Appendix C: Focus group moderator guide

National Institute of Nursing Research (NINR)
Pediatric Palliative Care Focus Group
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Public reporting burden for this collection of information is estimated to average 90 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
Like traditional focus groups, online sessions run approximately 90 minutes and include a mix of question types to ensure an engaged session. Generally, a moderator will spend the following amount of time garnering feedback on each type of question: closed-end questions – 1 minute; open-end questions – 3 minutes; grid questions – 1-3 minutes; discussion room – 5-30 minutes. These time estimates are merely a guide and depending on the actual length of the group, all of the questions outlined in the guide may not be used.

Ogilvy will provide the sample for the online focus group session and will ensure respondent anonymity. This information will not be shared with other offices or agencies.

The moderator will begin with a 'Welcome/Directions' section and then a couple warm-up questions that cover general information related to the aim of the focus group.

The following provides distinctions for types of questions and terminology used throughout this document:

- **Media:** Static informational text or image that is not part of a question.

- **Open-end, Closed-end, Grid, Matrix questions:** Responses are seen only by the moderator/client – not other participants.

- **The Discussion Room chat questions:** Are more akin to a typical focus group conversation, with the responses viewed by all participants.

- **Probe questions:** As with any focus group, probe questions will only be used if more information is needed on a topic. The possible probe questions are listed in this moderator's guide to give examples of questions that may be asked, depending on the information that the focus group respondents give.

Note: The research vendor cannot currently accommodate split sample designs, skip patterns, or randomized questions (although it can randomize answer choices and stimuli).

MODERATOR'S GUIDE

Introduction
 [MEDIA]

Welcome (1 MIN)

Welcome to this group session. Today we will be discussing pediatric palliative care.

First, a few words about what will happen during this session. You are currently connected online to me (the Moderator) and numerous other participants. Over the next 90 minutes, you will respond to the questions you see appear on the right-side of your browser window. Please answer these questions openly and honestly. Your answers to these questions are anonymous and will not be seen by other participants.

Occasionally, you may find yourself waiting briefly as others finish their answer. Please be patient for the next question should you finish answering before others - the next question will always appear shortly.

At any time during the session, the Moderator may begin an instant messaging chat discussion. You should respond to the Moderator's questions as the discussion proceeds. Note that for these chats, you will also be able to see other participants' comments and respond to them. Please be courteous and polite.

All information disclosed during the focus group meeting will be kept private under the Privacy Act and none of the information discussed during the open chats will be shared with any other individual or organization outside of the purpose of this focus group.

We greatly appreciate your participation and you will receive a $40 honorarium for taking the time to contribute your opinions tonight. However, you must answer all of the questions throughout the session until the Moderator finishes the session, or you will not receive your honorarium.

As I mentioned, today we will be discussing pediatric palliative care. Palliative care is comprehensive treatment of the discomfort, symptoms and stress of serious illness with the goal to prevent and ease suffering and improve the patient's quality of life. It is available to patients of any age and at any stage of an illness, and in the pediatric setting, it is tailored to meet the needs of this unique patient population being treated for a serious illness or life-limiting condition.

If you encounter any technical difficulties while participating in this focus group, please send an email to support@stratalys.com.

[CLOSED-ENDED] If you are ready to get started, please select 'Yes" below and then click the Submit button...
 * Yes, let's get started! [Note - Only a "yes" answer is available because this prompt is used only to indicate to the moderator that all participants are on the same page and ready to begin.]

Setting the Stage –Palliative Care Perspectives

Q1. [OPEN] What does the term "palliative care" mean to you?

Q2. [CLOSED-END] How comfortable are you initiating conversations about palliative care with pediatric patients and their families?

- Very comfortable
- Somewhat comfortable
- Not very comfortable
- Not at all comfortable

[MEDIA] Ok, I'm going to open a chat discussion so that we can talk as a group and respond to each other's comments. The chat discussion window will appear on the right side of your screen.

You should pay careful attention to the Moderator's questions that will appear in red text. You will enter your own comments in the box at the bottom of the screen and add them to the discussion by clicking the Send button.

Q3. [DISCUSSION ROOM] What is most concerning to you when it comes to discussing palliative care with pediatric patients and their families?
- [PROBE] What barriers specifically prevent you from discussing palliative care with your pediatric patients and their families? [PROBE ON: TIME CONSTRAINTS, LACK OF KNOWLEDGE]
- [PROBE] What additional resources would be helpful to have when discussing palliative care with pediatric patients and their families?

Pilot Program Description

[MEDIA] I'd like to have you read the following description about a potential pilot program. After you read the description, please answer the questions that follow.

[SHOW PILOT PROGRAM DESCRIPTION]

A pilot program is being launched to directly address barriers that might prevent health care professionals from recommending palliative care for pediatric patient populations. The pilot program aims to assist health care professionals in initiating and facilitating ongoing conversations about palliative care with parents and families of pediatric patients living with a serious illness or life-limiting condition. The pilot program may offer various resources/tools that could assist health care professionals. An overview of the importance of palliative care, instruction on how to use the materials, and enhance communications skills will be provided during the pilot program.

Q4. [CLOSED-END] How beneficial do you believe this pilot program would be for people like you?
- Very beneficial
- Somewhat beneficial
- Not very beneficial
- Not at all beneficial

Q5. [DISCUSSION ROOM] What are your first impressions of this pilot program? What about it stands out to you?
- [PROBE] How do you believe you would use the information from this pilot program to care for your seriously ill pediatric patients?

Video Module Evaluation

[MEDIA] I am now going to show you a few materials that are in development for the pilot program. The first is a description of a series of videos that are under development. We will show illustrations of two video vignettes and a description of a third video. Please review and then answer the questions that follow.

[SHOW VIDEO DESCRIPTION AND SAMPLE STORYBOARDS WITH MODERATOR READING THE SCRIPTS]

Q6. [GRID] Please indicate how much you agree or disagree with each of the following statements about this message.
[scale strongly agree, somewhat agree, somewhat disagree, strongly disagree]
- I learned something new after seeing the teaching modules
- I would be likely to try the examples provided in the teaching modules
- I would share the information presented in the teaching modules with my colleagues

Q7. [CLOSED-END] How beneficial do you believe this video would be for people like you?
- Very beneficial
- Somewhat beneficial
- Not very beneficial
- Not at all beneficial

Q8. [DISCUSSION ROOM] How would you sum up in just a few words your first impression of this tool? Do you like it? Not like it? Why?
- [PROBE] How do you feel about:
    o ... the tone of the video?
    o ... the language used in the video?
    o ... the format of this information?

Q9. [DISCUSSION ROOM] Let's discuss this a bit more. How realistic were the examples in the teaching modules?
- [PROBE] What makes it difficult to carry out the recommendations outlined in the teaching modules?
- [PROBE] Do you see yourself using this... or something like it in the future? Why? Why not?
- [PROBE] Which actions, if any, are you likely to implement? Why? Why not?
- [PROBE] What could be changed to make it more effective?

Q10. [DISCUSSION ROOM] Thinking back to the information the pilot program is trying to convey, is there anything else you would add?

Interactive Worksheet/Tear-off Pad Evaluation

[MEDIA] Please review the following document description and then answer the questions that follow.

[SHOW INTERACTIVE WORKSHEET/ TEAR-OFF PAD]

Q11. [GRID] Please indicate how much you agree or disagree with each of the following statements about this message.
[scale strongly agree, somewhat agree, somewhat disagree, strongly disagree]
- I learned something new after reading it
- I would be likely to try the exercises outlined
- I would share the information in the document with my colleagues

Q12. [CLOSED-END] How beneficial do you believe this document would be for people like you?
- Very beneficial
- Somewhat beneficial
- Not very beneficial
- Not at all beneficial

Q13. [DISCUSSION ROOM] How would you sum up in just a few words your first impression of this tool? Do you like it? Not like it? What makes you say that?
- [PROBE] How do you feel about:
  - ... the tone of the document?
  - ... the language used in the document?
  - ... the format in which the information was presented?

Q14. [DISCUSSION ROOM] Let's discuss this a bit more. Do you disagree with any of the recommendations provided in the worksheet? If so, which ones and why?
- [PROBE] Do you see yourself using this... or something like it in the future? Why? Why not?
- [PROBE] Which actions, if any, are you likely to implement? Why? Why not?
- [PROBE] What could be changed to make it more effective?
- [PROBE] What makes it difficult to carry out the recommendations outlined in the worksheet?

Q15. [DISCUSSION ROOM] Thinking back to the information the pilot program is trying to convey, do you feel like anything is missing? What additional topics would you want covered in the worksheet?

Campaign Name Evaluation

[MEDIA] Now, I am going to show you a couple of potential names that are being considered for the pilot program and a subsequent communications campaign that may follow. Please review and then answer the questions that follow.

[SHOW CAMPAIGN NAMES – randomized]

Palliative Care: Conversations Matter

Palliative Care: Choices for Children

Q16. [MATRIX] Now that you've seen the potential campaign names, which name...?

- Most catches your attention
- Is most compelling to you
- Best fits the pilot program description you read earlier
  - **Palliative Care: Conversations Matter**

- **Palliative Care: Choices for Children**

[MEDIA] Now, I am going to show you a couple of potential taglines that are being considered for the campaign. Please review and then answer the questions that follow.

[SHOW CAMPAIGN TAGS – randomized]

Easing symptoms and enhancing lives.
Discussing options and enhancing lives.

Q17. [MATRIX] Which Tag...?

- Most catches your attention
- Is most compelling to you
- Best fits the pilot program description you read earlier
- *Easing symptoms and enhancing lives.*
- *Discussing options and enhancing lives.*

Q18. [DISCUSSION ROOM] Let's discuss these names as a group. We'll start by discussing the name [INSERT MOST ATTENTION-GETTING CAMPAIGN NAME AND TAG FROM Q16 and 17]. What about this particular combination is most engaging? If you did NOT find this engaging, what specifically was less engaging about it? [REPEAT WITH NEXT NAME AND TAG CHOSEN]

Logo Design Evaluation

[MEDIA] Now, I am going to show you a couple of potential logos for the pilot program (that have combined the names and tags) and potential communications campaign. Please review and then answer the questions that follow.

[SHOW logo designs, make sure they are clearly marked a VS. b. VS. c. VS. d. first individual and randomized, then side by side]

Q19. [CLOSED-END] Now that you've seen the potential logos, which one catches your attention the most? [randomize]
- Logo A
- Logo B
- Logo C
- Logo D

Q20. [DISCUSSION] Let's discuss [insert top response from Q19].
- [PROBE] What about it is especially attention-getting or appealing?
- [PROBE] What do you like or dislike about the graphics of this logo?

Now, let's discuss [INSERT NEXT LOGO] (repeat as needed for all options)
- [PROBE] What about it is especially attention-getting or appealing?
- [PROBE] What do you like or dislike about the graphics of this logo?

Q21. [DISCUSSION] Thinking back to the information the pilot program is trying to convey, what additional information or tools would you need to help you talk about palliative care to pediatric patients and their families?

- Is there anything else you would add that you think could enhance the pilot program?

Close

Thank you so much for your participation. This has been extremely helpful to us. You may close your browser now.