

**Five Mini Focus Groups With
Adults 50 Years of Age and Older**

MODERATOR'S GUIDE

90 Minutes

Fall 2021

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BACKGROUND [< 5 minutes]

- Welcome. Thank you for your participation.
- My name is xxx. **(After stating their name, the moderator should state that he or she is not an employee of the National Institute on Aging or the federal government, and that he or she is an independent researcher.)**
- My role is to facilitate this discussion and end on time at x:xx a.m./p.m.
- During today's discussion you will receive a copy of an Advance Care Planning Guide that we would like to get your feedback on.

**MODERATOR: CONFIRM THAT PARTICIPANTS RECEIVED THE
CONVERSATION GUIDE VIA EMAIL.**

Here is some guidance for our conversation:

- Please talk one at a time.
- Please talk in a voice at least as loud as mine.
- Please mute your line when you are not speaking to reduce background noise.
- I need to hear all of your opinions; for example, everyone should have more or less equal "airtime."
- There are no right or wrong answers. That said, if someone disagrees with what someone else says, please speak up. We respect all opinions.
- This discussion is private — first names only. No names will be used in the summary report.
- Your participation is voluntary. You are free to decline to answer a question or leave this discussion at any time.
- I did not have anything to do with the development of the material we are going to review. If you have constructive criticism, I will not be offended or penalized.
- Please be honest.

- This discussion is not intended to test your knowledge of what you read in the material. Rather, it is to test how well the brochure communicated what it is intending to say.
- Our time together is limited — please don't be offended if I have to interrupt you to turn to the next question. There is simply a lot to cover, and we have to finish on time.
- We would like to audio-record this discussion so that when it comes time to write the summary report, we will have the “raw” data to turn to, as needed. Does anyone object to our audio-recording this focus group discussion? **[Dismiss participant(s) if so.]**
- Project staff, including a notetaker, are on the line listening to today's discussion.

PARTICIPANT INTRODUCTIONS [< 5 minutes]

When I call your first name, please let us know:

1. Your city and state.
2. If you had heard the term “advance care planning” or “advance directive” before being contacted for this focus group.

REACTIONS TO MATERIAL [75-80 total minutes]

MODERATOR: ASK THE QUESTIONS BELOW. IF SOMETHING ISN'T COVERED IN ONE DISCUSSION, IT CAN BE ADDRESSED IN ANOTHER DISCUSSION. THIS GUIDE IS NOT INTENDED AS ONE IN WHICH EVERY SINGLE QUESTION MUST BE POSED.

We're now going to go through several sections of the document the recruiter emailed to you. Please make sure you have the document open to reference.

CONTENT PART 1: What is advance care planning? [20 minutes]

Let's start on the page that reads, “Chapter 1: What is advance care planning?” Please take 5 minutes to read this chapter through “Why do I need advance care planning” on your own. You may read quietly or aloud to yourself; however, please ensure you are on mute. Please feel free to highlight or bold anything that is confusing to you or that you have questions about.

At the beginning of this chapter, there is a personal story.

1. How helpful is it to have this personal story included in the chapter?
 - a. What, if anything, would you change about this story/real-life example?
2. Are there any questions you would want answered before reading more?
3. After reading this chapter, please define “advance directive” in your own words?
4. Was there anything you found confusing or difficult to understand in this section?

- a. What suggestions do you have for how to make this information easier to understand?

CONTENT PART 2: How do I start advance care planning? [10 minutes]

In Chapter 2, there is a tool that can help you think through what you value, what matters most, and what makes your life meaningful. Reflecting on your values is a first step in advance care planning.

Let's look at the tool on **page 9** titled, "Think about what matters most in life."

5. How likely are you to use this tool for yourself?
6. What, if anything, would you change about this tool to improve it?

CONTENT PART 3: Tips for talking with your doctor about advance care planning? [15 minutes]

Onto the next section titled, "Tips for talking with your doctor about advance care planning" on **page 16**.

7. After reading this section, would you be comfortable talking to your doctor about advance care planning?
 - a. If not, what else would want to do or know before talking to your doctor?
8. This chapter also includes a "Before your visit" worksheet and tips for talking with your doctor about advance care planning. How helpful are these tips?
 - a. How likely are you to use them?
9. What do you think about the conversation starters?
 - a. Were there any you really liked? What did you like about them?
 - b. Were there any you did not like? Why?

CONTENT PART 4: How do I choose a health care proxy? [10 minutes]

Let's look at **page 19**. There is a section titled, "What is a health care proxy and what decisions can they make?" Read until you reach "Whom should I choose as my healthcare proxy."

10. Was there anything you found confusing or difficult to understand in this section?
 - a. What suggestions do you have for how to make these words or concepts easier to understand?

Next, turn to **page 21**. Take a look at the worksheet provided titled, "Who should I choose as my health care proxy?"

11. How likely would you be to use this worksheet to help determine who to choose as your health care proxy?
12. After reading this, would you be ready to choose a health care proxy? If not, what else would you want to know before choosing one?

CONTENT PART 5: How to make your plans official? [10 minutes]

Moving on, we will now look at, “Chapter 5: How to make your plans official” on page 24. Please take a moment to read the first paragraph, box, and steps to advance care planning.

13. What do you think of the information in the blue box?
14. What, if anything, is unclear about these steps?
 - a. What questions do you have about the steps to advance care planning?
 - b. How likely are you to follow these steps?

OVERALL IMPRESSIONS [10 minutes]

Now let’s talk about the content or text we reviewed, in *general* terms.

15. After reading the information, who do you think this conversation guide is for? That is, who is the ideal “target audience” for this conversation guide?
16. What are your overall reactions to what you read?
17. In big picture/very broad terms, what did you especially like about what you read?
18. In big picture/very broad terms, what did you especially dislike about what you read?
19. How could the authors of this document make the information *more* relevant to you?
20. What would you title this document? Explain your response.
21. How should NIA consider getting the word out about this material?

CONCLUSION [1 minute]

Would anyone like to share anything further before we conclude?

Thank you for your time. The National Institute on Aging greatly appreciates your feedback.