

Serious Illness Survey for Home-Based Programs

Overview of the Differences Between the Full and Abridged Surveys

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. For more information, contact seriousillness@rand.org.

Survey development was funded by the Gordon and Betty Moore Foundation and carried out within the Quality Measurement and Improvement Program in RAND Health Care.

For more information on this publication, visit www.rand.org/t/TLA1547-1.

About RAND

The RAND Corporation is a research organization that develops solutions to public policy challenges to help make communities throughout the world safer and more secure, healthier and more prosperous. RAND is nonprofit, nonpartisan, and committed to the public interest. To learn more about RAND, visit www.rand.org. For more information about RAND Health Care, see www.rand.org/health-care.

Research Integrity

Our mission to help improve policy and decisionmaking through research and analysis is enabled through our core values of quality and objectivity and our unwavering commitment to the highest level of integrity and ethical behavior. To help ensure our research and analysis are rigorous, objective, and nonpartisan, we subject our research publications to a robust and exacting quality-assurance process; avoid both the appearance and reality of financial and other conflicts of interest through staff training, project screening, and a policy of mandatory disclosure; and pursue transparency in our research engagements through our commitment to the open publication of our research findings and recommendations, disclosure of the source of funding of published research, and policies to ensure intellectual independence. For more information, visit www.rand.org/about/principles.

RAND's publications do not necessarily reflect the opinions of its research clients and sponsors.

Published by the RAND Corporation, Santa Monica, Calif.

© 2021 RAND Corporation

RAND® is a registered trademark.

This work is licensed under a Creative Commons Attribution – NonCommercial-NoDerivatives 4.0 International License.



Differences Between the Full and Abridged Versions of the RAND Serious Illness Survey for Home-Based Programs

The RAND research team developed the Serious Illness Survey for Home-Based Programs using a systematic literature review of tools that measure experiences with serious illness care; qualitative interviews with patients, family caregivers, and health care providers from a diverse set of serious illness programs nationwide; a technical expert panel composed of experts in serious illness care quality; and cognitive interviews with patients and family caregivers to test draft questions and questionnaires.

Wherever possible, we adapted survey items from previously validated survey instruments, such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Clinician & Group Survey and the CAHPS® Hospice Survey.

A draft version of the survey was tested between October 2019 and January 2020 among patients of 32 serious illness programs that provide home-based care across the United States, prior to the onset of the coronavirus disease 2019 (COVID-19) pandemic.

Results of this field test were used to refine and finalize two versions of the survey instrument: (1) a full version that contains 36 items and (2) an abridged version that contains 21 items.

The abridged version of the survey should be used if the cost or time of administering the full version would be prohibitive. The primary differences between the full and abridged versions are that the abridged version omits

- some descriptive questions (such as those regarding number and type of visits and race and ethnicity)
- some questions that evaluate care (such as those regarding support for family members and friends)
- screening questions (such as those asking whether a respondent has a particular symptom).¹

Table 1 compares the question text in the full and abridged versions of the survey.

¹ In place of screening questions, the abridged version offers response options that allow the respondent to indicate that the question is not applicable (e.g., “I did not have pain”).

Table 1. Comparison of Question Text in Full and Abridged Versions of the Serious Illness Survey for Home-Based Programs

Full Version Item Number	Abridged Version Item Number	Question Text	Response Options: Full Version	Response Options: Abridged Version (if different)
1	N/A	In the last 3 months, how many times did someone from this program <u>visit you at home</u> ?	“None,” “1 to 2 times,” “3 to 4 times,” “5 to 6 times,” “7 or more times”	N/A
2	N/A	In the last 3 months, how many times did you talk to someone from this program <u>on the phone or by video</u> for questions or help with your care?	“None,” “1 to 2 times,” “3 to 4 times,” “5 to 6 times,” “7 or more times”	N/A
3	1	If you only see or talk to one person from this program, think about that person when the question says <u>people from this program</u> . In the last 3 months, how often did people from this program spend enough time with you?	“Never,” “Sometimes,” “Usually,” “Always”	Same as full version
4	2	In the last 3 months, how often did people from this program explain things to you in a way you could understand?	“Never,” “Sometimes,” “Usually,” “Always”	Same as full version
5	3	In the last 3 months, how often did people from this program listen carefully to you?	“Never,” “Sometimes,” “Usually,” “Always”	Same as full version
6	4	In the last 3 months, how often did you feel that people from this program cared about you as a whole person?	“Never,” “Sometimes,” “Usually,” “Always”	Same as full version
7	5	In the last 3 months, how often did you feel heard and understood by people from this program?	“Never,” “Sometimes,” “Usually,” “Always”	Same as full version
8	6	In the last 3 months, how often did people from this program seem to know the important information about your medical history?	“Never,” “Sometimes,” “Usually,” “Always”	Same as full version
9	7	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?	“Yes, definitely,” “Yes, somewhat,” “No”	Same as full version

Full Version Item Number	Abridged Version Item Number	Question Text	Response Options: Full Version	Response Options: Abridged Version (if different)
10	8	In the last 3 months, did someone from this program talk with you about all the medicines you are taking?	“Yes, definitely,” “Yes, somewhat,” “No,” “I do not take any medicines”	Same as full version
11	9	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?	“Yes, definitely,” “Yes, somewhat,” “No,” “I did not want help from this program with everyday activities”	Same as full version
12	10	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?	“Yes, definitely,” “Yes, somewhat,” “No,” “I did not contact this program between visits for questions or help with my care”	Same as full version
13	N/A	In the last 3 months, did you have any pain?	“Yes,” “No”	N/A
14	11	In the last 3 months, did you get as much help as you wanted for [your] pain? ^a	“Yes, definitely,” “Yes, somewhat,” “No,” “I did not want help for my pain”	“Yes, definitely,” “Yes, somewhat,” “No,” “I did not want help for my pain,” “I did not have pain”
15	N/A	In the last 3 months, did you have any trouble breathing?	“Yes,” “No”	N/A
16	12	In the last 3 months, did you get as much help as you wanted for [your] breathing? ^a	“Yes, definitely,” “Yes, somewhat,” “No,” “I did not want help for my breathing”	“Yes, definitely,” “Yes, somewhat,” “No,” “I did not want help for my breathing,” “I did not have trouble breathing”
17	N/A	In the last 3 months, did you have any feelings of anxiety or sadness?	“Yes,” “No”	N/A
18	13	In the last 3 months, did you get as much help as you wanted for [your] feelings of anxiety or sadness? ^a	“Yes, definitely,” “Yes, somewhat,” “No,” “I did not want help for my anxiety or sadness”	“Yes, definitely,” “Yes, somewhat,” “No,” “I did not want help for my anxiety or sadness,” “I did not have feelings of anxiety or sadness”

Full Version Item Number	Abridged Version Item Number	Question Text	Response Options: Full Version	Response Options: Abridged Version (if different)
19	N/A	In the last 3 months, did you have family members or friends involved in your care?	"Yes," "No"	N/A
20	N/A	In the last 3 months, did the people from the program involve <u>your family members or friends</u> in discussions about your health care as much as <u>you</u> wanted?	"Yes, definitely," "Yes, somewhat," "No"	N/A
21	N/A	In the last 3 months, did your family members or friends get as much emotional support as <u>they</u> wanted from this program?	"Yes, definitely," "Yes, somewhat," "No," "My family members or friends did not want emotional support from this program"	N/A
22	14	Did someone from this program ever talk with you about what you should do during a health emergency?	"Yes, definitely," "Yes, somewhat," "No"	Same as full version
23	15	Did someone from this program ever talk with you about what is important in your life?	"Yes, definitely," "Yes, somewhat," "No"	Same as full version
24	16	Did someone from this program ever talk with you about what your health care options would be if you got sicker?	"Yes, definitely," "Yes, somewhat," "No"	Same as full version
25	17	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?	0–10	Same as full version
26	N/A	Would you recommend this program to your friends and family?	"Definitely no," "Probably no," "Probably yes," "Definitely yes"	N/A
27	N/A	Are you <u>usually</u> able to leave your home or building to go outside, even if you use a cane, walker, or other people for support?	"Yes, by myself," "Yes, with help," "No"	N/A
28	N/A	Are you <u>usually</u> able to get in and out of bed?	"Yes, by myself," "Yes, with help," "No"	N/A

Full Version Item Number	Abridged Version Item Number	Question Text	Response Options: Full Version	Response Options: Abridged Version (if different)
29	18	In general, how would you rate your physical health?	"Excellent," "Very good," "Good," "Fair," "Poor"	Same as full version
30	19	In general, how would you rate your mental or emotional health?	"Excellent," "Very good," "Good," "Fair," "Poor"	Same as full version
31	20	What is the highest grade or level of school that you have completed?	"8th grade or less," "Some high school but did not graduate," "High school graduate or GED," "Some college or 2-year degree," "4-year college graduate," "More than 4-year college degree"	Same as full version
32	N/A	Are you of Hispanic, Latino, or Spanish origin or descent?	"No, not Hispanic/Latino/Spanish;" "Yes, Puerto Rican;" "Yes, Mexican, Mexican American, Chicano/a;" "Yes, Cuban;" "Yes, other Spanish/Hispanic/ Latino"	N/A
33	N/A	What is your race? Please choose one or more.	"White," "Black or African American," "Asian," "Native Hawaiian or other Pacific Islander," "American Indian or Alaska Native"	N/A
34	N/A	What language do you <u>mainly</u> speak at home?	"English," "Spanish," "Some other language"	N/A

Full Version Item Number	Abridged Version Item Number	Question Text	Response Options: Full Version	Response Options: Abridged Version (if different)
35	21	Did someone help you complete this survey? Please choose one or more.	“Yes, they read the questions to me,” “Yes, they wrote down the answers I gave,” “Yes, they answered the questions for me,” “Yes, they translated the questions into my language,” “Yes, they helped in some other way,” “No, no one helped me complete this survey”	Same as full version
36	N/A	In thinking about your experiences with the program, is there anything that is going well or that you wish would go differently? Please tell us about those experiences.	Open text field	N/A

NOTE: N/A = not applicable.

^a Text in brackets does not appear in the abridged version of survey.