## Appendix A: Recruitment Plan and Screener

National Institute of Nursing Research (NINR)
Pediatric Palliative Care Materials Review Interview

OMB Number: 0925-0653 Expiration Date: 04/30/2018

Public reporting burden for this collection of information is estimated to average 10 minutes per screening call, including time for reviewing instructions and 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 Dr., MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0653). Do not return the completed form to this address.

RIVA Market Research, in partnership with BETAH Associates, Inc., and on behalf of the National Institute of Nursing Research, will conduct interviews to receive feedback on *Palliative Care:*Conversations Matter® campaign materials from families of children with serious illnesses. The following outlines the interview respondent recruitment process, including questions that will be used to determine and select participants.

## Interview Design

- 12 individual interviews with parents, guardians, or other adult family members
  - 6 in-person (DC/MD/VA area) respondents will be invited to an interview facility, but will also have option for home visit/interview if requested
  - o 6 by phone (elsewhere in U.S.)
- 60-minute interviews
- Timing: 2015
- Honorarium: \$40 per respondent
- Materials to be reviewed: collectively referred to as a "Family Information Kit":
  - O Fact sheet about pediatric palliative care
  - O Resource sheet with ideas for finding support
  - O Collection of family stories about palliative care experiences

## Eligibility criteria

## Participants must:

- Be a family member of child with serious illness (includes childhood cancers, genetic disorders, heart and lung conditions, neurologic disorders, and others)
  - There is no restriction around the age of the child, whether the child is living, or when the experience occurred for the family
- Live in the United States
- Be at least 18 years old
- Speak English as a first language
- Be able to read at or above an 8th-grade level (to review and provide feedback on materials)

- Based on the screener, a sample will be pulled from an existing database.
- Once a list of potential respondents is compiled, phone calls will be placed mainly in the late afternoon to ask the screener questions. If someone qualifies, they are invited to participate.
- The overall goal will be to contact a representative/balanced mix of respondents in terms of location (geographical, urban/rural), gender, and family role. However, no specific minimum or maximum numbers of demographic groups are set.

SCREENER		
Good morning/afternoon,	My name is	and I am calling from
RIVA Market Research on behalf of th	e National Institute of Nursing F	Research, part of the National
Institutes of Health. We are looking fo	or family members of children w	vith serious illnesses to provide
feedback on materials related to pallia	ative care for families. Eligible p	participants will provide comments
on the materials during a one-hour in	terview this September, and wi	ll receive a \$40 Visa gift card for
participating. This screener call will ta	ke 10 minutes or less.	

2. Please tell me your age.

Under 18	Disqualify
□ 18-29	
□ 30-39	
<b>40-49</b>	Continue
□ 50-64	
☐ 66 or over	

1. <Do not read> Record gender: ☐ Male ☐ Female

3. What is your first language?

English	Continue
Spanish	
French	Disgualify
Chinese	Disqualify
Other	

4. What is the highest level of education you have completed?

Less than a high school diploma	Disqualify
☐ High School	
☐ Associate degree/some college	Continue
☐ Bachelor's degree	
☐ Graduate school	

5. Are you or have you ever been the parent or family member of a child with a serious illness?

Yes	Continue
No	Disqualify

6. Please describe your relationship to the child.

☐ Parent/guardian	
☐ Sibling	
☐ Grandparent	Continue
☐ Aunt/uncle	
□ Other:	

7.	What type of illness or condition was diagnosed? (Screener will be provided a list of illnesses for each
	category to help with classification.)

☐ Cancer	
☐ Genetic disorder	
☐ Neurological disorder	Continue
☐ Heart or lung condition	
☐ Cognitive or cerebral condition	
☐ Other	

8. How old was the child when you first learned of the illness?

☐ <1 year old	
☐ 1-4 years	
☐ 5-9 years	Continue
☐ 10-14 years	
☐ 15-17 years	

- 9. Please tell me your zip code. (Screener will use a recruitment area tool, like <a href="http://www.eurekafacts.com/recruitment-area.html">http://www.eurekafacts.com/recruitment-area.html</a>, to determine eligibility for in-person interview)
- 10. Are you available September <date> at <time> to participate in a <phone/in-person> interview at <location, if applicable>?

If selected to participate: I would like to send you a confirmation letter with more detail. Can you please provide a phone number and email address (or mailing address, if phone interview or no email address) where you prefer to be reached?

Thank you so much for your time today. We will be in touch with you soon.