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Appendix A: English Language Survey of End of Life Care

**Survey of End-of-Life Care**

**[ORGANIZATION NAME]**

**This survey asks about the person listed on the survey cover letter and the care he or she received during the last month of life.**

**Who Should Fill Out the Survey?**

* The person in your household who knows the most about the care received by the **person on the survey cover letter who recently passed away**.

**How to Fill Out the Survey**

* Please use a dark colored pen to fill out the survey.
* Please put an “X” in the square by your answer, like this:

 Yes

🞏 No

* At times you will be asked to skip some questions. When this happens you will see an arrow with a note that tells you where to go next, like this:

🞏 Yes

 No 🡺 **If No, go to Question 3**

If you want to know more about this survey, call XXX-XXX-XXXX. All calls to that number are free.

Public reporting burden for this collection of information is estimated to average 12 minutes per response, the estimated time to complete this survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (XXXX-XXXX) AHRQ, 5600 Fishers Lane, #07241A, Rockville, MD 20857

**The Person Who**

**Recently Passed Away**

1. **How are you related to the person on the survey cover letter who recently passed away?**

🞏 My spouse or partner

🞏 My parent

🞏 My mother-in-law or father-in-law

🞏 My grandparent

🞏 My aunt or uncle

🞏 My sister or brother

🞏 My child

🞏 My friend

🞏 Other (please print):

**Your Family Member**

1. **For this survey, the phrase "your family member" refers to the person who recently passed away.**

**During the last month of life, how often did you oversee or take part in your family member’s care?**

🞏 Never 🡺 **If Never, go to Question 31**

🞏 Sometimes

🞏 Usually

🞏Always

**Your Family Member’s**

**Health Care Providers**

1. **Health care providers include doctors, nurses, physician assistants, or other professionals who provide care, including those from hospice or a nursing home.**

**During the last month of life, did your family member get care from a health care provider?**

🞏 Yes

🞏 No 🡺 **If No, go to Question 31**

1. **During the last month of life, where did your family member get care from a health care provider? Please choose one or more.**

🞏 Doctor’s office or clinic

🞏 Hospital or emergency room

🞏Hospice facility or hospice house

🞏 At home (or a relative’s home)

🞏 Assisted living facility

🞏 Nursing home or skilled nursing facility

🞏 By phone or video call

🞏Another place (please print):

**Your Family Member’s**

**Last Month of Life**

1. **These questions ask about experiences with your family member's health care providers during his or her last month of life. During the last month of life, did you or your family member need to contact a health care provider during regular office hours?**

🞏 Yes

🞏 No 🡺 **If No, go to Question 7**

1. **When you or your family member contacted a health care provider during regular office hours, how often did you get the help needed?**

🞏 Never

🞏 Sometimes

🞏 Usually

🞏Always

1. **During the last month of life, did you or your family member need to contact a health care provider during evenings, weekends, or holidays for questions or help with his or her care?**

🞏 Yes

🞏 No 🡺 **If No, go to Question 9**

1. **When you or your family member contacted a health care provider during evenings, weekends, or holidays, how often did you get the help needed?**

🞏 Never

🞏 Sometimes

🞏 Usually

🞏Always

1. **During the last month of life, how often did your family member’s health care providers explain things in a way that was easy to understand?**

🞏 Never

🞏 Sometimes

🞏 Usually

🞏Always

1. **During the last month of life, how often did your family member’s health care providers seem to know the important information about his or her medical history?**

🞏 Never

🞏 Sometimes

🞏 Usually

🞏Always

1. **During the last month of life, how often were you and your family member kept informed about his or her condition?**

🞏 Never

🞏 Sometimes

🞏 Usually

🞏Always

1. **During the last month of life, how often did health care providers treat your family member with dignity and respect?**

🞏 Never

🞏 Sometimes

🞏 Usually

🞏Always

1. **During the last month of life, how often did you feel that health care providers really cared about your family member?**

🞏 Never

🞏 Sometimes

🞏 Usually

🞏Always

1. **During the last month of life, how often did health care providers listen carefully to you and your family member?**

🞏 Never

🞏 Sometimes

🞏 Usually

🞏Always

1. **During the last month of life, did health care providers involve you and your family member in decisions as much as you both wanted?**

🞏 Yes, definitely

🞏 Yes, somewhat

🞏 No

1. **During the last month of life, did your family member have any pain?**

🞏 Yes

🞏 No 🡺 **If No, go to Question 18**

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

🞏 Yes, definitely

🞏 Yes, somewhat

🞏 No

1. **During the last month of life, did your family member have trouble breathing or receive treatment for trouble breathing?**

🞏 Yes

🞏 No 🡺 **If No, go to Question 20**

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

🞏 Never

🞏 Sometimes

🞏 Usually

🞏Always

1. **During the last month of life, did your family member show any feelings of anxiety or sadness?**

🞏 Yes

🞏 No 🡺 **If No, go to Question 22**

1. **How often did your family member get the help he or she needed for feelings of anxiety or sadness?**

🞏 Never

🞏 Sometimes

🞏 Usually

🞏Always

1. **During the last month of life, how much emotional support did you and your family member get from health care providers?**

🞏 Too little

🞏 Right amount

🞏Too much

**Your Family Member’s Wishes**

1. **A person may have wishes or preferences about the care or services he or she would like at the end of life. Did you know your family member’s wishes for care?**

🞏 Yes, definitely

🞏 Yes, somewhat

🞏 No 🡺 **If No, go to Question 26**

1. **Did health care providers do the best they could to respect your family member's wishes?**

🞏 Yes, definitely

🞏 Yes, somewhat

🞏 No

1. **Did health care providers do anything that went against your family member's wishes?**

🞏 Yes, definitely

🞏 Yes, somewhat

🞏 No

1. **People may sign a document that gives directions on the medical care they want if they cannot speak for themselves. This is sometimes called an Advance Directive or Living Will. Did your family member have a signed document like this?**

🞏 Yes

🞏 No

🞏 Don’t know

1. **During the last month of life, how much medical care did your family member get?**

🞏 Too little

🞏 Right amount

🞏Too much

1. **Where was your family member when he or she passed away?**

🞏 Home (or a relative’s home)

🞏 Assisted living facility

🞏 Nursing home or skilled nursing facility

🞏 Hospital

🞏Hospice facility or hospice house

🞏Other place (please print):

1. **Did health care providers do the best they could to honor your family member's desired location to pass away?**

🞏 Yes, definitely

🞏 Yes, somewhat

🞏 No

🞏 Don’t know

**Overall Rating of Health Care**

1. **Using any number from 0 to 10, where 0 is the worst health care possible and 10 is the best health care possible, what number would you use to rate your family member’s health care during the last month of life?**

🞏 0 Worst health care possible

🞏 1

🞏 2

🞏 3

🞏 4

🞏 5

🞏 6

🞏 7

🞏 8

🞏 9

🞏 10 Best health care possible

**About Your Family Member**

1. **During the last month of life, did your family member have any of the following conditions?**

 **Yes No**

* 1. Angina, heart disease

 or heart attack? 🞏🞏

b. COVID-19? 🞏🞏

c. The flu (Influenza)

 or pneumonia? 🞏🞏

d. Hypertension or high

 blood pressure? 🞏🞏

e. Cancer? 🞏🞏

f. Emphysema, asthma,

 COPD (chronic

 obstructive pulmonary

 disease), or other

 lung problems? 🞏🞏

g. Alzheimer’s or

 other dementia? 🞏🞏

h. Diabetes or high

 blood sugar? 🞏🞏

1. Renal failure or

 kidney disease? 🞏🞏

j. Other condition? (please print):

🞏My family member had no health conditions

🞏I did not know my family member’s health conditions

1. **What was the cause of your family member’s death? Please choose one or more.**

🞏 Accident or injury

🞏 COVID-19

🞏 The flu (Influenza) or pneumonia

🞏Heart disease or heart attack

🞏Cancer

🞏COPD (chronic obstructive pulmonary disease) or other lung problems

🞏Stroke

🞏Alzheimer’s or other dementia

🞏Diabetes or high blood sugar

🞏 Renal failure or kidney disease

🞏Other cause (please print):

🞏Don’t know

1. **What is the highest grade or level of school that your family member 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

🞏Don’t know

1. **Was your family member of Hispanic, Latino, or Spanish origin or descent?**

🞏 No, not Spanish/Hispanic/Latino

🞏 Yes, Puerto Rican

🞏 Yes, Mexican, Mexican American, Chicano/a

🞏 Yes, Cuban

🞏 Yes, Other Spanish/Hispanic/ Latino

1. **What was your family member’s race? Please choose one or more.**

🞏 White

🞏 Black or African American

🞏 Asian

🞏 Native Hawaiian or other Pacific Islander

🞏 American Indian or Alaska Native

**About You**

1. **What is your age?**

🞏 18 to 24

🞏 25 to 34

🞏 35 to 44

🞏 45 to 54

🞏 55 to 64

🞏 65 to 74

🞏 75 to 84

🞏 85 or older

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

🞏 Male

🞏 Female

1. **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

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

🞏 English

🞏 Spanish

🞏 Some other language (please print):

1. **In thinking about your family member’s care in the last month of life, is there anything that went well, or anything that you wish had gone differently? Please explain what happened, where it happened, and how it felt to you and/or your family member.**

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| --- |
|  |

**Thank you.**

**Please return the completed survey in the postage-paid envelope.**

 **[NAME OF SURVEY VENDOR]**

**[RETURN ADDRESS OF SURVEY VENDOR]**