

# CAHPS Hospice Survey

## Telephone Script (English)

### Overview

This telephone interview script is provided to assist interviewers while attempting to reach the caregiver of the sampled decedent. The script explains the purpose of the survey and confirms necessary information about the caregiver and decedent.

### General Interviewing Conventions and Instructions

- The telephone introduction script must be read verbatim
- All text that appears in lowercase letters must be read out loud
- Text in UPPERCASE letters must not be read out loud
  - YES and NO response options are only to be read if necessary

*Note: It is not permissible to **capitalize** underlined content, as text that appears in uppercase letters throughout the CATI script must not be read out loud. Survey vendors are permitted to emphasize underlined content in a different manner if underlining is not a viable option, such as placing quotes (“”) or asterisks (\*\*) around the emphasized content.*

- All questions and all answer categories must be read exactly as they are worded
  - During the course of the survey, use of neutral acknowledgment words such as the following is permitted:
    - Thank you
    - Alright
    - Okay
    - I understand, or I see
    - Yes, Ma’am
    - Yes, Sir
- Read the scripts from the interviewer screens (reciting the survey from memory can lead to unnecessary errors and missed updates to the scripts)
- Adjust the pace of the CAHPS Hospice Survey interview to be conducive to the needs of the respondent
- No changes are permitted to the order of the question and answer categories for the “Core,” “About Your Family Member” and “About You” CAHPS Hospice Survey questions
  - The first forty “Core” questions must remain together
  - The three “About Your Family Member” questions must remain together
  - The four “About You” questions must remain together
- All transitional statements must be read
- Text that is underlined must be emphasized
- Characters in < > must not be read
- [Square brackets] are used to show programming instructions that must not actually appear on electronic telephone interviewing system screens

- **Only one language (i.e., English or Spanish) can appear on the electronic interviewing system screen**
- MISSING/DON'T KNOW (DK) is a valid response option for each item in the electronic telephone interviewing system scripts. This allows the telephone interviewer to go to the next question if a caregiver is unable to provide a response for a given question (or refuses to provide a response). In the survey file layouts, a value of "MISSING/DK" is coded as "M – Missing/Don't Know."
- Skip patterns should be programmed into the electronic telephone interviewing system
  - Appropriately skipped questions should be coded as "88 – Not Applicable." For example, if a patient answers "No" to Question 4 of the CAHPS Hospice Survey, the program should skip Question 5, and go to Question 6. Question 5 must then be coded as "88 – Not Applicable." Coding may be done automatically by the telephone interviewing system or later during data preparation.
  - When a response to a screener question is not obtained, the screener question and any questions in the skip pattern should be coded as "M – Missing/Don't Know." For example, if the patient does not provide an answer to Question 4 of the CAHPS Hospice Survey and the interviewer selects "M – Missing/Don't Know" to Question 4, then the telephone interviewing system should be programmed to skip Question 5, and go to Question 6. Question 5 must then be coded as "M – Missing/Don't Know." Coding may be done automatically by the telephone interviewing system or later during data preparation.

## INITIATING CONTACT

**START:** Hello, may I please speak to [SAMPLED CAREGIVER NAME]?

- <1> YES [GO TO INTRO]
- <2> PROXY IDENTIFIED [COLLECT PROXY INFORMATION THEN RETURN TO INTRO]
- <3> NO, REFUSAL [GO TO REFUSAL]
- <4> NO, NOT AVAILABLE RIGHT NOW [SET CALLBACK]
- <5> ALREADY RETURNED SURVEY BY MAIL [GO TO MAILED]
- <6> PATIENT DIDN'T RECEIVE CARE AT NAMED HOSPICE [GO TO DISAVOWAL]

**IF ASKED WHO IS CALLING:**

This is [INTERVIEWER NAME] calling from [VENDOR NAME]. We are working with [HOSPICE NAME] and the U.S. Department of Health and Human Services to conduct a survey about hospice care.

**IF THE SAMPLED CAREGIVER IS NOT AVAILABLE:**

Can you tell me a convenient time to call back to speak with (him/her)?

**IF THE SAMPLED CAREGIVER SAYS THIS IS NOT A GOOD TIME:**

If you don't have the time now, when is a more convenient time to call you back?

**IF SOMEONE OTHER THAN THE SAMPLED CAREGIVER ANSWERS THE PHONE, RECONFIRM THAT YOU ARE SPEAKING WITH THE SAMPLED CAREGIVER WHEN HE OR SHE PICKS UP.**

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## INITIATING CONTACT WITH A PROXY RESPONDENT

**START:** Hello, may I please speak to [PROXY CAREGIVER NAME]?  
<1> YES [GO TO INTRO]  
<2> NO [GO TO REFUSAL]  
<3> NO, NOT AVAILABLE RIGHT NOW [SET CALLBACK]

### IF ASKED WHO IS CALLING:

This is [INTERVIEWER NAME] calling from [VENDOR NAME]. We are working with [HOSPICE NAME] and the U.S. Department of Health and Human Services to conduct a survey about hospice care.

### IF THE PROXY CAREGIVER IS NOT AVAILABLE:

Can you tell me a convenient time to call back to speak with (him/her)?

### IF THE PROXY CAREGIVER SAYS THIS IS NOT A GOOD TIME:

If you don't have the time now, when is a more convenient time to call you back?

IF SOMEONE OTHER THAN THE PROXY CAREGIVER ANSWERS THE PHONE, RECONFIRM THAT YOU ARE SPEAKING WITH THE PROXY CAREGIVER WHEN HE OR SHE PICKS UP.

\*\*\*\*\*

## CALL BACK TO COMPLETE A PREVIOUSLY STARTED SURVEY

**START:** Hello, may I please speak to [SAMPLED CAREGIVER NAME/PROXY CAREGIVER NAME]?  
<1> YES [GO TO CONFIRM RESPONDENT]  
<2> NO [REFUSAL]  
<3> NO, NOT AVAILABLE RIGHT NOW [SET CALLBACK]

### IF ASKED WHO IS CALLING:

This is [INTERVIEWER NAME] calling from [SURVEY VENDOR]. Is [SAMPLED CAREGIVER NAME/PROXY CAREGIVER NAME] available to complete a survey that [HE/SHE] started at an earlier date?

**CONFIRM RESPONDENT:** Before we continue with the survey, I would like to confirm that I am speaking with [SAMPLED CAREGIVER NAME/PROXY CAREGIVER NAME].

CONTINUE SURVEY WHERE PREVIOUSLY LEFT OFF.

## **SPEAKING WITH CAREGIVER**

**INTRO** Hi, my name is [INTERVIEWER NAME] and I'm calling from [VENDOR NAME].

[HOSPICE NAME] is conducting a survey about the hospice services that patients and their families receive. It is part of a national initiative sponsored by the United States Department of Health and Human Services to measure the quality of care in hospices. We realize this may be a difficult time for you, but we hope that you will take a few minutes to help us learn about the quality of hospice care that you and your loved one received.

Your participation is voluntary and will not affect any health care or benefits you receive. The interview will take [FILL: approximately 11 minutes/SURVEY VENDOR SPECIFY]. Your answers will be combined with other respondents and shared with the hospice for purposes of quality improvement.

**IF ASKED WHETHER SOMEONE ELSE CAN SERVE AS PROXY FOR SAMPLED CAREGIVER:**

For this survey, we need to speak to the person in your household who is the most knowledgeable about the hospice care received by [DECEDENT NAME]. ONCE THE MOST KNOWLEDGEABLE PERSON'S NAME IS PROVIDED: [Is he/she OR are you] the most knowledgeable about the hospice care received by [DECEDENT NAME]?

**IF NEEDED AND SPEAKING WITH THE SAMPLED CAREGIVER:**

We received your name from [HOSPICE NAME] because you were listed as the caregiver for [DECEDENT NAME].

**IF NEEDED AND SPEAKING WITH PROXY FOR SAMPLED CAREGIVER:** We received your name from [SAMPLED CAREGIVER] because he/she indicated that you were knowledgeable about the hospice care received by [DECEDENT NAME].

- <1> YES [GO TO CONTINUE]
- <2> PROXY IDENTIFIED [COLLECT PROXY INFORMATION, THEN RETURN TO PROXY INTRO]
- <3> NO, WILL RETURN COMPLETED MAILED SURVEY [GO TO CALLBACK]
- <4> NO, CALL BACK [GO TO CALLBACK]
- <5> NO, OR UNAVAILABLE DURING FIELD PERIOD [GO TO ITEM TO CODE INELIGIBLE, ETC.,]
- <6> REFUSE [GO TO REFUSAL]
- <7> ALREADY RETURNED SURVEY BY MAIL [GO TO MAILED]
- <8> NOT INVOLVED IN CARE AND NO PROXY IDENTIFIED [GO TO INELIGIBLE]
- <9> PATIENT DIDN'T RECEIVE CARE AT NAMED HOSPICE [GO TO DISAVOWAL]

\*\*\*\*\*

**CONTINUE**

This call may be monitored [OPTIONAL: and/or recorded] for quality improvement purposes. May we begin?

- <1> YES [BEGIN SURVEY]
- <2> NO, CALL BACK [GO TO CALLBACK]
- <3> REFUSE [GO TO REFUSAL]

\*\*\*\*\*

**MAILED**

Thank you so much for completing the survey by mail. Perhaps we still have not gotten it but we'll check our records again. We may need to contact you again in case we still have not received it. [END CALL]

\*\*\*\*\*

**INELIGIBLE**

I'm sorry, for this project we are only speaking with family members or friends who took part in or oversaw hospice care for their family members. Thank you for your time. Have a good (day/evening). [END CALL]

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**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 from the hospice team for feelings of anxiety or sadness? Would you say...

<1> Never,

<2> Sometimes,

<3> Usually, or

<4> Always?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q28 While your family member was in hospice care, did he or she ever become restless or agitated?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

<1> YES

<2> NO

[GO TO Q30]

[<88> NOT APPLICABLE]

<M> MISSING/DK

[GO TO Q30]

Q29 Did the hospice team give you the training you needed about what to do if your family member became restless or agitated? Would you say...

<1> Yes, definitely,

<2> Yes, somewhat, or

<3> No?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q30 Moving your family member includes things like helping him or her turn over in bed, or get in and out of bed or a wheelchair. Did the hospice team give you the training you needed about how to safely move your family member? Would you say...

- <1> Yes, definitely,
- <2> Yes, somewhat,
- <3> No, or
- <4> I did not need to move my family member.

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q31 Did the hospice team give you as much information as you wanted about what to expect while your family member was dying? Would you say...

- <1> Yes, definitely,
- <2> Yes, somewhat, or
- <3> No?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q32 Some people receive hospice care while they are living in a nursing home. Did your family member receive care from this hospice while he or she was living in a nursing home?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

- <1> YES
- <2> NO [GO TO Q35]

[<88> NOT APPLICABLE]

<M> MISSING/DK [GO TO Q35]

Q33 While your family member was in hospice care, how often did the nursing home staff and hospice team work well together to care for your family member? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]

<M> MISSING/DK



Q34 While your family member was in hospice care, how often was the information you were given about your family member by the nursing home staff different from the information you were given by the hospice team? Would you say...

- <1> Never,
- <2> Sometimes,
- <3> Usually, or
- <4> Always?

[<88> NOT APPLICABLE]

<M> MISSING/DK

Q35\_INTRO The next set of questions is about you.

Q35 While your family member was in hospice care, how often did the hospice team listen 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 The next questions are about your family member.

Q41 What is the highest grade or level of school that your family member completed?  
[OPTIONAL: Did he or she...]

READ ANSWER CHOICES ONLY *IF NECESSARY*

- <1> Complete 8th grade or less,
- <2> Complete some high school, but did not graduate,
- <3> Graduate from high school or earn a GED,
- <4> Complete some college or earn a 2-year degree,
- <5> Graduate from a 4-year college, or
- <6> Complete more than a 4-year college degree?
- <7> RESPONDENT INDICATES THAT HE OR SHE DOES NOT  
KNOW FAMILY MEMBER'S LEVEL OF EDUCATION

<M> MISSING

ACADEMIC TRAINING BEYOND A HIGH SCHOOL DIPLOMA THAT DOES NOT LEAD TO A BACHELORS DEGREE SHOULD BE CODED AS 4. IF THE RESPONDENT DESCRIBES NON-ACADEMIC TRAINING, SUCH AS TRADE SCHOOL, PROBE TO FIND OUT IF THE FAMILY MEMBER HAS A HIGH SCHOOL DIPLOMA AND CODE 2 OR 3, AS APPROPRIATE.

Q42 Was your family member of Hispanic, Latino, or Spanish origin or descent?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

<X> YES

<1> NO

<M> MISSING/DK

IF YES: Would you say your family member was (READ ALL RESPONSE CHOICES)

<2> Puerto Rican,

<3> Mexican, Mexican American, Chicano/a,

<4> Cuban, or

<5> Other Spanish/Hispanic/Latino?

<M> MISSING/DK

[NOTE: FOR TELEPHONE INTERVIEWING, QUESTION 43 IS BROKEN INTO PARTS A – E.]

Q43 When I read the following, please tell me if the category describes your family member's race. I am required to read all five categories. Please answer yes or no to each of the categories.

READ ALL RACE CATEGORIES PAUSING AT EACH RACE CATEGORY TO ALLOW CAREGIVER TO REPLY TO EACH RACE CATEGORY.

IF THE RESPONDENT REPLIES, “WHY ARE YOU ASKING ABOUT MY FAMILY MEMBER’S RACE?.” We ask about your family member’s race for demographic purposes. We want to make sure that the people we include accurately represent the racial diversity in this country.

IF THE RESPONDENT REPLIES, “I ALREADY TOLD YOU ABOUT MY FAMILY MEMBER’S RACE:.” I understand, however the survey requires me to ask about all races so results can include people who are multiracial. If the race does not apply to your family member please answer no. Thanks for your patience.

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

- Q43A Was your family member White?
- <1> YES/WHITE
  - <0> NO/NOT WHITE
  
  - <M> MISSING/DK
- Q43B Was your family member Black or African American?
- <1> YES/BLACK OR AFRICAN AMERICAN
  - <0> NO/NOT BLACK OR AFRICAN AMERICAN
  
  - <M> MISSING/DK
- Q43C Was your family member Asian?
- <1> YES/ASIAN
  - <0> NO/NOT ASIAN
  
  - <M> MISSING/DK
- Q43D Was your family member Native Hawaiian or other Pacific Islander?
- <1> YES/NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER
  - <0> NO/NOT NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER
  
  - <M> MISSING/DK
- Q43E Was your family member American Indian or Alaska Native?
- <1> YES/AMERICAN INDIAN OR ALASKA NATIVE
  - <0> NO/NOT AMERICAN INDIAN OR ALASKA NATIVE
  
  - <M> MISSING/DK

Q44\_INTRO The next questions are about you.

Q44 What is your age?

READ ANSWER CHOICES ONLY *IF NECESSARY*

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

<M>MISSING/DK

Q45 INTERVIEWER ASK ONLY *IF NEEDED*: Are you male or female?

- <1> MALE
- <2> FEMALE

<M>MISSING/DK

Q46 What is the highest grade or level of school that you have completed?  
[OPTIONAL: Did you...]

READ ANSWER CHOICES ONLY *IF NECESSARY*

- <1> Complete 8th grade or less,
- <2> Complete some high school, but did not graduate,
- <3> Graduate from high school or earn a GED,
- <4> Complete some college or earn a 2-year degree,
- <5> Graduate from a 4-year college, or
- <6> Complete more than a 4-year college degree?

<M> MISSING/DK

ACADEMIC TRAINING BEYOND A HIGH SCHOOL DIPLOMA THAT DOES NOT LEAD TO A BACHELORS DEGREE SHOULD BE CODED AS 4. IF THE RESPONDENT DESCRIBES NON-ACADEMIC TRAINING, SUCH AS TRADE SCHOOL, PROBE TO FIND OUT IF SHE/HE HAS A HIGH SCHOOL DIPLOMA AND CODE 2 OR 3, AS APPROPRIATE.

Q47 What language do you mainly speak at home? Please listen to all response choices before you answer. Would you say that you mainly speak...

- |                          |              |
|--------------------------|--------------|
| <1> English,             | [GO TO END]  |
| <2> Spanish,             | [GO TO END]  |
| <3> Chinese,             | [GO TO END]  |
| <4> Russian,             | [GO TO END]  |
| <5> Portuguese,          | [GO TO END]  |
| <6> Vietnamese,          | [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 PATIENT REPLIES WITH MULTIPLE LANGUAGES, PROBE:  
Would you say that you mainly speak [LANGUAGE A] or [LANGUAGE B]?

NOTE: IF THE PATIENT REPLIES THAT THEY SPEAK AMERICAN,  
PLEASE CODE AS 1 – ENGLISH.

Q47A What other language do you mainly speak at home?

NOTE: PLEASE DOCUMENT THE OTHER LANGUAGE AND MAINTAIN  
IN YOUR INTERNAL RECORDS

**END** Those are all the questions I have. [OPTIONAL: Should you like the number for bereavement support at [HOSPICE NAME], I can provide that to you now.]

INTERVIEWER: PROVIDE CONTACT INFORMATION AS NEEDED.

Thank you for your time.

PRA Disclosure Statement:

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