

NCCAM Focus Group Discussion Guide

Audience: Consumers

Focus groups to be held in person

- *GROUP 1: FEMALE AGE 18-44*
- *GROUP 2: FEMALE AGE 45+*
- *GROUP 3: MALE AGE 18+*

Introduction (10 Minutes)

Good evening and thank you for joining our discussion this evening. My name is [INSERT NAME] and I'll be the group moderator for the evening. Before we get started I'd like to let you know that this study is being conducted on behalf of the National Institutes of Health (NIH). Please note that an agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it has a current valid OMB control number. The OMB control number for this study is 0925-0530. This discussion is voluntary. We will not collect any personal information that would allow anyone to identify you. Any information you do provide will be kept private to the fullest extent of the law.

Has anyone in the room participated in a focus group before? Great, for those of you who have, welcome back, and for those of you who haven't before, my hope is that you'll have an enjoyable discussion. I want to notify you of some information and cover some ground rules before we begin to be sure that we have a smooth discussion this evening.

First, you'll notice a few microphones in the room, as well as the one-way mirror behind me. Tonight's discussion will be video and audio taped so that I can refer back to the tapes as I summarize our discussion this evening. This allows me to pay attention to our discussion without having to take notes. I also have some colleagues behind the mirror that will be taking some notes as well. We are only using your first names this evening, and won't collect any other personally identifiable information.

Next, to ensure the discussion is comfortable for everyone I want to cover some ground rules:

- Please talk one at a time so that we can all pay attention to the conversation
- Please talk in a voice as loud as mine so that everyone can hear
- Avoid side conversations. We want to include everyone in the discussion and listen to everyone's opinions, so please avoid any side conversations.
- I'd like everyone to participate, so let's aim for equal air time. I may ask some follow-up questions to ensure I understand some opinions.
- Be respectful of other's opinions. We may all agree on certain things, and we may disagree on others, but I want to hear and respect all of your opinions.
- Be sure that your cell phones are turned off, and put them away for the next 2 hours.
- If you need to use the restroom or get some refreshments, please feel free to step out briefly, but please only one person be out of the room at a time so we can continue the discussion.

Public reporting burden for this collection of information is estimated to average 2 hours per focus group, 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 (0925-0530). Do not return the completed form to this address.

Finally, I'd like everyone around the table to introduce themselves. Please tell me your name, a little bit about yourself, and tell me about how you primarily get information about health care options available to you. Let's start on my left, go around the table, and then I'll finish the circle.

Terminology (15 Minutes)

- When it comes to dealing with a disease or condition, or just working towards a better sense of health and wellness, people use many different approaches. Aside from conventional medicine, what are some health care practices you've personally used? [MODERATOR TO RECORD RESPONSES ON FLIP CHART]
 - o What other health or wellness practices have you heard of?
 - PROBE: Herbal medicines (also known as botanicals), vitamins, minerals, probiotics, meditation, yoga, acupuncture, massage/spinal manipulation, homeopathy, naturopathy, traditional healing, traditional Chinese medicine, Ayurvedic medicine
 - o What are the reasons you choose to use these health and wellness practices?
 - PROBE: Relieve symptoms? Reduce pain? Lose weight? Manage stress? Avoid side-effects from drugs? Others?
 - o What have your experiences been with these types of health and wellness practices?
 - Have they been positive?
 - Are they effective for you?
 - In your opinion, are they effective alternatives to conventional medicine, are they good additions to conventional medicine, or do you rely more on conventional medicine?
 - We've talked about a number of health and wellness practices, and there are probably others that some people might categorize along with these, such as [MODERATOR MENTIONS PRACTICES NOT YET DISCUSSED] herbal medicines (also known as botanicals), vitamins, minerals, probiotics, meditation, yoga, acupuncture, massage/spinal manipulation, homeopathy, naturopathy, traditional healing, traditional Chinese medicine and Ayurvedic medicine. When you think of these types of health care practices, how would you categorize them as a group of practices? For example, modern medicine today, including pharmaceuticals and physician visits is called 'conventional medicine'. What would you call these?
 - o What terms do you hear others use?
 - o What is your preferred term?
 - o What do you think is used most commonly?
 - o Is a combination of these terms better than one term alone?
 - Which ones?
- [ROTATE INTEGRATIVE HEALTH, COMPLEMENTARY MEDICINE OR THERAPIES AND ALTERNATIVE MEDICINE]
- What is your initial impression of the term "integrative health"?
 - o What health practices do you think are included in integrative health?
 - o Is integrative health a neutral, positive or negative term?
 - o Do you associate this with anything else?
 - What about the idea of different health care professionals working together as a team -- like doctors, nurses, physical therapists, dieticians, etc. -- to improve patient health?

- o Do you think integrative health and integrative medicine are the same thing, or different things?
- What is your initial impression of the term “complementary medicine”?
 - o What health practices are included in complementary medicine?
 - o Is complementary medicine a neutral, positive or negative term?
 - o Do you think complementary medicine is the same or different from integrative health/integrative medicine?
- What is your initial impression of the term “alternative medicine”?
 - o What health practices are included in alternative medicine?
 - o Is alternative medicine a neutral, positive or negative term?
 - o Do you think alternative medicine is the same or different from the other terms we’ve spoken about?
- Thinking about the health care practices we’ve been speaking about, do you think one of these terms is better at describing them?
 - o Which one?
 - o For what reasons do you think it’s better?
 - o Do you think some of these terms could be combined, for example calling this ‘complementary and integrative health’?
 - Are there benefits to combining these?
 - If you heard this term, would it be clear to you what type of health practices we’re talking about?

Judging Credibility (15 Minutes)

- By a show of hands, how many of you search for health and wellness information online?
- What factors contribute to whether you feel the health and wellness information that you find online is credible?
 - o What types of sources do you feel are credible?
 - Does information about clinical trials make it more credible?
 - Do you find information more credible if a doctor wrote it?
 - o Do you discuss the information later with your doctor?
 - o Do you discuss the information later with your friends or family?
- If no:
 - o Why not?
 - Possible factors to discuss:
 - Feelings that the information is unreliable or less reliable than one’s doctor
 - Difficulty finding relevant information
 - Difficulty understanding the information provided
 - Barriers to access: lack of time or a reliable Internet connection
- Do you look for information about alternative or complementary health and wellness practices, like the ones we spoke about earlier?
 - o If yes:
 - What prompted you to seek the information?
 - Do you use the same sources you would use for conventional health care information, or are there other sources you use?
 - What sources do you use?
 - How do you judge how reliable the information is?
 - What do you look for?
 - Do you typically find what you are looking for?
 - How do you use the information?
 - Do you discuss it with your doctor?
 - Do you try or decide not to try a treatment method discussed?

- Do you advise someone else whether or not to use a treatment method?
- o If no:
 - Have you ever been interested in seeking this type of information?
 - If yes: Why didn't you look for the information?

Information Products (45 Minutes)

[ROTATE COLD AND FLU INFORMATION WITH SPINAL MANIPULATION INFORMATION]

- When you're experiencing [a cold or flu/back pain], what things do you do to try and cure it quickly?

- o Do you take conventional medicines, either prescription or OTC?
- o Do you do other things to help make you feel better?
 - What kinds of things?
 - [COLD AND FLU: Vitamins, diet, supplements, other things?]
 - [BACK PAIN: Lying down, stretching, pain relievers, other things?]
 - Where do you learn about these things?
 - How do you determine if these things are effective or not?
 - Do you try to find information about them before you use them?
- o If you were looking up information on these other things you can do to help treat [a cold or flu/back pain], what type of information would be important to you?

[MODERATOR USES FOLLOWING QUESTIONS TO PROMPT DISCUSSION, IF "YES" ONLY ANSWERS, SEEK EXPLANATION]

- Would you want to see different treatment options?
- Would you want to see information about clinical studies relating to those treatment options?
- Would you want the source of the information to make a recommendation about whether you should use each treatment method?
- Would you want the source of the information to highlight the safety of the treatment?
- Would you want tips about how to discuss each treatment with your doctor?
- Would you want the source of information to suggest different places to find each treatment?
- Would you want to see what consumers and/or health care providers think about the treatment methods?
- I want to pass around a packet of information about [cold and flu/back pain] treatment options and get your reactions to it.

[MODERATOR TO PASS AROUND APPROPRIATE FACT SHEET]

Please briefly browse through this packet and then we'll discuss it as a group.

- o What are your initial reactions to this information?
- o Do you think this information is credible?
- o Overall, do you think this is something you would read if you came across it when looking up information?
 - Why or why not?
 - Is it too long or short?
 - IF TOO LONG: What would you recommend removing?
 - IF TOO SHORT: What needs to be added?
 - Is it organized in a way that helps you understand it?
 - Is it useful to you?
 - What information is most useful?
 - Least useful?
 - Is there information that doesn't need to be here?
 - Is there information that is missing?
 - Is all of the language used here language you understand?
 - Are there specific terms that you don't understand?
 - Is the information here evidence-based?
 - Is this science-based information?

- Do you think this information is balanced?
- Overall, is this the information you would be looking for about complementary or alternative treatments for [a cold or flu/back pain]?
- After reading this fact sheet, are there other things you would do if you had [a cold or flu/back pain]?
 - Would you discuss the treatment with your doctor?
 - Would you discuss the treatment with friends or family?
 - Would you use the treatment?
 - Would you seek more information about the treatment?
 - Would you recommend the treatment to someone?
- o Do you think that the fact sheet is recommending using a specific treatment, advising against the treatment, or just providing you with information so you can make your own decision?
 - What language in the fact sheet led you to that conclusion?
 - Were there other things that made you feel this way?
- I want to pass around another packet of information about [cold or flu/back pain] and get your reactions to it. Please take a few minutes again and browse through this one briefly. [MODERATOR TO HAND OUT OTHER FACT SHEET]
- What are your initial reactions to this information?
 - o Are these reactions different than your initial reactions to the previous information?
 - Why or why not?
 - What's different about this one?
 - Are your expectations different based on the topic being covered?
 - How so?
 - o Overall do you think this is information you would read if you came across it when looking up information?
 - Why or why not?
 - o Do you think this information is credible?

NCCAM Messaging (25 Minutes)

- Looking again at these fact sheets, is anyone aware of who NCCAM is?
 - o [IF YES] Please tell me a little about what you know of them.
 - o Based on the information you've seen on this sheet, what is your opinion of NCCAM?
- I'm going to pass around some information about NCCAM and have you review it. In front of you are 2 highlighters, one blue and one orange. As you read through this information about NCCAM, please use the blue highlighter to mark any words or phrases that make you feel positive about the organization and the work they do. Please use the orange highlighter to mark any words or phrases that make you feel negative about NCCAM. We'll talk about this information as a group once finished.

The National Center for Complementary and Alternative Medicine (NCCAM) is a part of the National Institutes of Health and is the Federal Government's lead agency for scientific research on the diverse medical and health care systems, practices, and products whose origins come from outside mainstream medicine. With nearly 40 percent of Americans using some form of integrative health approaches, it is critical for consumers, patients, and health care professionals to have credible information about the safety and efficacy of these practices. NCCAM fills a critical need by funding research around the most pressing questions about the safety and efficacy of integrative health approaches. NCCAM is focusing on important, relevant research in the areas of integrative health that hold the most promise and that are amenable to scientific investigation. In developing its research priorities, NCCAM looks at several questions: Are many people using it? Is it promising? Can it be scientifically studied? Are there safety questions? Can the research change health practices? NCCAM answers questions that matter most to consumers,

patients and health care professionals, and makes research findings available so you can use them to inform health care decision-making.

- What are your initial reactions to this information?
 - o Overall does it make you feel positive or negative?
 - For what reasons?
 - o What's the most positive part of this messaging for you?
 - For what reason?
 - o What's the most negative part?
 - For what reason?
 - o After reading this information, do you have any questions about who NCCAM is?
 - What questions do you have?
 - What other information would you like to be a part of this?
 - o Does this seem like a credible organization to provide the information you reviewed earlier?
 - Why or why not?
 - Are there other organizations that you think would be more credible providing this information?
 - Which organizations?
- How important do you think it is to study health practices that come from outside mainstream or conventional medicine?
 - o PROBE: What makes you say that?
 - o What aspects should be studied?
 - Is it important to study how safe the practice is compared to other treatments?
 - Is it important to study how effective the practice is compared to other treatments?
 - Is it important to study how these practices contribute to overall wellness?
 - Is it important to study who is using these practices and why?
 - Which is most important? Which is least important?
 - o Would you find this information useful?
 - o How important is this information to your health decisions?

Conclusion (5 Minutes)

- Is there anything else you'd like to share, or anything we've discussed that you'd like to add to, before we finish?

Thank and close