

BASELINE SURVEY

National Institute of Nursing Research (NINR)
Palliative Care: Conversations Matter Evaluation
OMB #: xxxx-xxxx Expiration Date: xx/xx/xxx

Public reporting burden for this collection of information is estimated to average 20 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **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 other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (xxxx-xxxx). Do not return the completed form to this address.

CONSENT FOR PARTICIPATION

Before you take the questionnaire today, we need to ask you to formally consent to participate. Please carefully read the following statements and check the box below acknowledging that you understand each statement and agree to participate in the two waves of the questionnaire that will be administered over the next 12 months.

- I understand that my participation is voluntary. I can choose not to answer questions and I can withdraw from the questionnaires at any point.
- I understand that all information collected in the questionnaires is secure to the extent permitted by law, and will not be disclosed to anyone but the researchers conducting this study, except as otherwise required by law. All findings will be reported in aggregate.
- I will not be asked any personally identifying information when responding to the questionnaires. My personal identity will be protected. A transcript of the questionnaires will be stored securely and will only be accessible to the research team. No one will be identified in reports resulting from these questionnaires.

NINR is authorized to conduct the following questionnaires under section 42USC 285q of U.S. Law.

If you have questions about the questionnaires or your participation, please contact Adrienne Burroughs by email at adrienne.burroughs@nih.gov or by phone at 301-496-0256.

I am at least 18 years old.

- Yes
 No

By selecting "I Accept," I acknowledge and accept the consent statement and agree to participate in both questionnaires.

- Accept
 I Do Not Accept

Please note: No survey responses are saved until you hit the "submit" button at the end of the survey. Therefore, please try to complete the survey in one sitting. If you use the "Back" button, you will lose previous answers. For open ended questions, please do not enter any personally identifying information. To read NINR's privacy policy, [click here](#).

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BASELINE SURVEY

1. Which state do you work in?

(AK)

2. Which of the following best describes your position?

- Primary care physician
- Specialist physician
- Registered nurse
- Nurse practitioner
- Clinical nurse specialist
- Other (please specify)

3. Which of the following best describes your area of specialty? (Select all that apply)

- Oncology
- Pediatrics
- Primary Care (general medicine, internist, family medicine)
- Surgery
- Other (please specify):

4. How often do you work with pediatric patients?

- Daily
- A few times a week
- Once a week
- A few times a month
- Once a month
- Less than once a month
- Never

5. What percentage of your patient base is pediatric?

- 100%
- 76-99%
- 51-75%
- 26-50%
- 1-25%
- 0%

6. Have you received special training or a certification in pediatric palliative care?

- Yes, training
- Yes, certification
- No, neither training nor certification

7. Does the setting in which you currently work offer any palliative care services for the pediatric population?

- Yes
- No
- Not sure

8. For how many years have you been caring for pediatric patients living with serious illnesses or life-limiting conditions?

- Less than 1 year
- 1-2 years
- 3-5 years
- 6-10 years
- More than 10 years
- I don't treat pediatric patients living with serious illnesses or life-limiting conditions

9. Which of the following components, if any, do you believe palliative care includes? (Select all that apply)

- Pain management
- Counseling
- Symptom management
- Spiritual support
- Social work services
- Other (please specify)
- None of these

For the rest of the survey, please think back about your experiences over the last six months.

10. With which of the following people, if any, do you typically discuss palliative care for a pediatric patient? (Select all that apply)

- Patient
- Parent or caregiver
- Sibling
- Other family member
- Registered Nurse
- Nurse Practitioner/Clinical Nurse Specialist
- Other health care practitioners
- Other members of the multi-disciplinary team (e.g., social workers, chaplain, etc.)
- Other (please specify)
- None of these

11. How prepared do you feel discussing palliative care with pediatric patients and their families?

- Extremely prepared
- Very prepared
- Somewhat prepared
- Not very prepared
- Not at all prepared

Continue

BASELINE SURVEY

12. At what stage in a pediatric patient's treatment would you initiate the palliative care conversation with patients and their families?

- Immediately after the diagnosis
- Early in the treatment process
- After a number of treatments are unsuccessful
- When no other life-prolonging treatments are available
- Other (please specify)
- Not sure

13. To what extent do you agree or disagree with each of the following statements.

| | Strongly agree | Somewhat agree | Somewhat disagree | Strongly disagree | Don't know |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| a. Palliative care is only appropriate for my pediatric patients at the end of life. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. I rarely think about palliative care when treating my pediatric patients who have a serious illness or life-limiting condition that is not necessarily terminal. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. A child's viewpoint should be included as much as that child can understand and give opinions. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d. There is no difference between pediatric palliative care and end-of-life care for children. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| e. I rarely am the one to <u>initiate</u> the conversation about palliative care with my pediatric patients and their families. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f. Pediatric palliative care can be delivered concurrently with life-prolonging care. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g. Palliative care can enhance my pediatric patients' quality of life. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

14. Which of the following, if any, do you believe are the benefits of palliative care for pediatric patients and their families? (Select all that apply)

- Builds families' trust and confidence in health care providers' recommendations for their child's treatment and care
- Helps reduce the child's pain throughout the course of the illness
- Helps improve patient's quality of life
- Helps increase overall satisfaction with care
- Provides support to patients and their families during a very difficult time
- Reduces family stress
- Helps to manage physical symptoms
- Helps to manage emotional symptoms
- Other (please specify)
- None of these

15. To what extent do you agree or disagree with each of the following statements.

| | Strongly agree | Somewhat agree | Somewhat disagree | Strongly disagree | Don't know |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| a. I have access to resources and tools to help start and manage conversations about palliative care for my pediatric patients and their families. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. I find it difficult to determine when to initiate the conversation about palliative care for my pediatric patients and their families. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. I feel equipped with the necessary information to help parents and families understand the benefits of palliative care for their child. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Thank you so much for completing this survey. Your feedback is very important to us.

If you have questions about the survey or your participation, please contact Adrienne Burroughs by email at adrienne.burroughs@nih.gov or by phone at 301-496-0256.



POST-CAMPAIGN SURVEY

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CONSENT FOR PARTICIPATION

Before you take the questionnaire today, we need to ask you to formally consent to participate. Please carefully read the following statements and check the box below acknowledging that you understand each statement and agree to participate in all three waves of the questionnaire that will be administered every four to five months over the next 9 months.

- a. I understand that my participation is voluntary. I can choose not to answer questions and I can withdraw from the questionnaires at any point.
- b. I understand that all information collected in the questionnaires is secure to the extent permitted by law, and will not be disclosed to anyone but the researchers conducting this study, except as otherwise required by law. All findings will be reported in aggregate.
- c. I will not be asked any personally identifying information when responding to the questionnaires. My personal identity will be protected. A transcript of the questionnaires will be stored securely and will only be accessible to the research team. No one will be identified in reports resulting from these questionnaires.

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If you have questions about the questionnaires or your participation, please contact Adrienne Burroughs by email at adrienne.burroughs@nih.gov or by phone at 301-496-0256.

I am at least 18 years old.

- Yes
 No

By selecting "I Accept," I acknowledge and accept the consent statement and agree to participate in all three questionnaires.

- Accept
 I Do Not Accept

Please note: No survey responses are saved until you hit the "submit" button at the end of the survey. Therefore, please try to complete the survey in one sitting. If you use the "Back" button, you will lose previous answers. For open ended questions, please do not enter any personally identifying information. To read NINR's privacy policy, [click here](#).

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POST SURVEY

1. Which of the following components, if any, do you believe palliative care includes? (Select all that apply)

- Pain management
- Counseling
- Symptom management
- Spiritual support
- Social work services
- Other (please specify)
- None of these

For the rest of the survey, please think back about your experiences over the last twelve (12) months, since the Palliative Care: Conversations Matter campaign began

2. With which of the following people, if any, do you typically discuss palliative care for a pediatric patient? (Select all that apply)

- Patient
- Parent or caregiver
- Sibling
- Other family member
- Registered Nurse
- Nurse Practitioner/Clinical Nurse Specialist
- Other health care practitioners
- Other members of the multi-disciplinary team (e.g., social workers, chaplain, etc.)
- Other (please specify)
- None of these

3. To what extent do you agree or disagree with each of the following statements.

| | Strongly agree | Somewhat agree | Somewhat disagree | Strongly disagree | Don't know |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| a. Palliative care is only appropriate for my pediatric patients at the end of life. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. I rarely think about palliative care when treating my pediatric patients who have a serious illness or life-limiting condition that is not necessarily terminal. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. A child's viewpoint should be included as much as that child can understand and give opinions. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d. There is no difference between pediatric palliative care and end-of-life care for children. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| e. I rarely am the one to <u>initiate</u> the conversation about palliative care with my pediatric patients and their families. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f. Pediatric palliative care can be delivered concurrently with life-prolonging care. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g. Palliative care can enhance my pediatric patients' quality of life. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

4. Compared to twelve (12) months ago, how prepared do you feel to discuss pediatric palliative care with your pediatric patients and their families?

- Much more prepared
- Somewhat more prepared
- Neither more prepared nor less prepared
- Somewhat less prepared
- Much less prepared

5. At what stage in a pediatric patient's treatment would you initiate the palliative care conversation with patients and their families?

- Immediately after the diagnosis
- Early in the treatment process
- After a number of treatments are unsuccessful
- When no other life-prolonging treatments are available
- Other (please specify)
- None of these

6. Which of the following, if any, do you believe are the benefits of palliative care for pediatric patients and their families? (Select all that apply)

- Builds families' trust and confidence in health care providers' recommendations for their child's treatment and care
- Helps reduce the child's pain throughout the course of the illness
- Helps improve patient's quality of life
- Helps increase overall satisfaction with care
- Provides support to patients and their families during a very difficult time
- Reduces family stress
- Helps to manage physical symptoms
- Helps to manage emotional symptoms
- Other (please specify)
- None of these

7. To what extent do you agree or disagree with each of the following statements.

| | Strongly agree | Somewhat agree | Somewhat disagree | Strongly disagree | Don't know |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| a. I have access to resources and tools to help start and manage conversations about palliative care for my pediatric patients and their families. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. I find it difficult to determine when to initiate the conversation about palliative care for my pediatric patients and their families. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c. I feel equipped with the necessary information to help parents and families understand the benefits of palliative care for their child. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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POST SURVEY

8. About which of the following topics did you learn from the campaign and its materials? (Select all that apply)

- How to initiate difficult discussions
- How to provide guidance and recommendations to pediatric patients with a serious illness or life-limiting condition and their families
- How to promote continued pediatric palliative care conversations
- How to ensure pediatric patients with a serious illness or life-limiting condition and their families' needs are understood and followed throughout treatment
- How to ensure you convey all of the necessary information/ recommendations
- Other (please specify)
- None of these

9. Since the campaign began, which components have you used in your work with pediatric patients and their families navigating a serious illness or life-limiting condition? (Select all that apply)

- Information from the video modules
- Information from the interactive worksheet/ tear-off pad
- General information you received in the workshop
- Information from other health care providers participating in the workshop
- Other (please specify)
- None of these

10. Compared to twelve (12) months ago, has the amount of time that you spend discussing palliative care with your pediatric patients and their families navigating a serious illness or life-limiting condition changed? It has...

- Significantly increased
- Somewhat increased
- No change
- Somewhat decreased
- Significantly decreased

11. Compared to twelve (12) months ago, are you initiating conversations about palliative care with your pediatric patients and their families who are navigating a serious illness or life-limiting condition earlier in the treatment process?

- Much earlier
- Somewhat earlier
- No difference
- Somewhat later
- Much later

12. How satisfied are you with the information that you received from the campaign materials?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not very satisfied
- Not at all satisfied

13. How have you used the information from the kick-off workshop and the campaign materials to treat your pediatric patients with a serious illness or life-limiting condition?

14. Since attending the kick-off workshop, which, if any, of the following have you done?

- Talked with other health care professionals about pediatric palliative care
- Talked with other health care professionals about specific content from the workshop or materials
- Recommended pediatric palliative care
- Thought about actions you would take in relation to what you heard in the workshop
- Changed the way you communicate with patients about pediatric palliative care
- Changed the way you communicate with patients' families about pediatric palliative care
- Other (please specify)
- None of these

15. Compared to twelve (12) months ago, how often have you referred or recommended your pediatric patients and their families who are navigating a serious illness or potentially life-limiting condition to palliative care specialists (e.g., physicians, nurses, psychiatrists, social workers, chaplains, etc.)?

- Much more often
- Somewhat more often
- No change
- Somewhat less often
- Much less often

16. Compared to twelve (12) months ago, are you referring or recommending your pediatric patients and their families who are navigating a serious illness or life-limiting condition to palliative care specialists (e.g., physicians, nurses, psychiatrists, social workers, chaplains, etc.) earlier in the treatment process?

- Much earlier
- Somewhat earlier
- No difference
- Somewhat later
- Much later

17. What aspects of the campaign materials did you find most beneficial? Please be as specific as possible.

18. What aspects of the campaign materials did you find least beneficial and how would you change them? Please be as specific as possible.

19. What other tools or information do you need to help you discuss palliative care with your pediatric patients and their families?

20. How likely are you to recommend the campaign materials to other health care providers in your field?

- Extremely likely
- Very likely
- Somewhat likely
- Not very likely
- Not at all likely

Thank you so much for completing this survey. Your feedback is very important to us.

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