Attachment C

Moderator's Guide for Consumer Focus Groups
Electronic Health Records and Health IT

Need in the room: Pencils for all participants. Flip chart for moderator.

Introduction [10 minutes]
Welcome and thank you for joining us. My name is [moderator's name] and I will be your moderator for this focus group session, which is about electronic health records and health information technology (health IT). I'd like to hear your views about issues related to this topic, and I'm also interested in your thoughts on some messages and materials written about this topic. I am not an expert on this topic; rather I am an independent moderator trained to facilitate our discussion. Our client for this research is the U.S. Department of Health and Human Services, located in Washington, D.C. Our discussion should last about an hour and a half.

Disclosure
- Observation: There is a one-way mirror in this room, with observers on the other side who are interested in hearing your views on these topics, but don't want to interrupt the conversation.
- Audio taping and video recording: This session will be recorded by audio and video tape to enable us to capture everything being said today. We will use the tape to assist us in writing our report to our client.
- Confidentiality assured: Your name or any other personal information will not appear in the report.
- **** All of your answers will be confidential, so feel free to say exactly what is on your mind. Nothing will be attributed to any particular person in our report. After we have written a report about all the opinions we have heard here and in other locations, all tapes and notes will be destroyed.

Ground rules
- We need to hear from everyone, so ask that everyone speaks one at a time please.
- There are no right or wrong answers, to these questions; we want your personal opinion.
- As the Moderator here, I am neutral on these topics. Please feel free to be candid and honest – tell us how you really feel and not what you think we want to hear.
- It's okay to disagree; if you disagree with something you hear please be respectful of other's right to their opinion, and be willing to offer your own views and opinions.
- If anyone needs to use the restrooms, they are located [specify]. Please feel free to get up and use them. There is no need to stop the discussion.

Do you have any questions before we get started?

Participant introductions
- Brief introductions around the table
    o First name and occupation

Perceptions of Electronic Health Records and Health IT (45 minutes)
- How many of you are familiar with electronic health records?
    o How would you describe them?
    o What are some of the benefits of having electronic health records? [Probe, if necessary: convenience, consistency in recordkeeping, not having to give the same information over and over, all your doctor's having your complete medical history, emergency situations etc.]

- Do your various doctors' use electronic health records?
    o If so, what has your experience been?
        ▪ Do you like electronic health records? Dislike them? What makes you say that?

- Did you know you can give consent to have your electronic health records shared?
    o Have you given consent at your various doctor's offices to have your electronic health records shared?
        ▪ How well was the consent process explained to you?
        ▪ What did that involve?
        ▪ Did you sign a consent form?
        ▪ Do you know what you consented to?   What?
        ▪ How comfortable were you with the process?
        ▪ How do you think the process could be improved? (More explanation? Better written materials?)

- Are you aware of the term "health information exchange"?
    o Do you know what the term means?
        ▪ [Read definition of health information exchange: "Health information exchange (HIE) is the transmission of healthcare-related data among facilities, health information organizations (HIO) and government agencies according to national standards. HIE is an integral component of the health information technology (HIT) infrastructure under development in the United States."]
    o What do you think might be some of the benefits of health information exchange?
        ▪ [Probe: all your doctors having access to your complete medical history, not having to give the same information over and over again emergency situations, etc.]
    o Does this sound like it could be useful to you?
        ▪ Why?

- Do you have any concerns about the use of electronic health records?
    o What concerns or issues do you have?

- ▪ [Probe, if necessary: privacy/confidentiality concerns, security concerns, etc.]

- "Privacy" refers to *your ability to exercise control* over the collection, use, and distribution of your health information. How concerned are you with the privacy of your current medical records?
  - o Over the past year, have you withheld information from a health care provider because you were concerned about the privacy of your medical records?
  - o How concerned are you about the privacy of your medical information through an EHR?
  - o How does having your medical information in electronic form affect your perception of the privacy of your medical record?

- "Security" refers to the *technology, tools or procedures used to protect your health information* from someone who is not authorized to view it. How concerned are you with the security of your current medical records?
  - o How concerned are you about the security of your medical information through an EHR?
  - o How does having your medical information in electronic form affect your perception of the security of your medical record?

- Have you heard of any protections or safety measures that can safeguard the privacy and security of your medical records?
  - o What have you heard?

- Have you heard of the term "health information technology" or "health IT"?
  - o What have you heard?
  - o [Read definition of health information technology: The application of information processing involving both computer hardware and software that deals with the storage, retrieval, sharing, and use of health care information, data, and knowledge for communication and decision making.]

- How is the term "health information technology" different from "electronic health records"?
  - o Probe, if necessary:
    - ▪ Is health information technology a broader term?
    - ▪ Does health information technology include electronic health records?
    - ▪ What else might the term include?

- Based on what we've discussed so far do you have any concerns regarding electronic health records and health information exchange? What are some of your concerns?
      [WRITE RESPONSES ON FLIPCHART. POSSIBLE RESPONSES INCLUDE:]
  - o Use or sale of information for pharmaceutical or marketing research
  - o Discrimination from employers, insurers, and programs
  - o Increased cost of health care
  - o Unauthorized people having access to my health records
  - o People becoming aware of my private medical condition
  - o Greater access to my medical records by a wide variety of people

- We have come up with a good list of concerns about electronic health records and the electronic exchange of health information. I want to understand why you have these concerns.

   [FOR EACH KEY CONCERN MENTIONED, PROBE ON UNDERLYING CAUSES:]
   - o What are some of the reasons this is a concern to you?
   - o Do you think the exchanging or sharing of electronic health information increase this risk? How so?
   - o What could possibly happen for a person if this risk was to occur?
   - o How likely do you think it is this could happen?
   - o Who would you be concerned would misuse this information?
   - o Who would you trust to help prevent this from happening?
   - o What might make you less concerned about this happening?

Materials Testing (25 minutes)

Several documents have been developed to explain information relating to electronic health records and Health IT. These documents will be made available to consumers on government web sites and through partnering organizations. I'd like to get your reactions to these documents. We'll go through two separate documents.

[Hand out documents regarding electronic health records and/or health IT per the schedule below:]

Materials to Test	Caregivers		Diabetic Consumers		Tagalog Speakers		Vietnamese Speakers		Russian Speakers		Korean Speakers		Chinese Speakers		Spanish Speakers		Total
	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	
Video #1 (storyboard): "Your Rights"	√	√	√	√													**4**
Factsheet: "Your Health Information Privacy Rights"	√				√				√	√	√		√	√	√		**8**
Factsheet: "Sharing Information with Family and Friends"		√				√	√	√		√		√		√	√	√	**9**
Factsheet: "A Patient's Guide to the HIPAA Privacy Rule"					√	√	√	√	√		√	√	√			√	**9**
OCR Tagline: "Know Your Rights."	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	**16**
Spanish OCR Tagline "Conozca sus Derechos"															√	√	**2**
Spanish ONC Tagline "TI Salud"															√	√	**2**
"Putting the I in Health IT" Campaign Concept			√	√													**2**
Total Materials Tested	**3**	**3**	**3**	**3**	**3**	**3**	**3**	**3**	**3**	**3**	**3**	**3**	**3**	**3**	**5**	**5**	

Please take a few minutes to read the first document…

[For each document, ask:]
- What is your first impression of this document?
    o Do you like it? Not like it? What makes you say that?

- In your own words, what do you think is the main idea this document is trying to get across?
    o How well do you think the main idea comes across in this document?

- Is this document trying to get people to do something?
    o What action would this document make you take?

- Are there any words used in this document that are unusual or unfamiliar?
  - What other words could be used in their place?

- Are there any words or phrases that are confusing, unclear or hard to understand?
  - [If you would please circle for me any words or phrases that are unclear, confusing, or hard to understand]

- Is this document believable?
  - Why or why not?
  - Is there any additional information you would need to more strongly believe this message?
  - Is there anything you want to know about this topic that this document does not tell you?

- Does this document catch your attention? Why or why not?
  - What makes the document appealing or unappealing?
  - Is there anything that would make the document more appealing to you?
  - Is there anything you want to know that this document/video does not tell you?

- Is this document believable, or not?
  - Why or why not?
  - What additional information would you need to more strongly believe this message?

- Is this document/video appealing?
  - What makes the message appealing or unappealing?
  - Is there anything that would make it more appealing?

Sources and Channels (8 minutes)
- For you to pay attention to them, where would these messages and materials need to be placed?

- Do you like the idea of having these materials available in your doctor's office?
  - How likely would you be to read this information in your doctor's waiting room or take it home to read?

- Has your doctors' talked to you about electronic health records?
  - What did he/she tell you about them?

- Would you trust this information if your doctor told it to you?
  - What other sources would you trust receiving this information from?
  - Are there specific media outlets, such as newspapers, magazines, TV stations, online sites (web sites, blogs, and chat rooms) or organizations you would trust?

Wrap Up (2 minutes)

- Compared to when you started this session, are you now more interested in learning about electronic health records and health IT?
- Have your opinions or attitudes about electronic health records and health IT changed because of this session?
  - o If so, how would you describe the change?

On behalf of HHS, I want to thank all of you for your valuable time and input here today.
- Check with clients for additional questions.
- Collect all materials.