

Script for consumer focus group [topic development]

Topic of focus group: [TOPIC]

Intended audience: [consumer / caregiver]

Location: [enter location]

Date of focus group: [enter date]

Objective of assessment: To understand consumers' experiences with and decisions for [CONDITION, TREATMENT]

Materials:

- Informed consent forms (2 copies per participant)
- Files and laptop for note taker
- Stationary (flipchart, markers, pens)
- Audiorecording

Obtain informed consent

As participants arrive, have them read and sign the informed consent form. Give each person an unsigned copy of the form to keep.

For consumer focus group (60-120 minutes total)

The time suggestions are estimates and may not be followed exactly.

Introduction

(5 minutes)

Time in minutes for each section	Topic	Elapsed time at end of section
10	Set up / informed consent	10
5	Introduction (welcome; background, ground rules)	15
10	Warm-up (introductions)	25
20	1: Experience with [CONDITION]	45
10	2: Decision making	55
15	3: Important factors	70
10	4: Information seeking	80
15	5: Materials and dissemination	95
20	6: Use of evidence in decision making	115
5	Closing	120

1. Welcome

- Hello. My name is {FIRST NAME} and I'm the moderator for today's discussion. This is [NAME], who will be helping me during the discussion today by taking notes.
- I work for the [ORGANIZATION NAME]

2. Background and Disclosures

- Our discussion today is part of a research project sponsored by the Eisenberg Center at Baylor College of Medicine in Texas.
- The Eisenberg Center is funded by the Agency for Healthcare Research and Quality, or AHRQ, a federal government agency. The Eisenberg Center organizes research results into information summaries that are useful to patients, physicians, and others.
- We are here today to get your ideas about what information may be helpful to people making decisions about treating [CONDITION]. The Eisenberg Center wants to make sure that the information they present is easy to understand and useful for people making these decisions. That's why we are talking with people like you who have first-hand experience with [CONDITION].
- We will be video and audio taping today's session so that we can make sure we capture all of your comments. We are not doing this for the purpose of identifying who said what—instead, we're interested in making sure that we know what you said.
- When we write our report, no one's name will be used.

3. Go over ground rules.

Now, I'd like to go over some ground rules for our discussion today.

[REFER TO FLIP CHART #1 – POST IN ROOM]

- Our discussion will last until XX PM. We won't be taking any formal breaks, but at any time during the group you may get up to go to the restroom [DESCRIBE LOCATION] or to get something to eat or drink. The only thing that I ask is that there's only one person out of the room or moving around at a time.
- There are no wrong answers to any of the questions—I'm interested in hearing your true opinions.
- The goal of today's discussion is to have everyone participate. However, not everyone has to answer every single question that I ask.
- Because I want to hear everyone's opinions, please make sure that you are sharing the time with other people. Although not everyone has to answer every single question, I want to hear from all of you, so make sure that you're giving everyone the chance and the time to share their opinions.

- Since we're recording, it's very important for us to have only one person speaking at a time. So please take turns—let's give everyone a chance to share their opinions.
- We have a lot to talk about today, so there may be times when I need to move the discussion along. Please understand that when I ask that we move to a new topic or speaker, I don't mean to be rude.
- If you have a cell phone or a pager, please make sure to set it to "vibrate."
- Any questions about the guidelines?

Warm-up

(10 minutes)

Let's start with brief introductions. We'll go around the table. When you introduce yourself, please tell us [REFER TO FLIP CHART #2]:

- Your first name
- The city or town where you live
- How long you have had [CONDITION, INJURY] / How long you have taken [MEDICINE]

1: Experience with [CONDITION]

(20 minutes)

Thank you. I would like to talk about your experiences with your [CONDITION].

Experience with treatments

- What parts of your life do you feel have been most affected by your [CONDITION]?
 - o How did your [CONDITION] affect your everyday life?
- What kinds of things have you done for your [CONDITION]?
 - o Would you consider this treatment for your [CONDITION]? Why or why not?
 - o [GET TALLY FOR EACH TYPE OF "TREATMENT" – TREATMENT TYPES]
 - o When did you do this / have the treatment?
 - o Has anyone had more than one kind of treatment?
 - o What has worked well?
 - o What has not worked well?

Effectiveness

- On a scale of 0 to 10, where 0 is "does not work at all" and 10 is "works extremely well," how well do you think what you are doing works for [CONDITION]? Go ahead and write down your number on the paper in front of you.
 - o What number did you write down?

- o What are your reasons for choosing [number]?
- o What would it take to get a 10?
- o What would it take to get a 3?

Side Effects

- Has anyone’s family member had side effects with their treatments? Tell me about it.
- How do you get information about the possible side effects of these treatments?

Other Concerns

- What other questions and concerns, if any, do you have about the treatments your family member is currently doing?
 - o Outcomes such as XXX?
 - o Drug interactions?
 - o Food interactions?
 - o Cost?
 - o Insurance?

2: Decision making

(10 minutes)

Thank you for sharing that information. Now, let’s talk about the process for deciding what treatment to get for your [CONDITION].

- How did you decide what to do for your [CONDITION]?
 - o What factors did you think about?
 - PROBE FOR:
 - Benefits
 - Side effects
 - Cost
 - Alternative treatments considered
 - Quality of life aspects
 - o Did you talk to anybody about what you were deciding to do? If so, who? What did they say?
 - PROBE FOR:
 - Friends
 - Family

- What health care providers did you talk to about your [CONDITION]? [PROBE FOR: physicians, nurses, SPECIALIST TYPES, other]
- What did you discuss with your doctor or other clinicians as you decided which treatment to get? How would you characterize these conversations?
 - o What did the doctor tell you about the different treatment options?
 - o Did you ask questions about the injury or treatments? If so, what questions did you ask your doctor?
 - Were there any questions that you had that you didn't ask your doctor?
 - o What did you think about the doctor's advice and recommendations?
 - o How did the information or advice you received from friends or family affect your discussions with your doctor? How did it affect your decisions to get treatment and which treatment to get?
 - o Knowing what you know now, what would you do the same? What would you do differently?

3: Important factors

(15 minutes)

Now I'd like you to think about the following situation.

Let's imagine that you have a good friend who has been told by a doctor that she has a [CONDITION]. Her doctor has told her that she will need to get treatment for her [CONDITION].

Your friend has an appointment with her doctor next week to talk about choosing the best treatment for her. She wants your advice about what things she should consider.

- What would you tell your friend?
IF NEEDED: What kinds of things should she consider when she is thinking about choosing a treatment for her [CONDITION]?

WRITE ANSWERS ON FLIP CHART #3.

SPECIFIC PROMPTS FOR THE MODERATOR IN CASE BRAINSTORMING FAILS:

- COST
- INSURANCE COVERAGE
- SIDE EFFECTS / PROBLEMS
- SAFETY
- RECOVERY TIME
- HOW WELL THE TREATMENT WORKS / USEFULNESS
- INTERACTIONS
- LONG TERM CONSIDERATIONS

IF ITEMS RELATED TO SAFETY AND EFFECTIVENESS (SIDE EFFECTS, PROBLEMS, INTERACTIONS, USEFULNESS) ARE NOT MENTIONED DURING THE BRAINSTORM:

- I noticed no one mentioned [ISSUE]? Is this something she should consider? Why or why not?

4: Information seeking

(10 minutes)

You have generated a great list of things to consider when deciding how to treat a [CONDITION]. Let's talk about where you might get information about the things on this list.

- Has anyone ever looked for information about the things on this list?
 - For those that have looked, what kind of information did you look for?
 - Were you able to find information? IF YES:
 - Where did you get the information?
 - How useful was it?
 - What role, if any, did the information play in your decision about treatment choices?
 - For those that haven't look for information, where would you go to get information?
 - Have you looked for information like this for other health issues? IF YES, why didn't you look for information this time?
 - Is there anything on this list that you would not look for information about?
 - I'd like to talk more about any written information or pictures that you looked at about [CONDITION] or treatment options. What kinds of written information or pictures have you looked at?
 - How did you get these materials?
 - What did you like about how the information was presented?
 - How could the information be improved?
 - Did anyone use the Internet to exchange information with others who have similar health issues? If so, what kind of information did you share?
 - How did that help you in making decisions about your treatment?
 - Were there any other ways that exchanging information over the Internet helped you? If so, what were they?

5: Materials and dissemination

(15 minutes)

Imagine someone is putting together information about different treatment options for people with [CONDITION]. This information might be presented in a brochure or some other document.

- What should be in this brochure about treatment options related to [CONDITION]? What kinds of things would you want to know?
- What things would be most important to talk about?
 - If you had to choose one thing that was most important to include in the brochure, what would it be?
- What sources of information would be most important?
 - What information from medical studies?
 - Patients' stories or point of views?
 - From different types of health care providers?
- Of the things on this list, which ones are most important to include in the brochure? For what reasons?
- What information do you think would help you understand whether a treatment might help or harm you?
- Is there anything on this list that does not need to be included in the brochure? How come?
- What sources of information would be most important?
 - Do you want to hear about results of medical studies? What information about medical studies would be important to include?
 - What about patients' stories or points of view?
- Is there any other information that should be included in the brochure?

Dissemination

Let's say that the brochure has been made.

- What do you think would be the best way to make information like this available to you? How about your family? What about other people?
 - What about at your doctor's office? Would you read something like this in the waiting room? Would you want to talk about this brochure during a visit?
 - How likely would you be to go on the Internet to get his booklet or computer program?
- What would make you more likely to read the brochure?
- What would help you feel confident that the information in the brochure is accurate? Would you want to know anything about where the information in the brochure comes from? What would you want to know?
- What sources do you trust the most to provide health information like this?
- What sources are the least trustworthy?

6: Use of evidence in decision making

(20 minutes)

Now, I'd like to talk a bit about medical evidence.

- What do you think of when I say the term “medical evidence”? What does that mean to you? Can you give me an example of medical evidence related to [CONDITION]?
- What do you think of when I say “research study”? What does that mean to you? Is it the same or different from medical evidence? How so?

Thank you for your responses.

For our next questions, I want to make sure we are all talking about medical evidence in the same way. To find out what types of care work best, doctors and others do scientific studies or research studies of patient care. The results from these research studies are called medical evidence. Each patient is different, but medical evidence can show whether some types of health care can get better results than others for patients with certain conditions.

Now, let's imagine that you read the results from a single research study that said a specific treatment, or treatment A, worked well to help people with [CONDITION] improve [outcome of interest].

- How would you use this information? What would you do with it? Who would you talk to about it?
- What would you consider working well? What would that mean to you?
- What would you want to know about the research study to be able to trust the information? What would make you confident that the information is accurate?

Sometimes, researchers combine the results of many different research studies to compare how well different treatments work for the same condition. This is called a research synthesis or a systematic review.

- Have you heard of these terms? What do you think of them?

We just discussed the results from a single research study that showed treatment A worked well to improve [outcome of interest]. Let's say researchers looked at many studies related to [outcome of interest] among people with [CONDITION] in a research synthesis or systematic review.

When the researchers compared the research study for treatment A to other studies, they found that the study was not as strong as other studies in looking at the effectiveness of treatment A. In other words, the researchers found that the single study about treatment A was not a high quality study.

Based on the results of **all** the research studies they looked at, the researchers concluded that the medical evidence did not support the effectiveness of treatment A in improving [outcome of interest] for people with [CONDITION].

- How would you react to this information?
 - o What would help you feel confident that these results are accurate?

- o Would you want to know anything about where the research information comes from? What would you want to know?
- How do you use information from research studies or systematic reviews, if at all, in making a decision about treatments for [CONDITION]?
 - o IF SO, how do you like to get this information? From your doctor, a brochure, online, or somewhere else?

Closing

(5 minutes)

Those are all the questions I have today. Before we go, does anyone have any final comments on anything that we've talked about today?

Thank you very much for your time and participation today.