

Appendix 1

UTHSC & WCCRI BC AET App Study

Focus Group Moderator Guide

Study Objective: Improve symptom management and adjuvant endocrine therapy (AET) treatment adherence among women with breast cancer

Good morning/afternoon and welcome to this focus group, sponsored by the West Cancer Center Research Institute (WCCRI) and UT Health Science Center. My name is (*name*), and I will serve as the moderator for today's conversation. This is (*name*), and she's here to take notes. We are here today to learn from you. Before we get started with the discussion, let's go around the room and have each person introduce herself.

1. Tell us your first name and your favorite restaurant in the city.

The moderator will instruct each woman to introduce herself as well as write her name on a table tent (name facing the group). The moderator will inform the group that pseudonyms are allowed to maintain anonymity.

Now that we've all become acquainted, I'd like to go over a few guidelines before we begin, so that we can really get the most out of our time together. This focus group session will be audiotaped for research purposes only. There will be no public broadcast of today's session. The audio recordings will only be used for the purposes outlined in the consent form each of you signed, so your identity and comments will remain confidential. Are there any questions? Let's begin. I am turning on the tape.

1. First, we are so excited to have you all here and really want to hear what everyone has to say. You can help us with that by speaking clearly and distinctly so we can all hear what you have to say; if I think that the audiotape won't pick up what you are saying, I will ask you to speak up because we want to capture your thoughts.

2. Second, we want to make sure that everyone can complete their thoughts and that we will be able to tell what you said on the audiotape. Whenever possible, please try to avoid interrupting or speaking while someone else is speaking.

3. Third, please let us know if you disagree with someone's opinion, but please do it in a respectful way.

4. Fourth, we value each person's opinions, so please contribute to the conversation. Don't just sit there quietly. If I notice that we haven't heard from you in a while, I will ask you whether you have anything to contribute, because sometimes it is hard to break into a conversation with so many ladies in one room.

5. On the other hand, please be aware and sensitive to the fact that everyone deserves an opportunity to be heard. Please make sure you're not the only one speaking.

6. In order to feel comfortable sharing with each other, we will all need to keep what is said in today's conversation confidential. Please feel free to mention that you participated in this focus group; however, please do not discuss any of the specifics about what any one person said, especially if it is of a sensitive nature.

Today, you will be asked to provide feedback about the enrollment process for a new study as well as your thoughts and suggestions for improving the content of a new web-based app used by patients at the West Cancer Center to improve communication about adjuvant endocrine therapy (AET) medication. Your honest feedback is important to the study team. Your thoughts and feelings about the content we are going to present to you will help improve the intervention, including the web app, for women with breast cancer.

You should have a small notebook and a packet in front of you. The notebook is yours to keep. Use it to jot down notes or questions or exchange information with other focus group members. The packet has five sheets, labeled Sheet A through Sheet G. You will be given instructions pertaining to these sheets throughout the discussion.

2. The overall purpose of the THRIVE study is improve patient-provider communication about AET medication through the use of web-based app. Sheet A provides examples of AETs, both generics and name brands.

What do you think the WCCRI team should know about women's physical/mental/emotional/spiritual needs when taking AETs?

*Probe #1: What recommendations would you make to the WCCRI team?

Now, I'd like to get your thoughts about the study enrollment process the team plans to implement.

(Moderator will read the short narrative about the general enrollment process)

A few days after being prescribed their first adjuvant endocrine therapy prescription, eligible women will receive a call from a research coordinator to tell them about the study and invite their participation. Interested individuals will schedule a time to

meet in person with the research nurse shortly after picking up their AET pills. During this initial visit, women will be asked to bring in their AET pills and the nurse will (1) review the study consent form, (2) ask them to complete a brief, 10-minute survey, and (3) give them a new, electronic pill bottle monitor to be used with their AET prescription. The monitor looks just like a regular pill bottle. To compensate participants for their time and effort, they will receive \$25 for each follow-up survey completed and pill bottle reading plus a \$25 bonus for 100% completion for up to \$200 for a year participation.

3. What do you think about the THRIVE enrollment process, as I have described it?

4. Think back to when you first received your AET prescription. When would have been the best time to approach you for participation in a study?

Thanks for your feedback on the study enrollment process. Now let's switch gears and think about how technology can impact communication in the medical setting.

5. How do you think use of technology, like the tablet used in the West Cancer Clinics, can increase communication between physicians and their patients?

*Probe #1: What topics would you most like to discuss via an app with your healthcare provider?

*Probe #2: Are there any topics you might feel MORE comfortable discussing electronically rather than face to face?

*Probe #3: Are there any topics that you might feel uncomfortable discussing with your healthcare provider in any format?

Please direct your attention to the packet. What I've given you are examples of a web-based app that has been developed to help providers improve communication with patients about taking their medications according to the prescribed regimen and side effects. For the next few minutes, I'd like you to provide feedback on the existing app. Feel free to write on the packet; the more, the better. As I describe each item, circle aspects you like, put Xs over aspects you don't like, and write any additional feedback you think is helpful.

Participants will receive reminders by email or text message to use the study app. Sheet B provides examples of those reminder messages.

6. Women are encouraged to use the app as much as possible, especially when they want to tell their doctor about new or changing symptoms. How frequently would you like to receive app reminders? How frequently is too frequently?

*Probe #1: Would you prefer a more personalized tailored message from your doctor? Would you delete the app? Turn off notifications?

Now, let's take a look at Sheet C. Here you will see an example of the flow of questions a person will receive through the app if she takes her AET medicine as prescribed and has no new symptoms to report.

Is the language in the questions clear? Do you like the layout of the app messages? Are there other symptoms that should be included? Feel free to mark up the packets. We are grateful for any feedback and recommendations you provide, so we can improve the existing app.

Now let's take a look at Sheet D. Here you will see an example of the flow of questions a person will receive if she does not take her AET medicine as prescribed or has new or changing symptoms to report. Again, provide feedback about the content of the app.

Now, let's take a look at Sheet E. Here are some examples of text messages patients may receive after using the app based on what they report.

(Moderator will read the directions. Moderator will also read each message to participants and direct them to provide feedback. Remind them to score each message.)

Finally, please look at Sheet F and G. Here are some examples of general messages, with and without graphics, patients may receive that are unrelated to what they report on the app.

Do you like these types of messages? Do you prefer graphic or no graphic? Why? How often would you like to receive these kinds of messages? Specifically, how often when you first receive an AET prescription, and how often once you've been on AET for a while?

(Moderator will read the directions. Moderator will also read each message to participants and direct them to provide feedback. Remind them to score each message.)

Sheet G instructions – circle the ones you like and cross out the ones you don't like.

7. What do you think of the sample messages? What other kind of content would be helpful in the messages a patient could receive through the app?

7b. In addition to text-only feedback messages, would self-esteem/self-affirmations, photos, or video messages be effective? Why? Why not?

8. Thank you for your participation in that feedback. I'd like three or four volunteers to briefly describe what you liked best and least about this program you just viewed.

*Probe #1: How could this study/program be improved?

(If there is duplication in answers, the moderator should probe participants to provide new feedback/evaluations.)

(Notetaker will collect the packets from participants.)

9. How do you think real-time communication with a provider would impact how you take your medication and your health care?

*Probe #1: Do you think others would be completely honest in their answers knowing that their care team members are monitoring them? Why? Why not?

10. What are your thoughts about using this app?

*Probe#1: How do you feel about using this app on your own?

*Probe#2: Do you have family members or friends who are able to help you use the app?

11. Do you have data usage or privacy concerns? Would you worry about exceeding your data plan limit?

12. We have had a great discussion today about several important topics. Did I miss anything? Is there a topic or concern that you have that I didn't mention? Is there something that I should have asked but didn't? This is the open-format session of the conversation. Please feel free to add anything you think will help the WCCRI provide better care.

This concludes today's focus group session. Thank you so much for your time and great answers. Please leave your materials on the table. Please see the receptionist outside for your gift card incentive.

Appendix 2

THRIVE Study: Focus Group Moderator Guide

AET medication adherence message testing

THRIVE Study objective: Improve symptom management and adjuvant endocrine therapy (AET) treatment adherence among women with breast cancer

Good afternoon and welcome to another THRIVE study focus group, sponsored by the West Cancer Center and Research Institute (WCCRI) and UT Health Science Center. My name is Janeane Anderson, and I will serve as the moderator for today's conversation. Ilana Graetz and Ryan Blue are here to take notes.

Each of you were selected to participate in today's discussion because of your prior participation in a focus group. During that focus group, we discussed how web-based app technology can improve patient-provider communication and AET medication adherence among women with breast cancer. You provided feedback on some text-based and graphic messages. The THRIVE study team took your comments and suggestions and made changes to the app. Today, we would like to share some of those changes with you. We would also like your help in developing a new set of messages.

Before we get started with the discussion, let's go around the room and have each person introduce herself.

1. Tell us your first name and your favorite hobby or pastime.

The moderator will instruct each woman to introduce herself as well as write her name on a table tent (name facing the group). The moderator will inform the group that pseudonyms are allowed to maintain anonymity.

Now that we've all become acquainted, I'd like to go over a few rules before we begin.

1. First, please try to speak clearly and distinctly so we can all hear what you have to say; if I think that the audiotope won't pick up what you are saying, I will ask you to speak up because we want to capture your thoughts.

2. Second, please try to avoid interrupting or speaking while someone else is speaking. We want to make sure that everyone can complete their thoughts, and that we will be able to hear what you said in the audiotope.

3. Third, please let us know if you disagree with someone's opinion, but please do it in a respectful way.

4. Fourth, we value each person's opinions, so please contribute to the conversation. Don't just sit there quietly. If I notice that we haven't heard from you in a while, I will ask you whether you have anything to contribute, because sometimes it is hard to break into a conversation with so many ladies in one room.

5. On the other hand, please be aware and sensitive to the fact that everyone deserves an opportunity to be heard. Please

make sure you're not the only one speaking.

6. Please feel free to mention that you participated in this focus group. However, please do not discuss any of the specifics about what any one person said, especially if it is of a sensitive nature. In order to feel comfortable sharing with each other, we will all need to keep what is said confidential.

This focus group session will be audiotaped for research purposes only. There will be no public broadcast of today's session. The audio recordings will only be used for the purposes outlined in the consent form each of you signed. Your identity and comments will remain confidential. Are there any questions? (Pause for questions). Let's begin. I am turning on the tape.

Today, you will be asked to provide additional, detailed feedback about the content of a web-based app used by the WCCRI. Specifically, you will be asked to review mock-ups of the app, evaluate the effectiveness of messaging for AET adherence, and help the THRIVE study team develop new messages for the app. As always, your honest feedback is important to the study team. Your thoughts and feelings about the content we are going to present to you will help improve the intervention, including the web app, for women with breast cancer.

You should have a coffee mug and a packet in front of you. The coffee mug is our gift to you. The packet has 12 sheets, labeled Sheet A through Sheet M. Later on in the focus group discussion, you will break out into small groups for an interactive activity.

2. To begin our discussion, I'd like you to visualize a woman like you on an AET medication, maybe even the medication you're currently taking. This woman has some difficulty following her doctor's prescription orders and does not take her pill daily. She also speaks of pretty severe side effects similar to ones you've experienced in the past (or may currently experience). This woman comes to you for advice. What do you tell her?

3. Keep this same woman in your mind. She also tells you that she is reluctant to talk to her doctor about her AET-related symptoms and side effects because she knows her doctor is going to lecture her about the dangers of not taking her pill exactly as she should. What advice could you give her about ways to improve communication with her oncology care team?

Probe #1: Has your oncologist said something to you that was particularly effective that helped you take your AET pill exactly as he or she prescribed? If so, what did your oncologist say to you?

4. What are your motivations for staying healthy?

Probe #1: How do you achieve your health goals?

Please direct your attention to the packet. What I've given you are examples of a web-based app that has been developed to help providers improve communication with patients about taking their medications exactly as the doctor prescribed and common side effects. For the next few minutes, I'd like you to provide feedback on the app updates.

(Moderator will solicit feedback for each of the app changes)

5. First, some changes were made to the overall aesthetic of the app. If you look at Sheet A, then you will notice the new THRIVE study logo and custom colors. This logo and color combination will appear several times as you navigate the app.

6. Participants from the first rounds of focus groups suggested a free text option for providing information about their AET-related symptoms and side effects. Sheet B is an example of this option.

7. Participants from the first rounds of focus groups also asked for a more precise way to report side effects. For instance, participants said they wanted a way to indicate where on their bodies they experienced pain. So, we now have a body map for app users. Sheet C is an example of this new option.

8. Please turn to Sheet D. Here you will find that a patient dashboard has been added to the app. The dashboard screen is designed to help patients better navigate the app, namely helping participants track their own symptoms and communicate them with their care team.

9. The importance of social support was a theme that came up in each of the first four focus groups. In order to address patients' social/emotional support needs, the app will feature a link to a list of social support organizations on the WCCRI website. What do you think about this new feature? Do you think patients will access the organizations via this link? Why or why not?

10. What additional medical educational information should be incorporated into the study app?

11. Do you think women like you would find non-medical general topics (e.g., jokes, Bible verses, inspirational quotes) appropriate for the study app? Why or why not?

Please turn to Sheets E-J. You may remember some of these messages from the focus group you participated in several

months ago. Some of the messages are new to you. Today, I want you to take a careful look at the message content and think about whether the message meets your standards for Attention, Motivation, Personal relevance, Appropriateness, Attractiveness (graphic messages), and overall Acceptability. An explanation of each of those concepts is on an easel at the front and back of this room. For instance, after seeing a motivation message, how likely are you to adopt the practice or behavior?

(Moderator will review Sheets E-J with focus group participants and solicit written (ratings) and verbal feedback.)

12. Please turn to Sheets K-M. In addition to receiving only text-based messages, patients will also receive messages with graphics about relevant topics (e.g., AET medication reminders, tips for healthy living, affirmations). Examples of those images are on Sheets K-M. Please circle the "thumbs up" if you like the image and "thumbs down" if you do not.

Thank you for your detailed feedback on existing app messages. Now, you will be tasked with developing new text-based and graphic messages for the study app. Please divide yourselves in small groups of 2-3. For the next 25 minutes, each group should brainstorm as many messages as it can to encourage study participants to do three important things: (1) take their AET medication exactly how their doctor has prescribed; (2) communicate symptoms with their doctors; and (3) develop and maintain a happy, healthy lifestyle. The pieces of paper on the wall have been provided to help each group present their new ideas, so make sure you write the messages on these sheets of paper.

(Moderator sets a timer for 25 minutes. Moderator walks around each group to monitor progress and troubleshoot any challenges.)

Ok, ladies. Time is up! Each group should select a spokesperson to present her ideas to the larger group. When your group is not presenting, think about comments and suggestions you have for the new messages being offered by others. Who is the first volunteer?

(Participants present their ideas for new app messages and provide feedback.)

We have had a great discussion today about content and messaging for the THRIVE study app. Did I miss anything? Did any new message ideas come to your mind that you would like to share? Is there a topic or concern that you have that I didn't mention? Is there something that I should have asked but didn't? This is the open-format session of the conversation. Please feel free to add anything you think will help improve the study app and, ultimately, WCCRI patient care. (Pause for comments from participants).

This concludes today's focus group session. Thank you so much for your time and great answers. Please leave your materials on the table. Please see the receptionist outside for your gift card incentive.