Attachment A: Moderator's Guide

Moderator's Guide: Personal Health Record IT Facts

Moderator's Note
Important: Before beginning, you will need to review the Participant List and make a note whether this Participant keeps a personal file of health information for him/herself or a family member.

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, privacy form, and participant questionnaire ahead of time.*

I. Introduction (5 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.

I will be leading today's session and **[notetaker's first name]** will be taking notes to help us remember what you say and how you interact with the materials. We will also be audio/video taping the session. We can take a break whenever you need to, just let me know. The entire session will take about an hour and a half. Okay?

Privacy

I just want to confirm that you have read and signed the consent form?

Moderator's Note
If participant says "Yes," continue. If participant says "No," have participant sign the forms.

To remind you, all of the information we collect here today is private. For example, we do not have your name on the questionnaire, so your answers will not be identified as yours. In addition, we will not use your name, address, image, or any other identifying information in any reports or papers based on this research.

II. About the Session and Establishing Context (5 minutes)

If you don't have any questions right now, I will begin with a few contextual questions. Sound good?

1. Do you use any <u>online</u> services that involve your personal information, such as online banking, bill paying, tax e-filing, or personal health record?

2. [If yes, ask] Do you ever read the company's privacy information online to understand its privacy practices? [If no, ask "Why not?"]

3. What do you think privacy policies tell you? [**Probe:** Are a company's privacy policies important to you? Why? Why not?]

4. [If participant didn't mention PHRs in question 1.] Have you ever heard of or used an electronic Personal Health Record, often called a P-H-R

for short? If so, can you describe PHRs to me? [If not, ask them to take a guess as to what they think a Personal Health Record is.]

Thank you. For the remainder of the session, we will be focusing on facts about personal health records, the information contained in them, and how PHR vendors manage that personal information as they provide consumers with the PHR service.

<table>
<tr><td>Moderator's Note</td></tr>
<tr><td>Some participants who are unfamiliar with PHRs may be selected to read a few additional paragraphs of contextual information about PHRs before proceeding.

If participant <u>is</u> selected to read the contextual material, please follow the procedure below before conducting the Think-Aloud. If participant <u>is not</u> selected, please skip to Section III: Think-Aloud Introduction.</td></tr>
</table>

[If participant is selected] I am going to show you some generic information about personal health records. Please look it over and I will have some questions for you when you are ready.

<table>
<tr><td>Moderator's Note</td></tr>
<tr><td>Hand participant the card with the information below (or updated equivalent) and give them time to read and process it.

"A Personal Health Record (PHR) is an online record containing an individual's personal health information. PHRs typically include information such as health history, vaccinations, allergies, test results, and prescription information. The information in the PHR can be drawn from multiple sources while being managed, shared, and controlled by the individual."</td></tr>
</table>

a. Based on this, can you tell me in your own words what a Personal Health Record is? [Probe: What additional information do you want to know? What is confusing? What could be improved? Why?]

b. What additional comment or questions do you have about a PHR?

III. Think-Aloud Introduction (5 minutes)

In a moment, I am going to show you information from a fictitious company that discusses personal health records and facts about using and protecting your personal information online. As you read and think about the information, I will ask you to talk **out loud** so I can hear what you are thinking about, reacting to, questioning, confused by, liking, and disliking. As you move between sections, please tell me what you are seeing and reading. Please also let me know whether you are reading, skimming, scrolling through, or skipping a particular section altogether. I want you to share your ideas, questions, suggestions, and any confusion that you might have about any part the document.

I know this might seem unusual, especially if you are normally a quiet person, but it's really important for us to hear what you are thinking about and reacting to as you read through the information — including what you see, what you are doing, what makes sense, and what doesn't. So, if you are quiet, I will ask you questions to get you talking again. Sound good?

Please remember, we are not testing your knowledge or reading comprehension! We are testing the document and its information to get a better sense of what information works and doesn't work, what is understandable and what isn't. Okay? Do you have any questions?

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 what you would like to eat.

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 cover? [Design question]**

- **Where are you looking in the menu? [Navigation question]**

- **Does anything catch your eye? What? [Emphasis question]**

- **What do you think that this symbol means? [Symbol question]**

- **How is this menu organized? [Organization question]**

- **Would you eat here? Why? [Impression question]**

- **What would you order? Why? How? [Task question]**

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?

Great! You understand what the next part of the session will be like and what I need you to talk about as you look at the information. You answered the questions I asked you in exactly the right way. You noticed design elements, talked about how you were moving around in the document,

mentioned what caught your eye, explained what content made sense to you versus what was confusing, and talked about organization. You will do a lot of talking out loud and I will ask some questions. And when you are finished talking, then I will ask you some additional questions that are similar to these. Do you have any questions before we get started?

IV.   Think-Aloud [15 minutes]

In a moment, I am going to show you information from a fictitious company that discusses personal health records and policies about using and protecting your personal information online. I would like you to imagine that you have been considering a PHR and are reviewing the websites of several PHR companies. Now you are reviewing how each company manages PHR information if you sign up for their service. This is a printout/website of one of the company's policies.

As soon as you look at the materials, please start talking aloud. As you first begin to look at the information, I want you to tell me what you are specifically looking at on any page or section, how you are navigating through and reading the document, and what you are thinking about as you are reading. Remember to tell me what you like or don't like about what you see, what you are confused by and why, and anything else that you are reacting to or questioning. If you are quiet, I will remind you to talk aloud.

Ready? Any questions?

Great! Thank you for working with that.

V. General Impression Questions (15 minutes)

Now, I want to follow up with a few questions, and please remember there are no right or wrong answers. Also, feel free to look back at the information at any time. This isn't a memory quiz! Okay?

General Reactions

[Moderator: Please note that participants will cover many topics as he or she does the think-aloud and then answers Question 1. Please review Probe questions and follow-up on those probes the participants does not initially relay.]

1. What is your overall reaction to the information? [**Probe as needed:**

   a. What questions come up?

   b. What works? Why?

   c. What is unclear? Why?

   d. How do you feel about the vendor after reading the document? Why?

2. What do you see as the risks involved in using a PHR? [**Probe**: What, if anything, would you be concerned about? Why?]

3. What do you see as the benefits? Why?

4. If you were directed to this information when researching or signing up for a PHR, would you read it? Why? Why not? [**Probe:** Would you skim it? Where would you stop reading? Why? Do you think it's important for <u>the vendor</u> to provide with this information?]

5. [*If the person has reported early in the session that he or she has read online privacy and security information before now.*] How does this information compare to other data use and security information you've read?

6. Is there particular information you were looking for or wanted to specifically know as you began to read? What information? [**Probe:** Were you able to find this information? Where was your attention focused? Why?]

7. Would the information provided be useful to make an informed decision about PHRs? Would you focus on any particular information to make a decision? Which information and what decisions? Why?

[Moderator: Place laminated sheet with the <u>Clear/Confusing</u> scale in front of participant.]

8. On a scale of 1 to 7, with "1" being very clear and "7" being very confusing, how do you rate the information? Why?

VI. Specifics (20 minutes)

Content and Navigation

[Moderator: point participant to the paragraph above the table on the At-A-Glance page.]

9. *[Refer participant to introductory sentences/page.]* Would you describe this section as a "snapshot" or "at-a-glance"? [**Probe**: Does it actually give you enough of a snapshot for a quick review? Does it all make sense to you? Why? Are there any topics not in this section that you think should be included? Are there any topics that you think do not need to be included in this section? Do you think an at-a-glance box is helpful in understanding the rest of the information?]

10. From this first section, what other sections do you want to go to for more information? Why? [**Probe:** Are there any sections you don't want or need to explore further? Why? Does the opening section provide enough information on those topics? How?]

11. *From the introductory section, is it clear what you have to do to get additional information on any of these topic areas? Why or why not? Please explain.*

Moderator's Note
Hand participant slips of paper labeled with the different topics of the introductory section.

Now that you are familiar with this information, I am going to ask you some questions about ordering. Please order these topics in the way that makes the most sense to you.

12. Please tell me about your order? Why that order?

[Moderator: If it seems appropriate, remind participants again that this is not a test of their memory, rather we are trying to get better sense of what information is and is not understandable.]

13. What types of personal information do you store in your PHR?

14. Do you give permission for others to access and/or view your personal information in your PHR? [**Probe:** Can anyone access your PHR? Do you give permission for anyone other than yourself to access your PHR? Why? Why not?]

15. How does the vendor use your personal information in your PHR? [**Probe:** Are there different ways a vendor uses your personal information? Which ways? Please explain.]

16. Do you tell the vendor *how* to use or not use your personal information? If so, how do you go about doing that? [**Probe**: Do you give the vendor permission to use your information?]

17. Does the vendor sell your information? [**Probe**: For what purposes do they sell your information? What is the difference between selling your information and sharing your information? What would you do if you wanted to know more about the vendor's selling or sharing practices?]

18. What else would you want or need to know about how your information is used? [**Probe**: What specific questions do you have about these uses? [Once they offer other questions, ask] Why?

19. Does the vendor protect and secure your personal information in specific ways? How? [**Probe:** What methods do they use to secure and protect your information? Is this important information for you to know about? Why?]

[Moderator: Probe on any mention of HIPAA with a goal of listening for what the participant understands about HIPAA (rather than simply recognizing the letters HIPAA) and how they relate HIPAA and PHR information. Additionally, explore what they assume about specific laws comprehensively protecting their personal information.]

20. How do you close your PHR? [**Probe:** Is it clear how <u>the vendor</u> handles your personal information after you close your PHR? Why or why not?]

21. Are there any particular features in any of the tables that make them easier or harder to understand?

22. Does the information in the table columns make sense together? Do all of the column headings make sense to you?

23. Do the introductory sentences help explain the purpose of the tables?

24. Are there any words or terms that don't make sense? Which ones? Why? [**Probe:** What would you suggest using as an alternative? Are there any words that don't have definition links that should? Are there any words not included in the terminology section that should be?]

25. If you were tasked with naming this packet of information, what would you call it? Why?

[Moderator: remind participants that the information may be online to get them thinking about the following information.]

26. Where would you expect to find this information on a company's home page? What should the link to be called? Why? [**Probe**: Would the location of the link to this information on the PHR page make a difference to you? Why or why not?]

Break (5 minutes)

VIII. Comparison (15 minutes)

Moderator's Note
Have participant review a second version.

Now I'd like you to look at a second version from another fictitious PHR vendor. I'm going to give you a few minutes to review it so you get a sense of what it's telling you, and I want you to talk out loud just like you did with the first one even though we won't take the same amount of time. When you're done, I'll ask you some more questions. Okay?

Moderator's Note
Give participant a few minutes to familiarize him/herself with the other version. Remind him/to talk aloud if needed.

27. What is your overall reaction to this second document? Why?

28. What are the differences between the two? [Probe: **Are the differences clear? Can you compare them easily? Why? Why not?]**

Moderator's Note
Focus the participant the section about the vendor types.

29. What type of vendor sponsors each of these PHRs?

30. Can you tell the difference between the vendor types for each of these? How can you tell the difference? [**Probe:** Do the vendor explanations clearly explain the differences between types? Do the

explanations about access, use, and closing a PHR help distinguish between vendor types? Does knowing the different types matter to you? Why or why not?]

31. Is there anything else you want to know and understand about the different vendor types in order to more clearly understand the differences between them and be able to make an informed decision about which one to use? [**Probe:** Does it make a difference to you to know that a vendor is a healthcare provider versus a healthcare insurer versus your employer versus a technology company? Why? Why not?]

32. Between these two, which one would you choose? Why? [**Probe:** What aspect of this information guides you to make that decision?]

IX. Wrap-up (5 minutes)

33. Do the vendors provide you with enough information to inform your decision about choosing them as your Personal Health Record vendor? Why? Why not? [**Probe**: What else would you want to know from them? Why?]

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

34. On a scale of 1 to 7, with "1" being very likely and "7" being very unlikely, what is the likelihood you would read information such as this before signing up for a Personal Health Record? Why? Why not? [**Probe**: Are you more or less likely to read a company's policy information presented this way compared to others you may have read?]

35. Okay, that wraps up my questions. Do you have any additional thoughts or questions for us?

Thank you for your time and all the comments you have given us.

We want to remind you that we do not work for or endorse any PHR company. If you are interested in learning more about PHRs on your own, you may do so by investigating the individual PHR vendors.

We appreciate your help! You can pick up your payment at the desk out front [or wherever the testing facility designates].

Attachment B: Participant Recruitment Package

Participant Recruitment Telephone Script

1. Hello, my name is **[first and last name]**. May I speak to **[name]**?

    If someone other than Participant asks why you are calling, say "I'm calling from **[your company]** regarding an important study of online health record information. We are paying participants to help us with this study."

    ❐ No one by that name at this number
    ❐ Speaking to Participant/ Participant comes to the phone ➔ Go to question 3

2. Confirm you have dialed correctly. Ask if Participant was ever at this number (do they have his/her new number)?

    If no new number is given, finalize as not located.

3. Hello, my name is **[your name]** and I'm calling from **[your company's name]** for the Kleimann Communication Group. Kleimann Communication Group is conducting a study on online health record information.

    We have chosen you to participate in a one-on-one interview being held on **[Date].** In this interview, we will ask you to read some materials about online health record information and get your reaction to them.

4. We will pay you **[$____]** at the end of the interview for your participation. Do you have a few minutes to answer some pre-qualifying questions? (If "No," what would be a convenient time to call back?)

    [Include if necessary: "We are not selling anything. Everything you say is private, and your identity or other identifying information will not be used."]

    [If needed: The exact location of the interview is _____]

(Check One Answer)

- ❏ Yes
- ❏ No ➜ Call back time _____
- ❏ Refuse ➜ Terminate. Thank participant.

5. Do you read and speak English at home?

- ❏ Yes
- ❏ No ➜ Terminate. I am sorry, but you do not fit the background we need for participation in this particular study. Thank you for talking with us.

6. Do you have, and regularly use, a home computer to get online?

- ❏ Yes
- ❏ No

7. Have you ever worked for the US Health and Human Services Department?

- ❏ Yes ➜ Terminate. I am sorry, but you do not fit the background we need for participation in this particular study. Thank you for talking with us.
- ❏ No

8. Do currently work in the healthcare industry?

- ❏ Yes ➜ Terminate. I am sorry, but you do not fit the background we need for participation in this particular study. Thank you for talking with us.
- ❏ No

9. What is your current age?

- ❏ Enter age _____

10. Do you regularly use the internet for financial transactions such as online banking or tax e-filing?

- ❏ Yes
- ❏ No

11. Do you currently keep a personal file of your own, or a family member's, medical records? If yes, do you keep paper files or electronic files?

☐ Yes, I keep paper files.
☐ Yes, I keep electronic files.
☐ No

12. What is the highest level of education you have completed?

☐ Less than high school
☐ High school or GED
☐ Some college or a 2-year college program
☐ College graduate
☐ Graduate school

13. What is your race? You may select one or more than one category

☐ American Indian or Alaskan Native
☐ Asian
☐ Black or African-American
☐ Hispanic/Latino
☐ Native Hawaiian or other Pacific Islander
☐ White
☐ Other _____

14. What is your gender?

☐ Female
☐ Male

15. What is your household income level?

☐ Less than $25,000
☐ $25,001 to $50,000
☐ $50,001 to $75,000
☐ $75,001 to $100,000
☐ $100,001 or more

16. Do you have children under age 18 in your household?

☐ Yes
☐ No

17. Have you ever been the primary caregiver for a chronically or elderly family member?

☐ Yes
☐ No

18. Do you manage a chronic health condition (such as asthma or diabetes) for yourself or child?

☐ Yes
☐ No

19. Do you use any electronic or online services to manage your own or someone else's health and medical information?

☐ Yes
☐ No

20. Do you use, or have you considered using, a Personal Health Record (PHR) to manage your own or someone else's health and medical information?

☐ Yes, I have considered a PHR.
☐ Yes, I have currently have a PHR
☐ No

I will now give you the interview times that we have available. The interviews will take no longer than 90 minutes. **[Calendar needs to be updated before each call. Revise this calendar as necessary.]**

[Date]				
[Time]				

☐ No, can't make those times ➜ Thank for time, end of interview

❐ Refuse ➜ Thank participant for time, end of interview

❐ Yes, I'll take the _____ time slot. ➜ Enter selection.

[Follow your company's confirmation procedure, or continue with the following…]

I will send you a letter confirming the time and date and exact location of the interview. The letter will include a number for you to call if you have any questions. In order to send you the letter, I need to have your current address.

If address is listed, verify that it is still correct:

❐ Yes, address is correct ➜ continue
❐ No, address is not correct ➜ make corrections below, then continue.

Address: _____City/state/zip: _____

If do not have address listed, ask participant to give a current address and list below.

And to make sure I send it to the right person, can I check the spelling of your name? (Verify name is correct as listed, make any changes below.)

❐ Yes, name is correct ➜ continue
❐ No, name is not correct ➜ make corrections below, then continue

Participant's correct name: _____

We will need to call you the day before the interview to remind you about the appointment. Is it OK to call you at this number?

❐ Yes, ok to call this number ➜ continue
❐ No, call different number ➜ record number below

Number to call to remind Participant: _____

Thank you for your help. I'm glad you can come to the interview.
Please watch for a reminder letter from (Testing Facility Name).

Acknowledgment Letter to Participants

[Date]

Dear **[participant]**:

Thank you for agreeing to participate in the research being conducted by Kleimann Communication Group. Below are the date, time, and location that we have reserved for you. We are also attaching directions to our research facility. We will pay you **$[insert amount]** for your participation. If you use glasses or contacts, please do not forget to bring them with you so you can read the materials.

[Date, time, and location here]

If you cannot keep this appointment, please call us immediately at **[local number here]** so that we have the chance to find a replacement.

We look forward to meeting you and having your valuable insights for this important research.

Sincerely,

Participant Reminder Telephone Script

1. Hello, my name is **[first and last name]**. May I speak to **[name from confirmed participant list]**?

   Speaking to Participant, Participant comes to the phone ➜ Go to question 3

   If someone other than Participant asks why you are calling, say: I'm calling regarding an important study of taxpayer communication that **[name from confirmed participant list]** is participating in. Is **[confirmed participant]** in?

2. If no, ask, may I leave a message for him or her? ➜ Go to question 3

3. My name is **[first and last name]** and I'm calling from **[your company's name]** for the Kleimann Communication Group to confirm **[name of confirmed participant's or your]** participation on **[date and time]** for the research study. Will you still be able to make it? Please remember to bring your glasses or contacts so you can use them to read the materials.

   If leaving a message say, will you please give **[name of confirmed participant]** this message and have them call me at **[telephone number]** to confirm that they will be able to make it.

   [Thank Participant or person taking message.]

Attachment C: Consent Form

Consent Form

Kleimann Communication Group is working on a project for the US Department of Health and Human Services. We are not employees of any federal agency.

This project will collect information about health information technology. We want to assure you that we will maintain the privacy of your identity and participation in this project.

This form is to inform you of your rights as you talk with us today. We want you to understand the following:

- Your participation is completely voluntary. You do not have to answer any questions you do not want to.
- You may stop participating at any time.
- Your answers and comments will be kept private and stored in locked offices. Your name or personal information will not be used in any report for this project.
- The interview will take no more than 90 minutes to complete.
- We are audio- and video-taping our session with you, but it is only so that we can review your comments and accurately describe them.
- We are keeping electronic logs of your computer actions during the test so that we can accurately describe them.
- Even if you sign this form, you can stop participating at any time.

If you agree to help us, please print your name, then sign and date this form below.

We thank you for your participation in this important project.

Your Name (please print):_____

Your Signature:_____

Today's Date:_____

Attachment D: Participant Questionnaire

Participant Questionnaire

1. What is your gender?

   ❐ Male
   ❐ Female

2. What is your age?

   ❐ Under 30
   ❐ 30-34
   ❐ 35 to 44
   ❐ 45 to 54
   ❐ 55 to 64
   ❐ 65+

3. Do you read and speak English fluently at home?

   ❐ Yes
   ❐ No

4. Are you married?

   ❐ Yes
   ❐ No

5. Do you have any children under the age of 18?

   ❐ Yes, how many? _____
   ❐ No

6. What is your race? You may select one or more than one category

   ❐ American Indian or Alaskan Native
   ❐ Asian
   ❐ Black or African-American

❏ Hispanic/Latino
❏ Native Hawaiian or other Pacific Islander
❏ White
❏ Other _____

7. What is your current annual household income (the total income of all persons who live in your household except for renters and dependents):

❏ Less than $25,000
❏ $25,001 to $50,000
❏ $50,001 to $75,000
❏ $75,001 to $100,000
❏ $100,001 or more

8. What is the highest level of education you have completed?

❏ Less than high school
❏ High School or GED
❏ Some college or a 2-year college program
❏ College graduate
❏ Graduate school

9. Do you currently keep a personal file of your own, or a family member's, medical records? If yes, do you keep paper files or electronic files?

❏ Yes, I keep records of paper.
❏ Yes, I keep records of electronically. Please explain:

_____
_____
_____
_____

❏ No

10. Do currently work in the healthcare industry?

❏ Yes
❏ No

11. Have you worked in the healthcare industry in the past two years?

   ☐ Yes. Please specify:

_____
_____
_____
_____

   ☐ No

12. Do you have, and regularly use, a computer to get online?

   ☐ Yes
   ☐ No

13. Do you regularly use the internet for financial transactions such as online banking, bill paying, or tax e-filing?

   ☐ Yes
   ☐ No

14. Have you ever been a primary caretaker for a chronically ill or elderly family member?

   ☐ Yes
   ☐ No

15. Do you manage a chronic health condition (such as asthma or diabetes) for yourself, a child, or another family member?

   ☐ Yes
   ☐ No

16. Do you manage a chronic health condition (such as asthma or diabetes) for yourself, a child, or another family member?

   ☐ Yes
   ☐ No

17. Do you use any electronic or online services to manage your own or someone else's health and medical information?

❙ Yes
❙ No

18. Have you considered using, or do you currently use, on online Personal Health Record or PHR to manage your own or someone else's health and medical information?

❙ Yes, I have a PHR.
❙ Yes, I have considered a PHR.
❙ No

Thank you. You have finished the questionnaire.