



The Office of the National Coordinator for
Health Information Technology



**U.S. Department of Health and Human Services
(HHS)
The Office of the National Coordinator for Health
Information Technology (ONC)
eConsent Trial Project
Focus Group Facilitator Guide**

**Produced for the U.S. Department of Health and Human Services by:
APP Design, Inc.**

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Acronym Index

Acronym	Definition
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HITECH	Health Information Technology for Economic and Clinical Health Act
VA	Veterans Affairs
WCA	Woman's Christian Association
WNY	Western New York

1.0 Introduction

As a component of the eConsent Trial project sponsored by the U.S. Department of Health and Human Services (HHS), the APP Design Team will be conducting patient focus group sessions in Western New York (WNY). We are working to develop and pilot eConsent education and consent decision capture technology at several WNY health care provider facilities. Key to this effort is the inclusion of patient input before, during, and after the pilot to identify what patients feel they require to make a meaningful decision and to assess the knowledge gained and satisfaction with the education and electronic consent (eConsent) capture pilot. This Facilitator's Guide will provide specific information for focus group facilitators to achieve consistency in the execution of each focus group session. A total of eight focus group sessions will be conducted. There will be four sessions held at one selected facility and four sessions at another facility.

2.0 Conducting the Focus Group

The focus group sessions are designed to elicit information from participants for the purpose of verifying the information collected in the project's February 2012 patient survey (OMB 0990-0376) and to gather any additional information which may be useful in developing the educational materials and technology to be used in the eConsent pilot. Focus group participants will be asked a series of questions, and their answers will be documented by focus group facilitators.

2.1 Getting Started with the Focus Group

To ensure uniformity and create an environment conducive to productive and informative participant participation, we have developed the guidelines and scripts for the focus groups. There will be two facilitators at each session, and each will be wearing a name tag.

The facilitators will be given a list of participants for each focus group. As participants enter the room, the facilitator will welcome and ask participants to sign in. Pens and paper will be available for participants.

2.1.1 General Guidelines for Focus Group Facilitators

When facilitators conduct the focus group sessions, they will follow these guidelines:

- Do not interrupt participants/respondents.
- Do not re-word their responses without permission and do so only to make the response more clear.
- Assume that questions are really statements about what the participant thinks, and clarify as needed.
- If participants have complaints, thank them for their comments and move on.
- If discussion goes too far afield, remind respondents what the last question was in an attempt to re-direct.
- If there is silence, ask the question again.

- Try not to move too quickly through the questions.
- Be enthusiastic.

2.1.2 Information and Guidelines for Focus Group Participants

The facilitators will welcome the participants and provide general information upfront. They will guide each session accordingly:

Welcome, and thank you for taking time to attend this focus group. We plan to spend the first 15 minutes covering introductions and the educational material (a PowerPoint presentation), 60 minutes in a structured conversation, and 15 minutes to wrap up.

A few housekeeping items before we commence:

- Restrooms are located (insert detail by location)
- Emergency exits are located at (insert detail by location)
- Please help yourself to refreshments
- Participation in this group is voluntary

A few ground rules as we begin:

- We want to encourage everyone to participate.
- Please speak one at a time, and do not interrupt others.
- We will be documenting the discussion on the flipchart paper.
- No individual will be associated with any specific information.

Any questions so far? If not, then let's begin. *[If yes, take note of the questions asked.]*

2.2 Script: Focus Group Educational Presentation

The facilitators will then move into presenting the educational material (the PowerPoint presentation) as follows:

Before we get started asking you questions, we need to be sure everyone is on the same page in terms of information you already have, so let's look at the slide presentation. As you watch and listen to this presentation, we ask that you hold onto your questions until the conclusion of the presentation. So please take note of any questions you may have and we will pause at the end to take any of your questions.

The facilitators will present the educational material (the PowerPoint presentation).

Introduction: We are convening patient focus groups for the eConsent Trial project sponsored by the U.S. Department of Health and Human Services (HHS). Our team, including HEALTHeLINK, is working to develop and pilot eConsent education and consent decision capture technology at several Western New York (WNY) health care provider facilities. HHS

would like to help patients better understand the choices they may have about allowing providers to electronically share their medical information.

The facilitators will cover each slide of the education material (the PowerPoint presentation), beginning with the goal and agenda. The facilitators will then provide a brief introduction of themselves. The facilitators will then provide an explanation of how medical information may be collected and accessed followed by an explanation of who is in the health information exchange in WNY. This explanation includes specifics on types of participants. The facilitators will cover what type of information may be accessible. The facilitators will also provide an overview of legal considerations. The facilitators will then cover who might have access. The four consent options will then be covered.

Conclusion: So why are you here? Your input will help us shape both the content and the delivery method of providing this education to the patient population in your region in a future pilot.

Any questions? *[If not, proceed; and if yes, take note of the questions asked.]*

2.3 Script: Focus Group Questions

Following the PowerPoint presentation, the facilitators will guide the conversation in each session based on the following questions:

We will be conducting exercises as well as asking specific questions today. As you answer, we will be documenting your responses, and we will review our discussion at the end of the focus group session.

1. What information do you want to know before giving your providers consent to electronically access your medical information? For this focus group, granting consent includes the option to reject giving consent. Consent is the same as allowing or not allowing those who are treating you to access your medical information through a health information exchange.

[Focus group facilitators should ask the first general, open-ended question and document any responses from participants. Allow for silence; ask several times if there is anything else anyone wants to add. Next, ask each of the sub-questions.]

- a. What do you want to know about *why* your provider may want to share your medical information?
 - *Is the “why” important to you?*
 - What do you want to know about what happens after you grant consent?
- b. What do you want to know about *who might have access* to your medical information?
 - *Is the “who” important to you?*

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- What specifics do you want to know about the penalties if someone misuses your information?
 - c. What do you want to know about *what* data in your health information is accessible upon consent?
 - *Is the “what” important to you?*
 - d. What do you want to know about how your *medical information is kept secure and confidential?*
 - What do you want to know about the laws related to sharing your medical information?
 - e. What else is important for you to know before you give your provider consent to electronically share your medical information?
 - f. What comes to mind when you hear “access your health information” and “share your health information?”
2. How do you want to receive the information you need before you give your provider consent to electronically share your medical information?

If silence, provide the following prompts:

- *Video on mobile device, specifically a tablet*
- *Brochure from provider*
- *Email from provider*
- *Video posted on Internet/online/website by provider*
- *Information posted on Internet/online/website by provider*

[Focus group facilitators — follow same directions as above.]

- a. If you prefer to receive the information in a video on a mobile device, can you explain why?
- b. If you prefer to receive the information in writing in a brochure from your provider, can you explain why?
- c. If you prefer to receive the information in an email from your provider, can you explain why?
- d. If you prefer to receive the information in a video posted online by your provider, can you explain why?
- e. If you prefer to receive the information in writing posted online by your provider, can you explain why?

[Focus group facilitators orally review the documentation on the flipchart and ask participants using the same directions as above.]

- f. Is there anything else you would like to add?
3. Bullet/List exercise: *[Ask participants to rank the statements one through seven, one most important to know and seven least important to know. Participants will then be*

instructed to star the statements that he/she thinks are critical to know; all seven can be starred or none or as few or as many as he/she thinks.]

- Information we collect and how we collect it
- How we use your information
- How we share your information
- Your choices regarding our use of your information
- How long we keep your information
- How we protect your information
- How you may access and correct your personally identifiable information

2.4 Script: Concluding the Focus Group

The facilitators will conclude each session with:

Thank you for participating in the focus group today. We greatly appreciate your time; the information you have provided us will inform final recommendations for creating and delivering educational material which will be used in a pilot to help patients better understand the choices they have about allowing entities involved in their care to electronically share their medical information.

Thank you again for your participation and involvement in this project.