

**SAMPLE
NCCAM Patient Focus Group**

Moderator's Guide

Objectives of these focus groups are to:

- Among patients who have communicated with conventional physicians about their CAM use, gain insights into when and how they discuss CAM with physicians, particularly primary care providers, and what facilitates or hinders such communication
- Among patients who have not communicated with conventional care providers about their CAM use:
 - o Gain insights into what hinders such communication and what might facilitate it
 - o Explore reactions to message concepts to gain insight into what types of message appeals and content are most likely to gain attention, resonate with, and persuade CAM users to discuss CAM use with their conventional care providers

I. Introduction and Purpose (5 minutes)

Good evening. My name is _____ and I will be facilitating our discussion tonight. Can everyone hear me clearly? Thank you for taking the time to join us. As a reminder, our discussion tonight is about complementary and alternative medicine.

A. Taping & Observers

This call is being audio taped, and some of my colleagues who are working on this project are listening in. We will prepare a report on tonight's discussion; however, your individual comments remain confidential and none of you will be identified by name in the report.

B. Introduce Topic, Participants

Let's introduce everyone on the line, so we all know who is here. When I call your first name -- USE FIRST NAMES -- please tell us if there is some other name you prefer to be called, and the city and state where you're located.

[CALL NAMES]

II. Describe Process (5 minutes)

Some tips for getting the most out of the session:

1. When you have something to say, jump right in, don't wait to be called on. I can't see you raising your hand.
2. This is hard to get used to, but it makes the session work better for everyone: Every time you speak, please say your first name in the first sentence, so people can respond to you.

3. My role is to guide our discussion by asking some questions, and keep us on track to end on time. As you know, we are planning on the discussion taking about 90 minutes.
4. Your role is to speak to the topics raised based on your own opinion or viewpoint. We want to know what everyone thinks. There aren't any right or wrong answers, and we're interested in what you know AND what you don't know. Feel free to agree with someone else, let us know if your opinion is different, or expand on what people say.
5. Hopefully you're all sitting somewhere private, where you won't be interrupted and none of us will be distracted with background noise, like barking dogs, televisions, cell phones or people talking.
6. Please try to stay with us during the discussion, and don't take other calls. But if you must, we'll ignore the clicks. Get back ASAP. Then please interrupt us if you can't figure out what we're talking about. Better to have you back participating.
7. Any questions?

III. Definitions of CAM and its role in their healthcare (20 minutes)

1. (BRIEFLY) Let's start off with the first thing that comes to mind when you hear the phrase "complementary and alternative medicine" (POLL EACH PARTICIPANT.)

During our discussion, I may refer to complementary and alternative medicine as "CAM."

So that we're all on the same page, when we talk about complementary and alternative medicine in this discussion, we're including a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. What is considered to be CAM changes continually, as those therapies that are proven to be safe and effective become adopted into conventional health care and as new approaches to health care emerge.

Complementary medicine is used together with conventional medicine. For example, using [aromatherapy](#) to help lessen a patient's discomfort following surgery.

Alternative medicine is used in place of conventional medicine, such as using a special diet to treat cancer instead of undergoing surgery, radiation, or chemotherapy.

Major types of complementary and alternative medicine:

1. Alternative Medical Systems, such as [homeopathic medicine](#), [naturopathic medicine](#), [traditional Chinese medicine](#) and [Ayurveda](#).
2. Mind-Body Interventions, such as meditation, prayer, mental healing, and therapies that use creative outlets such as art, music, or dance.
3. Biologically Based Therapies substances found in nature, such as herbs, foods, and vitamins. This category includes [dietary supplements](#).
4. Manipulative and Body-Based Methods, such as [chiropractic](#) or [osteopathic manipulation](#) and [massage](#).
5. Energy Therapies, including biofield therapies such as [qi gong](#) ("chee-GUNG"), [Reiki](#), and [Therapeutic Touch](#), and bioelectromagnetic-based therapies which involve the unconventional use of [electromagnetic fields](#), such as pulsed fields, magnetic fields, or alternating-current or direct-current fields.

2. What types of doctors do you most frequently visit? (primary care, cardiologist, etc.)

3. What types of complementary and alternative medicine have you used, and how have you used them—for general wellness, to treat a specific illness or condition, etc? Did you use NAME OF CAM as a *complementary* treatment—e.g., in conjunction with some conventional treatment, or as an *alternative* treatment—e.g., instead of conventional treatment.
4. In your own healthcare, what is the role of conventional medicine and complementary and alternative options? (EXPOUND IF NECESSARY: Different people use and think of complementary and alternative healthcare differently. Some rely solely on alternative therapies, some try alternatives first and then turn to conventional medicine if they don't work, some mostly rely on conventional therapies but may try an alternative if they think conventional therapy isn't working, some use alternative and conventional approaches together)
5. What has appealed to you about the complementary or alternative treatments you have used or want to try? What do they offer that conventional medicine does not? (PROBE: ease of accessing treatment, comfort/discomfort, feelings of safety, cost, control, provider involvement)
6. What does conventional medicine offer that CAM does not? (PROBE: ease of accessing treatment, comfort/discomfort, feelings of safety, cost, control, provider involvement)

IV. Disclosure and Discussions of CAM use with HCPs (20 minutes)

1. What do you perceive are your conventional healthcare provider(s)' attitudes toward using complementary or alternative medicines or treatments? In what way, if any, do attitudes vary by type of complementary or alternative approach? By type of use (e.g., general wellness vs. for specific conditions)?
2. Under what circumstances do you communicate to your conventional medical providers any CAM you may be using or may have used? Are you asked about CAM use on health history forms? What types of CAM? Who, if anyone, verbally asks you about CAM use? The nurse at the beginning of office visits? The doctor/NP/PA? Does the provider ask you to bring in all of your medications, including prescription, OTC, and supplements?
3. (ALL) How important do you think it is to let your doctor know you are using a complementary or alternative medical approach? To discuss it with him or her?
4. (FOR GROUPS WHO HAVE DISCUSSED CAM USE WITH PROVIDERS) Under what circumstances do you *discuss* CAM with your healthcare provider?
 - a. Who initiates the conversation? You or the provider? With which healthcare provider do you discuss CAM use (physician, nurse, nurse practitioner)?
 - b. What is the context of the conversation?(Does the doctor ask you generally what you are doing for general wellness or to address a specific condition? Or ask you about specific supplements or other CAM treatments? What, specifically, do you discuss? Whether or not to use a specific form of CAM? Side effects? Interactions with conventional treatments? Whether you think it is working or not?)
 - c. Does your doctor or other healthcare provider routinely ask about complementary and alternative medicine at all visits? If not, under what circumstances?

- d. What types of complementary or alternative approaches do you most often discuss with your physician? Which ones are *you* most comfortable discussing? Least? Which ones are your *providers* most comfortable discussing? Least?
 - e. Has your doctor or other healthcare provider referred you to other providers for CAM treatments or provided any CAM treatments directly? What type?
 - f. Have you ever taken information on complementary and alternative medicine that you found on the internet, in a magazine or through another source to your physician? What kind of information? Study results? Advertisements? Magazine or newspaper articles? How did your doctor react?
5. How important do you think your doctors think it is to discuss any complementary or alternative medical approaches you may be using?
 - a. What do you think your doctors want to know? (Do they want to know about all types of CAM or only certain types? Which types?)
 6. What do you/would you expect from your physician when discussing complementary or alternative approaches that you might be using or considering (general advice, referrals to practitioners, discussions of side effects or interactions with conventional treatment, referrals to websites or a toll free number or clearinghouses)?
 7. What do you see as the benefits of disclosing or discussing your use of complementary and alternative medicine with your conventional medical doctors? What are the drawbacks?
 8. What are the benefits of *not* disclosing/discussing your use of complementary or alternative approaches with conventional medical providers? The drawbacks?
 9. What specifically might keep you from discussing a complementary or alternative medicine or approach that you were using or considering? (PROBE: didn't know you should, don't think of it, lack of time, belief that provider won't be interested, not being asked)
 10. What might prompt you to discuss a complementary or alternative medicine or treatment with a healthcare provider? (HCP asks, more time, specific illness, concern about side effects.) What could healthcare providers do to encourage you to *discuss* CAM use?

V. Sources of Additional Information (5-10 minutes)

1. If you want additional information about a CAM therapy, where and how do you or would you get it? (- word of mouth, Mass media, websites—which ones?, etc.)
2. Have you ever gone to the websites of the National Institutes of Health or the National Center for Complementary and Alternative Medicine? MedlinePlus?
3. What additional information would you like to know about CAM?
4. In what form would you like to receive the information? (Web site, brochure in doctor's office, newsletter delivered to your email or home, etc.)

VI. Reactions to message concepts (20 minutes)

[INSTRUCT PARTICIPANTS TO OPEN HANDOUT]

Let's say you're reading an article or watching the news one day and you come across one of these statements.

Please look over these statements and select the one that would be MOST likely to convince you to talk to your doctor about a complementary or alternative approach that you are using or considering, and the one that would be LEAST likely. Circle the MOST likely and cross out the LEAST likely. The first one says . . .

[READ EACH FROM HANDOUT #1]

1. [GIVE PARTICIPANTS A FEW MINUTES, THEN POLL EACH AND RECORD MOST AND LEAST LIKELY.]
2. [REPEAT FOR EACH MESSAGE]
 - a. What came to mind when you heard or read [REPEAT MESSAGE]?
 - b. How believable was this message? [PROBE: What would make it more believable?]
 - c. What concerns did you have about it, if any?
 - d. After hearing or seeing this message, how likely would you be to talk to your doctor about a complementary or alternative treatment you are using or considering? [PROBE: What makes you say that?]
 - e. What made this message the one MOST likely to get you to talk to your doctor about CAM?
 - f. What made this message the one LEAST likely?
 - g. What would improve this message? What could be deleted? Added?

VII. Closing (5 minutes)

1. I've asked all of the questions I have for the night. You've been very helpful. Does anyone want to add anything else before we close?
2. On behalf of the National Institutes of Health, I'd like to thank you all for joining us tonight. Your comments have been very helpful to us in learning more about how patients and healthcare providers can better communicate about complementary and alternative medicine.
3. You should be getting a more substantial thank-you in the mail in a week or so.