

# Serious Illness Survey for Home-Based Programs

## Abridged 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 Q21 and Q21@2 are not asked of proxy respondents.

## SURVEY INTRODUCTION

**I1.** 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 5 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 5 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 [GOTO 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-INTRO-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.

### Q1-INTRO-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.

### Q1-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 . . .

### Q1-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

**Q2-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 . . .

**Q2-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

**Q3-PATIENT**

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

**Q3-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

**Q4-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 . . .

**Q4-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

**Q5-PATIENT**

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

**Q5-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

**Q6-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 . . .

**Q6-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

**Q7-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 . . .

**Q7-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

**Q8-PATIENT**

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

**Q8-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

**Q9-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 . . .

**Q9-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

**Q10-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 . . .

**Q10-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

**Q11-PATIENT**

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

**Q11-PROXY**

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

<1> yes, definitely

<2> yes, somewhat,

<3> no,

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

<5> [PATIENT: I / PROXY: (he/she)] did not have pain?

<d> DON'T KNOW

<r> REFUSE

**Q12-PATIENT**

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

**Q12-PROXY**

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

<1> yes, definitely,

<2> yes, somewhat,

<3> no,

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

<5> [PATIENT: I / PROXY: (he/she)] did not have trouble breathing?

<d> DON'T KNOW

<r> REFUSE

**Q13-PATIENT**

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

**Q13-PROXY**

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

<1> yes, definitely,

<2> yes, somewhat,

<3> no,

<4> [PATIENT: I / PROXY: (he/she)] did not want help for [PATIENT: my / PROXY: (his/her)]  
anxiety or sadness, or

<5> [PATIENT: I / PROXY: (he/she)] did not have anxiety or sadness?

<d> DON'T KNOW

<r> REFUSE

**Q14-PATIENT**

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

**Q14-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

**Q15-PATIENT**

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

**Q15-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

**Q16-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 . . .

**Q16-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

**Q17-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?

**Q17-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

**Q18-PATIENT**

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

**Q18-PROXY**

The next set of questions refer to [PATIENT].

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

**Q19-PATIENT**

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

**Q19-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

**Q20-PATIENT**

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

**Q20-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> REFUSE

**Q21skip.** IF RESPONDENT = PROXY, GO TO END

**Q21-PATIENT** Did someone help you complete this survey?

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

**Q21@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

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