

Focus Group Moderator's Guide

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Notice of Privacy Practices (NPPs)

Moderator's Note

Greet participants as they arrive. Ask them to take a seat and make themselves comfortable. Also make sure that everyone has name tents (first names only on both sides).

Important: *Remind sites to administer the consent forms and participant questionnaire ahead of time.*

I. Introduction (10 Minutes)

Introduction of Moderator and Notetaker

Welcome, and thank you for coming today. My name is **[moderator's first name]** and this is **[notetaker's first name]**. We are from Kleimann Communication Group, an independent consulting firm in Washington, DC. Before we get started, I want you to know that I will be reading from a script. We are talking with a number of people today and we want to say the same thing in the same way to everyone.

Today, we are going to ask for your opinions and comments about health and medical Notices of Privacy Practices (NPPs). This testing is part of a major project initiated by the Office of the National Coordinator for Health Information Technology (ONC) at the Department of Health and Human Services to improve the customer experience and understanding. We're here because we believe we can learn a great deal from you.

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0955-0002. The time required to complete this information collection is estimated to average 90 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: U.S. Department of Health & Human Services, OS/OCIO/PRA, 200 Independence Ave., S.W., Suite 336-E, Washington D.C. 20201, Attention: PRA Reports Clearance Officer

I will be moderating today's session and my colleague will be taking notes to help us accurately collect your comments. We will be audio-taping this session to ensure that we collect complete information. The entire session will take about 90 minutes. If you need to go to the restroom at any time during the session, please feel free to do so. The restrooms are located _____.

Privacy

I have a few questions to ask you about the paperwork you filled out when you arrived. Can you please answer either yes or no to each of the questions that I will ask you? (If participant nods or shakes head, ask him or her to say the answer out loud for our tape.)

- Did you fill out a questionnaire when you arrived today?
- Were you given consent forms to participate in this session and for us to audiotape and videotape your session today?
- Did you read and sign those forms?
- Did you give permission for both audiotape and videotape? (If did not give permission for video, say, "One of my colleagues in back will make sure that the video is off. ")

NOTE TO MODERATOR: Do not proceed with the session unless the participant answers "yes" to each of the first three questions. (Participant must agree to audio but video is optional). Do you have any questions?

All of the information we collect today will be kept private to the extent permitted by law, and we will not identify you by name when we compile our results. In addition, we will not use your full name, address, or any other personal identifying information other than your image in reports, papers, or videos based on this research. I want to remind you that you may end the interview at any time.

Instructions

- We are very interested in what you have to say during our time together today. However, sometimes, I may interrupt the discussion to make sure that we cover everything on our agenda.
- We're going to use several guidelines during this session:
- First, it's okay **not** to respond to every question I ask. You may not have a comment on every topic, but please remember that all of your comments are very important to us. Please feel free to tell us whatever you're thinking throughout the session. There are no right or wrong answers. We just want to know what you think.
- Second, please do not hold side conversations. We want to hear from everyone and side conversations make that difficult.
- Third, we want to make sure that everyone can hear what you say, so please speak up.
- Fourth, everyone should self-monitor. Please be courteous when speaking. We want everyone to have a chance to speak.
- Fifth, we are required by law to report to you the OMB control number for this public information request. That number is 0955-0002.
- Do you have any questions so far?

Participant Introductions

- Now, let's go around the room and have each of you introduce yourself to the group by giving your first name. Remember, please only give the group your first name. I'll start. My name is _____.

Introduction to Focus Group Session

- How many of you have participated in this type of focus group before? (Ask for a show of hands and record responses.)

I. Establishing Context and Current Opinion (15 minutes)

Today's session will focus on health and medical information Notices of Privacy Practices (NPPs), called NPPs. NPPs are notices you receive when you visit your doctor or another health care provider or from your health insurer when you enroll in a health plan.

1. Before we go any further, can you tell me what a health or medical information Notice of Privacy Practices (NPP) is?
2. Do you recall receiving an NPP when you visited your doctor or health care provider or from your health insurer when you enrolled in a health plan?
3. [For those that answered yes above, ask] Did you read the privacy notice? [If they did not read it, ask] Why not?
4. What do you think a health entity's privacy notice tells you?
5. Can you do anything with a privacy notice?
[Probe: Are there any actions that you can take?]
6. Is what a company does with your personal information important to you? Why? Why not?
7. What concerns do you have about privacy in terms of your health care information?

II. Sample Privacy Notice (15 minutes)

Next we want to show you a sample privacy notice. Please go ahead and read through the notice to yourself. Look up when you are finished reading and then I will have some more questions to ask.

Moderator's Note

Pass out sample privacy notice

1. On a scale of 1-5, with 1 being not at all comfortable and 5 being very comfortable, how do you feel after reading this notice?
Why?
2. What do you think about this notice? (round robin)
3. On a scale of 1 to 5, with “1” being very confusing and “5” being very clear, how would you rate the information in the notice?
4. Do you think most people would understand the information?
What specifically do you think people will NOT understand?
5. Do you think **COMPANY LISTED IN SAMPLE NOTICE** is providing you with enough information in the notice to understand what they do with your personal health/medical information or data? Why? Why not?
6. Did you learn anything new about how your health or medical information can be used from this notice?
7. What do you think about this privacy notice? (What do you like, what do you dislike?)
8. Do you feel the notice is more about your rights or the health entity’s rights or well balanced?
9. Do you have any concerns after reading this notice? Why?
10. What additional questions does this notice raise?
11. What do you think you are supposed to do with this privacy notice?
[Probe: Are there any actions that you can take?]

12. Would you do anything differently in the future based on the information you learned from this NPP?

Break(5 minutes)

Moderator's Note

We're about half way finished. Let's go ahead and take a short break and I will set up for the next part. You can go get a drink, or use the restroom and I will come get you all from the waiting room

III. Education and Informed Opinion (35 minutes)

Moderator's Note

The purpose of this task is to provide education about the topics followed by a facilitated discussion to solicit more informed opinions.

Privacy notices describe how medical information about you may be used and disclosed and how you can get access to this information. Health care entities are required by law to share this information with their patients (you). What we are going to now is show you a list of the information that is currently required to be in these notices and get your opinions on what information is most and least important to you.

We are passing out a list of all of the required information for health privacy notices. Go ahead and take a look at that list and make notes to yourself about which information is most important and least important to you specifically. We want you to rate each item on a scale

of 1-5 with 1 being “not at all important” to 5 being “very very important.” Please look up when you are finished.

[Moderator: Place laminated sheet with the Not important/Very important scale in front of each participant.]

LIST WILL BE BASED ON LEGAL REQUIREMENTS

Thank you all for going through and doing that. We will be collecting your sheets from you and will summarize all of the information but for now let’s talk about the items you rated a 5 as being “very very important.” You will see that on this flipchart we have recreated the list. Let’s go around the room and have each of you tell me the item that you gave a 5 to. Our notetaker will record this information on the flip chart.

Moderator’s Note

Circle items that received the most 5 ratings.

Let’s talk about the top three items that received the highest number of “5” votes and that you all feel are most important. (Go one by one)

1. Why is X important to you?
2. Why is Y important to you?
3. Why is Z important to you?

IV. Wrap-up (10 minutes)

1. ***[Moderator: Place laminated sheet with Likely/Unlikely scale in front of participant.]***

On a scale of 1 to 5, with “1” being very unlikely and “5” being very likely, what is the likelihood you would read a privacy notice the next time you encounter one? Why?

2. Now that you know what you know, please tell me “What do you think are the advantages of a health privacy notice? What are the disadvantages?”
3. Do you have any additional thoughts or questions about health information notices of privacy practices?

Thank you for your time and all the comments you have given us. We appreciate your help! Do you have any questions for me? *[Answer, if possible]*. You can pick up your payment at the desk out front [or wherever the testing facility designates].