DRAFT Hospice Survey

Survey content subject to pending rulemaking – August 2024

Please answer the survey questions about the care the patient listed on the survey cover letter received from this hospice:

[NAME OF HOSPICE]

All of the questions in this survey will ask about experiences with this hospice.

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

OMB # XXXX-XXXX Expires TBD

Who Should Fill Out the Survey?

• The person in your household who knows the most about the hospice care received by the patient listed on the survey cover letter.

How to Fill Out the Survey

- Please use a dark colored pen.
- Please put an X inside the square by your answer, like this:

	Yes
\boxtimes	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 → If Yes, Go to Question 1 No

You may notice a number on the survey. This number is used to let us know if you returned your survey so we do not have to send you reminders.

The Hospice Patient

1. How are you related to the patient listed on the survey cover letter?

- ¹ My spouse or partner
- ² My parent
- ³ My mother-in-law or father-inlaw
- ⁴ My grandparent
- ⁵ My aunt or uncle
- ⁶ My sister or brother
- ⁷ My child
- ⁸ My friend
- ⁹ Other (please print):
- 2. For this survey, the phrase "family member" refers to the patient listed on the survey cover letter.

In what locations did your family member receive care from this hospice? Please choose one or more.

¹ Home

- ² Assisted living facility
- ³ Nursing home
- ⁴ Hospital
- ⁵ Hospice facility/hospice house
- ⁶ Other (please print):

Your Role

- 3. While your family member was in hospice care, how often did you take part in or oversee care for them?
 - ¹□ Never → If Never, go to Question 32
 - ² Sometimes
 - ³ Usually
 - ⁴ Always

Your Family Member's Hospice Care

For the rest of the questions, please think only about your family member's experience with the hospice listed on the survey cover.

4. For this survey, the <u>hospice team</u> means all the nurses, doctors, social workers, chaplains and others who gave hospice care to your family member.

While your family member was in hospice care, did you need to contact anyone on the hospice team during evenings, weekends, or holidays for questions or help?

¹ Yes

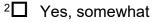
- ² No \rightarrow If No, go to Question 6
- 5. How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always

- 6. How often did the hospice team let you know when they would arrive to care for your family member?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always
- 7. When you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always
- 8. How often did the hospice team explain things in a way that was easy to understand?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always
- 9. How often did the hospice team keep you informed about your family member's condition?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always
- 10. How often did the hospice team treat your family member with dignity and respect?
 - ¹D Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always

- 11. How often did you feel that the hospice team really cared about your family member?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always
- 12. Did the hospice team provide care that respected your family member's wishes?
 - ¹ Yes, definitely
 - ² Yes, somewhat
 - ³□ No
- 13. Did the hospice team make an effort to listen to the things that mattered most to you or your family member?
 - ¹ Yes, definitely
 - ² Yes, somewhat
 - ³□ No
- 14. Did you talk with the hospice team about any problems with your family member's hospice care?
 - ¹ Yes
 - ² No \rightarrow If No, go to Question 16
- 15. How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always

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- 16. While your family member was in hospice care, did they have any pain?
 - ¹ Yes
 - ² No \rightarrow If No, go to Question 18
- 17. Did your family member get as much help with pain as they needed?
 - ¹ Yes, definitely



- ³□ No
- 18. While your family member was in hospice care, did they ever have trouble breathing or receive treatment for trouble breathing?
 - ¹ Yes
 - ² No \rightarrow If No, go to Question 20
- 19. How often did your family member get the help they needed for trouble breathing?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always
- 20. While your family member was in hospice care, did they ever have trouble with constipation?
 - ¹ Yes
 - ² No \rightarrow If No, go to Question 22

- 21. How often did your family member get the help they needed for trouble with constipation?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always
- 22. While your family member was in hospice care, did they show any feelings of anxiety or sadness?
 - ¹ Yes
 - ² No \rightarrow If No, go to Question 24
- 23. How often did your family member get the help they needed <u>from the</u> <u>hospice team</u> for feelings of anxiety or sadness?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always

Your Own Experience with Hospice

24. Hospice teams may teach you how to care for family members who need pain medicine, have trouble breathing, are restless or agitated, or have other care needs.

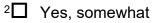
> Did the hospice team teach you how to care for your family member?

- ¹ Yes, definitely
- ² Yes, somewhat

³□ No

⁴ I did not need this teaching

- 25. While your family member was in hospice care, how often did the hospice team listen carefully to you?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always
- 26. Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?
 - ¹ \square Yes, definitely



- ³□ No
- 27. Support for religious, spiritual, or cultural beliefs may include talking, praying, quiet time, or respecting traditions.

While your family member was in hospice care, how much support for your religious, spiritual, or cultural beliefs did you get from the hospice team?

- ¹ Too little
- ² Right amount
- ³ Too much
- 28. While your family member was in hospice care, how much <u>emotional</u> support did you get from the hospice team?
 - ¹ Too little
 - ² Right amount
 - ³ Too much

- 29. In the weeks <u>after</u> your family member died, how much emotional support did you get from the hospice team?
 - ¹ Too little
 - ² Right amount
 - ³ Too much

Overall Rating of Hospice Care

30. Please answer the following questions about the hospice named on the survey cover. Do not include care from other hospices in your answers.

> Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?

- $^{0}\square$ 0 Worst hospice care possible
- ¹ 1
- ² 2
- ³□ 3
- ₄□ 4
- ⁵□ 5
- ⁶ 6
- ⁷🗖 7
- 8 🗖 8
- ⁹🔲 9
- ¹⁰ 10 Best hospice care possible

hos	uld you recommend this spice to your friends and nily?	34.
	Definitely no	
	Probably no	
	Probably yes	
	Definitely yes	2
	out Your Family Member	
32.Wh of s	at is the highest grade or level school that <u>your family member</u> npleted?	35.
1	8 th grade or less	
2	Some high school but did not	
	graduate	
	High school graduate or GED	:
	Some college or 2-year degree	4
5	4-year college graduate	
6		
7	degree	36.
۲ L	Don't know	50.
His	s <u>your family member</u> of panic, Latino, or Spanish gin or descent?	
1 2		ų
2 🗖 3 🗖	Yes, Cuban	
3	Yes, Mexican, Mexican American, Chicano/a	-
4	Yes, Puerto Rican	8
5	Yes, Other Spanish/Hispanic/ Latino	37.

34. What was <u>your family member's</u> race? Please choose one or more.

- ¹ American Indian or Alaska Native
- ² Asian
- ³ Black or African American
- ⁴ Native Hawaiian or other Pacific Islander
- ⁵**□** White
- 35. How often was your family member treated unfairly by the hospice team because of their race or ethnicity?
 - ¹ Never
 - ² Sometimes
 - ³ Usually
 - ⁴ Always

About You

36. What is your age?

- ¹□ 18 to 24
- ² 25 to 34
- ³ 35 to 44
- ⁴ 45 to 54
- ⁵□ 55 to 64
- ⁶□ 65 to 74
- ⁷ 75 to 84
- 8☐ 85 or older

37. Are you male or female?

- ¹ Male
- ² Female

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

- ¹ 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
- ⁶□ More than 4-year college degree

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

- ¹ English
- ² Spanish
- ³ Chinese
- ⁴ Russian
- ⁵ Portuguese
- ⁶ Vietnamese
- ⁷D Polish
- ⁸ Korean
- ⁹□ Some other language (please print):

THANK YOU

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

COMPANY Attn: NAME STREET CITY, STATE ZIP

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