Form Approved
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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.

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

2. 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

3. 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**

4. 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

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

   ☐ Yes
   ☐ No ➔ **If No, go to Question 7**

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

   ☐ Never
   ☐ Sometimes
   ☐ Usually
   ☐ Always

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

   ☐ Yes
   ☐ No ➔ **If No, go to Question 9**

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

   ☐ Never
   ☐ Sometimes
   ☐ Usually
   ☐ Always

9. **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

10. **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

11. **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

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

    ☐ Never
    ☐ Sometimes
    ☐ Usually
    ☐ Always

13. 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

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

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

15. 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

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

- ☐ Yes
- ☐ No ➔ **If No, go to Question 18**

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

- ☐ Yes, definitely
- ☐ Yes, somewhat
- ☐ No

18. 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**

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

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

20. 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**

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

- ☐ Never
- ☐ Sometimes
- ☐ Usually
- ☐ Always

22. During the last month of life, how much <u>emotional</u> support did you and your family member get from health care providers?

- ☐ Too little
- ☐ Right amount
- ☐ Too much

Your Family Member's Wishes

23. 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**

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

- ☐ Yes, definitely
- ☐ Yes, somewhat
- ☐ No

25. Did health care providers do anything that <u>went against</u> your family member's wishes?

- ☐ Yes, definitely
- ☐ Yes, somewhat
- ☐ No

26. 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

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

- ☐ Too little
- ☐ Right amount
- ☐ Too much

28. 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):

_____

29. 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

30. 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 <u>during the last month of life</u>?

- ☐ 0 Worst health care possible
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10 Best health care possible

About Your Family Member

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

	Yes	No
a. 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?	☐	☐
i. 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

32. 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

33. What is the highest grade or level of school that <u>your family member</u> 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

34. Was <u>your family member</u> 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

35. What was <u>your family member's</u> 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

36. 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

37. Are you male or female?

- ☐ Male
- ☐ Female

38. 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

39. What language do you <u>mainly</u> speak at home?

- ☐ English
- ☐ Spanish
- ☐ Some other language (please print):

_____

40. 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.

Thank you.

Please return the completed survey in the postage-paid envelope.
[NAME OF SURVEY VENDOR]
[RETURN ADDRESS OF SURVEY VENDOR]