CAHPS[®] Hospice Survey

Please answer the survey questions about the care the patient received from this hospice:

[NAME OF HOSPICE]

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

If you want to know more about this survey, please call [TOLL FREE NUMBER]. All calls to that number are free.

OMB#0938-1257

CAHPS® Hospice Survey

SURVEY INSTRUCTIONS

 ◆ Please give this survey to the person in your hospice care received by the person listed of ◆ Use a dark colored pen to fill out the survey. ◆ Place an X directly inside the square indicated Yes No 	on the survey cover letter.
 To indicate an answer selected was in error select another square. You are sometimes told to skip over some quill see an arrow with a note that tells you will see. 	
Yes → If Yes, Go to Question 1No	
THE HOSPICE PATIENT 1. How are you related to the person listed on the survey cover letter? 1 My spouse or partner 2 My parent 3 My mother-in-law or father-in-law 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 person 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

YOUR ROLE	6. While your family member was in
3. While your family member was in hospice care, how often did you take part in or oversee care for him or her?	hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?
 Never → If Never, go to Question 41 Sometimes Usually 	¹ ☐ Never ² ☐ Sometimes ³ ☐ Usually ⁴ ☐ Always
⁴ ☐ Always YOUR FAMILY MEMBER'S HOSPICE CARE	7. While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you
As you answer the rest of the questions in this survey, please think only about your family member's experience with the hospice named on the survey cover.	get help as soon as you needed it? 1 Never 2 Sometimes 3 Usually
 4. For this survey, the hospice team includes all the nurses, doctors, social workers, chaplains and other people who provided hospice care to your family member. While your family member was in hospice care, did you need to contact the hospice team during evenings, weekends, or holidays for questions or help with your family member's care? ¹□ Yes ²□ No → If No, go to Question 6 	8. While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand? 1 Never 2 Sometimes 3 Usually 4 Always
 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 	9. While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition? 1 Never 2 Sometimes 3 Usually 4 Always

hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?	carefully to you when you talked with them about problems with your family member's hospice care? 1 Never 2 Sometimes
¹ ☐ Never ² ☐ Sometimes ³ ☐ Usually	² ☐ Sometimes ³ ☐ Usually ⁴ ☐ Always
 ⁴ ☐ Always 11. While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect? 	 15. While your family member was in hospice care, did he or she have any pain? ¹□ Yes ²□ No → If No, go to Question 17
 Never Sometimes Usually Always 	 16. Did your family member get as much help with pain as he or she needed? ¹□ Yes, definitely ²□ Yes, somewhat
12. While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member? 1 Never 2 Sometimes 3 Usually 4 Always	 3 □ No 17. While your family member was in hospice care, did he or she receive any pain medicine? 1 □ Yes 2 □ No → If No, go to Question 21 18. Side effects of pain medicine include things like sleepiness. Did any
 13. While your family member was in hospice care, did you talk with the hospice team about any problems with your family member's hospice care? ¹□ Yes ²□ No → If No, go to Question 15 	member of the hospice team discuss side effects of pain medicine with you or your family member? 1 Yes, definitely 2 Yes, somewhat 3 No

training you needed about what side effects to watch for from pain medicine?	training you needed about how to help your family member if he or she had trouble breathing?
 ¹☐ Yes, definitely ²☐ Yes, somewhat ³☐ No 20. Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member? ¹☐ Yes, definitely ²☐ Yes, somewhat ³☐ No ⁴☐ I did not need to give pain medicine to my family member 	 ¹□ Yes, definitely ²□ Yes, somewhat ³□ No ⁴□ I did not need to help my family member with trouble breathing 24. While your family member was in hospice care, did your family member ever have trouble with constipation? ¹□ Yes ²□ No → If No, go to Question 26 25. How often did your family member get the help he or she needed for
 21. While your family member was in hospice care, did your family member ever have trouble breathing or receive treatment for trouble breathing? ¹□ Yes ²□ No → If No, go to Question 24 	trouble with constipation? 1 Never 2 Sometimes 3 Usually 4 Always 26. While your family member was in
 22. How often did your family member get the help he or she needed for trouble breathing? ¹□ Never ²□ Sometimes ³□ Usually ⁴□ Always 	hospice care, did he or she show any feelings of anxiety or sadness? ¹☐ Yes ²☐ No → If No, go to Question 28 27. How often did your family member get the help he or she needed from the hospice team for feelings of anxiety or sadness? ¹☐ Never ²☐ Sometimes ³☐ Usually ⁴☐ Always

4 0.	hospice care, did he or she ever	NURSING HOME
29.	become restless or agitated? ¹☐ Yes ²☐ No → If No, go to Question 30 Did the hospice team give you the training you needed about what to do if your family member became	32. Some people receive hospice care while they are living in a nursing home. Did your family member receive care from this hospice while he or she was living in a nursing home?
	restless or agitated? ¹ Yes, definitely ² Yes, somewhat ³ No	 No → If No, go to Question 35 While your family member was in hospice care, how often did the nursing home staff and hospice team work well together to care for your
t c t r	Moving your family member includes things like helping him or her turn over in bed, or get in and out of bed or a wheelchair. Did the hospice team give you the training you needed about how to safely move your family member?	family member? 1 Never 2 Sometimes 3 Usually 4 Always
	 ¹□ Yes, definitely ²□ Yes, somewhat ³□ No ⁴□ I did not need to move my family member 	34. While your family member was in hospice care, how often was the information you were given about your family member by the nursing home staff different from the information you were given by the
31.	Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?	hospice team? 1 Never 2 Sometimes 3 Usually
	 Yes, definitely Yes, somewhat No 	⁴ □ Always

YOUR OWN EXPERIENCE WITH HOSPICE

35.	While your family member was in hospice care, how often did the hospice team listen carefully to you? 1 Never 2 Sometimes 3 Usually	39. Please answer the following questions about your family member's care from the hospice named on the survey cover. Do not include care from other hospices in your answers.
36.	Always Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs	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? One is not because of the control of the con
	did you get from the hospice team? 1 Too little 2 Right amount 3 Too much	² □ 2 ³ □ 3 ⁴ □ 4 ⁵ □ 5
37.	While your family member was in hospice care, how much emotional support did you get from the hospice team?	⁶ □ 6 ⁷ □ 7 ⁸ □ 8 ⁹ □ 9 ¹⁰ □ 10 Best hospice care possible
	 ¹☐ Too little ²☐ Right amount ³☐ Too much 	40. Would you recommend this hospice to your friends and family?
38.	In the weeks <u>after</u> your family member died, how much emotional support did you get from the hospice team?	 ¹□ Definitely no ²□ Probably no ³□ Probably yes ⁴□ Definitely yes
	 ¹☐ Too little ²☐ Right amount ³☐ Too much 	

OVERALL RATING OF HOSPICE CARE

ABOUT YOUR FAMILY MEMBER **ABOUT YOU** 41. What is the highest grade or level of 44. What is your age? school that your family member ¹□ 18 to 24 completed? ²□ 25 to 34 ¹ □ 8th grade or less ³□ 35 to 44 ²☐ Some high school but did not ⁴□ 45 to 54 graduate ⁵□ 55 to 64 ³ ☐ High school graduate or GED ⁶□ 65 to 74 ⁴□ Some college or 2-year degree $^{7}\Box$ 75 to 84 ⁵ □ 4-year college graduate ⁸□ 85 or older ⁶ ☐ More than 4-year college degree ⁷ □ Don't know 45. Are you male or female? ¹□ Male 42. Was your family member of Hispanic, Latino, or Spanish origin or descent? ²☐ Female ¹ □ No, not Spanish/Hispanic/Latino 46. What is the highest grade or level of ²☐ Yes, Puerto Rican school that you have completed? ³☐ Yes, Mexican, Mexican American, ¹ □ 8th grade or less Chicano/a ²☐ Some high school but did not ⁴ ☐ Yes, Cuban graduate ⁵ Yes, Other Spanish/Hispanic/ ³ ☐ High school graduate or GED Latino ⁴□ Some college or 2-year degree 43. What was your family member's ⁵ □ 4-year college graduate race? Please choose one or more. ⁶ ■ More than 4-year college degree ¹□ White 47. What language do you mainly speak ²☐ Black or African American at home? ³□ Asian ¹☐ English ⁴☐ Native Hawaiian or other Pacific ² ☐ Spanish Islander

8 November 2014

³☐ Chinese

print):

⁴□ Some other language (please

⁵☐ American Indian or Alaska Native

THANK YOU

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

[NAME OF SURVEY VENDOR] [RETURN ADDRESS OF SURVEY VENDOR]

CAHPS[®] Hospice Survey

Please answer the survey questions about the care the patient received from this hospice:

[NAME OF HOSPICE]

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

If you want to know more about this survey, please call [TOLL FREE NUMBER]. All calls to that number are free.

OMB#0938-1257

CAHPS® Hospice Survey

SURVEY INSTRUCTIONS

- ♦ Please give this survey to the person in your household who knows the most about the hospice care received by the person listed on the survey cover letter.
- Use a dark colored pen to fill out the survey.
- ♦ Answer <u>all</u> the questions by completely filling in the circle to the left of your answer.
 - 0 Yes
 - No
- ♦ To indicate an answer selected was in error, clearly draw a line through the circle and select another circle.
- ♦ You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:
 - Yes → If Yes, Go to Question 1
 - 0 No

THE HOSPICE PATIENT

- 1. How are you related to the person listed on the survey cover letter?
 - ¹O My spouse or partner
 - ²0 My parent
 - ³O My mother-in-law or father-in-law
 - ⁴O My grandparent
 - ⁵O My aunt or uncle
 - ⁶O My sister or brother
 - ⁷0 My child
 - ⁸0 My friend
 - ⁹O Other (please print):

- 2. For this survey, the phrase "family member" refers to the person listed on the survey cover letter. In what locations did your family member receive care from this hospice? Please choose one or more.
 - ¹O Home
 - ²O Assisted living facility
 - ³O Nursing home
 - ⁴O Hospital
 - ⁵O Hospice facility/hospice house
 - ⁶O 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 him or her?
 - 10 Never → If Never, go to Question 41
 - ²0 Sometimes
 - ³O Usually
 - ⁴O Always

YOUR FAMILY MEMBER'S HOSPICE CARE

As you answer the rest of the questions in this survey, please think only about your family member's experience with the hospice named on the survey cover.

- 4. For this survey, the hospice team includes all the nurses, doctors, social workers, chaplains and other people who provided hospice care to your family member. While your family member was in hospice care, did you need to contact the hospice team during evenings, weekends, or holidays for questions or help with your family member's care?
 - ¹0 Yes
 - ²0 No → 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?
 - ¹0 Never
 - ²O Sometimes
 - ³O Usually
 - ⁴O Always

- 6. While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?
 - ¹0 Never
 - ²0 Sometimes
 - ³O Usually
 - ⁴O Always
- 7. While your family member was in hospice care, 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?
 - ¹0 Never
 - ²O Sometimes
 - ³O Usually
 - ⁴O Always
- 8. While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?
 - ¹0 Never
 - ²O Sometimes
 - ³O Usually
 - ⁴O Always
- 9. While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?
 - ¹0 Never
 - ²O Sometimes
 - ³O Usually
 - ¹0 Always

10.	While your family member was in
	hospice care, how often did anyone
	from the hospice team give you
	confusing or contradictory
	information about your family
	member's condition or care?

¹0 Never

²0 Sometimes

³O Usually

⁴O Always

11. While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

¹0 Never

²O Sometimes

³O Usually

⁴O Always

12. While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?

¹0 Never

²O Sometimes

³O Usually

⁴O Always

13. While your family member was in hospice care, did you talk with the hospice team about any problems with your family member's hospice care?

¹0 Yes

²0 No → If No, go to Question 15

14. How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?

¹0 Never

²0 Sometimes

³O Usually

⁴0 Always

15. While your family member was in hospice care, did he or she have any pain?

¹0 Yes

²0 No → If No, go to Question 17

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

¹O Yes, definitely

²0 Yes, somewhat

³0 No

17. While your family member was in hospice care, did he or she receive any pain medicine?

¹0 Yes

²0 No → If No, go to Question 21

18. Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with you or your family member?

¹O Yes, definitely

²O Yes, somewhat

³0 No

- 19. Did the hospice team give you the training you needed about what side effects to watch for from pain medicine?
 - ¹0 Yes, definitely
 - ²0 Yes, somewhat
 - ³0 No
- 20. Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?
 - ¹O Yes, definitely
 - ²0 Yes, somewhat
 - 3 0 No
 - ⁴O I did not need to give pain medicine to my family member
- 21. While your family member was in hospice care, did your family member ever have trouble breathing or receive treatment for trouble breathing?
 - ¹0 Yes
 - ²0 No → If No, go to Question 24
- 22. How often did your family member get the help he or she needed for trouble breathing?
 - ¹0 Never
 - ²0 Sometimes
 - ³O Usually
 - ⁴O Always

- 23. Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?
 - ¹0 Yes, definitely
 - $^2\mathbf{0}$ Yes, somewhat
 - ³0 No
 - ⁴O I did not need to help my family member with trouble breathing
- 24. While your family member was in hospice care, did your family member ever have trouble with constipation?
 - ¹0 Yes
 - ²0 No → If No, go to Question 26
- 25. How often did your family member get the help he or she needed for trouble with constipation?
 - ¹0 Never
 - ²0 Sometimes
 - ³O Usually
 - ⁴O Always
- 26. While your family member was in hospice care, did he or she show any feelings of anxiety or sadness?
 - ¹0 Yes
 - No \rightarrow If No, go to Question 28
- 27. How often did your family member get the help he or she needed <u>from the hospice team</u> for feelings of anxiety or sadness?
 - ¹0 Never
 - ²0 Sometimes
 - ³O Usually
 - ¹0 Always

- 28. While your family member was in hospice care, did he or she ever become restless or agitated?
 - ¹0 Yes
 - 2 0 No → If No, go to Question 30
- 29. Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?
 - ¹0 Yes, definitely
 - ²0 Yes, somewhat
 - ³**0** No
- 30. Moving your family member includes things like helping him or her turn over in bed, or get in and out of bed or a wheelchair. Did the hospice team give you the training you needed about how to safely move your family member?
 - ¹0 Yes, definitely
 - ²O Yes, somewhat
 - ³0 No
 - ⁴O I did not need to move my family member
- 31. Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?
 - ¹0 Yes, definitely
 - ²O Yes, somewhat
 - ³0 No

HOSPICE CARE RECEIVED IN A NURSING HOME

- 32. Some people receive hospice care while they are living in a nursing home. Did your family member receive care from this hospice while he or she was living in a nursing home?
 - ¹0 Yes
 - 2 0 No → If No, go to Question 35
- 33. While your family member was in hospice care, how often did the nursing home staff and hospice team work well together to care for your family member?
 - ¹0 Never
 - ²O Sometimes
 - ³O Usually
 - ⁴O Always
- 34. While your family member was in hospice care, how often was the information you were given about your family member by the nursing home staff different from the information you were given by the hospice team?
 - ¹0 Never
 - ²0 Sometimes
 - ³O Usually
 - 40 Always

YOUR OWN EXPERIENCE WITH HOSPICE

- 35. While your family member was in hospice care, how often did the hospice team listen carefully to you?
 - ¹0 Never
 - ²O Sometimes
 - ³O Usually
 - ⁴O Always
- 36. Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?
 - ¹O Too little
 - ²0 Right amount
 - ³O Too much
- 37. While your family member was in hospice care, how much emotional support did you get from the hospice team?
 - ¹0 Too little
 - ²0 Right amount
 - ³0 Too much
- 38. In the weeks <u>after</u> your family member died, how much emotional support did you get from the hospice team?
 - ¹O Too little
 - ²0 Right amount
 - ³O Too much

OVERALL RATING OF HOSPICE CARE

39. Please answer the following questions about your family member's care from 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?

- ⁰0 0 Worst hospice care possible
- ¹0 1
- ²0 2
- ³**0** 3
- ⁴0 4
- ⁵0 5
- ⁶0 6
- ⁷0 7
- 8 O⁸
- ⁹0 9
- ¹⁰0 10 Best hospice care possible
- 40. Would you recommend this hospice to your friends and family?
 - ¹O Definitely no
 - ²O Probably no
 - ³0 Probably yes
 - ⁴O Definitely yes

ABOUT YOUR FAMILY MEMBER

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

- ¹O 8th grade or less
- ²O Some high school but did not graduate
- ³O High school graduate or GED
- ⁴O Some college or 2-year degree
- ⁵O 4-year college graduate
- ⁶O More than 4-year college degree
- ⁷0 Don't know

42. Was <u>your family member</u> of Hispanic, Latino, or Spanish origin or descent?

- No, not Spanish/Hispanic/Latino
- ²0 Yes, Puerto Rican
- ³O Yes, Mexican, Mexican American, Chicano/a
- ⁴O Yes, Cuban
- 50 Yes, Other Spanish/Hispanic/ Latino

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

- ¹0 White
- ²O Black or African American
- ³O Asian
- Native Hawaiian or other Pacific Islander
- ⁵O American Indian or Alaska Native

ABOUT YOU

44. What is your age?

- ¹0 18 to 24
- ²0 25 to 34
- ³0 35 to 44
- ⁴0 45 to 54
- ⁵0 55 to 64
- ⁶0 65 to 74
- ⁷0 75 to 84
- ⁸0 85 or older

45. Are you male or female?

- ¹0 Male
- ²0 Female

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

- ¹0 8th grade or less
- ²O Some high school but did not graduate
- ³O High school graduate or GED
- ⁴O Some college or 2-year degree
- ⁵0 4-year college graduate
- ⁶O More than 4-year college degree

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

- ¹0 English
- ²O Spanish
- ³O Chinese
- Some other language (please print):

THANK YOU

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

[NAME OF SURVEY VENDOR] [RETURN ADDRESS OF SURVEY VENDOR]

Sample Initial Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[HOSPICE OR VENDOR LETTERHEAD] [SAMPLED CAREGIVER NAME] [ADDRESS] [CITY, STATE ZIP]

Dear [SAMPLED CAREGIVER NAME]:

[HOSPICE NAME] is conducting a survey about the hospice services that patients and their families receive. You were selected for this survey because you were identified as the caregiver of [DECEDENT NAME]. We realize this may be a difficult time for you, but we hope that you will help us learn about the quality of care that you and your family member or friend received from the hospice.

Questions [NOTE THE QUESTION NUMBERS] in the enclosed survey are part of a national initiative sponsored by the United States Department of Health and Human Services (HHS) to measure the quality of care in hospices. The Centers for Medicare & Medicaid Services (CMS), which is part of HHS, is conducting this survey to improve hospice care. CMS pays for most of the hospice care in the U.S. It is CMS's responsibility to ensure that hospice patients and their family members and friends get high quality care. One of the ways they can fulfill this responsibility is to find out directly from you about the hospice care your family member or friend received. Your participation is voluntary and will not affect any health care or benefits you receive.

We hope that you will take the time to complete the survey. After you have completed the survey, please return it in the pre-paid envelope. Your answers will be combined with other respondents and may be shared with the hospice for purposes of quality improvement. [OPTIONAL: You may notice a number on the survey. This number is used to let us know if you returned your survey so we don't have to send you reminders.]

If you have any questions about the enclosed survey, please call the toll-free number 1-800-xxx-xxxx. Thank you for helping to improve hospice care for all consumers.

Sincerely, [HOSPICE ADMINISTRATOR] [HOSPICE NAME]

Sample Follow-up Cover Letter for the CAHPS Hospice Survey

[HOSPICE OR VENDOR LETTERHEAD]

[HOSPICE OR VENDOR LETTERHEAD] [SAMPLED CAREGIVER NAME] [ADDRESS] [CITY, STATE ZIP]

Dear [SAMPLED CAREGIVER NAME]:

Our records show that you were recently a caregiver for [DECEDENT NAME] at [NAME OF HOSPICE]. Approximately three weeks ago, we sent you a survey regarding the care you and your family member or friend received from this hospice. If you have already returned the survey to us, please accept our thanks and disregard this letter. However, if you have not done so already, we would greatly appreciate it if you would take the time to complete this important questionnaire.

We hope that you will take this opportunity to help us learn about the quality of care your family member or friend received. The results from this survey will be used to help ensure that all Americans get the highest quality hospice care.

Questions [NOTE THE QUESTION NUMBERS] in the enclosed survey are part of a national initiative sponsored by the United States Department of Health and Human Services (HHS) to measure the quality of care in hospices. Your participation is voluntary and will not affect any health care or benefits you receive.

Please take a few minutes and complete the enclosed survey. After you have completed the survey, please return it in the pre-paid envelope. Your answers will be combined with other respondents and may be shared with the hospice for purposes of quality improvement. [OPTIONAL: You may notice a number on the survey. This number is used to let us know if you returned your survey so we don't have to send you reminders.]

If you have any questions about the enclosed survey, please call the toll-free number 1-800-xxx-xxxx. Thank you for helping to improve hospice care for all consumers.

Sincerely,
[HOSPICE ADMINISTRATOR]
[HOSPICE NAME]