Appendix A: Focus group screener and consent

National Institute of Nursing Research (NINR)Pediatric Palliative Care Focus Groups ScreenerOMB #: 0925-0653Expiration Date: 03/31/2015

Public reporting burden for this collection of information is estimated to average 10 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 (0925-0653). Do not return the completed form to this address.

Overview

Ogilvy Public Relations and Stratalys Research, on behalf of the National Institute of Nursing Research (NINR), is advancing two national online focus groups to collect information on the attitudes, preferences, and experiences of NINR stakeholders relating to future communication materials. The following document provides an overview of the focus group design as well as the screening criteria and questions that will be used to recruit health care provider (HCPs) audiences.

Focus Group Design

- Two national online focus groups
 - o Participants will include physicians; nurses; and social workers who treat pediatric patients living with a serious illness or life-limiting condition
- 10-12 participants in each group
- 90 minute session to be held in May 2012

Screening criteria:

- Must be a physician, nurse, or social worker
- Must spend some of their workday in a hospital
- Must consult with patients and/or their families
- Physicians and nurses must treat or consult with pediatric patients living with a serious illness or life-limiting condition
- Social workers who work or consult with pediatric patients living with a serious illness or life-limiting condition

Identification and selection of potential respondents:

- A convenience sample will be used.
- Potential focus group participants will be identified through national online research using search engines such as Google. Only publically available contact information (that is posted on their employer's website) will be used for outreach to potential participants.
- The online research will use the screening criteria described above to identify potential respondents.
- Ogilvy Public Relations will reach out to a geographically diverse range of potential respondents.
- The overall goal will be to contact an equal mix of physicians, nurses, and social workers.
- All contact information will be pulled from the website of each potential participant's employer.
- The screener will be administered online and respondents will receive login information via email. If
 no publically available email address is found, potential participants will be contacted via phone to
 gauge interest before being enrolled in the online screener.

<u>Screener</u>

(INTRO)

We would like to invite you to participate in an online group discussion. To express our appreciation for assisting us with your insights, we will offer a participant honorarium paid to you via check if you qualify and complete the 90 minute online session. Participation in this screener will take 10 minutes or less.

[TYPE: Static Text]

1.) (DEMOGRAPHICS SPECIALTY) First, which of the following best describes your position? [TYPE: Multiple Choice]

1:	Primary care physician
2:	Specialist physician
3:	Registered nurse
4:	Nurse practitioner
5:	Clinical nurse specialist
6:	Social worker
7:	Other (please specify) - [TERMINATE, IF SCREENING CRITERIA IS NOT MET]

2.) (DEMOGRAPHICS PERCENTAGE OF TIME SPENT IN HOSPITAL) What percentage of your workday is spent in a hospital? [TYPE: Multiple Choice]

1:	100%
2:	76% - 99%
3:	51% - 75%
4:	26% - 50%
5:	1% - 25%
6:	0% - [TERMINATE]

3.) (DEMOGRAPHICS TIME SPENT CONSULTING WITH PATIENTS) How often do you consult with patients or their families? [TYPE: Multiple Choice]

1:	Daily
2:	A few times a week
3:	Once a week
4:	A few times a month
5:	Once a month
6:	Less than once a month
7:	Never - [TERMINATE]

4.) (DEMOGRAPHICS PERCENTAGE OF PATIENT BASE THAT IS PEDIATRIC) What percentage of your patient base is pediatric? [TYPE: Multiple Choice]

1:	100%
2:	76% - 99%
3:	51% - 75%
4:	26% - 50%
5:	1% - 25%
6:	0% - [TERMINATE]

5.) (DEMOGRAPHICS NUMBER OF YEARS SPENT WORKING WITH PEDIATRIC PATIENTS) How long have you been working with pediatric patients? [TYPE: Multiple Choice]

1:	5 years or less	
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	6-10 years
3:	11-15 years
4:	16-20 years
5:	21-25 years
6:	26-30 years
7:	More than 30 years

[ASK PHYSICIANS/ NURSES ONLY]

6.) How often do you consult on pediatric patients who are living with a serious illness or life-limiting condition? [TYPE: Multiple Choice]

1:	Daily
2:	A few times a week
3:	Once a week
4:	A few times a month
5:	Once a month
6:	Less than once a month
7:	Never - [TERMINATE]

[ASK SOCIAL WORKERS ONLY]

7.) What percentage of the pediatric patients that you work with are living with a serious illness or lifelimiting condition? [TYPE: Multiple Choice]

1:	100%
2:	76% - 99%
3:	51% - 75%
4:	26% - 50%
5:	1% - 25%
6:	0% - [TERMINATE]

8.) Have you received any special training or a certification in pediatric palliative care? [TYPE: Multiple Choice]

1:	Yes
2:	No
3:	Not sure

9.) (First recruit) Would you be available to participate in an online focus group on **one** of the days/times listed below? The group session will last for approximately 90 minutes. You will receive a \$40 honorarium for participating for the entire 90 minute session. [TYPE: Multiple Choice]

Yes, I would like to participate on [INSERT DATE] from 8-9:30pm EASTERN (7-8:30 CENTRAL; 6-7:30 MOUNTAIN; 5-6:30 PACIFIC) or on [INSERT DATE] from 8-9:30pm EASTERN (7-8:30 CENTRAL; 6-7:30 MOUNTAIN; 5-6:30

PACIFIC).2: No, I would not like to participate. [TERMINATE]

10.) (CONNECTION CHECK) What type of Internet connection do you currently have at home? [TYPE: Multiple Choice]

1: Dial-up connection [TERMINATE]

2: Broadband connection (e.g., cable, DSL, Fios, etc.)

(SESSION1) Congratulations! You have agreed to participate in an online focus group session on ...

[INSERT DATE] from 8-9:30pm EASTERN 7-8:30 CENTRAL; 6-7:30 MOUNTAIN; 5-6:30 PACIFIC

- Prior to the session, you will receive an email confirmation from 'Stratalys Research' with a link and instructions for logging into the group.
- You may log in up to 20 minutes before the start time of the session. You will not be allowed into the session if you log in late.
- You will not need any special hardware to join the online focus group.
- <u>NOTE</u>: Please make sure you can devote the entire 90 minutes to the session. You must complete the entire session in order to receive your honorarium. Also, please try to ensure that you are able to focus on the session by eliminating any distractions.

11.) CONSENT FOR PARTICIPATION

As a next step, we need to ask you to formally consent to participate in the focus group. Please carefully read the following statements and check the box below acknowledging that you understand each statement and agree to participate in the focus group.

- a) I understand that my participation is voluntary. I can choose not to answer questions and I can withdraw from the focus group at any point during the session.
- b) I understand that all information collected in this focus group is private under the Privacy Act, 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 during the focus group. My personal identity will be protected. A transcript of the focus group will be stored securely and will only be accessible to the research team. No one will be identified in reports resulting from this focus group.

NINR is authorized to conduct this focus group under section 42USC 285q of U.S. Law.

If you have questions about this focus group or your participation, please contact Christina Beckerman by email at christina.beckerman@ogilvy.com or by phone at (202) 729-4261.

I am at least 18 years old.

1:	Yes
2:	No

By checking this box, I acknowledge and accept the consent statement and agree to participate in this focus group.

1: Accept

2: I Do Not Accept [TERMINATE]

To complete your registration for the online focus group, we would like you to answer a few more background questions ... [TYPE: Static Text]

12.) (DEMOGRAPHICS GENDER) Gender. [TYPE: Multiple Choice]

1:	Male
2:	Female
3:	Do not wish to respond

[ASK PHYSICIANS ONLY]

13.) (DEMOGRAPHICS YEARS PRACTICING MEDICINE) How long have you been practicing medicine? [TYPE: Multiple Choice]

1:	5 years or less
2:	6-10 years
3:	11-15 years
4:	16-20 years
5:	21-25 years
6:	26-30 years
7:	More than 30 years

[ASK NURSES ONLY]

14.) (DEMOGRAPHICS YEARS PRACTICING NURSING) How long have you been working in the field of nursing? [TYPE: Multiple Choice]

1:	5 years or less
2:	6-10 years
3:	11-15 years
4:	16-20 years
5:	21-25 years
6:	26-30 years
7:	More than 30 years

[ASK SOCIAL WORKERS ONLY]

15.) (DEMOGRAPHICS YEARS WORKING IN FIELD) How long have you been working in the field of social work? [TYPE: Multiple Choice]

1:	5 years or less
2:	6-10 years
3:	11-15 years
4:	16-20 years
5:	21-25 years
6:	26-30 years
7:	More than 30 years

16.) (DEMOGRAPHICS STATE) In what state do you currently work? [TYPE: Multiple Choice]

2: Alaska 3: Arizona 4: Arkansas 5: California 6: Colorado 7: Connecticut 8: Delaware 9: District of Columbia 10: Florida 11: Georgia 12: Hawaii 13: Idaho 14: Illinois 15: Indiana 16: Iowa 17: Kansas 18: Kentucky 19: Louisiana 20: Maine 21: Maryland 22: Massachusetts 23: Michigan 24: Minnesota 25: Mississippi 26: Missouri 27: Montana 28: Nebraska 29: Nevada 30: New Hampshire 31: New Jersey 32: New Mexico 33: New York 34: North C	1:	Alabama
 4: Arkansas 5: California 6: Colorado 7: Connecticut 8: Delaware 9: District of Columbia 10: Florida 11: Georgia 12: Hawaii 13: Idaho 14: Illinois 15: Indiana 16: Iowa 17: Kansas 18: Kentucky 19: Louisiana 20: Maine 21: Maryland 22: Massachusetts 23: Michigan 24: Minnesota 25: Mississippi 26: Missouri 27: Montana 28: Nebraska 29: Nevada 30: New Hampshire 31: New Jersey 32: New York 34: North Carolina 	2:	Alaska
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9:District of Columbia10:Florida11:Georgia12:Hawaii13:Idaho14:Illinois15:Indiana16:Iowa17:Kansas18:Kentucky19:Louisiana20:Maine21:Maryland22:Massachusetts23:Michigan24:Minnesota25:Misissispipi26:Missouri27:Montana28:Nebraska29:Nevada30:New Hampshire31:New Jersey32:New Mexico33:New York34:North Carolina	7:	Connecticut
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11:Georgia12:Hawaii13:Idaho14:Illinois15:Indiana16:Iowa17:Kansas18:Kentucky19:Louisiana20:Maine21:Maryland22:Massachusetts23:Michigan24:Minnesota25:Mississippi26:Missouri27:Montana28:Nebraska29:Nevada30:New Hampshire31:New Jersey32:New Mexico33:New York34:North Carolina	9:	District of Columbia
 12: Hawaii 13: Idaho 14: Illinois 15: Indiana 16: Iowa 17: Kansas 18: Kentucky 19: Louisiana 20: Maine 21: Maryland 22: Massachusetts 23: Michigan 24: Minnesota 25: Mississippi 26: Missouri 27: Montana 28: Nebraska 29: Nevada 30: New Hampshire 31: New Jersey 32: New York 34: North Carolina 	10:	Florida
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 20: Maine 21: Maryland 22: Massachusetts 23: Michigan 24: Minnesota 25: Mississippi 26: Missouri 27: Montana 28: Nebraska 29: Nevada 30: New Hampshire 31: New Jersey 32: New Mexico 33: New York 34: North Carolina 	18:	Kentucky
 21: Maryland 22: Massachusetts 23: Michigan 24: Minnesota 25: Mississippi 26: Missouri 27: Montana 28: Nebraska 29: Nevada 30: New Hampshire 31: New Jersey 32: New Mexico 33: New York 34: North Carolina 	19:	Louisiana
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 23: Michigan 24: Minnesota 25: Mississippi 26: Missouri 27: Montana 28: Nebraska 29: Nevada 30: New Hampshire 31: New Jersey 32: New Mexico 33: New York 34: North Carolina 	21:	Maryland
 24: Minnesota 25: Mississippi 26: Missouri 27: Montana 28: Nebraska 29: Nevada 30: New Hampshire 31: New Jersey 32: New Mexico 33: New York 34: North Carolina 	22:	Massachusetts
 25: Mississippi 26: Missouri 27: Montana 28: Nebraska 29: Nevada 30: New Hampshire 31: New Jersey 32: New Mexico 33: New York 34: North Carolina 	23:	Michigan
 26: Missouri 27: Montana 28: Nebraska 29: Nevada 30: New Hampshire 31: New Jersey 32: New Mexico 33: New York 34: North Carolina 	24:	Minnesota
 27: Montana 28: Nebraska 29: Nevada 30: New Hampshire 31: New Jersey 32: New Mexico 33: New York 34: North Carolina 	25:	Mississippi
 28: Nebraska 29: Nevada 30: New Hampshire 31: New Jersey 32: New Mexico 33: New York 34: North Carolina 	26:	Missouri
 29: Nevada 30: New Hampshire 31: New Jersey 32: New Mexico 33: New York 34: North Carolina 	27:	Montana
 30: New Hampshire 31: New Jersey 32: New Mexico 33: New York 34: North Carolina 	28:	Nebraska
 31: New Jersey 32: New Mexico 33: New York 34: North Carolina 	29:	Nevada
32: New Mexico33: New York34: North Carolina	30:	New Hampshire
33: New York 34: North Carolina	31:	New Jersey
34: North Carolina	32:	New Mexico
35: North Dakota		
	35:	North Dakota

36:	Ohio
37:	Oklahoma
38:	Oregon
39:	Pennsylvania
40:	Rhode Island
41:	South Carolina
42:	South Dakota
43:	Tennessee
44:	Texas
45:	Utah
46:	Vermont
47:	Virginia
48:	Washington
49:	West Virginia
50:	Wisconsin
51:	Wyoming
52:	Do not wish to respond

19.) (DEMOGRAPHICS EMAIL) Please enter a <u>business</u> email address in the box below so that we can send you your login information for the group session. We will ONLY use your email to send you this one additional message with your login information. Your email will NOT be used for ANY OTHER PURPOSES. Please make sure to not use a personal email address such as yahoo or gmail. Check your email address carefully to make sure you typed it correctly! [TYPE: Open-ended]

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