

Individual Interview (1:1)

Moderator's Guide:

Notice of Privacy Practices (NPPs)

Moderator's Note

Greet participant and thank him or her for coming. Ask participant to take a seat and if he or she had any trouble finding the site.

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

I. Introduction (5 Minutes)

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 research and design 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.

I will be leading today's session and **[notetaker's first name]** will be taking notes to help us remember what you say. We will be audio- and video-taping this session to ensure that we collect complete information. The entire session will take about 90 minutes, and we can take a break whenever you need to, just let me know.

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

Today, we are going to ask for your feedback 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 patient experience and understanding. We're here because we believe we can learn a great deal from you.

Confidentiality

I just want to confirm that you have all read and signed the consent forms. I want to assure you that all of the information we collect here today is confidential and we will not identify you by name. For example, you do not put your name on the questionnaire that we've asked you to complete, so your answers cannot be identified as yours. In addition, we will not use your name, address, or any other identifying information in reports, papers, or other information based on this research.

Did you read and sign the consent and confidentiality forms? I just want to confirm. Did you agree to audio-taping? Did you agree to video-taping?

Moderator's Note

If participants say "Yes," continue. If participants say "No," have participant sign the forms.

Thank you. Did you read and sign the non-disclosure form?

Moderator's Note

If participants say "Yes," continue. If participants say "No," have participant sign the forms.

Thank you. I want to remind you that this project is confidential, so please do not talk to others about this project.

II. About the Session and Establishing Context (10 minutes)

Today's session will focus on health and medical Notice of Privacy Practices (NPPs), called NPPs. NPPs are notices you receive when you visit your doctor or a 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 Notice of Privacy Practices (NPP) is?
2. Do you recall receiving an NPP either 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 practices tells you? Are there any actions that you can take with a privacy notice?
5. Is what a company does with your personal information important to you? Why? Why not?
6. Why do you think that a health care provider or insurer might share your personal information?
7. Is there some information you would not want shared? Who would you not be comfortable with your doctor sharing your health information?
8. Is there some information that you would not mind if it was shared? Probe: Would you be comfortable with your doctor sharing your information with some people or for certain reasons? Who and for what reasons?
9. What concerns do you have about privacy in terms of your health care information?

III. Think-Aloud Introduction (5 minutes)

Now for the purpose of this session, I want you to pretend that you are seeing a new doctor at a new office and have come in early for your appointment because they told you they had some paperwork for you.

Okay? Any questions at this point?

Moderator's Note (20 minute check)

Put the scenario card on the table while reading below.

In a moment I am going to hand you a health and medical Notice of Privacy Practices (NPP) for you to review and sign. When I hand you the notice, I'll ask you to look it over and, at the same time, talk out loud about what you are looking at. That means you need to speak up and tell me everything you are thinking about, reacting to, and questioning as you are reading it.

When you turn a page, tell me which page you are on. Please let me know whether you are reading, skimming, or skipping a particular section altogether. I also want you to share any ideas, questions, suggestions, or confusion that you might have about any part of the notice.

I know that talking aloud might seem unusual, but it is important that we hear what you are thinking about as you look at the notice — including what you see and what you are doing. If you are quiet, I will ask you questions to get you talking again.

Remember, we are not testing you. We simply want to understand what works and what does not work in the notice.

To practice this technique of thinking aloud, I am first going to give you a menu from a restaurant. I want you to talk out loud about the menu as you decide whether you want to eat there and what you would like to eat.

Please look at the menu and tell me what you are thinking, reading, and doing every step of the way. To get you started, what is the first thing you notice?

Moderator's Note

Give participant the menu and allow the participant several minutes to try out the protocol. Get participant comfortable with talking about what they are looking at, reading, voicing questions, confusion, and decisions. Ask them what they are reading, where they are looking, and when they can make a decision. Sample questions:

- *What do you think of the overall design?*
- *Where are you looking in the menu?*
- *Does anything catch your eye? What?*
- *When finished, is there any information that is missing? (Use a menu with no prices so key info is missing) Is that information that would be important to you? Why?*

Great. You understand what the next part of the session will be like. You will do a lot of talking out loud and I will ask some questions but you will be able to look back at the notice to answer any of my questions. Do you have any questions before we get started?

Moderator's Note

Answer any questions participant might have.

IV. Think-Aloud (15 minutes for Design 1)

Moderator's Note

The purpose of this task is to observe and record how test participants react to the notice, including what they look at, the sequence that they look at the information, and how they use, overlook, interpret, and misinterpret the information they see.

Health and medical entities are required by law to provide patients with a Notice of Privacy Practices (NPP). As I mentioned before, remember that for this scenario you are visiting a new doctor for the first time and have come early to fill out your paperwork. The NPP is one of the documents they give you to review. I am going to give you a print-out of a sample NPP from a fictitious health company. Once I give it to you, please start talking aloud, telling me what you notice and react to.

Tell me what you are looking at on the page, which page you are on when you turn the page, and the part of the page that you are looking at after turning the page. Remember to tell me what you like or don't like about what you see, what you are confused about, and anything else that you are thinking about.

Again, I might ask you questions about what you are noticing, reacting to, and questioning. If you are quiet, I will remind you to talk aloud.

Ready? Any questions? Here is the notice. To help get you started, what is the first thing you notice?

Moderator's Note

*Hand participant the first **NPP** notice.*

Prompt whenever the participant seems to move to other sections (i.e. “and now you’re looking at the _____ section.”). Ask him/her what he/she is looking at. Remind participant to tell us what he/she is thinking, what he/she likes and dislikes, and what he/she understands and what he/she does not understand.

Great! Thank you for working with that.

V. General Impression Questions (10 minutes)

Now that you have had a chance to look through and familiarize yourself with this NPP, I have some specific questions to ask you. Remember, there are no right or wrong answers. Feel free to look back at the notice as much as you’d like.

General Reactions

10. What is your reaction to this notice?
11. Please tell me 5 words that you would use to describe this notice.
12. Did you learn anything new from this notice?
[Probe: Did you know that before reading this?]
13. [**Moderator:** Place laminated sheet with the Clear/Confusing scale in front of participant.]

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?

14. Does this notice help you know about how this health group handles your personal health and medical information? Why? Why not?
15. Do you think most people would understand the information? Why? Why not?

16. Do you think this NPP is providing you with enough information in the notice to understand what they do with your personal health and medical information or data? Why? Why not?

Moderator: *Jot down some specific they may mention for the Comparison section.*

Moderator: *Probe on any mention of HIPAA.*

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

Now I have a few questions about **ENTITY's** privacy practices.

VI. Specifics (10 minutes)

Content

17. What personal health information does **ENTITY** collect?
18. *[If needed, ask]* What other kinds of personal information does **ENTITY** collect?
19. Generally, how does **ENTITY** use and disclose your personal health information?
[Probe: Are there different ways they use and disclose your personal health information? Which ways? Is it clear?]
20. How do they use your personal information for health-care operations?
21. Why might they contact you personally?
22. Does **ENTITY** share your personal health information? If so, how?
[Probe: With whom?]
23. Do they share your information for medical research?
24. Do they share your information for organ and tissue donation?
25. Do they share your information for law enforcement purposes?
26. Can you tell **ENTITY** not to share your personal health information? If so, how do you go about doing that?
[Probe: Please show me.]
27. Does **ENTITY** sell your personal health information?

28. Can you tell **ENTITY** not to sell your personal health information?
If so, how do you go about doing that? [Probe: Please show me.]
29. How does **ENTITY** protect your personal health information?
[Probe: What does “protect your information” mean to you? How does that make you feel?]
30. Does **ENTITY** have to notify you when your privacy has been breached?
31. What can you do if you believe your privacy rights have been violated?

Words

32. [**Moderator:** Hand a highlighter to the participant and put the **ENTITY** NPP in front of them.]

Please highlight 5 words or concepts about which you want further explanation? [If needed, say “as you’ve mentioned....”]
[Probe: What’s going on with those words or concepts that makes you want further explanation?]

33. Are there any other words or phrases that you want to mention? Why? Please explain.

VII. Comparison of Design 2 (15 minutes)

Moderator's Note

*Hand participant the **SECOND ENTITY** notice.*

Now I'd like you to look at a second NPP from another fictitious health entity called **ENTITY 2**. I'm going to give you a few minutes to review this notice so you have a sense of what it's telling you. You don't have to talk aloud as you go through it but if you want to give me any general impressions, please do. When you're done reviewing it, I'll ask you some more questions. Okay?

Moderator's Note

Give participant a few minutes to familiarize him/herself with the other versions. Ask him/her to place the notices side-by-side before continuing the conversation.

34. What is your reaction to this second NPP?

35. [**Moderator:** Place laminated sheet with the Clear/Confusing scale in front of participant.]

On a scale of 1 to 5, with "1" being very confusing and "5" being very clear, how would you rate the information in this second notice? Why?

36. Do you think they are providing you with enough information in the notice to understand how they collect, use, and share (or not share) your personal health and medical information and data? Why? Why not?

37. How would you compare these two notices? Can you compare what one entity does with what the other entity does? How?

38. Assuming the services are the same, would you choose one entity over another? Why?
39. Would the health sharing and protection practices help you decide whether to use a particular entity?

Moderator: Probe here on specifics they may have mentioned in the First Notice as compared to this notice.

Moderator: Probe on any mention of HIPAA.

VIII. Wrap-up (5 minutes)

40. [**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 NPP next time you encounter one? Why?

[Probe: Would you choose to share or not share your personal health information? Why? Are there situations where it wouldn't matter to you? Are there situations where it would matter? What situations?]

41. Now that you know what you know, please tell me “What do you think are the advantages of NPPs? What are the disadvantages?”
42. Do you have any additional thoughts or questions about NPPs?

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].

