

Existing Question (2024)	Proposed Question (2025)	Type of Change	Reason for Change	Burden Change
1. How are you related to the person listed on the survey cover letter?	1. How are you related to the patient listed on the survey cover letter?	Wording change "person" to "patient"	Clarification to specify which individual from survey cover letter	No
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.	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.	Wording change "person" to "patient"	Clarification to specify which individual from survey cover letter	No
3. While your family member was in hospice care, how often did you take part in or oversee care for him or her?	3. While your family member was in hospice care, how often did you take part in or oversee care for them?	Wording change "him or her" to "them"	Simplified and gender-neutral language	No

<p>(4-Intro) 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.</p>	<p>(4-Intro) For the rest of the questions, please think only about your family member's experience with the hospice listed on the survey cover.</p>	<p>Wording changes "As you answer" to "For" AND "named" to "listed"</p>	<p>Improve readability/lower reading level</p>	<p>No</p>
<p>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?</p>	<p>4. For this survey, the hospice team 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?</p>	<p>Wording change</p>	<p>Improve readability/lower reading level</p>	<p>No</p>
<p>5. How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?</p>	<p>5. How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?</p>			<p>No</p>

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?	6. How often did the hospice team let you know when they would arrive to care for your family member?	Wording change	Improve readability/lower reading level	No
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?	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?	Wording change	Improve readability/lower reading level	No
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?	8. How often did the hospice team explain things in a way that was easy to understand?	Wording change	Improve readability/lower reading level	No
9. While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?	9. How often did the hospice team keep you informed about your family member's condition?	Wording change	Improve readability/lower reading level	No

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?		Item removed	Item removed because of the complexity of its wording, low intraclass correlation coefficient (ICC) and low correlation with overall rating, and ceiling effects.	Yes
11. While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?	10. How often did the hospice team treat your family member with dignity and respect?	Wording change	Improve readability/lower reading level	No
12. While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?	11. How often did you feel that the hospice team really cared about your family member?	Wording change	Improve readability/lower reading level	No
	12. Did the hospice team provide care that respected your family member's wishes?	New item	New item to address stakeholder requests for items on patient care preferences.	Yes
	13. Did the hospice team make an effort to listen to the things that mattered most to you or your family member?	New item	New item to address stakeholder requests for items addressing what matters most to patients.	Yes

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?	14. Did you talk with the hospice team about any problems with your family member's hospice care?	Wording change	Improve readability/lower reading level	No
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?	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?			No
15. While your family member was in hospice care, did he or she have any pain?	16. While your family member was in hospice care, did they have any pain?	Wording change	Simplified and gender-neutral language	No
16. Did your family member get as much help with pain as he or she needed?	17. Did your family member get as much help with pain as they needed?	Wording change	Simplified and gender-neutral language	No

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

Item dropped

This item (and all other items used to calculate the existing multi-item Getting Hospice Care Training measure) dropped and replaced with a single-item Getting Hospice Care Training measure with strong psychometric performance. Addresses stakeholder request for a shorter instrument.

Yes

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?

Item dropped

This item (and all other items used to calculate the existing multi-item Getting Hospice Care Training measure) dropped and replaced with a single-item Getting Hospice Care Training measure with strong psychometric performance. Addresses stakeholder request for a shorter instrument.

Yes

19. Did the hospice team give you the training you needed about what side effects to watch for from pain medicine?

Item dropped

This item (and all other items used to calculate the existing multi-item Getting Hospice Care Training measure) dropped and replaced with a single-item Getting Hospice Care Training measure with strong psychometric performance. Addresses stakeholder request for a shorter instrument.

Yes

20. Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?

Item dropped

This item (and all other items used to calculate the existing multi-item Getting Hospice Care Training measure) dropped and replaced with a single-item Getting Hospice Care Training measure with strong psychometric performance. Addresses stakeholder request for a shorter instrument.

Yes

21. While your family member was in hospice care, did your family member ever have trouble breathing or receive treatment for trouble breathing?	18. While your family member was in hospice care, did they ever have trouble breathing or receive treatment for trouble breathing?	Wording change	Simplified and gender-neutral language	No
22. How often did your family member get the help he or she needed for trouble breathing?	19. How often did your family member get the help they needed for trouble breathing?	Wording change	Simplified and gender-neutral language Item replaced with a single comprehensive multi-item Getting Hospice Care Training measure with a single-item measure with strong psychometric performance. Addresses stakeholder request for a shorter instrument.	No
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?		Item dropped		Yes
24. While your family member was in hospice care, did your family member ever have trouble with constipation?	20. While your family member was in hospice care, did they ever have trouble with constipation?	Wording change	Simplified and gender-neutral language	No
25. How often did your family member get the help he or she needed for trouble with constipation?	21. How often did your family member get the help they needed for trouble with constipation?	Wording change	Simplified and gender-neutral language	No

26. While your family member was in hospice care, did he or she show any feelings of anxiety or sadness?	22. While your family member was in hospice care, did they show any feelings of anxiety or sadness?	Wording change	Simplified and gender-neutral language	No
27. How often did your family member get the help he or she needed from the hospice team for feelings of anxiety or sadness?	23. How often did your family member get the help they needed from the hospice team for feelings of anxiety or sadness?	Wording change	Simplified and gender-neutral language	No
28. While your family member was in hospice care, did he or she ever become restless or agitated?		Item dropped	This item (and all other items used to calculate the existing multi-item Getting Hospice Care Training measure) dropped and replaced with a single-item Getting Hospice Care Training measure with strong psychometric performance. Addresses stakeholder request for a shorter instrument.	Yes

29. Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?

Item dropped

This item (and all other items used to calculate the existing multi-item Getting Hospice Care Training measure) dropped and replaced with a single-item Getting Hospice Care Training measure with strong psychometric performance. Addresses stakeholder request for a shorter instrument. Yes

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?

Item dropped

Dropped this item, as it is not included in scored measures. Also addresses stakeholder request for a shorter instrument. Yes

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?

Item dropped

Not included in scored measures. Also addresses stakeholder request for a shorter instrument.

Yes

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?

Item dropped

Not included in scored measures. Also addresses stakeholder request for a shorter instrument.

Yes

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?

Item dropped

Not included in scored measures. Also addresses stakeholder request for a shorter instrument.

Yes

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?

New item

Replaces existing multi-item Getting Hospice Care Training measure. Yes

35. While your family member was in hospice care, how often did the hospice team listen carefully to you?

25. While your family member was in hospice care, how often did the hospice team listen carefully to you?

No

31. Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?

26. Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?

No

<p>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?</p>	<p>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?</p>	<p>Wording change</p>	<p>Edits to item to address stakeholder requests for items addressing cultural sensitivity.</p> <p>No</p>
<p>37. While your family member was in hospice care, how much emotional support did you get from the hospice team?</p>	<p>28. While your family member was in hospice care, how much emotional support did you get from the hospice team?</p>		<p>No</p>
<p>38. In the weeks after your family member died, how much emotional support did you get from the hospice team?</p>	<p>29. In the weeks after your family member died, how much emotional support did you get from the hospice team?</p>		<p>No</p>

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.

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?

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?

Wording change

Improve readability/lower reading level

No

40. Would you recommend this hospice to your friends and family?

31. Would you recommend this hospice to your friends and family?

No

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

32. What is the highest grade or level of school that your family member completed?

No

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

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

No

43. What was your family member's race? Please choose one or more.	34. What was your family member's race? Please choose one or more.	No
44. What is your age?	35. How often was your family member treated unfairly by the hospice team because of their race or ethnicity? New item	New item to address stakeholder requests for items addressing cultural sensitivity. Yes
45. Are you male or female?	36. What is your age?	No
46. What is the highest grade or level of school that you have completed?	37. Are you male or female?	No
46. What is the highest grade or level of school that you have completed?	38. What is the highest grade or level of school that you have completed?	No
47. What language do you mainly speak at home?	39. What language do you mainly speak at home?	No