

IRB Study No. Pro00006539

**Moderator's Guide:
mHealth Privacy and Security Consumer Research Focus Group**

Site: _____

Date: _____ Start Time: _____ End Time: _____

Researchers: _____

Number of participants: _____

Focus group leader will need:

1. Cards on which participants will write their first names
2. Paper and pens for focus group participants
3. Flip charts prepared for question #1, #2a, #7
4. Flip chart with lists prepared in advance for these questions:
 - # 8 - List of mobile device specific messages
 - #12 - List of mobile device messages sent to doctor
5. Screen shots of technologies for question #1
6. Sample screen shots for question #6, and
7. Computer with links to the websites for questions #6, #9

INTRODUCTION

Thank you very much for coming today to participate in this discussion group. My name is _____, and this is _____. We are here today to discuss using email, cell phones and text messages to communicate health information with your doctor or health care provider.

We will be here for about an hour and half. During that time I will ask questions and _____ will take some notes. For some questions we'll ask for volunteers to answer, and sometimes we will go around the table so everyone has a chance to talk. We will be audio taping the group so that the team can go back and listen to your ideas and opinions. As we explained during the consent, your name or identity will never be used to discuss our findings.

mHealth Privacy and Security Consumer Research
MAXIMUS Federal Services

IRB Study No. Pro00006539

What you say is very important to us. Don't worry about being right. There are no wrong answers! We want your honest opinions, and we want to hear whatever you have to say. We don't have to agree during this focus group.

At the end of the session we will offer you a \$50 Visa gift card for your time and travel.

To help the discussion go smoothly we would like you to write your first name on these cards. We're also going to give you paper and a pen in case you want to write anything down.

[Hand out cards, paper and pens.]

If you need to get up to stretch or get refreshments or use the restroom during the hour, go ahead and do that. The refreshments are _____. Restrooms are located _____. Before we start, does anyone have questions? Okay, let's begin.

SECTION 1 – GENERAL USAGE PATTERNS AND PREFERENCES

1. It's hard to walk down the street today without seeing people on cell phones, talking or texting. And when they get to where they're going, many of them spend more time on a computer, or a tablet like an iPad, or a cell phone. We are going to focus on the use of cell phones, smart phones (cell phones that can connect to the internet and have advanced features like email and apps), and computer tablets like iPads. We will use the term "mobile devices" today to refer to these electronic devices that you can carry with you. So let's start by making a list of all the things you currently do using the internet, your cell phones, smart phones and iPad type devices.

[Leader makes the list on the chart paper as participants suggest items for list.]

Internet	Cell Phones	Smart Phone/iPad Type Device
<i>[Email, web search]</i>	<i>[Calls, texts]</i>	<i>[Banking, purchasing, apps]</i>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

[include probe for an app that requires GPS such as Four Square and Yelp (See attachment A for visual aids)

2. People carry around and use their mobile devices because it makes many things easier and more convenient. And it seems that many people are willing to make tradeoffs when it comes to mobile communication. People can make tradeoffs between:

- convenience vs. price;
- price vs. better network connections;
- improved access to tasks; and
- information vs. privacy of that information, and so on...

2a. Let's take a few of the things we put on this list.

[Moderator chooses 3]

IRB Study No. Pro00006539

How would you rate the convenience value of these tools? Convenience means doing this via a mobile device saves time, effort, maybe even money, etc. [See Attachment A for visual]

_____	_____	_____
Very convenient	Very convenient	Very convenient
Convenient	Convenient	Convenient
Somewhat convenient	Somewhat convenient	Somewhat convenient
Not convenient	Not convenient	Not convenient

2b. Lets talk about privacy and security.

Privacy means you have the ability to have some control over how your information is collected, used, or shared.

By **security**, we mean having safeguards, including technology and other tools, in place to protect your information.

How much of a concern is privacy and security for you when you're using your mobile device for any of these functions?

[If group is vague, only then force to the following categories by show of hands]

Not concerned much at all

Somewhat concerned

Very concerned

2c. How many of you have some security / privacy concerns but still use your mobile device to perform these tasks anyway?

[Moderator probe either why /why not?]

3. When you think of all the ways you are currently using your mobile device - what types of improvements would you most like to see?

4a. Do any of you look for health information on a mobile device?

4b. Do you communicate with a doctor or other health care provider on a mobile device?

4c. *[If some participants do so, then ask]:* Do you communicate on your own behalf, or on behalf of someone else, for example, an elderly parent? Or both?

[If yes, probe]

5. When you're looking for health information for yourself or someone else do you have a preference between mobile devices (phone, tablet) vs. phone conversations to communicate with the provider?

6. Here are some of the types of health information that can now (or in the near future) be exchanged between you and your health care provider through mobile communication - through a text message, email, patient electronic health record or personal health record (PHR), a smart phone application, iPad device, (e.g. through a health app) or through video calls such as Skype.

Let's think about the following types of messages coming to you via text, email, and smart phone.

[Project visuals of the following, see Attachment A for visuals]

- General health info
 1. screening reminders - for example, time for your mammogram, or annual physical
 2. general health tips - for example, how to reduce cholesterol, or ways to add more vegetables into your diet.

IRB Study No. Pro00006539

3. STD text message

- Here's a look at a texting program that sends regular text reminders to pregnant women during their pregnancy:

[Show Text4Baby video at

<http://www.youtube.com/watch?v=x5P5fuUs-zU&feature=related>

(.20sec - 1.20minutes)]

6a. What do you think about sending or receiving this information?

[Moderator probe any statements of concerned or not concerned]

7. In summing up: could we make a list of the types of personal health information you (in the group) are not comfortable exchanging through mobile devices:

[Moderator record list] [See Attachment A for visual]

SECTION 2- EXCHANGING HEALTH INFORMATION VIA MOBILE

A. COMMUNICATION FUNCTION (SENDING AND RECEIVING INFO)

8. Now here's a list of some other information your health care provider might send to you, or that you might send him/her, again through mobile communication - through a text message, email, a smart phone application (e.g. through a health app) or through video calls such as Skype.

[Show second list on flip chart and go down list. Probe for initial response and why you would or would not like to get or send the information using a mobile device.] [See Attachment A for visual]

- Lab test results [Show mockup of text message for the lab test result.]
- Information about yourself that you collect at home and send to your doctor (weight, diet, glucose level, etc.)
- Medication/refill reminders or information
- Images, for example sending your provider a picture of an ankle injury, or your provider sending you an image of a health condition

IRB Study No. Pro00006539

- Diagnostic information such as blood sugar monitoring that goes directly from your glucometer to your doctor's office
- Receiving your health information via an electronic health record.

[Show excerpt from Kaiser Patient Portal]

8a. What do you think about sending and receiving this kind of health information?

[Probe any statements of concerned or not concerned.]

8b. Are there any types of information or messages you think would be too sensitive - that you'd rather **NOT** send to or receive from your provider on a mobile device?

[Suggest STD test results or behavioral health data if participants ask for examples, but try not to lead them to specific answers.]

8c. Looking at these types of information again, do you have a preference - mobile device vs. phone conversations to communicate with the provider?

8d. Is there anything that would make you more comfortable with receiving or sending some of this health information via a mobile device?

B. MONITORING / TRACKING VIA MOBILE

9. More and more technology is being developed to help us and our doctors monitor our health with the goal of living healthier lives.

Let's take a look at a short piece of video from a talk that a Dr. David Kraft is giving about new technologies on the horizon.

[Show excerpt from the following TED Lecture by Dr. David Kraft]

IRB Study No. Pro00006539

http://www.ted.com/talks/daniel_kraft_medicine_s_future.html, 6:35 min – 8:40 minutes]

So as you see, some mobile devices are capable of collecting information - monitoring things about you - what your heart rate or blood pressure is during the day; how much you are walking, where you are located, etc.

For instance, as we mentioned at the start of our discussion, phones can have GPS turned on to track where you are located. So,

- Mobile devices can track your location and give you health-related information based on where you are at that time, for example information on air quality
- Mobile devices can track your movements to measure how many calories you have burned
- Mobile devices can enable tracking of an Alzheimer's patient who needs to be located
- Mobile devices can have motion detector capabilities to track your movement and detect if you have fallen
- Mobile devices can track your habits, such as the number of emails, texts and phone calls you are making

9a. What do you think about using a mobile device for these purposes?

[Probe any statements of concerned or not concerned]

10. OK. We (have/haven't) talked about WHO is sending or receiving the messages in all the examples we've been talking about from reminders and tips, to lab results and monitoring your movements.

10a. Would you be comfortable using a mobile device to communicate (send or receive) the types of information we've been talking about with the following?

- Your own doctor or other provider?
- Your health plan?
- A government entity (such as your local health department) or a federal health agency?
- A commercial business, such as an internet company where your personal health record is stored?

10b. When it comes to each of these “receivers” of the information, do you have a preference - mobile device vs. phone conversations to communicate with the provider?

SECTION 3 - PRIVACY AND SECURITY (INCLUDING STORAGE AND SECURITY)

So far we've been talking about the kinds of information that can be sent back and forth via mobile devices. In this final part of our focus group we're going to look at the data itself - where is it stored? Who sees it?

11. When data is sent to and from mobile devices, or when it is collected by a mobile device in the ways that we have been talking about, it may be stored temporarily or permanently in different places and by different companies. And in some cases, those companies may share the information they are storing for a variety of purposes, including marketing.

For example when messages are sent via text, the telecommunication (AT&T, Verizon, etc.) provider may keep copies of those text messages for some amount of time. Or, if a health app collects your location and other data about your habits in order to help you manage your migraines, the application provider may keep copies of that information for a while.

In addition to where data gets stored it may be possible for one entity to share it with another. For example a pharmaceutical company that has been collecting and storing your prescription information may share that data with researchers who may be studying the drug's use; companies holding your information, including health information, have also been known to combine data from different sources and use the information for marketing and other purposes.

11a. By a show of hands how many people are familiar with this idea that some mobile data can be stored and used for other purposes? [*hand count*]

11b. What are your thoughts about personal health information being sent by, stored by, or shared by the following types of entities:

- Telecommunication providers, such as your internet provider or cell phone provider?
- Technology companies, such as Microsoft, Google or health app developers?

[if concerns are raised, probe for the types of concerns]

11c. *[If “selling” has not come up ask the following:]* What are your thoughts, reactions to these entities “selling” your personal health information?

11d. Let’s go back to the example of a recent blood test result. Think about possibilities for where this data (your blood test result) are stored. If your blood test results are stored by a third party (i.e., a company other than your provider, such as a technology company), would it help if your data were stored anonymously?

11e. How would someone go about finding out how a company or entity may be storing or sharing your information?

SECTION 4 - REMEDIES

We’re just about done. Thank you for all your input thus far.

12. OK. Now let’s think about remedies - ways to address your concerns. Let’s talk about what policies or safeguards you would like to see in place regarding personal health information on mobile devices.

Recall that in this discussion, **privacy** means you have the ability to have some control over how your information is collected, used, or shared. By **security**, we mean having safeguards, including technology and other tools, in place to protect your information.

Early on you (all / some) mentioned that mobile technology has a high convenience value. It makes life’s tasks easier, faster...

You also discussed concerns you have about the privacy and or security of your personal health information traveling via mobile device.

IRB Study No. Pro00006539

Privacy means you have the ability to have some control over how your information is collected, used, or shared. If you could design what type of privacy protections you'd be content with, what would be adequate for you, when it comes to using mobile devices for personal health information, what would that be.

For starters, let's go back to our example of **blood tests**. [*See Attachment A for visual*]

12a. What type of privacy protections would be adequate for you to use a mobile device to communicate with your provider about blood test results?

12b. Let's talk about other types of information besides blood test results. What type of privacy protections would be adequate for you to use your mobile device to communicate with your provider about:

- diagnoses
- medication taking
- blood pressure monitoring
- monitoring the amount of movement and exercise you get for 24 hours using a GPS locator device

12c. [*If the following haven't been mentioned follow up with:*]

- Would you want to know what information is being collected about you and how that information is used or shared?
- Would you want to be able to see who had accessed your information?

13a. How important would it be to have extra features on your mobile device that make it difficult or impossible for other people to see your information without your permission, such as encryption of messages, or an auto-lock/PIN feature that requires a pass code for someone to use the device.

13b. What other security measures and safeguards would need to be put in place to make you feel comfortable with using your mobile device for health purposes?

IRB Study No. Pro00006539

13c. Would you be willing to pay for this extra security?

14. Now for our last question. We've talked a lot today about how much cell phones and technology are a part of our daily lives. Imagine five years into the future, when things will certainly have changed even more than they have in the last five years.

What do you envision in the future? What health-related information or aids would you like to see mobile devices provide by 2017?

That's it! We're finished. You've been a great group and the information you've provided here will be very helpful. Now we will offer you a \$50 Visa gift card to thank you for your time. When you get your envelope, please check to make sure the gift card is in the envelope and sign the receipt. Thank you very much!

[Hand out the gift cards in envelopes and receipts to be signed. Collect receipts.]