

## Appendix C: Interview Script and Questions

National Institute of Nursing Research (NINR)  
Pediatric Palliative Care Materials Review Interview  
OMB #: 0925-0653 Expiration Date: 04/30/2018

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### Color Legend

**Blue: In-person interview moderator queues**

**Red: Phone interview moderator queues**

**Purple: General moderator queues (both formats)**

### Introductory Statements

Hello, my name is \_\_\_\_\_ and I will be leading our discussion today. I work for RIVA, a research firm in Rockville, MD. I am working on this project for the National Institute of Nursing Research as a consultant.

I want to thank you for participating in this interview. We know how important your time is. Our session today will take no longer than 60 minutes. Please let me know if you would like to take a break at any point.

#### **Review restroom location and other logistical information**

I will be audio recording our session so I can write an accurate report. Your responses will not be tied to your name, and none of the responses will be published in any way.

#### **Address any other applicable disclosures based on facility setup**

Before we begin, we need you to formally consent to participate in this interview.

*If in person:* Please read this form, sign both copies, and let me know if you have any questions.

#### **Present forms, providing one copy to participant after signing**

*If by phone:* I will read a consent form and ask you to provide your verbal permission for the recording.

Thank you. Before we talk about the materials for review, do you have any questions or is there anything special you need me to know?

#### **Address questions or comments as appropriate**

We appreciate your willingness to answer questions today. This project intends to help the families of children with serious illnesses understand and access palliative care. Your comments will allow us to make these materials as useful as possible to other families who may be looking for support.

## Questions Segment

If you are ready to begin the question and answer portion of the interview, let us get started. Here are some simple guidelines for our time together:

- Please be willing to provide positive and negative comments.
- There are no wrong answers. Just say what you believe.
- It is okay to say “I don’t know” or “I’m not sure” as an answer today.
- Please stop me at any time if you do not understand my question or would like to ask one.

First, we will talk about the fact sheet, *Pediatric Palliative Care At-a-Glance*, which provides basic information about palliative care for families. I will read the sheet aloud as you follow along.

### Put other two sheets aside

**Repeat title to ensure respondent is viewing correct sheet**

**Read the sheet aloud while respondent reads/views**

1. On a scale from 1 to 5, where 1 is very easy and 5 is very difficult, how easy to understand is this fact sheet?

① Very easy      ② Easy      ③ Neutral      ④ Difficult      ⑤ Very difficult

PROBE: Please explain what specifically is unclear.

2. How could this information be more useful to families?

PROBE: What could be added? How will this addition be helpful?

PROBE: What could be deleted because it is unnecessary or not helpful? What are some reasons that you see it as unnecessary or not helpful?

3. What do you think about the photos used?

PROBE: How do they enhance the content – if they do?

PROBE: How do they detract from the content – if they do?

4. In what situations would you share this resource with other families who may need palliative care?

PROBE: What would make you want to share this information?

PROBE: What would make you *not* want to share this information?

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Next, we will review the sheet, “*Pediatric Palliative Care Tips: Finding Support*,” which provides tips for finding resources. I will read the sheet aloud as you follow along.

### Put other two sheets aside

**Repeat title to ensure respondent is viewing correct sheet**

**Read the sheet aloud while respondent reads/views**

1. On a scale from 1 to 5, where 1 is very easy and 5 is very difficult, how easy to understand is this tip sheet?

- ① Very easy      ② Easy      ③ Neutral      ④ Difficult      ⑤ Very difficult

PROBE: Please explain what specifically is unclear.

2. How could this information be more useful to families?

PROBE: What could be added? How will this addition be helpful?

PROBE: What could be deleted because it is unnecessary or not helpful? What are some reasons that you see it as unnecessary or not helpful?

3. What do you think about the photos used?

PROBE: How do they enhance the content – if they do?

PROBE: How do they detract from the content – if they do?

4. In what situations would you share this resource with other families who may need palliative care?

PROBE: What would make you want to share this information?

PROBE: What would make you *not* want to share this information?

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The last piece to discuss is a collection of stories, which are actual experiences of families who volunteered to tell their stories about palliative care. I will read the sheet aloud as you follow along.

**Put other two sheets aside**

**Repeat title to ensure respondent is viewing correct sheet**

**Read the sheet aloud while respondent reads/views**

1. On a scale from 1 to 5, where 1 is very easy and 5 is very difficult, how easy to read are the stories?

- ① Very easy      ② Easy      ③ Neutral      ④ Difficult      ⑤ Very difficult

PROBE: Please explain what specifically is difficult to read or understand.

2. What do you think about the way the stories are presented visually?

PROBE: What do the visuals provide for you?

PROBE: What do you dislike about the look?

3. In what ways, if at all, do you relate to the families from these stories?

PROBE: What specific elements speak to you?

4. Imagine you are first learning about palliative care. In what ways, if any, would these stories encourage you to learn more or ask questions about palliative care?

PROBE: If these stories would not encourage you, where do they miss the mark? Could they be revised to be more encouraging? If so, how?

5. In what situations would you share this resource with other families who may need palliative care?

PROBE: What would make you want to share this information?

PROBE: What would make you *not* want to share this information?

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Now that we have reviewed all three pieces separately, I would like you to think about them as a kit of information for families, where all three pieces are provided as a set.

**Show sheets side by side**

**Ensure respondent looks at sheets in order so both parties have same view**

1. What is your overall impression of the kit?  
Finish this sentence: "The kit works because....."  
Finish this sentence: "The kit does not work because ....."
2. Thinking about all of the pieces, what is the main message or idea that stays with you?  
PROBE: What makes that theme or point stay with you?
3. Think about when you first learned of your child's illness. In what ways, if at all, would this kit have been helpful?
4. Going forward, in what ways, if any, would you use this kit?
5. In your opinion, would this kit be useful to caregivers and health providers as well, so they can offer the information to families?  
PROBE: What are some reasons you feel this kit would/would not be useful to caregivers and health providers?
6. In which of the following ways would you *most likely* share this kit with others, and why?
  - a. In person (hard copies)  
PROBE: Where might you share the hard copies?
  - b. On social media
  - c. Via email (attachments or links)
  - d. I would not be likely to share this kit with others
7. Before we wrap up, do you have any final comments or suggestions?

Thank you so much for your time today. The National Institute of Nursing Research truly appreciates your feedback on these materials. Your comments have been very helpful.

**Supply incentive or direct to reception for incentive**  
**Inform respondent that incentive will be mailed**  
**Provide contact information for any follow-up questions**