

# Serious Illness Survey for Home-Based Programs

## Telephone Survey

The Serious Illness Survey for Home-Based Programs assesses the experiences of patients who receive care from programs that provide serious illness care in patients' homes. Access the complete set of survey resources, including guidance on administration, sampling, and analysis, at [www.rand.org/Serious-Illness-Survey](http://www.rand.org/Serious-Illness-Survey). For more information, contact [seriousillness@rand.org](mailto:seriousillness@rand.org).

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For more information on this publication, visit [www.rand.org/t/TLA1547-1](http://www.rand.org/t/TLA1547-1).

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## 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.
- 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.
- The pace of the interview should be adjusted to be conducive to the needs of the respondent.
- All transitional statements must be read.
- Text that is underlined must be emphasized .
- Characters in < > must not be read.
- DON'T KNOW or REFUSE are valid response options for each item in the telephone survey. This allows the 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).
- If an electronic telephone interviewing system is used, skip patterns should be programmed.

## Proxy Respondents

- The survey instrument allows for a proxy respondent in the event that the patient is unable to complete the survey on his/her own.
  - The proxy should be someone who knows about the care the patient received from the program.
  - Employees of the program should not be proxy respondents or help patients complete the survey.
- The proxy respondent should respond regarding the patient's experience rather than their own experience unless a question indicates otherwise.
  - The telephone *Survey Introduction* provides text for the identification of a proxy respondent.
- Each question has both a patient and a proxy version. Questions ending in “-PATIENT” should be read if the patient is the respondent. Questions ending in “-PROXY” should be read if the proxy is the respondent.
  - Questions Q35 and Q35@2 are not asked of proxy respondents.

## SURVEY INTRODUCTION

**11.** Hi, my name is [INTERVIEWER NAME] and I'm calling from [ORGANIZATION CONDUCTING THE SURVEY]. May I speak with [PATIENT]?

- <1> YES [GO TO I2]
- <2> CALL BACK NEEDED [SCHEDULE CALLBACK]
- <3> PATIENT NOT ABLE TO DO PHONE CALL, PROXY NEEDED [GO TO I3]
- <4> PATIENT DECEASED [GO TO DECEASED]
- <5> UNAVAILABLE DURING FIELD PERIOD, PROXY NEEDED [GO TO I3]
- <6> REFUSE [GO TO REFUSAL]
- <7> ALREADY RETURNED SURVEY BY MAIL [GO TO SRVMAILED]
- <8> WILL RETURN SURVEY BY MAIL [GO TO WILLMAIL]
- <9> NO ONE BY THAT NAME IN HOUSEHOLD [CODE LOCATING PROBLEM]

## **12. PATIENT COMES TO PHONE:**

(Hi, my name is [INTERVIEWER NAME] and I'm calling from [ORGANIZATION].)

We are calling because you receive care from [PROGRAM]. [PROGRAM] is trying to learn how to make care better for people who receive care from this program. As part of this effort, we are conducting a survey about the care people receive from [PROGRAM]. We hope that you will help us learn about the care you get from [PROGRAM] by completing this survey with us.

The survey will take about 10 minutes. It is your choice to answer the survey, and your choice will not affect any of the services you get from [PROGRAM]. Your answers will be shared with the program to help them learn how they can improve care for people like you.

### **IF NEEDED:**

1. IF APPLICABLE: You may remember getting a letter or a survey from us in the mail.
2. People from [PROGRAM] visit you in your home or talk to you by phone or video. They may take your blood pressure, review your medicines, or talk with you about your symptoms.
3. If you have any questions about the study, I can give you the number of someone to call. You can call [PHONE NUMBER] and ask to speak with [NAME].

### **IF PATIENT WANTS HELP TO ANSWER SURVEY:**

Thank you for letting me know. If you like, someone can help you answer the questions. Or, if you prefer, someone can answer the questions for you. This person needs to be someone who knows about the care you receive from [PROGRAM]. Is there someone who can help?

Can we start the survey?

- <1> YES (**INCLUDING WITH HELPER**) [GO TO MONITOR]
- <2> CALL BACK NEEDED [SCHEDULE CALLBACK]
- <3> PATIENT WANTS ANOTHER PERSON TO BE PROXY [GO TO I4]
- <4> NEEDS PROXY/HELPER BUT NONE AVAILABLE [CODE NOHELP]
- <5> UNAVAILABLE DURING FIELD PERIOD [CODE UNAVAILABLE]
- <6> PROGRAM DISAVOWAL [CODE PROGRAM DISAVOWAL]
- <7> REFUSE [GO TO REFUSAL]
- <8> ALREADY RETURNED SURVEY BY MAIL [GO TO SRVMAILED]
- <9> WILL RETURN SURVEY BY MAIL [GO TO WILLMAIL]

**13. IF PATIENT IS NOT ABLE TO SPEAK ON THE PHONE, FIND PROXY:**

Thank you for letting me know. We are calling because [PATIENT] receives care from [PROGRAM] and we are interested in learning about the care he or she receives.

We would like to interview someone else to answer on [PATIENT]'s behalf. This person needs to be someone who knows about the care [PATIENT] receives from [PROGRAM]. Is there someone who could answer these questions for (him/her)?

- <1> YES, PERSON ON PHONE WILL BE PROXY [GO TO I4]
- <2> YES, ANOTHER PERSON MAY BE PROXY [GO TO I4]
- <3> NO PROXY AVAILABLE [CODE NOHELP]
- <4> REFUSE [GO TO REFUSAL]
- <5> ALREADY RETURNED SURVEY BY MAIL [GO TO SRVMAILED]
- <6> WILL RETURN SURVEY BY MAIL [GO TO WILL MAIL]

**14. COLLECT PROXY INFORMATION:**

What is (your/that person's) name? Could I also get (your/his/her) address and phone number?

NAME: \_\_\_\_\_  
ADDRESS: \_\_\_\_\_  
PHONE NUMBER: \_\_\_\_\_

**15. PROCEED WITH PROXY:**

IF PROXY COMES TO PHONE, PROCEED TO INTERVIEW. ELSE SCHEDULE CALLBACK.

- <1> YES, PROXY COMES TO PHONE [GO TO I6]
- <2> CALL BACK NEEDED [SCHEDULE CALLBACK]

**16. PROXY INTRO:**

(Hi, my name is [INTERVIEWER NAME] and I'm calling from [ORGANIZATION].)

(As I mentioned,) we are calling because [PATIENT] (receives/received) care from [PROGRAM]. Since [PATIENT] cannot complete the survey, I'm calling today to conduct the survey with you. We hope that you will help us learn about the care [PATIENT] gets from [PROGRAM].

The survey will take about 10 minutes. It is your choice to answer the survey, and your choice will not affect any of the services [PATIENT] gets from [PROGRAM]. Your answers will be shared with the program to help them learn how they can improve care for people like [PATIENT].

**IF NEEDED:**

1. People from [PROGRAM] visit(ed) [PATIENT] at home, or talked with (him/her) by phone or video. They may (take/have taken) (his/her) blood pressure, review (his/her) medicines, or talk with (him/her) about (his/her) symptoms.
2. If you have any questions about the study, I can give you the number of someone to call. You can call [PHONE NUMBER] and ask to speak with [NAME].

Can we start the survey?

- <1> YES [GO TO MONITOR]
- <2> CALL BACK NEEDED [SCHEDULE CALLBACK]
- <3> DIFFERENT PROXY NEEDED [GO TO I4]
- <4> REFUSE [GO TO REFUSAL]
- <5> ALREADY RETURNED SURVEY BY MAIL [GO TO SRVMAILED]
- <6> WILL RETURN SURVEY BY MAIL [GO TO WILLMAIL]

**MONITOR**

This call may be monitored for quality improvement purposes. May we begin?

- <1> YES [GO TO Pnote]
- <2> NO, CALLBACK [SCHEDULE CALLBACK]
- <3> NO [GO TO REFUSAL]

**REFUSAL** Thank you for your time, I'll make a note in our records that you don't want any follow-up calls. [END CALL]

**DECEASED** I'm very sorry for your loss. Thank you for your time. [END CALL]

**WILLMAIL** Thank you for your time, I'll make a note in our records. [END CALL]

**SRVMAILED** Thank you for your time, I'll make a note in our records. [END CALL]

## INTERVIEW

### Pnote:

IF PROXY AND <sex = 1>, USE “he, him, his”

IF PROXY AND <sex = 2>, USE “she, her, hers”

IF PROXY AND <sex = M or missing>, USE “he/she, him/her, his/hers”

IF PROXY = GO TO intro1p

IF NO PROXY = GO TO Q1

**intro1p** Please remember that all survey questions refer to the patient’s care. Unless a question says otherwise, please do not consider your own experiences or information in the answers you provide.

### Q1-PATIENT

People from this program may take your blood pressure, review your medicines, or talk with you about your symptoms. Visits with this program can be in your home, by video, or by phone. In the last 3 months, how many times did someone from this program visit you at home?

Would you say . . .

### Q1-PROXY

People from this program may take [PATIENT]’s blood pressure, review (his/her) medicines, or talk with (him/her) about their symptoms. Visits with this program can be in (his/her) home, by video, or by phone. In the last 3 months, how many times did someone from this program visit (him/her) at home? Would you say . . .

<0> none,

<1> 1 to 2 times,

<2> 3 to 4 times,

<3> 5 to 6 times, or

<4> 7 or more times?

<d> DON’T KNOW

<r> REFUSE

**Q2-PATIENT**

In the last 3 months, how many times did you talk to someone from this program on the phone or by video for questions or help with your care? Would you say . . .

**Q2-PROXY**

In the last 3 months, how many times did [PATIENT] talk to someone from this program on the phone or by video for questions or help with their care? Would you say . . .

- <0> none,
- <1> 1 to 2 times,
- <2> 3 to 4 times,
- <3> 5 to 6 times, or
- <4> 7 or more times?
- <d> DON'T KNOW
- <r> REFUSE

**Q3-PATIENT**

If you only see or talk to one person from this program, think about that person when the question says people from this program.

In the last 3 months, how often did people from this program spend enough time with you? Would you say . . .

**Q3-PROXY**

If [PATIENT] only sees or talks to one person from this program, think about that person when the question says people from this program.

In the last 3 months, how often did people from this program spend enough time with (him/her)? Would you say . . .

- <1> never,
- <2> sometimes,
- <3> usually, or
- <4> always?
- <d> DON'T KNOW
- <r> REFUSE

**Q4-PATIENT**

In the last 3 months, how often did people from this program explain things to you in a way you could understand? Would you say . . .

**Q4-PROXY**

In the last 3 months, how often did people from this program explain things to [PATIENT] in a way (he/she) could understand? Would you say . . .

- <1> never,
- <2> sometimes,
- <3> usually, or
- <4> always?
- <d> DON'T KNOW
- <r> REFUSE

**Q5-PATIENT**

In the last 3 months, how often did people from this program listen carefully to you? Would you say . . .

**Q5-PROXY**

In the last 3 months, how often did people from this program listen carefully to [PATIENT]? Would you say . . .

- <1> never,
- <2> sometimes,
- <3> usually, or
- <4> always?
- <d> DON'T KNOW
- <r> REFUSE

**Q6-PATIENT**

In the last 3 months, how often did you feel that people from this program cared about you as a whole person? Would you say . . .

**Q6-PROXY**

In the last 3 months, how often did [PATIENT] feel that people from this program cared about (him/her) as a whole person? Would you say . . .

- <1> never,
- <2> sometimes,
- <3> usually, or
- <4> always?
- <d> DON'T KNOW
- <r> REFUSE

**Q7-PATIENT**

In the last 3 months, how often did you feel heard and understood by people from this program? Would you say . . .

**Q7-PROXY**

In the last 3 months, how often did [PATIENT] feel heard and understood by people from this program? Would you say . . .

- <1> never,
- <2> sometimes,
- <3> usually, or
- <4> always?
- <d> DON'T KNOW
- <r> REFUSE

**Q8-PATIENT**

In the last 3 months, how often did people from this program seem to know the important information about your medical history? Would you say . . .

**Q8-PROXY**

In the last 3 months, how often did people from this program seem to know the important information about [PATIENT]'s medical history? Would you say . . .

- <1> never,
- <2> sometimes,
- <3> usually, or
- <4> always?
- <d> DON'T KNOW
- <r> REFUSE

**Q9-PATIENT**

In the last 3 months, did someone from this program talk with you about the care or treatment you get from your other doctors or health care providers? Would you say . . .

**Q9-PROXY**

In the last 3 months, did someone from this program talk with [PATIENT] about the care or treatment (he/she) gets from (his/her) other doctors or health care providers? Would you say . . .

- <1> yes, definitely,
- <2> yes, somewhat, or
- <3> no?
- <d> DON'T KNOW
- <r> REFUSE

**Q10-PATIENT**

In the last 3 months, did someone from this program talk with you about all the medicines you are taking? Would you say . . .

**Q10-PROXY**

In the last 3 months, did someone from this program talk with [PATIENT] about all the medicines (he/she) is taking? Would you say . . .

<1> yes, definitely,

<2> yes, somewhat,

<3> no, or

<4> [PATIENT: I do not / PROXY: (he/she) does not] take any medicines?

<d> DON'T KNOW

<r> REFUSE

**Q11-PATIENT**

Everyday activities include things like getting ready in the morning, getting meals, or going places in your community.

In the last 3 months, did someone from this program talk with you about how to get help with everyday activities? Would you say . . .

**Q11-PROXY**

Everyday activities include things like getting ready in the morning, getting meals, or going places in your community.

In the last 3 months, did someone from this program talk with [PATIENT] about how to get help with everyday activities? Would you say . . .

<1> yes, definitely,

<2> yes, somewhat,

<3> no, or

<4> [PATIENT: I / PROXY: (he/she)] did not want help from this program with everyday activities?

<d> DON'T KNOW

<r> REFUSE

**Q12-PATIENT**

In the last 3 months, when you contacted this program between visits for questions or help with your care, did you get the help you needed? Would you say . . .

**Q12-PROXY**

In the last 3 months, when [PATIENT] contacted this program between visits for questions or help with (his/her) care, did (he/she) get the help (he/she) needed? Would you say . . .

<1> yes, definitely,

<2> yes, somewhat,

<3> no, or

<4> [PATIENT: I / PROXY: (he/she)] did not contact this program between visits for questions or help with [PATIENT: my / PROXY: (his/her)] care?

<d> DON'T KNOW

<r> REFUSE

**Q13-PATIENT**

In the last 3 months, did you have any pain?

**Q13-PROXY**

In the last 3 months, did [PATIENT] have any pain?

READ YES/NO RESPONSE CHOICES ONLY *IF NECESSARY*

<1> YES

<2> NO [GO TO Q15]

<d> DON'T KNOW [GO TO Q15]

<r> REFUSE [GO TO Q15]

**Q14-PATIENT**

In the last 3 months, did you get as much help as you wanted for your pain? Would you say . . .

**Q14-PROXY**

In the last 3 months, did [PATIENT] get as much help as (he/she) wanted for (his/her) pain? Would you say . . .

<1> yes, definitely

<2> yes, somewhat,

<3> no, or

<4> [PATIENT: I / PROXY: (he/she)] did not want help for [PATIENT: my / PROXY: (his/her)] pain?

<d> DON'T KNOW

<r> REFUSE

**Q15-PATIENT**

In the last 3 months, did you have any trouble breathing?

**Q15-PROXY**

In the last 3 months, did [PATIENT] have any trouble breathing?

READ YES/NO RESPONSE CHOICES ONLY ***IF NECESSARY***

<1> YES

<2> NO [**GO TO Q17**]

<d> DON'T KNOW [**GO TO Q17**]

<r> REFUSE [**GO TO Q17**]

**Q16-PATIENT**

In the last 3 months, did you get as much help as you wanted for your breathing? Would you say . . .

**Q16-PROXY**

In the last 3 months, did [PATIENT] get as much help as (he/she) wanted for (his/her) breathing? Would you say . . .

<1> yes, definitely,

<2> yes, somewhat,

<3> no, or

<4> [PATIENT: I / PROXY: (he/she)] did not want help for [PATIENT: my / PROXY: (his/her)] breathing?

<d> DON'T KNOW

<r> REFUSE

**Q17-PATIENT**

In the last 3 months, did you have any feelings of anxiety or sadness?

**Q17-PROXY**

In the last 3 months, did [PATIENT] have any feelings of anxiety or sadness?

READ YES/NO RESPONSE CHOICES ONLY ***IF NECESSARY***

<1> YES

<2> NO [**GO TO Q19**]

<d> DON'T KNOW [**GO TO Q19**]

<r> REFUSE [**GO TO Q19**]

**Q18-PATIENT**

In the last 3 months, did you get as much help as you wanted for your feelings of anxiety or sadness? Would you say . . .

**Q18-PROXY**

In the last 3 months, did [PATIENT] get as much help as (he/she) wanted for (his/her) feelings of anxiety or sadness? Would you say . . .

- <1> yes, definitely,
- <2> yes, somewhat,
- <3> no, or
- <4> [PATIENT: I / PROXY: (he/she)] did not want help for [PATIENT: my / PROXY: (his/her)] anxiety or sadness?
- <d> DON'T KNOW
- <r> REFUSE

**Q19-PATIENT**

In the last 3 months, did you have family members or friends involved in your care?

**Q19-PROXY**

In the last 3 months, did [PATIENT] have family members or friends involved in (his/her) care?

READ YES/NO RESPONSE CHOICES ONLY ***IF NECESSARY***

- <1> YES
- <2> NO [**GO TO Q22**]
- <d> DON'T KNOW [**GO TO Q22**]
- <r> REFUSE [**GO TO Q22**]

**Q20-PATIENT**

In the last 3 months, did people from this program involve your family members or friends in discussions about your health care as much as you wanted? Would you say . . .

**Q20-PROXY**

In the last 3 months, did people from this program involve [PATIENT]'s family members or friends in discussions about (his/her) health care as much as (he/she) wanted? Would you say . . .

- <1> yes, definitely,
- <2> yes, somewhat, or
- <3> no?
- <d> DON'T KNOW
- <r> REFUSE

**Q21-PATIENT**

In the last 3 months, did your family members or friends get as much emotional support as they wanted from this program? Would you say . . .

**Q21-PROXY**

In the last 3 months, did [PATIENT]'s family members or friends get as much emotional support as they wanted from this program? Would you say . . .

<1> yes, definitely,

<2> yes, somewhat,

<3> no, or

<3> [PATIENT: my / PROXY: (his/her)] family members or friends did not want emotional support from this program?

<d> DON'T KNOW

<r> REFUSE

**Q22-PATIENT**

Did someone from this program ever talk with you about what you should do during a health emergency? Would you say . . .

**Q22-PROXY**

Did someone from this program ever talk with [PATIENT] about what (he/she) should do during a health emergency? Would you say . . .

<1> yes, definitely,

<2> yes, somewhat, or

<3> no?

<d> DON'T KNOW

<r> REFUSE

**Q23-PATIENT**

Did someone from this program ever talk with you about what is important in your life? Would you say . . .

**Q23-PROXY**

Did someone from this program ever talk with [PATIENT] about what is important in (his/her) life? Would you say . . .

<1> yes, definitely,

<2> yes, somewhat, or

<3> no?

<d> DON'T KNOW

<r> REFUSE

**Q24-PATIENT**

Did someone from this program ever talk with you about what your health care options would be if you got sicker? Would you say . . .

**Q24-PROXY**

Did someone from this program ever talk with [PATIENT] about what (his/her) health care options would be if (he/she) got sicker? Would you say . . .

- <1> yes, definitely,
- <2> yes, somewhat, or
- <3> no?
- <d> DON'T KNOW
- <r> REFUSE

**Q25-PATIENT**

Using any number from 0 to 10, where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate your care from this program?

**Q25-PROXY**

Using any number from 0 to 10, where 0 is the worst care possible and 10 is the best care possible, what number would [PATIENT] use to rate (his/her) care from this program?

- ENTER NUMBER: [0-10]
- <d> DON'T KNOW
- <r> REFUSE
- <88> NOT APPLICABLE

**Q26-PATIENT**

Would you recommend this program to your friends and family? Would you say . . .

**Q26-PROXY**

Would [PATIENT] recommend this program to (his/her) friends and family? Would you say . . .

- <1> definitely no,
- <2> probably no,
- <3> probably yes, or
- <4> definitely yes?
- <d> DON'T KNOW
- <r> REFUSE

**Q27-PATIENT**

Are you usually able to leave your home or building to go outside, even if you use a cane, walker, or other people for support? Would you say . . .

**Q27-PROXY**

The next set of questions refer to [PATIENT].

Is [PATIENT] usually able to leave (his/her) home or building to go outside, even if (he/she) uses a cane, walker, or other people for support? Would you say . . .

<1> yes, by [PATIENT: myself / PROXY: himself/herself],

<2> yes, with help, or

<3> no?

<d> DON'T KNOW

<r> REFUSE

**Q28-PATIENT**

Are you usually able to get in and out of bed? Would you say . . .

**Q28-PROXY**

Is [PATIENT] usually able to get in and out of bed? Would you say . . .

<1> yes, by [PATIENT: myself / PROXY: himself/herself],

<2> yes, with help, or

<3> no?

<d> DON'T KNOW

<r> REFUSE

**Q29-PATIENT**

In general, how would you rate your physical health? Would you say . . .

**Q29-PROXY**

In general, how would [PATIENT] rate (his/her) physical health? Would you say . . .

<1> excellent,

<2> very good,

<3> good,

<4> fair, or

<5> poor?

<d> DON'T KNOW

<r> REFUSE

**Q30-PATIENT**

In general, how would you rate your mental or emotional health? Would you say . . .

**Q30-PROXY**

In general, how would [PATIENT] rate (his/her) mental or emotional health? Would you say . . .

- <1> excellent,
- <2> very good,
- <3> good,
- <4> fair, or
- <5> poor?
- <d> DON'T KNOW
- <r> REFUSE

**Q31-PATIENT**

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

**Q31-PROXY**

What is the highest grade or level of school that [PATIENT] has completed?

**READ ANSWER CHOICES IF NECESSARY:** Is it . . .

- <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, or
- <6> More than 4-year college degree?
- <d> DON'T KNOW
- <r> REFUSED

**Q32-PATIENT**

Are you of Hispanic, Latino, or Spanish origin or descent?

**Q32-PROXY**

Is [PATIENT] of Hispanic, Latino, or Spanish origin or descent?

**READ YES/NO RESPONSE CHOICES ONLY IF NECESSARY**

- <X> YES
- <1> NO [GO TO Q33]
- <d> DON'T KNOW [GO TO Q33]
- <r> REFUSE [GO TO Q33]

**Q32.2-PATIENT**

Would you say you are . . .

**Q32.2-PROXY**

Would (he/she) say (he/she) is . . .

(READ ALL RESPONSE CHOICES)

- <2> Puerto Rican,
- <3> Mexican, Mexican American, Chicano/a,
- <4> Cuban, or
- <5> Other Spanish/Hispanic/Latino?
- <d> DON'T KNOW
- <r> REFUSE

**Q33-PATIENT**

What is your race? When I read the following, please tell me if the category describes your race. I am required to read all five categories. Please answer yes or no to each of the categories.

**Q33-PROXY**

What is [PATIENT]'s race? When I read the following, please tell me if the category describes (his/her) 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 RESPONDENT TO REPLY TO EACH RACE CATEGORY.

IF THE RESPONDENT REPLIES, "WHY ARE YOU ASKING ABOUT MY RACE?": We ask about your 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 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 you, please answer no. Thanks for your patience.

READ YES/NO RESPONSE CHOICES ONLY **IF NECESSARY**

**Q33@1-PATIENT**

Are you White?

**Q33@1-PROXY**

Is (he/she) White?

- <1> YES
- <2> NO
- <d> DON'T KNOW
- <r> REFUSE

**Q33@2-PATIENT** Are you Black or African American?  
**Q33@2-PROXY** Is (he/she) Black or African American?

<1> YES  
<2> NO  
<d> DON'T KNOW  
<r> REFUSE

**Q33@3-PATIENT** Are you Asian?  
**Q33@3-PROXY** Is (he/she) Asian?

<1> YES  
<2> NO  
<d> DON'T KNOW  
<r> REFUSE

**Q33@4-PATIENT** Are you Native Hawaiian or other Pacific Islander?  
**Q33@4-PROXY** Is (he/she) Native Hawaiian or other Pacific Islander?

<1> YES  
<2> NO  
<d> DON'T KNOW  
<r> REFUSE

**Q33@5-PATIENT** Are you American Indian or Alaska Native?  
**Q33@5-PROXY** Is (he/she) American Indian or Alaska Native?

<1> YES  
<2> NO  
<d> DON'T KNOW  
<r> REFUSE

**Q34-PATIENT**

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

**Q34-PROXY**

What language does [PATIENT] mainly speak at home? Please listen to all response choices before you answer. Would you say that (he/she) mainly speaks . . .

- <1> English, [**GO TO Q35skip**]
- <2> Spanish, or [**GO TO Q35skip**]
- <3> Some other language?
- <d> DON'T KNOW [**GO TO Q35skip**]
- <r> REFUSE [**GO TO Q35skip**]

**Q34os-PATIENT**      What language do you mainly speak at home?

**Q34os-PROXY**      What language does (he/she) mainly speak at home?

SPECIFY: \_\_\_\_\_

**Q35skip.** IF RESPONDENT = PROXY, GO TO QUESTION Q36.

**Q35-PATIENT** Did someone help you complete this survey?

- <1> YES
- <2> NO [**GO TO Q36**]
- <d> DON'T KNOW [**GO TO Q36**]
- <r> REFUSE [**GO TO Q36**]

**Q35@2-PATIENT**      How did this person help you complete the survey? Did they . . .

CODE ALL THAT APPLY

- @1 read the questions to you?
- @3 answer the questions for you?
- @4 translate the questions into your language?
- @5 help in some other way?

- <1> YES
- <0> NO
- <d> DON'T KNOW
- <r> REFUSE

**Q36-PATIENT**

In thinking about your experiences with this program, is there anything that is going well or that you wish would go differently? Please tell us about those experiences.

**Q36-PROXY**

In thinking about [PATIENT]'s experiences with this program, is there anything that is going well or that (he/she) wishes would go differently? Please tell us about those experiences.

[ALLOW TEXT]

**END** Those are all the questions I have, thank you for your time.