

## Attachment 1: SURVEY – WORD VERSION

### NINR Pediatric Palliative Care Campaign Pilot Survey

#### Static information that must be in the beginning of the survey:

National Institute of Nursing Research (NINR)  
Pediatric Palliative Care Pilot Campaign Survey  
OMB #: 0925-XXXX      Expiration Date: XX/XXXX

The National Institute of Nursing Research (NINR) at the National Institutes of Health is conducting this survey to get feedback on the pediatric palliative care campaign materials used in two pilot campaign sites, so that changes to the materials can be made as needed. All pilot campaign participants are being asked to complete the survey.

Public reporting burden for this collection of information is estimated to average 30 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 (0925-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 questionnaire.

- a) I understand that my participation is voluntary. I can choose not to answer questions and I can withdraw from the questionnaire at any point.
- b) I understand that all information collected in the questionnaire 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. The purpose of the survey is to provide feedback on the campaign materials used in two pilot campaign sites. All findings will be reported in aggregate.
- c) I will not be asked any personally identifying information when responding to the questionnaire. My personal identity will be protected. A transcript of the questionnaire will be stored securely and will only be accessible to the research team. No one will be identified in reports resulting from the questionnaire.

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

If you have questions about the questionnaire or your participation, please contact Adrienne Burroughs by email at [adrienne.burroughs@nih.gov](mailto:adrienne.burroughs@nih.gov) or by phone at 301-496-0256.

I am at least 18 years old. **[REQUIRED]**

- a. Yes
- b. No

By selecting "I Accept," I acknowledge and accept the consent statement. **[REQUIRED]**

- a. Accept
- b. I Do Not Accept **[TERMINATE]**

**MAIN QUESTIONNAIRE**

**Static information:** 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. [Read NIH’s privacy policy.](#)

**A. PERCEPTIONS OF & BEHAVIORS TOWARD PEDIATRIC PALLIATIVE CARE**

**When answering the following questions, please consider your perceptions and behaviors toward pediatric palliative care prior to nine months ago, before the pilot program was initiated.**

1. **Before the pilot campaign began, which of the following components, if any, did you believe palliative care included? [SELECT ALL THAT APPLY]**
  - a. Pain management
  - b. Counseling
  - c. Symptom management
  - d. Spiritual support
  - e. Social work services
  - f. Other (please specify)
  - g. None of these [EXCLUSIVE RESPONSE]
  
2. **Before the pilot campaign began, to what extent did you agree or disagree with each of the following statements. [SELECT ONE RESPONSE FOR EACH STATEMENT]**

|  | <b>Strongly agree</b> | <b>Somewhat agree</b> | <b>Somewhat disagree</b> | <b>Strongly disagree</b> | <b>Don’t know</b> |
|--|-----------------------|-----------------------|--------------------------|--------------------------|-------------------|
| a. Health care providers need a specialty in pediatric palliative care to discuss its options with patients and their families.                                      |                       |                       |                          |                          |                   |
| b. Palliative care is only appropriate for my pediatric patients at the end of life.   |                       |                       |                          |                          |                   |
| c. I rarely thought about palliative care when treating my pediatric patients who had a serious illness or life-limiting condition that is not necessarily terminal. |                       |                       |                          |                          |                   |
| d. A child’s viewpoint should be included as much as that child can understand and give opinions.  |                       |                       |                          |                          |                   |

|   |  |  |  |  |  |
|---|--|--|--|--|--|
| e. Pediatric palliative care discussions should begin as soon as the patient is diagnosed with a serious illness or life-limiting condition.                                |  |  |  |  |  |
| f. There is no difference between pediatric palliative care and end-of-life care for children.  |  |  |  |  |  |
| g. I rarely was the one to <u>initiate</u> the conversation about palliative care with my pediatric patients and their families.  |  |  |  |  |  |
| h. Referring my pediatric patients and families for palliative care may help reduce the emotional trauma involved with having a serious illness or life-limiting condition. |  |  |  |  |  |
| i. Pediatric palliative care can be delivered concurrently with life-prolonging care.   |  |  |  |  |  |
| j. Palliative care can enhance my pediatric patients' quality of life.  |  |  |  |  |  |

3. **Before the pilot campaign began**, at what stage in a pediatric patient's treatment did you initiate a palliative care conversation with patients and their families?

**[SELECT ONE RESPONSE]**

- a. Immediately after the diagnosis
- b. Early in the treatment process
- c. After a number of treatments were unsuccessful
- d. When no other life-prolonging treatments were available
- e. Other (please specify)
- f. Not sure

4. **Before the pilot campaign began**, how often did you **refer or recommend** your pediatric patients and their families navigating a serious illness or potentially life-limiting condition to other palliative care specialists (e.g., psychiatrists, social workers, chaplains, etc.)? **[SELECT ONE RESPONSE]**

- a. Always
- b. Often
- c. Sometimes
- d. Rarely
- e. Never

**When answering the following question, please consider your perception of pediatric palliative care during the past nine months, while the pilot program was in progress.**

5. Has your understanding of “palliative care” in regard to pediatric patients changed during the pilot campaign? **[OPEN-END RESPONSE]**
- a. Yes. Please explain. \_\_\_\_\_
- b. No. Please explain. \_\_\_\_\_

**When answering the following questions, please consider your current perceptions and behaviors toward pediatric palliative care, after completion of the pilot program.**

6. **Now**, which of the following components, if any, do you believe palliative care includes? **[SELECT ALL THAT APPLY]**
- a. Pain management
- b. Counseling
- c. Symptom management
- d. Spiritual support
- e. Social work services
- f. Other (please specify)
- g. None of these **[EXCLUSIVE RESPONSE]**

7. **Now**, to what extent do you agree or disagree with each of the following statements. **[SELECT ONE RESPONSE FOR EACH STATEMENT]**

|   | <b>Strongly agree</b> | <b>Somewhat agree</b> | <b>Somewhat disagree</b> | <b>Strongly disagree</b> | <b>Don't know</b> |
|---|-----------------------|-----------------------|--------------------------|--------------------------|-------------------|
| a. Health care providers need a specialty in pediatric palliative care to discuss its options with patients and their families.                                     |                       |                       |                          |                          |                   |
| b. Palliative care is only appropriate for my pediatric patients at the end of life.  |                       |                       |                          |                          |                   |
| c. 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. |                       |                       |                          |                          |                   |
| d. A child's viewpoint should be included as much as that child can understand and give opinions.   |                       |                       |                          |                          |                   |
| e. Pediatric palliative care discussions should begin as soon as the patient is diagnosed with a serious illness or life-limiting condition.                        |                       |                       |                          |                          |                   |

|   |  |  |  |  |  |
|---|--|--|--|--|--|
| f. There is no difference between pediatric palliative care and end-of-life care for children.  |  |  |  |  |  |
| g. I rarely am the one to <u>initiate</u> the conversation about palliative care with my pediatric patients and their families.   |  |  |  |  |  |
| h. Referring my pediatric patients and families for palliative care may help reduce the emotional trauma involved with having a serious illness or life-limiting condition. |  |  |  |  |  |
| i. Pediatric palliative care can be delivered concurrently with life-prolonging care.   |  |  |  |  |  |
| j. Palliative care can enhance my pediatric patients' quality of life.  |  |  |  |  |  |

8. **Now**, at what stage in a pediatric patient's treatment do you initiate a palliative care conversation with patients and their families? **[SELECT ONE RESPONSE]**
- 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
9. **Now**, how often do you **refer or recommend** your pediatric patients and their families navigating a serious illness or potentially life-limiting condition to other palliative care specialists (e.g., psychiatrists, social workers, chaplains, etc.)? **[SELECT ONE RESPONSE]**
- Always
  - Often
  - Sometimes
  - Rarely
  - Never

## B. INFORMATION NEEDS

**When answering the following question, please consider your information needs around pediatric palliative care prior to nine months ago, before the pilot program was initiated.**

10. **Before the pilot campaign began**, to what extent did you agree or disagree with each of the following statements. **[SELECT ONE RESPONSE FOR EACH STATEMENT]**

|   | <b>Strongly agree</b> | <b>Somewhat agree</b> | <b>Somewhat disagree</b> | <b>Strongly disagree</b> | <b>Don't know</b> |
|---|-----------------------|-----------------------|--------------------------|--------------------------|-------------------|
| a. I had access to resources and tools to help start and manage conversations about palliative care for my pediatric patients and their families. |                       |                       |                          |                          |                   |
| b. I found it difficult to determine when to <u>initiate</u> the conversation about palliative care for my pediatric patients and their families. |                       |                       |                          |                          |                   |

**When answering the following question, please consider your current information needs around pediatric palliative care, after completion of the pilot campaign. [Put this question on a separate screen so that Q10 and Q11 are not on the same screen.]**

11. **Now**, to what extent do you agree or disagree with each of the following statements.  
**[SELECT ONE RESPONSE FOR EACH STATEMENT]**

|  | <b>Strongly agree</b> | <b>Somewhat agree</b> | <b>Somewhat disagree</b> | <b>Strongly disagree</b> | <b>Don't know</b> |
|--|-----------------------|-----------------------|--------------------------|--------------------------|-------------------|
| a. I have access to resources and tools to help start and manage conversations about palliative care for my pediatric patients and their families. |                       |                       |                          |                          |                   |
| b. I find it difficult to determine when to <u>initiate</u> the conversation about palliative care for my pediatric patients and their families.   |                       |                       |                          |                          |                   |

**C. PERCEPTIONS OF THE CAMPAIGN, MATERIALS, AND PILOT PROGRAM**

12. Which of the following topics did you learn over the past nine months from the pilot campaign and its materials? **[SELECT ALL THAT APPLY]**
- a. How to initiate difficult discussions
  - b. How to provide guidance and recommendations to patients and their families
  - c. How to keep palliative care conversations going
  - d. How to ensure patients and their families' needs are understood and followed throughout treatment
  - e. How to ensure you convey all of the necessary information/ recommendations
  - f. Other (please specify)
  - g. None of these [EXCLUSIVE RESPONSE]

13. **Since the pilot campaign began**, which components, if any, have you used in your day-to-day work with pediatric patients and their families navigating a serious illness or life-limiting condition? **[SELECT ALL THAT APPLY]**
- a. Information from the video modules
  - b. Information from the interactive worksheets/ tear-off pads
  - c. General information you received in the workshop
  - d. Information from other health care providers participating in the workshop
  - e. Other (please specify)
  - f. None of these **[EXCLUSIVE RESPONSE]**
14. How effective has the information presented in the campaign materials been in helping you to treat your pediatric patients living with a serious illness or life-limiting condition? **[SELECT ONE RESPONSE]**
- a. Extremely effective
  - b. Very effective
  - c. Somewhat effective
  - d. Not very effective
  - e. Not at all effective
15. How well did the campaign materials meet your information needs? **[SELECT ONE RESPONSE]**
- a. Extremely well
  - b. Very well
  - c. Somewhat well
  - d. Not very well
  - e. Not well at all
16. 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 potentially life-limiting condition? **[OPEN-END RESPONSE]**
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17. What aspects of the campaign materials did you find **most beneficial**? Please be as specific as possible. **[OPEN-END RESPONSE]**
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18. What aspects of the campaign materials did you find **least beneficial**? Please be as specific as possible. **[OPEN-END RESPONSE]**
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19. What specific aspects of the campaign materials could be changed to make them **more beneficial**? Please be as specific as possible. **[OPEN-END RESPONSE]**
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20. Is there any more information or other tools that you would need to help you discuss palliative care with your pediatric patients and their families? **[OPEN-END RESPONSE]**
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21. What types of pediatric palliative care materials do you think parents and families would like? **[OPEN-END RESPONSE]**

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22. How likely are you to recommend the campaign materials to other health care providers in your field? **[SELECT ONE RESPONSE]**
- a. Extremely likely
  - b. Very likely
  - c. Somewhat likely
  - d. Not very likely
  - e. Not at all likely

**BACKGROUND INFORMATION:**

23. Which of the following best describes your position? **[SELECT ONE RESPONSE]**
- a. Primary care physician
  - b. Specialist physician
  - c. Registered nurse
  - d. Nurse practitioner
  - e. Clinical nurse specialist
  - f. Other (please specify)

24. Which of the following best describes your area of specialty? **[SELECT ALL THAT APPLY]**
- a. Oncology
  - b. Pediatrics
  - c. Primary Care (general medicine, internist, family medicine)
  - d. Surgery
  - e. Outpatient care
  - f. Inpatient care
  - g. Other (please specify)



25. How often do you consult with **pediatric** patients? **[SELECT ONE RESPONSE]**

- a. Daily
- b. A few times a week
- c. Once a week
- d. A few times a month
- e. Once a month
- f. Less than once a month
- g. Never

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

**[SELECT ALL]**

- a. Yes, training
- b. Yes, certification
- c. No, neither training nor certification

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

If you have questions about the questionnaire or your participation, please contact Adrienne Burroughs by email at [adrienne.burroughs@nih.gov](mailto:adrienne.burroughs@nih.gov) or by phone at 301-496-0256.