDENT NAME]의 간병인으로 확인되었기 때문이 이 설문조사 참여에 선택 되셨습니다. 귀하께서 힘든 시간을 보내고 계실 것이란 것을 알고 있지만, 귀하 그리고 귀하의 가족 또는 친구가 받은 호스피스 케어의 수준에 관해서 알 수 있도록 도와 주시기 바랍니다.

동봉된 설문지에 들어 있는 질문[NOTE THE QUESTION NUMBERS]들은 호스피스의 서비스 수준을 측정하기 위해 미국 보건사회복지부(HHS)에서 후원하는 국가적인 이니셔티브(계획)의 한 부분입니다. HHS 의 한 부분인 '메디케어 및 메디케이드 서비스 센터'(CMS)가 호스피스 케어를 증진하기 위해서 이 설문 조사를 진행하고 있습니다. CMS 는 미국내 대부분의 호스피스 케어를 재정적으로 지원하고 있습니다. 호스피스 환자와 그의 가족 그리고 친구들이 수준 높은 케어를 받는 것을 보장할 책임이 CMS 에 있습니다. 이러한 책임을 이행하기 위한 방법으로 귀하의 가족과 친구들이 받은 호스피스 케어에 관해서 알고자 하는 것입니다. 귀하의 참여는 본인의 선택에 따라 자발적으로 이루어지는 것이며 귀하께서 받으시는 건강 관리와 혜택에는 영향을 미치지 않습니다.

귀하께서 시간을 내셔서 이 설문지를 작성해 주시기 바랍니다. 설문지 작성을 완료하시고 나서 제공된 우편 요금 선납 반송용 우편 봉투로 보내 주시기 바랍니다. 귀하의 답변은 품질 개선의 목적으로 호스피스에 공유 될 수 있습니다. [OPTIONAL:설문지에 나와 있는 번호를 보셨을 것입니다. 이 번호는 귀하께서 설문지를 돌려 보내 주셨는지 확인해서 추가로 후속 편지를 보내지 않도록 확인하기 위한 것입니다.]

동봉된 설문지에 관한 궁금증이 있으시면 무료 전화 번호 1-800-xxx-xxxx 번으로 연락해 주시기 바랍니다. 모든 고객을 위한 호스피스 케어의 품질을 향상시키는 데 도움을 주셔서 감사합니다.

감사합니다.
[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]

[SAMPLED CAREGIVER NAME]께:

기록에 따르면 귀하께서는 최근에 [DECEDENT NAME]에서 [NAME OF HOSPICE]의 간병인이셨습니다. 대략 3주 전에, 저희가 귀하께 귀하와 귀하의 가족 또는 친구가 이 호스피스로부터 받은 케어에 관한 설문지를 보냈습니다. 이미 설문지를 돌려 보내 주셨으면 감사드리고요, 이 편지를 무시하셔도 됩니다. 그러나, 아직 안 보내 주셨으면, 시간을 내주셔서 이 중요한 질문서를 작성해 주시면 대단히 감사하겠습니다.

저희는 귀하가 이번을 기회 삼아 귀하의 가족과 친구들이 받은 케어의 수준에 관해서 저희가 알 수 있도록 도와주시기 바랍니다. 이 설문지의 결과는 모든 미국인들이 최고의 호스피스 케어 받을 수 있도록 보장하는 데 도움을 주기 위해 사용될 것입니다.

동봉한 설문지의 질문[NOTE THE QUESTION NUMBERS]들은 호스피스 케어의 수준을 측정하기 위해서 미국 보건사회복지부(HHS)에서 지원하는 국가 계획의 한 부분입니다. HHS 의 한 부분인 '메디케어 및 메디케이드 서비스 센터'(CMS)가 호스피스 케어를 증진하기 위해서 이 설문 조사를 진행하고 있습니다. CMS 는 미국내 대부분의 호스피스 케어를 재정적으로 지원하고 있습니다. 호스피스 환자와 그의 가족 그리고 친구들이 수준 높은 케어를 받는 것을 보장할 책임이 CMS 에 있습니다. 이러한 책임을 이행하기 위한 방법으로 귀하의 가족과 친구들이 받은 호스피스 케어에 관해서 알고자 하는 것입니다. 귀하의 참여는 본인의 선택에 따라 자발적으로 이루어지는 것이며 귀하께서 받으시는 건강 관리와 혜택에는 영향을 미치지 않습니다.

시간을 내주셔서 동봉한 설문지를 작성해 주시기 바랍니다. 설문지 작성을 마치신 후에 우편 요금 선납 반송 봉투에 넣어서 돌려 보내 주시기 바랍니다. 귀하의 답변은 품질 향상을 위해 호스피스와 공유 될 수 있습니다. [OPTIONAL: 설문지에 나와 있는 번호를 보셨을 것입니다. 이 번호는 귀하께서 설문지를 돌려 보내 주셨는지 확인해서 귀하께 추가로 편지를 보내지 않도록 하기 위한 것입니다.]

동봉된 설문지에 관한 궁금증이나 질문이 있으시면, 무료 전화 1-800-xxx-xxxx번으로 전화해 주시기 바랍니다. 모든 고객을 위한 호스피스 케어 품질 향상을 위해 도움을 주셔서 감사합니다.

감사합니다.
[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:*

## Korean Version

1995 년의 종이 삭감법에 따르면, 어느 누구도 유효한 OMB 규제 번호가 없다면 정보 수집에 답변해야할 책임이 없습니다. 이 정보 수집에 유효한 OMB 규제 번호는 0938- 1257 입니다 (2023 년 12 월 31 일에 만료됨). 이 정보 수집을 완료하는 데 요구되는 시간은 지시사항을 검토하고, 존재하는 자료의 출처를 찾고, 필요한 자료를 모으고, 정보 수집을 작성하고 검토하는 것을 포함해서, 1-40 번 문제들(이 설문지의 "가족에 관해서" 질문 그리고 "귀하에 관해서" 질문)에 평균 11 분이 걸릴 것으로 예상됩니다. 귀하께서 예상된 시간의 정확성에 관해서 하실 말씀이 있으시거나 이 양식을 개선하는 데 조언을 주고자 하신다면 편지를 보내주시기 바랍니다. 주소: Centers for Medicare & Medicaid Services, 7500 Security Boulevard, C1-25-05, Baltimore, MD 21244-1850.

**Reply-by Date (Optional)**

*The following two options are available for adding a reply-by date to the* ***follow-up cover letter****.*

*Placed above the salutation, such as:*

답변 만료 날짜: [DATE (mm/dd/yyyy)]

*In the fourth paragraph after the sentence, "After you have completed the survey, please return it in the enclosed pre-paid envelope." An example of allowable reply-by text includes:*

[DATE (mm/dd/yyyy)]까지 동봉된 설문조사를 작성하고 우편 요금 선납 봉투에 넣어 보내주십시오.

# Appendix W

## Telephone Script (English)

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# 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 <u>must</u> be read out loud
- Text in UPPERCASE letters <u>must not</u> be read out loud
  - YES and NO response options are only to be read if necessary
    - Any alternative positive or negative response will be accepted

  *Note: It is <u>not</u> 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 emphasis underlined content in a different manner if underlining is not a viable option, such as placing quotes ("") or asterisks (**) around the text to be emphasized or italicizing the emphasized words.*

- 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
  - During the course of the survey, if the caregiver mentions the decedent by "he or him" or "she or her," the interviewer may use that pronoun during the interview rather than the required "him or her" or "he or she"
- The script must be read from the interviewer screens (reciting the survey from memory can lead to unnecessary errors and missed updates to the scripts)
- The pace of the CAHPS Hospice Survey interview should be adjusted 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 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 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 caregiver does not provide an answer to Question 4 of the CAHPS Hospice Survey and the interviewer selects "MISSING/DK" 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, this is [INTERVIEWER NAME]. May I please speak with [SAMPLED CAREGIVER NAME]?

<1> YES [GO TO INTRO]
<2> YES, RESPONDENT IS ANOTHER MEMBER OF THE HOUSEHOLD [GO TO CONFIRMATION]
<3> PROXY IDENTIFIED [COLLECT PROXY INFORMATION THEN RETURN TO INTRO]
<4> NO, REFUSAL [GO TO REFUSAL]
<5> NO, NOT AVAILABLE RIGHT NOW [SET CALLBACK]
<6> ALREADY RETURNED SURVEY BY MAIL [GO TO MAILED]
<7> 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?

IF THE SAMPLED CAREGIVER SAYS THIS IS NOT A GOOD TIME:
Can you tell me a convenient time to call back?

CONFIRMATION:
Am I speaking with [SAMPLED CAREGIVER]?
<1> YES [GO TO INTRO]
<2> NO [GO TO START]

******

**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?

IF THE PROXY CAREGIVER SAYS THIS IS NOT A GOOD TIME:
Can you tell me a convenient time to call 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 NEEDED TO CONFIRM SPEAKING TO RESPONDENT: This is [INTERVIEWER NAME] calling from [SURVEY VENDOR]. I am calling to complete a survey that you started at an earlier date. Before we continue with the survey, I would like to confirm that I am speaking with [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 may be 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 [DECEDENT NAME]. Are you or is another household member most knowledgeable?

IF OTHER HOUSEHOLD MEMBER: And may I please have that person's name?

AFTER RECORDING NAME: May I please speak to this person?

IF NEEDED AND SPEAKING WITH **THE SAMPLED CAREGIVER:** We received your name from [HOSPICE NAME] because you were listed as the caregiver for [DECEDENT NAME].

IF NEEDED AND SPEAKING WITH **PROXY FOR SAMPLED CAREGIVER:** We received your name from [SAMPLED CAREGIVER] because he/she indicated that you were knowledgeable about the hospice care received by [DECEDENT NAME].

<1> YES [GO TO CONTINUE]
<2> PROXY IDENTIFIED [COLLECT PROXY INFORMATION, THEN RETURN TO PROXY INTRO]
<3> NO, WILL RETURN COMPLETED MAILED SURVEY [GO TO CALLBACK]
<4> NO, CALL BACK [GO TO CALLBACK]
<5> NO, 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 - MIXED MODE**

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]

*******

**MAILED - TELEPHONE ONLY MODE**

I'm sorry, for this project we are only doing the survey by telephone. This is a very important study for [HOSPICE NAME] and they could use your help.

**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]

*******

**REFUSAL**

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 [DECEDENT 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 [DECEDENT 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 [DECEDENT 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> YES
<0> NO

<M> MISSING/DK

Q2C At a nursing home?

<1> YES
<0> NO

<M> MISSING/DK

Q2D At a hospital?

<1> YES
<0> NO

<M> MISSING/DK

Q2E At a hospice facility or hospice house?

<1> YES
<0> NO

<M> MISSING/DK

Q2F At some other place?

| | |
|---|---|
| <1> YES | [GO TO Q2G] |
| <0> NO | [GO TO Q3] |
| <M> MISSING/DK | [GO TO Q3] |

Q2G Where did your family member receive care?

NOTE: PLEASE DOCUMENT THE OTHER PLACE AND MAINTAIN IN YOUR INTERNAL RECORDS.

Q3 While your family member was in hospice care, how often did you take part in or oversee care for him or her? Would you say…

<1> Never, [GO TO Q41_INTRO]
<2> Sometimes,
<3> Usually, or
<4> Always?

<M> MISSING/DK

Q4_INTRO As you answer the rest of the questions in this survey, please think only about your family member's experience with [HOSPICE NAME].

Q4 For this survey, the hospice team includes all the nurses, doctors, social workers, chaplains and other people who provided hospice care to your family member. While your family member was in hospice care, did you need to contact the hospice team during evenings, weekends, or holidays for questions or help with your family member's care?

READ YES/NO RESPONSE CHOICES ONLY ***IF NECESSARY***

<1> YES
<2> NO [GO TO Q6]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q6]

Q5 How often did you get the help you needed from the hospice team during evenings, weekends, or holidays? Would you say…

<1> Never,
<2> Sometimes,
<3> Usually, or
<4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q6 While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member? Would you say…

<1> Never,
<2> Sometimes,
<3> Usually, or
<4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q7 While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it? Would you say…

<1> Never,
<2> Sometimes,
<3> Usually, or
<4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q8 While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand? Would you say…

<1> Never,
<2> Sometimes,
<3> Usually, or
<4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q9 While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition? Would you say…

<1> Never,
<2> Sometimes,
<3> Usually, or
<4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q10 While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care? Would you say…

<1> Never,
<2> Sometimes,
<3> Usually, or
<4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q11 While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect? Would you say…

<1> Never,
<2> Sometimes,
<3> Usually, or
<4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q12 While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member? Would you say…

<1> Never,
<2> Sometimes,
<3> Usually, or
<4> Always?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q13 While your family member was in hospice care, did you talk with the hospice team about any problems with your family member's hospice care?

READ YES/NO RESPONSE CHOICES ONLY ***IF NECESSARY***

NOTE: IF THE RESPONDENT REPLIES, "I DIDN'T HAVE ANY PROBLEMS," CODE RESPONSE AS "NO."

<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 <u>from the hospice team</u> 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_INTRO]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q35_INTRO]

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?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q39 Please answer the following questions about your family member's care from [HOSPICE NAME]. Do not include care from other hospices in your answers.

Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?

IF THE RESPONDENT DOES NOT PROVIDE AN APPROPRIATE RESPONSE, PROBE BY REPEATING: Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?

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

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q40 Would you recommend this hospice to your friends and family? Would you say…

<1> Definitely no,
<2> Probably no,
<3> Probably yes, or
<4> Definitely yes?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q41_INTRO We have a few more questions to ask you. 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 BACHELOR'S 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> Cuban,
<3> Mexican, Mexican American, Chicano/a,
<4> Puerto Rican, 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 American Indian or Alaska Native?

<1> YES/AMERICAN INDIAN OR ALASKA NATIVE
<0> NO/NOT AMERICAN INDIAN OR ALASKA NATIVE

<M> MISSING/DK

Q43B Was your family member Asian?

<1> YES/ASIAN
<0> NO/NOT ASIAN

<M> MISSING/DK

Q43C Was your family member Black or African American?

<1> YES/BLACK OR AFRICAN AMERICAN
<0> NO/NOT BLACK OR AFRICAN AMERICAN

<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 White?

<1> YES/WHITE
<0> NO/NOT WHITE

<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 BACHELOR'S 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, | [GO TO END] |
| <7> Polish, | [GO TO END] |
| <8> Korean, or | [GO TO END] |
| <9> Some other language? | [GO TO Q47A] |
| <M> MISSING/DK | [GO TO END] |

IF THE CAREGIVER REPLIES WITH MULTIPLE LANGUAGES, PROBE: Would you say that you mainly speak [LANGUAGE A] or [LANGUAGE B]?

NOTE: IF THE CAREGIVER 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.

We are very sorry for your loss. Thank you for your time.

READ ONLY ***IF APPROPRIATE***

Have a good (day/evening). [END CALL]

# Appendix X

## Telephone Script (Spanish)

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# 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 <u>must</u> be read out loud
- Text in UPPERCASE letters <u>must not</u> be read out loud
  - YES and NO response options are only to be read if necessary
    - Any alternative positive or negative response will be accepted

  *Note: It is <u>not</u> 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 emphasis underlined content in a different manner if underlining is not a viable option, such as placing quotes ("") or asterisks (**) around the text to be emphasized or italicizing the emphasized words.*

- 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
  - During the course of the survey, if the caregiver mentions the decedent by "he or him" or "she or her," the interviewer may use that pronoun during the interview rather than the required "him or her" or "he or she"
- The script must be read from the interviewer screens (reciting the survey from memory can lead to unnecessary errors and missed updates to the scripts)
- The pace of the CAHPS Hospice Survey interview should be adjusted 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 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 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 caregiver does not provide an answer to Question 4 of the CAHPS Hospice Survey and the interviewer selects "MISSING/DK" 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 - INICIANDO CONTACTO

**START:** Buenos(as) días(tardes/noches), Soy [INTERVIEWER NAME]. ¿Podría hablar con [SAMPLED CAREGIVER NAME]?

<1> SÍ [GO TO INTRO]
<2> SÍ, PERSONA ES OTRO MIEMBRO DEL HOGAR [GO TO CONFIRMATION]
<3> PROXY IDENTIFICADO [COLLECT PROXY INFORMATION THEN RETURN TO INTRO]
<4> NO, NEGATIVA [GO TO REFUSAL]
<5> NO, NO ESTÁ DISPONIBLE EN ESTE MOMENTO [SET CALLBACK]
<6> YA ENVIÓ LA ENCUESTA POR CORREO [GO TO MAILED]
<7> PACIENTE NO RECIBIÓ ATENCIÓN EN EL HOSPICIO NOMBRADO [GO TO DISAVOWAL]

<u>SI</u> LE PREGUNTAN QUIÉN LLAMA:
Soy [INTERVIEWER NAME] de [VENDOR NAME].Estamos trabajando con [HOSPICE NAME] y con el Departamento de Salud y Servicios Humanos de los Estados Unidos para realizar un estudio sobre los cuidados de hospicio.

SI EL CUIDADOR/PERSONA ENCARGADA DEL CUIDADO DEL PACIENTE NO ESTÁ O NO PUEDE ATENDER LA LLAMADA:
¿Puede decirme a qué hora es conveniente llamar?

SI EL CUIDADOR MUESTRA O DICE QUE NO ES UN BUEN MOMENTO:
¿Puede decirme a qué hora es conveniente volver a llamar?

CONFIRMATION:
¿Estoy hablando con [SAMPLED CAREGIVER]?

<1> SÍ [GO TO INTRO]
<2> NO [GO TO START]

******

**INITIATING CONTACT WITH A PROXY RESPONDENT - INICIANDO CONTACTO CON UN ENTREVISTADO PROXY**

**START:** Buenos(as) días (tardes/noches), ¿podría hablar con [PROXY CAREGIVER NAME]?

<1> SÍ [GO TO INTRO]
<2> NO [GO TO REFUSAL]
<3> NO, NO ESTÁ DISPONIBLE EN ESTE MOMENTO [SET CALLBACK]

SI LE PREGUNTAN QUIÉN LLAMA:
Soy [INTERVIEWER NAME] de [VENDOR NAME]. Estamos trabajando con [HOSPICE NAME] y con el Departamento de Salud y Servicios Humanos de los Estados Unidos para realizar un estudio sobre los cuidados de hospicio.

SI EL CUIDADOR PROXY NO ESTÁ O NO PUEDE ATENDER LA LLAMADA:
¿Puede decirme a qué hora es conveniente para volver a llamar?

SI EL CUIDADOR PROXY DICE QUE NO ES UN BUEN MOMENTO:
¿Puede decirme a qué hora es conveniente para volver a llamar?

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.

******

## CALL BACK TO COMPLETE A PREVIOUSLY STARTED SURVEY - NUEVA LLAMADA PARA TERMINAR LA ENCUESTA INICIADA ANTERIORMENTE

**START:** 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]

PARA CONFIRMAR QUE ESTÁN HABLANDO CON EL RESPONDENT:
Soy [INTERVIEWER NAME], y llamo de [VENDOR NAME]. Le estoy hablando para completar una encuesta que usted comenzó hace días atrás. Antes de continuar con la encuesta, me gustaría confirmar que estoy hablando con [CAREGIVER NAME].

CONTINUAR CON LA ENCUESTA DONDE SE DEJÓ.

******

## SPEAKING WITH CAREGIVER - HABLANDO CON EL CUIDADOR

**INTRO:** 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]. Es posible que sus respuestas se envíen al hospicio a fin de que éste emprenda tareas de mejoramiento de calidad.

SI LE PREGUNTAN SI OTRA PERSONA PUEDE SERVIR DE **PROXY DEL CUIDADOR MUESTRA**:

Para esta encuesta, tenemos que hablar con la persona de su hogar que esté más enterada sobre el cuidado de hospicio recibido por [DECEDENT NAME]. ¿Puede decirme si usted u otra persona del hogar está más enterada del cuidado recibido por él/ella?

IF OTHER HOUSEHOLD MEMBER: ¿Me podría decir el nombre de esa persona?

AFTER RECORDING NAME: ¿Puedo hablar con esa persona?

SI ***ES NECESARIO***, Y HABLA CON **EL CUIDADOR MUESTRA:**

Nos dieron su nombre en el [HOSPICE NAME] porque usted aparecía en sus registros como la persona encargada del cuidado de [DECEDENT NAME].

SI ***ES NECESARIO***, Y HABLA CON EL PROXY **DEL CUIDADOR MUESTRA:**

Nos dió su nombre [SAMPLED CAREGIVER] porque nos dijo que usted está al tanto de los cuidados paliativos/de hospicio que recibió [DECEDENT NAME].

<1> SÍ [GO TO CONTINUE]
<2> PROXY IDENTIFICADO [COLLECT PROXY INFORMATION, THEN RETURN TO PROXY INTRO]
<3> NO, VA A ENVIAR 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]

******

**CONTINUE - 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]

******

**MAILED - 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]

******

**MAILED – ENCUESTA POR TELÉFONO**

Lo siento, para este proyecto sólo estamos haciendo la encuesta por teléfono. Este es un estudio muy importante para [HOSPICE NAME] y podrían usar su ayuda.

******

**INELIGIBLE - 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]

******

**REFUSAL -NEGATIVA**

Gracias por su tiempo. Que tenga un(una/-) buen(buena/buenas) día(tarde/noches). [FINALICE LA LLAMADA/END CALL]

******

**DISAVOWAL - 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]

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**BEGIN CAHPS HOSPICE SURVEY QUESTIONS -**
**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 ABUELA O ABUELO | [GO TO Q2] |
| <5> | MI TÍA O TÍO | [GO TO Q2] |
| <6> | MI HERMANA O HERMANO | [GO TO Q2] |
| <7> | MI HIJA O HIJO | [GO TO Q2] |
| <8> | AMIGA O AMIGO | [GO TO Q2] |
| <9> | OTRO (POR FAVOR, ESPECIFIQUE) | [GO TO Q1A] |
| <M> | MISSING/DK | [GO TO Q2] |

Q1A ¿Cuál es su relación con [DECEDENT NAME]?

NOTA: POR FAVOR DOCUMENTE EL DATO DE PARENTESCO O RELACIÓN Y CONSÉRVELO EN SU ARCHIVO.

[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 [DECEDENT 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 APPLICABLE]
<M> MISSING/DK

Q7 Mientras su familiar estaba bajo los cuidados del hospicio, cuando usted o alguno de sus familiares le pedían ayuda al equipo del hospicio, ¿con qué frecuencia obtenían la ayuda tan pronto como la necesitaban? ¿Diría usted que...

<1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q8 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio explicaba las cosas de un modo fácil de entender? ¿Diría usted que...

<1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q9 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio lo(a) mantenía a usted informado(a) sobre el estado de su familiar? ¿Diría usted que...

<1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q10 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia alguien del equipo del hospicio le dio a usted informes contradictorios o confusos sobre el estado o los cuidados de su familiar? ¿Diría usted que...

<1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q11 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio trataba a su familiar con dignidad y respeto? ¿Diría usted que...

<1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q12 Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia sintió usted que al equipo del hospicio le importaba realmente su familiar? ¿Diría usted que...

<1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q13 Mientras su familiar estaba bajo los cuidados del hospicio, ¿habló usted con el equipo del hospicio sobre algún problema relacionado con la atención o el cuidado de su familiar?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO ***SI ES NECESARIO***

NOTA: SI LA PERSONA QUE CONTESTA DICE, "NO TUVE NINGÚN PROBLEMA," MARQUE "NO."

<1> SÍ
<2> NO [GO TO Q15]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q15]

Q14 ¿Con qué frecuencia el equipo del hospicio lo(a) escuchó con atención cuando usted les habló sobre algún problema relacionado con la atención o el cuidado de su familiar? ¿Diría usted que...

<1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q15 Mientras su familiar estaba bajo los cuidados del hospicio, ¿tuvo él(ella) algún tipo de dolor?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO ***SI ES NECESARIO***

<1> SÍ
<2> NO [GO TO Q17]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q17]

Q16 ¿Recibió su familiar toda la ayuda que necesitaba para aliviar el dolor? ¿Diría usted que...

<1> Sí, definitivamente,
<2> Sí, más o menos, o
<3> No?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q17 Mientras su familiar estaba bajo los cuidados del hospicio, ¿le dieron a él(ella) algún medicamento contra el dolor?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO ***SI ES NECESARIO***

<1> SÍ
<2> NO [GO TO Q21]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q21]

Q18 Entre los efectos secundarios de la medicina contra el dolor está la somnolencia. ¿El equipo del hospicio habló con usted o con su familiar sobre los efectos secundarios del medicamento contra el dolor? ¿Diría usted que...

<1> Sí, definitivamente,
<2> Sí, más o menos, o
<3> No?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q19 ¿El equipo del hospicio le dio la capacitación o información que usted necesitaba para saber de qué efectos secundarios del medicamento contra el dolor tenía usted que estar pendiente? ¿Diría usted que...

<1> Sí, definitivamente,
<2> Sí, más o menos, o
<3> No?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q20 ¿El equipo del hospicio le dio a usted la capacitación o información que usted necesitaba para saber si tenía que darle más medicamento contra el dolor a su familiar y, si sí, cuándo dárselo? ¿Diría usted que...

<1> Sí, definitivamente,
<2> Sí, más o menos,
<3> No, o
<4> No tuve necesidad de darle a mi familiar medicina para el dolor.

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q21 Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento tuvo él(ella) dificultad para respirar o recibió tratamiento para su dificultad para respirar?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO ***SI ES NECESARIO***

<1> SÍ
<2> NO [GO TO Q24]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q24]

Q22 ¿Con qué frecuencia su familiar recibió la ayuda que necesitaba para su dificultad para respirar? ¿Diría usted que...

<1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q23 ¿El equipo del hospicio le dio a usted la capacitación que usted necesitaba para saber cómo ayudar a su familiar si él(ella) tenía problemas para respirar? ¿Diría usted que...

<1> Sí, definitivamente,
<2> Sí, más o menos,
<3> No, o
<4> No tuve necesidad de ayudar a mi familiar con alguna dificultad para respirar.

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q24 Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento tuvo él(ella) problemas de estreñimiento?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO ***SI ES NECESARIO***

<1> SÍ
<2> NO [GO TO Q26]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q26]

Q25 ¿Con qué frecuencia su familiar recibió la ayuda que necesitaba para sus problemas de estreñimiento? ¿Diría usted que...

<1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q26 Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento él(ella) mostró ansiedad o tristeza?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO ***SI ES NECESARIO***

<1> SÍ
<2> NO [GO TO Q28]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q28]

Q27 ¿Con qué frecuencia su familiar recibió del equipo del hospicio la ayuda que necesitaba para su ansiedad o tristeza? ¿Diría usted que...

<1> Nunca,
<2> A veces,
<3> La mayoría de las veces, o
<4> Siempre?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q28 Mientras su familiar estaba bajo los cuidados del hospicio, ¿en algún momento estuvo su familiar inquieto o agitado?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO ***SI ES NECESARIO***

<1> SÍ
<2> NO [GO TO Q30]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q30]

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_INTRO]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q35_INTRO]

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 Tenemos algunas preguntas más para hacerle. 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 CODIFICARSE COMO **4.** SI EL ENTREVISTADO MENCIONA UNA FORMACIÓN NO ACADÉMICA, COMO UNA ESCUELA DE COMERCIO, TRATE DE AVERIGUAR SI SU FAMILIAR TIENE UN DIPLOMA DE BACHILLERATO, PREPARATORIA O HIGH SCHOOL Y ASIGNE EL CÓDIGO **2** O EL **3**, SEGÚN CORRESPONDA.

Q42 ¿Su familiar era de ascendencia u origen hispano, latino o español?

LEA LAS OPCIONES DE RESPUESTA SÍ/NO SÓLO ***SI ES NECESARIO***

<X> SÍ
<1> NO

<M> MISSING/DK

SI LA RESPUESTA ES SÍ: ¿Diría usted que su familiar era... (LEA TODAS OPCIONES DE RESPUESTA)

<2> Cubano(a),
<3> Mexicano(a), estadounidense de origen mexicano, chicano(a),
<4> Puertorriqueño(a), o
<5> De otro origen, hispano, latino, o español?

<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 Indio(a) Americano(a) o nativo(a) de Alaska?

<1> SÍ/ERA INDIO(A) AMERICANO(A)/NATIVO(A) DE ALASKA
<0> NO/NO ERA INDIO(A) AMERICANO(A) NI NATIVO(A) DE ALASKA

<M> MISSING/DK

Q43B ¿Su familiar era asiático(a)?

<1> SÍ/ ERA ASIÁTICO(A)
<0> NO/NO ERA ASIÁTICO(A)

<M> MISSING/DK

Q43C ¿Su familiar era negro(a) o afro-americano(a)?

<1> SÍ/ ERA NEGRO(A)/AFRO-AMERICANO(A)
<0> NO/NO ERA NEGRO(A) NI AFRO-AMERICANO(A)

<M> MISSING/DK

Q43D ¿Su familiar era nativo(a) de Hawáii 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 blanco(a)?

<1> SÍ/ ERA BLANCO(A)
<0> NO/NO ERA BLANCO(A)

<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 CODIFICARSE COMO **4.** SI EL ENTREVISTADO MENCIONA UNA FORMACIÓN NO ACADÉMICA, COMO UNA ESCUELA DE COMERCIO, TRATE DE AVERIGUAR SI SU FAMILIAR TIENE UN DIPLOMA DE BACHILLERATO, PREPARATORIA O HIGH SCHOOL Y ASIGNE EL CÓDIGO **2** O EL **3**, SEGÚN CORRESPONDA.

Q47 ¿Qué idioma habla usted principalmente en su casa? Por favor, escuche las 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, | [GO TO END] |
| <7> Polaco, | [GO TO END] |
| <8> Coreano, o | [GO TO END] |
| <9> 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

Lo siento mucho por su pérdida. Gracias por su tiempo.

LEER SOLO SI ***ES LO APROPIADO***

Que tenga un buen día (una buena tarde/ unas buenas noches).

[FINALICE LA LLAMADA/END CALL]

# Appendix Y

## Telephone Script (Russian)

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# CAHPS Hospice Survey
## Telephone Script (Russian)

## 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 <u>must</u> be read out loud
- Text in UPPERCASE letters <u>must not</u> be read out loud
  - YES and NO response options are only to be read if necessary
    - Any alternative positive or negative response will be accepted

  *Note: It is <u>not</u> 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 emphasis underlined content in a different manner if underlining is not a viable option, such as placing quotes ("") or asterisks (**) around the text to be emphasized or italicizing the emphasized words.*

- 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
  - During the course of the survey, if the caregiver mentions the decedent by "he or him" or "she or her," the interviewer may use that pronoun during the interview rather than the required "him or her" or "he or she"
- The script must be read from the interviewer screens (reciting the survey from memory can lead to unnecessary errors and missed updates to the scripts)
- The pace of the CAHPS Hospice Survey interview should be adjusted 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, Spanish, or Russian) 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 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 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 caregiver does not provide an answer to Question 4 of the CAHPS Hospice Survey and the interviewer selects "MISSING/DK" 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 - НАЧАЛО КОНТАКТА

**START (НАЧАЛО):** Алло, меня зовут [INTERVIEWER NAME]. могу ли я поговорить с [SAMPLED CAREGIVER NAME]?

<1> ДА [GO TO INTRO]
<2> ДА, респондент является другим членом семьи [GO TO CONFIRMATION]
<3> ВЫЯВЛЕНИЕ ЛИЧНОСТИ ЛИЦА, ЗАМЕЩАЮЩЕГО РАБОТНИКА ПО УХОДУ [COLLECT PROXY INFORMATION THEN RETURN TO INTRO]
<4> НЕТ, ОТКАЗ [GO TO REFUSAL]
<5> НЕТ, ЕГО/ЕЁ СЕЙЧАС НЕТ [SET CALLBACK]
<6> УЖЕ ОТПРАВИЛ ЗАПОЛНЕННУЮ АНКЕТУ ПО ПОЧТЕ [GO TO MAILED]
<7> ПАЦИЕНТ НЕ ПОЛУЧАЛ УХОД В УПОМЯНУТОМ ХОСПИСЕ [GO TO DISAVOWAL]

<u>ЕСЛИ</u> СПРОСЯТ, КТО ЗВОНИТ:

Это [INTERVIEWER NAME] звонит из [VENDOR NAME]. Мы работаем с [HOSPICE NAME] и с Министерством здравоохранения и социальных служб США над проведением опроса о качестве хосписного ухода.

ЕСЛИ ВЫБРАННЫЙ ДЛЯ ОПРОСА РАБОТНИК ПО УХОДУ НЕДОСТУПЕН:
Когда вам удобно перезвонить?

ЕСЛИ ВЫБРАННЫЙ ДЛЯ ОПРОСА РАБОТНИК ПО УХОДУ НА ДОМУ СКАЖЕТ, ЧТО СЕЙЧАС У НЕГО НЕТ ВРЕМЕНИ РАЗГОВАРИВАТЬ:
Когда вам удобно перезвонить?

**CONFIRMATION (ПОДТВЕРЖДЕНИЕ):**
Я разговариваю с [SAMPLED CAREGIVER]?
<1> ДА [GO TO INTRO]
<2> НЕТ [GO TO START]

******

**INITIATING CONTACT WITH A PROXY RESPONDENT -**
**НАЧАЛО РАЗГОВОРА С ЛИЦОМ, ЗАМЕНЯЮЩИМ РАБОТНИКА ПО УХОДУ**

**START (НАЧАЛО):** Алло, могу ли я поговорить с [PROXY CAREGIVER NAME]?

<1> ДА [GO TO INTRO]
<2> НЕТ [GO TO REFUSAL]
<3> НЕТ, ЕГО/ЕЁ СЕЙЧАС НЕТ [SET CALLBACK]

ЕСЛИ СПРОСЯТ, КТО ЗВОНИТ:
Это [INTERVIEWER NAME] звонит из [VENDOR NAME]. Мы работаем с [HOSPICE NAME] и с Министерством здравоохранения и социальных служб США над проведением опроса о качестве хосписного ухода.

ЕСЛИ ЛИЦО, ЗАМЕЩАЮЩЕЕ РАБОТНИКА ПО УХОДУ НЕДОСТУПНО:
Когда вам удобно перезвонить?

ЕСЛИ ЛИЦО, ЗАМЕЩАЮЩЕЕ РАБОТНИКА ПО УХОДУ НА ДОМУ, СКАЖЕТ, ЧТО СЕЙЧАС У НЕГО НЕТ ВРЕМЕНИ РАЗГОВАРИВАТЬ:
Когда вам удобно перезвонить?

ЕСЛИ НА ЗВОНОК ВМЕСТО ЛИЦА, ЗАМЕЩАЮЩЕГО РАБОТНИКА ПО УХОДУ, ОТВЕТИТ КТО-ЛИБО ДРУГОЙ, ТО ЕЩЁ РАЗ ПОДТВЕРДИТЕ, ЧТО ЧТО ВЫ БУДЕТЕ РАЗГОВАРИВАТЬ С ВЫБРАННЫМ ДЛЯ ОПРОСА РАБОТНИКОМ ПО УХОДУ, КОГДА ОН ИЛИ ОНА ПОДНИМЕТ ТРУБКУ.

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## CALL BACK TO COMPLETE A PREVIOUSLY STARTED SURVEY - ОБРАТНЫЙ ЗВОНОК С ЦЕЛЬЮ ЗАВЕРШЕНИЯ ПРОХОЖДЕНИЯ НАЧАТОГО ОПРОСА

**START (НАЧАЛО):** Алло, могу ли я поговорить с [SAMPLED CAREGIVER NAME/PROXY CAREGIVER NAME]?

<1> ДА [GO TO CONFIRM RESPONDENT]
<2> НЕТ [REFUSAL]
<3> НЕТ, ЕГО/ЕЁ СЕЙЧАС НЕТ [SET CALLBACK]

ЕСЛИ НУЖНО ПОДТВЕРДИТЬ ЧТО РАЗГОВАРИВАЕШЬ С РЕСПОНДЕНТОМ:
Я [INTERVIEWER NAME], звоню из [SURVEY VENDOR]. Я звоню чтобы завершить опрос который вы начали недавно. Прежде чем мы перейдем к опросу, я хотел(а) бы убедиться, что разговариваю с [CAREGIVER NAME]?

ПРОДОЛЖАЙТЕ ОПРОС С ТОГО МЕСТА, НА КОТОРОМ ВЫ ОСТАНОВИЛИСЬ В ПРОШЛЫЙ РАЗ

******

## SPEAKING WITH CAREGIVER - РАЗГОВОР С ЛИЦОМ, ОСУЩЕСТВЛЯЮЩИМ УХОД

**INTRO (ВВЕДЕНИЕ):** Здравствуйте, меня зовут [INTERVIEWER NAME], я звоню от [VENDOR NAME].

[HOSPICE NAME] проводит опрос о хосписном уходе, который получают пациенты и члены их семей. Данный опрос проводится в рамках государственной программы Департамента здравоохранения и социальных служб США для оценки качества медицинской помощи в хосписах. Мы понимаем, что сейчас для Вас может быть трудное время, но надеемся, что Вы найдете несколько минут, чтобы ответить на вопросы о качестве помощи в хосписе, которую получаете Вы и близкий для Вас человек.

Ваше участие является добровольным и не повлияет на какое-либо медицинское обслуживание или пособия, которые Вы получаете. Опрос займет примерно [FILL: около 11 минут/УКАЗЫВАЕТСЯ ПОСТАВЩИКОМ ОПРОСА]. Ваши ответы могут быть переданы хоспису для улучшения качества обслуживания.

ЕСЛИ СПРАШИВАЮТ, МОЖЕТ ЛИ КТО-ТО ЕЩЕ ВЫСТУПИТЬ В КАЧЕСТВЕ **ДОВЕРЕННОГО ЛИЦА ОПЕКУНА**:

Для этого опроса нам нужно поговорить с членом Вашей семьи, который больше всех осведомлен о хосписном уходе, получаемом [DECEDENT NAME]. Вы или кто то из вашей семьи более осведомлен?

ЕСЛИ ДРУГОЙ ЧЛЕН СЕМЬИ: Скажите пожалуйста как зовут этого члена вашей семьи?

ПОСЛЕ ЗАПИСИ ИМЕНИ: Могу ли я поговорить с этим членом вашей семьи?

---

В СЛУЧАЕ НЕОБХОДИМОСТИ И ПРИ РАЗГОВОРЕ С **ОПЕКУНОМ**: Нам дали ваши данные в [HOSPICE NAME], так как Вы числитесь там как опекун [DECEDENT NAME].

В СЛУЧАЕ НЕОБХОДИМОСТИ И ПРИ РАЗГОВОРЕ **С ДОВЕРЕННЫМ ЛИЦОМ ОПЕКУНА**: Мы получили Ваши данные от [SAMPLED CAREGIVER], так как он/она указали Вас как лицо, осведомленное о хосписном уходе, который получает [DECEDENT NAME].

<1> ДА [GO TO CONTINUE]
<2> ИДЕНТИФИКАЦИЯ ДОВЕРЕННОГО ЛИЦА [COLLECT PROXY INFORMATION, THEN RETURN TO PROXY INTRO]
<3> НЕТ, ПРИШЛЮ ОТВЕТЫ ПОЧТОЙ [GO TO CALLBACK]
<4> НЕТ, ПЕРЕЗВОНИТЕ [GO TO CALLBACK]
<5> НЕТ ИЛИ СЕЙЧАС ОТСУТСТВУЕТ НА МЕСТЕ [GO TO ITEM TO CODE INELIGIBLE, ETC.,]
<6> ОТКАЗ [GO TO REFUSAL]
<7> УЖЕ ПРИСЛАЛ ОТВЕТЫ НА ВОПРОСЫ ПО ПОЧТЕ [GO TO MAILED]
<8> НЕ УЧАСТВУЕТ В УХОДЕ И НЕ ИМЕЕТ ДОВЕРЕННОГО ЛИЦА [GO TO INELIGIBLE]
<9> ПАЦИЕНТ НЕ ПОЛУЧАЕТ УХОД В ДАННОМ ХОСПИСЕ [GO TO DISAVOWAL]

******

**CONTINUE - ПРОДОЛЖЕНИЕ**

В целях улучшения обслуживания этот звонок может записываться [ОПЦИОНАЛЬНО: и/или записываться]. Мы можем начинать?

<1> ДА [BEGIN SURVEY]
<2> НЕТ, ПЕРЕЗВОНИТЕ [GO TO CALLBACK]
<3> ОТКАЗ [GO TO REFUSAL]

******

**MAILED - ВЫСЛАНО ПО ПОЧТЕ**

Благодарим Вас за то, что Вы заполнили анкету и отправили ее по почте. Возможно, мы ещё не получили Ваши ответы, но я ещё раз проверю нашу учётную документацию. Возможно, нам придётся повторно связаться с Вами - в том случае, если мы всё-таки не получим Ваше письмо в ближайшее время. [END CALL]

******

**ОТПРАВЛЕНО - ТОЛЬКО В ТЕЛЕФОННОМ РЕЖИМЕ**

Мне очень жаль, но в рамках этого проекта мы проводим опрос только по телефону. Это очень важное исследование для хосписа [HOSPICE NAME], который мог бы воспользоваться Вашей помощью.

******

**INELIGIBLE - НЕ ОТВЕЧАЕТ ТРЕБОВАНИЯМ**

Извините, но в рамках этой программы мы говорим только с членами семьи или друзьями, которые принимали участие в хосписном уходе за членами их семей или наблюдали за ним. Спасибо, что уделили время. Всего доброго. [END CALL]

******

**REFUSAL - ОТКАЗ**

Благодарим Вас за уделенное нам время. Всего Вам доброго. [END CALL]

******

**DISAVOWAL - ОТРИЦАНИЕ**

Возможно, в наших записях была допущена ошибка. Благодарим Вас за уделенное нам время. Всего Вам доброго. [END CALL]

******

**BEGIN CAHPS HOSPICE SURVEY QUESTIONS -**
**НАЧАТЬ ОПРОС О ПРЕБЫВАНИИ В ХОСПИСЕ CAHPS**

Q1_INTRO Пожалуйста, ответьте на все вопросы анкеты о хосписном уходе за пациентом в [HOSPICE NAME]. Отвечая на вопросы, не включайте в них информацию об уходе в каком-либо другом хосписе.

БУДЬТЕ ГОТОВЫ К ТОМУ, ЧТОБЫ ПОПРАВИТЬ РЕСПОНДЕНТА, ЕСЛИ ЕГО ОТВЕТЫ БУДУТ ВЫХОДИТЬ ЗА РАМКИ ПРЕДЛОЖЕННЫХ ВАРИАНТОВ. В ЭТОМ СЛУЧАЕ ПРОСТО ПОВТОРИТЕ ВАРИАНТЫ ОТВЕТА, НО НЕ ИНТЕРПРЕТИРУЙТЕ ИХ ДЛЯ РЕСПОНДЕНТА.

Q1 Какова степень Вашего родства с [DECEDENT NAME]?

ЗАЧИТАЙТЕ ОТВЕТЫ, ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

| | |
|---|---|
| <1> МОЙ/МОЯ СУПРУГ/А ИЛИ ПАРТНЕР/ША | [GO TO Q2] |
| <2> МОЙ РОДИТЕЛЬ | [GO TO Q2] |
| <3> МОЯ/МОЙ ТЕЩА/СВЕКРОВЬ ИЛИ ТЕСТЬ/СВЕКР | [GO TO Q2] |
| <4> МОЙ/МОЯ ДЕДУШКА/БАБУШКА | [GO TO Q2] |
| <5> МОЯ/МОЙ ТЕТЯ ИЛИ ДЯДЯ | [GO TO Q2] |
| <6> МОЯ/МОЙ СЕСТРА ИЛИ БРАТ | [GO TO Q2] |
| <7> МОЙ РЕБЕНОК | [GO TO Q2] |
| <8> МОЙ ДРУГ | [GO TO Q2] |
| <9> ДРУГОЕ (УКАЖИТЕ) | [GO TO Q1A] |
| <M> MISSING/DK | [GO TO Q2] |

Q1A Какова Ваша степень родства с [DECEDENT NAME]?

ПРИМЕЧАНИЕ: ВНЕСИТЕ ДАННЫЕ О СТЕПЕНИ РОДСТВА В СВОИ ВНУТРЕННИЕ ЗАПИСИ.

[ПРИМЕЧАНИЕ: ДЛЯ ОПРОСА ПО ТЕЛЕФОН ВОПРОС Q2 РАЗБИТ НА ЧАСТИ A – G.]

Q2 В данной анкете фраза «член семьи» относится к [DECEDENT NAME]. Пожалуйста, отвечайте "да" или "нет" на каждый из вариантов ответа. Я зачитаю Вам все шесть вариантов. Где именно (в каких местах) член Вашей семьи получал помощь хосписа [HOSPICE NAME]?

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

Q2A Дома?

<1> ДА
<0> НЕТ

<M> MISSING/DK

Q2B В доме престарелых?

<1> YES
<0> NO

<M> MISSING/DK

Q2C В центре сестринского ухода?

<1> ДА
<0> НЕТ

<M> MISSING/DK

Q2D В больнице?

<1> ДА
<0> НЕТ

<M> MISSING/DK

Q2E В хосписе?

<1> ДА
<0> НЕТ

<M> MISSING/DK

Q2F В каком-либо другом месте?

| | |
|---|---|
| <1> ДА | [GO TO Q2G] |
| <0> НЕТ | [GO TO Q3] |
| <M> MISSING/DK | [GO TO Q3] |

Q2G Где член Вашей семьи получал уход?

ПРИМЕЧАНИЕ: ПОЖАЛУЙСТА, ЗАФИКСИРУЙТЕ В СВОИХ ЗАПИСЯХ ДАННЫЕ О ПРЕБЫВАНИИ В ДРУГИХ УЧРЕЖДЕНИЯХ И ХРАНИТЕ ЭТУ ИНФОРМАЦИЮ В СВОЕЙ УЧЁТНОЙ ДОКУМЕНТАЦИИ, ПРЕДНАЗНАЧЕННОЙ ДЛЯ ВНУТРЕННЕГО ПОЛЬЗОВАНИЯ.

Q3 Пока член Вашей семьи получал хосписную помощь, как часто Вы принимали в ней участие либо наблюдали? Можно ли сказать, что…

| | |
|---|---|
| <1> Ни разу, | [GO TO Q41_INTRO] |
| <2> Иногда, | |
| <3> Как правило, или | |
| <4> Постоянно? | |
| <M> MISSING/DK | |

Q4_INTRO При ответах на все остальные вопросы в данной анкете просим Вас учитывать исключительно опыт члена Вашей семьи с хосписом [HOSPICE NAME].

Q4 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?

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<1> ДА
<2> НЕТ [GO TO Q6]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q6]

Q5 Как часто Вы получали необходимую помощь от хосписной команды по вечерам, в выходные или праздничные дни? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q6 Когда член Вашей семьи получал хосписный уход, как часто хосписная команда информировала Вас о времени своего прибытия для оказания ему помощи? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q7 Когда член Вашей семьи получал хосписный уход, и он или Вы обращались к хосписной команде за помощью, как часто вы получали ее своевременно? Можно ли сказать, что...

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q8 Когда член Вашей семьи получал хосписный уход, как часто хосписная команда давала пояснения в простой и доступной форме? Можно ли сказать, что...

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q9 Когда член Вашей семьи получал хосписный уход, как часто хосписная команда информировала Вас о его состоянии? Можно ли сказать, что...

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q10 Когда член Вашей семьи получал хосписный уход, как часто кто-либо из хосписной команды предоставлял Вам невнятную или противоречивую информацию о состоянии здоровья члена Вашей семьи или уходе за ним? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q11 Когда член Вашей семьи получал хосписный уход, как часто хосписная команда относилась к нему с достоинством и уважением? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q12 Когда член Вашей семьи получал хосписный уход, как часто Вы испытывали ощущение, что хосписная команда действительно заботится о нем? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q13 Когда член Вашей семьи получал хосписный уход, обсуждали ли Вы с хосписной командой проблемы, которые возникали у Вас во время ухода за ним?

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

ПРИМЕЧАНИЕ: ЕСЛИ РЕСПОНДЕНТ ОТВЕЧАЕТ "У МЕНЯ НЕ БЫЛО НИКАКИХ ПРОБЛЕМ", ОТВЕТ РАСЦЕНИВАЕТСЯ КАК "НЕТ."

<1> ДА
<2> НЕТ [GO TO Q15]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q15]

Q14 Как часто хосписная команда внимательно Вас выслушивала, когда Вы рассказывали о проблемах, возникавших во время ухода за членом Вашей семьи? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q15 Когда член Вашей семьи получал хосписный уход, испытывал ли он боль?

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<1> ДА
<2> НЕТ [GO TO Q17]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q17]

Q16 Получал член Вашей семьи всю возможную необходимую ему помощь, когда испытывал боль? Можно ли сказать, что…

<1> Да, несомненно,
<2> Да, можно так сказать, или
<3> Нет?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q17 Когда член Вашей семьи получал хосписный уход, получал ли он какие-то обезболивающие препараты?

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<1> ДА
<2> НЕТ [GO TO Q21]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q21]

Q18 Побочные эффекты обезболивающих препаратов включают, например, сонливость. Обсуждал ли кто-либо из хосписной команды с Вами или членом Вашей семьи побочные эффекты обезболивающих препаратов? Можно ли сказать, что…

<1> Да, несомненно,
<2> Да, можно так сказать, или
<3> Нет?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q19 Проводила ли с Вами хосписная команда необходимое обучение на тему побочных эффектов, за которыми необходимо следить при приеме обезболивающих препаратов? Можно ли сказать, что…

<1> Да, несомненно,
<2> Да, можно так сказать, или
<3> Нет?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q20 Проводила ли с Вами хосписная команда необходимое обучение относительно того, в каких случаях и когда необходимо увеличивать дозу обезболивающего препарата члену Вашей семьи? Можно ли сказать, что…

<1> Да, несомненно,
<2> Да, можно так сказать,
<3> Нет, или
<4> У меня не было необходимости давать обезболивающие препараты члену моей семьи.

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q21 Когда член Вашей семьи получал хосписный уход, были ли у него проблемы с дыханием или получал ли он лечение в связи с затруднением дыхания?

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<1> ДА
<2> НЕТ [GO TO Q24]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q24]

Q22 Как часто член Вашей семьи получал всю необходимую помощь вследствие затрудненного дыхания? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q23 Проводила ли с Вами хосписная команда обучение по предоставлению помощи члену Вашей семьи, когда он испытывает проблемы с дыханием? Можно ли сказать, что…

<1> Да, несомненно,
<2> Да, можно так сказать,
<3> Нет, или
<4> У меня не было необходимости оказывать помощь члену моей семьи из-за затрудненного дыхания.

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q24 Когда член Вашей семьи получал хосписный уход, были ли у него запоры?

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<1> ДА
<2> НЕТ [GO TO Q26]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q26]

Q25 Как часто член Вашей семьи получал необходимую помощь вследствие запоров? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q26 Когда член Вашей семьи получал хосписный уход, испытывал ли он чувства тревоги или грусти?

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<1> ДА
<2> НЕТ [GO TO Q28]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q28]

Q27 Как часто <u>персонал хосписа</u> проявлял к члену Вашей семьи необходимое соучастие в моменты тревоги или грусти? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q28 Когда член Вашей семьи получал хосписный уход, испытывал ли он ощущение беспокойства и нервного возбуждения?

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<1> ДА
<2> НЕТ [GO TO Q30]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q30]

Q29 Проводила ли С Вами хосписная команда обучение на тему того, что делать в случае, если член Вашей семьи испытывает ощущение беспокойства или возбуждения? Можно ли сказать, что…

<1> Да, несомненно,
<2> Да, можно так сказать, или
<3> Нет?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q30 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? Можно ли сказать, что…

<1> Да, несомненно,
<2> Да, можно так сказать,
<3> Нет, или
<4> У меня не было необходимости передвигать члена моей семьи.

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q31 Предоставляла ли Вам хосписная команда всю необходимую информацию относительно того, чего ожидать, когда умирал член Вашей семьи? Можно ли сказать, что…

<1> Да, несомненно,
<2> Да, можно так сказать, или
<3> Нет?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q32 Некоторые люди получают хосписный уход, проживая в центре сестринского ухода. Получал ли член Вашей семьи уход от данного хосписа, проживая в центре сестринского ухода?

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<1> ДА
<2> НЕТ [GO TO Q35_INTRO]

[<88> NOT APPLICABLE]
<M> MISSING/DK [GO TO Q35_INTRO]

Q33 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? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q34 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? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q35_INTRO Следующая серия вопросов касается Вас.

Q35 Когда член Вашей семьи получал хосписный уход, как часто хосписная команда внимательно выслушивала Вас? Можно ли сказать, что…

<1> Ни разу,
<2> Иногда,
<3> Как правило, или
<4> Всегда?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q36 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? Можно ли сказать, что…

<1> Слишком мала,
<2> Достаточная, или
<3> Чрезмерная?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q37 Когда член Вашей семьи получал хосписный уход, насколько велика была эмоциональная поддержка со стороны хосписной команды? Можно ли сказать, что…

<1> Слишком мала,
<2> Достаточная, или
<3> Чрезмерная?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q38 В ближайшие недели после смерти члена Вашей семьи, насколько велика была эмоциональная поддержка со стороны хосписной команды? Можно ли сказать, что…

<1> Слишком мала,
<2> Достаточная, или
<3> Чрезмерная?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q39 Ответьте, пожалуйста, на следующие вопросы относительно ухода за членом Вашей семьи в хосписе [HOSPICE NAME]. Просим в своих ответах не упоминать об уходе, полученном в других хосписах.

Используя шкалу от 0 до 10, где 0 означает наихудшее качество хосписного ухода, а 10 - наилучшее качество хосписного ухода, которое только можно представить, оцените хосписный уход за членом Вашей семьи.

ЕСЛИ РЕСПОНДЕНТ НЕ ДАСТ ЧЕТКОГО ОТВЕТА, ПОВТОРИТЕ ВОПРОС: Используя шкалу от 0 до 10, где 0 - это наихудшее, а 10 - наилучшее качество хосписного ухода, какое только можно представить, оцените уровень хосписного ухода за членом Вашей семьи?

ЗАЧИТАЙТЕ ОТВЕТЫ, ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<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 Порекомендовали ли бы Вы данный хоспис своим друзьям и семье? Можно ли сказать, что…

<1> Точно нет,
<2> Скорее всего, нет,
<3> Скорее всего, да, или
<4> Да, несомненно?

[<88> NOT APPLICABLE]
<M> MISSING/DK

Q41_INTRO Мы бы хотели задать еще несколько вопросов. Они посвящены члену Вашей семьи.

Q41 Какое образование получил член Вашей семьи?
[ОПЦИОНАЛЬНО: Он или она…]

ЗАЧИТАЙТЕ ОТВЕТЫ, ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<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, или
<6> Обучение свыше четырех лет высшего образования?
<7> РЕСПОНДЕНТ СООБЩАЕТ, ЧТО НЕ ЗНАЕТ, КАКОЕ ОБРАЗОВАНИЕ ПОЛУЧИЛ ЧЛЕН ЕГО СЕМЬИ

<M> MISSING

ОБРАЗОВАНИЕ ВЫШЕ СРЕДНЕЙ ШКОЛЫ, НО БЕЗ ПОЛУЧЕНИЯ ДИПЛОМА БАКАЛАВРА, ОТНОСИТСЯ К ВАРИАНТУ **4**. ЕСЛИ РЕСПОНДЕНТ УКАЗЫВАЕТ НА ПРОХОЖДЕНИЕ ПРОФЕССИОНАЛЬНО-ТЕХНИЧЕСКОЙ ПОДГОТОВКИ В ТАКИХ УЧРЕЖДЕНИЯХ, КАК ПРОФЕССИОНАЛЬНОЕ УЧИЛИЩЕ, ТО УТОЧНИТЕ, ПОЛУЧИЛ ЛИ ЧЛЕН ЕГО СЕМЬИ АТТЕСТАТ ЗРЕЛОСТИ И ВЫБЕРИТЕ ВАРИАНТ **2** ИЛИ **3** В ЗАВИСИМОСТИ ОТ СИТУАЦИИ.

Q42 Был ли член Вашей семьи испанского либо латино-американского происхождения?

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<X> ДА
<1> НЕТ

<M> MISSING/DK

ЕСЛИ "ДА": Можно ли сказать, что член Вашей семьи был (ПРОЧТИТЕ ВСЕ ВАРИАНТЫ ОТВЕТА)

<2> он кубинец,
<3> он мексиканец, мексикано-американец, американец мексиканского происхождения,
<4> он пуэрториканец, или
<5> другого испанского/латино-американского происхождения?

<M> MISSING/DK

[ПРИМЕЧАНИЕ: В СЛУЧАЕ ТЕЛЕФОННОГО ОПРОСА ВОПРОС 43 РАЗБИТ НА ЧАСТИ А – Е.]

Q43 К какой расовой группе принадлежал член Вашей семьи? Я перечислю все пять вариантов. Пожалуйста, ответьте "да" или "нет" по каждому из них.

ПРОЧИТАЙТЕ ВСЕ ВАРИАНТЫ, СДЕЛАВ ПАУЗУ ПОСЛЕ КАЖДОГО ИЗ НИХ, ЧТОБЫ РЕСПОНДЕНТ МОГ ДАТЬ ОТВЕТ ПО КАЖДОМУ ВАРИАНТУ.

ЕСЛИ РЕСПОНДЕНТ ИНТЕРЕСУЕТСЯ, ПОЧЕМУ ВЫ СПРАШИВАЕТЕ О РАСОВОЙ ПРИНАДЛЕЖНОСТИ ЧЛЕНА ЕГО СЕМЬИ: Мы спрашиваем о расовой принадлежности для демографической статистики. Мы хотим, чтобы участие в опросе принимали представители всех рас, проживающих в стране.

ЕСЛИ РЕСПОНДЕНТ СООБЩАЕТ, ЧТО УЖЕ ОТВЕЧАЛ НА ВОПРОС О РАСОВОЙ ПРИНАДЛЕЖНОСТИ ЧЛЕНА СЕМЬИ: Я Вас понимаю, но условия опроса требуют спросить о расовой принадлежности, чтобы результаты опроса включали в себя ответы от участников разных рас. Если данный вопрос не относится к члену Вашей семьи, ответьте "нет." Благодарю Вас за понимание и за терпение.

ЗАЧИТАЙТЕ ОТВЕТЫ "ДА" И "НЕТ", ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

Q43A Был ли член Вашей семьи американским индейцем/американской индианкой или коренным жителем/коренной жительницей Аляски?

<1> ДА/АМЕРИКАНСКИЙ ИНДЕЕЦ/АМЕРИКАНСКАЯ ИНДИАНКА ИЛИ КОРЕННОЙ ЖИТЕЛЬ/КОРЕННАЯ ЖИТЕЛЬНИЦА АЛЯСКИ
<0> НЕТ/НЕ АМЕРИКАНСКИЙ ИНДЕЕЦ/НЕ АМЕРИКАНСКАЯ ИНДИАНКА И НЕ КОРЕННОЙ ЖИТЕЛЬ/КОРЕННАЯ ЖИТЕЛЬНИЦА АЛЯСКИ

<M> MISSING/DK

Q43B Был ли член Вашей семьи азиатского происхождения?

<1> ДА/АЗИАТСКОГО ПРОИСХОЖДЕНИЯ
<0> НЕТ/НЕ АЗИАТСКОГО ПРОИСХОЖДЕНИЯ

<M> MISSING/DK

Q43C Был ли член Вашей семьи чернокожим/чернокожей или афроамериканцем/афроамериканкой?

<1> ДА/АФРИКАНЕЦ/АФРИКАНКА ИЛИ АФРОАМЕРИКАНЕЦ/АФРОАМЕРИКАНКА
<0> НЕТ/НЕ АФРИКАНЕЦ/ НЕ АФРИКАНКА И НЕ АФРОАМЕРИКАНЕЦ/АФРОАМЕРИКАНКА

<M> MISSING/DK

Q43D Был ли член Вашей семьи коренным жителем/коренной жительницей Гавайских островов или других тихоокеанских островов?

<1> ДА/КОРЕННОЙ ЖИТЕЛЬ/КОРЕННАЯ ЖИТЕЛЬНИЦА ГАВАЙСКИХ ОСТРОВОВ ИЛИ ДРУГИХ ТИХООКЕАНСКИХ ОСТРОВОВ
<0> НЕТ/НЕ БЫЛ КОРЕННЫМ ЖИТЕЛЕМ /КОРЕННОЙ ЖИТЕЛЬНИЦЕЙ ГАВАЙСКИХ ОСТРОВОВ ИЛИ ДРУГИХ ТИХООКЕАНСКИХ ОСТРОВОВ

<M> MISSING/DK

Q43E Был ли член Вашей семьи представителем/ представительницей белой расы?

<1> ДА/БЕЛЫЙ/БЕЛАЯ
<0> НЕТ/НЕ БЕЛЫЙ/НЕ БЕЛАЯ

<M> MISSING/DK

Q44_INTRO Следующие вопросы касаются Вас.

Q44 Сколько Вам лет?

ЗАЧИТАЙТЕ ОТВЕТЫ, ТОЛЬКО ***ЕСЛИ ЭТО НЕОБХОДИМО***

<1> от 18 до 24 лет
<2> от 25 до 34 лет
<3> от 35 до 44 лет
<4> от 45 до 54 лет
<5> от 55 до 64 лет
<6> от 65 до 74 лет
<7> от 75 до 84 лет
<8> 85 лет и старше

<M>MISSING/DK

Q45 ИНТЕРВЬЮЕР ЗАДАЕТ ВОПРОС ТОЛЬКО ***В СЛУЧАЕ НЕОБХОДИМОСТИ***: Ваш пол?

<1> МУЖСКОЙ
<2> ЖЕНСКИЙ

<M>MISSING/DK

Q46 Какое образование Вы получили? [ОПЦИОНАЛЬНО: Ваше образование…]

ЗАЧИТАЙТЕ ОТВЕТЫ ТОЛЬКО ***В СЛУЧАЕ НЕОБХОДИМОСТИ***

<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, или
<6> Обучение свыше четырех лет высшего образования?
<M> MISSING/DK

ОБРАЗОВАНИЕ ВЫШЕ СРЕДНЕЙ ШКОЛЫ, НО БЕЗ ПОЛУЧЕНИЯ ДИПЛОМА БАКАЛАВРА, ОТНОСИТСЯ К ВАРИАНТУ **4**. ЕСЛИ РЕСПОНДЕНТ УКАЗЫВАЕТ НА ПРОХОЖДЕНИЕ ПРОФЕССИОНАЛЬНО-ТЕХНИЧЕСКОЙ ПОДГОТОВКИ В ТАКИХ УЧРЕЖДЕНИЯХ, КАК ПРОФЕССИОНАЛЬНОЕ УЧИЛИЩЕ, УТОЧНИТЕ, ПОЛУЧИЛ ЛИ ОН АТТЕСТАТ ЗРЕЛОСТИ И ВЫБЕРИТЕ ВАРИАНТ **2** ИЛИ **3** В ЗАВИСИМОСТИ ОТ СИТУАЦИИ.

Q47 На каком языке Вы в основном общаетесь дома? Пожалуйста, перед ответом прослушайте все варианты ответа. Можно ли сказать, что в основном Вы говорите на…

| | |
|---|---|
| <1> Английском, | [GO TO END] |
| <2> Испанском, | [GO TO END] |
| <3> Китайском, | [GO TO END] |
| <4> Русском, | [GO TO END] |
| <5> Португальском, | [GO TO END] |
| <6> Вьетнамском, | [GO TO END] |
| <7> Польском, | [GO TO END] |
| <8> Корейском, или | [GO TO END] |
| <9> Другом языке? | [GO TO Q47A] |
| <M> MISSING/DK | [GO TO END] |

ЕСЛИ РЕСПОНДЕНТ НАЗЫВАЕТ НЕСКОЛЬКО ЯЗЫКОВ, СПРОСИТЕ: Можно ли сказать, что в основном Вы говорите на [LANGUAGE A] или [LANGUAGE B]?

ПРИМЕЧАНИЕ: ЕСЛИ РЕСПОНДЕНТ ГОВОРИТ, ЧТО В ОСНОВНОМ ГОВОРИТ НА АМЕРИКАНСКОМ, ТО ВЫБЕРИТЕ ВАРИАНТ **1** - АНГЛИЙСКИЙ

Q47A На каких еще языках Вы в основном общаетесь дома?

ПРИМЕЧАНИЕ: УКАЖИТЕ ДРУГОЙ ЯЗЫК И ВНЕСИТЕ ЕГО В СВОИ ВНУТРЕННИЕ ЗАПИСИ

**END (КОНЕЦ)** Это все вопросы. [ОПЦИОНАЛЬНО: Если вам нужен номер для поддержки скорбящих в [HOSPICE NAME], я могу сейчас его вам предоставить]

ВЕДУЩИЙ ОПРОСА: ОСТАВЬТЕ КОНТАКТНУЮ ИНФОРМАЦИЮ, ЕСЛИ ЭТО НЕОБХОДИМО.

Примите наши соболезнования. Спасибо за уделенное время.

ПРОЧИТАТЬ, ТОЛЬКО ***ЕСЛИ НУЖНО***

Желаем приятного (дня/вечера). [END CALL]