

## Focus Group Discussion Guide | Patient Perceptions and Use of Outcomes & Education Information

### Notes to Facilitators:

#### Overview (2 minutes, 2 minutes total)

#	Question	Time
1	<p>a) Thank you for joining us. My name is _____, and I am a nurse at [Institution]. We are conducting focus groups to understand patient views about their treatment experiences. We would like to know more about your experience at [Institution] and what information is most helpful to you as a patient.”</p> <p>b) As the facilitator, I will ask questions to help you share your thoughts and I will ask follow-up questions to be sure I understand. The questions I ask do not have right or wrong answers. We are interested in your opinions, views, and experiences.</p> <p>c) In order to provide consistency throughout all of the focus groups, I will be referring to a discussion guide while asking questions.”</p> <p>d) This focus group will last approximately 2 hours and we will take a break about halfway through.</p>	1 minute
2	<p>A few things to go over before we begin:</p> <p>a) Each of you have a folder with the copies of the informed consent. An [Institution] employee reviewed this consent verbally, but we want to make sure you fully understand and have a chance to ask any questions. We will review the consent document in a moment.</p> <p>b) We want to capture everyone’s comments within the conversation; so please try to talk one person at a time. If you have a thought while someone else is speaking, please write it down on the notepad in front of you. I will be sure that each person who wishes to comment has a chance to do so.</p> <p>c) We understand you may want to provide a lot of detailed information about your experience, but since we want to hear from all individuals in the focus group we will ask each of you to express your thoughts briefly.</p> <p>d) Please place all cell phones and pagers on silent. We also ask you would not take calls or text messages during the focus group.</p>	1 minute

#### Informed Consent Review (5 minutes, 7 minutes total)

#	Question	Estimated Time
3	<p>a) At this time we will now review the informed consent.</p> <p>b) Your participation in this focus group is voluntary. If any question makes you feel uncomfortable, you can refuse to answer the question. You may choose not to participate without any penalty or loss of benefits to which you are otherwise entitled.</p> <p>c) The information you provide is confidential. Your name will not be associated with the information you provide. We also ask participants to respect each other’s privacy and confidentiality.</p>	1 minute

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- d) This discussion will be video- and audio-taped, and will be transcribed by [Contractor]. The videotapes, audiotapes, and transcripts will be provided to [Institution]. The tapes and transcripts will be stored on password-protected computers and locked file cabinets.
- e) There is no cost for you to take part. Your participation in this study will be over after you finish the focus group discussion today. After completing this study, you will have a signed copy of the informed consent to take home and a \$100 check for your time.

4 At this time, please review the full informed consent. If you have any questions, please ask them at this time. If you agree to participate, please sign the highlighted top line of the last page of both copies of the consent form.” 2 minutes  
*(Provide time for participants to read the full informed consent, ask questions, and sign and date their name.)*

5 “Has everyone signed and dated both copies of the informed consent?”  
*(If yes, pick up the informed consents and start the focus group. If no, clarify any questions, and then pick up the informed consents. Study team member will sign both copies of the consent for each subject. At the break one copy will be returned to each subject.)* 2 minutes  
 “Please hold onto one of your consents for your own records, and put the other back in your folder and we’ll pick them up.”  
*(Assistant will pick up folders and flip through quickly, ensuring each consent is signed correctly. Then place folders back into box/binder, which will be handed to study team during the break.)*

**Introductions** (6 minutes, 13 minutes total)

#	Question	Estimated Time
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6	“We will now begin with introductions.”  “Again, my name is _____ <i>(facilitator introduces herself)</i> and our other staff member is _____ <i>(facilitator introduces second staff member)</i> . S/he <i>(the second staff member)</i> will be responsible for assisting us in capturing your comments, making notes, and writing on the flip chart.”	
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	“Each of you are from the same clinical cancer care center.”	6 minutes
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“To introduce yourself, please share only your first name. We think you’re all from [Location], and just as an icebreaker, you can also share what part of the [Metropolitan area] you’re from if you’d like. After you have introduced yourself, please write your first name on the table tent card in front of you to help us in remembering names during the discussion.”  
*(Allow time for responses. The second staff member will record the first name on the notepad on the table)*

**Health Outcomes** (26 minutes, 39 minutes total)

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#	Question	Estimated Time
7	<p>a) We are now going to spend some time thinking and talking about a concept called “health outcomes”. You may have heard this term used in the media and in stories about health care. But we want to learn your personal views about “Health Outcomes”</p> <p>b) So, when I say “health outcomes” or “health-related outcomes,” what do you think of? On your notepad, write down your thoughts about this concept; what it means to you. Then we will talk about these. <i>(Allow participants two to three minutes to write down their ideas regarding outcomes.)</i></p> <p><i>Probe if needed:</i> Thoughts might include touching on physical, mental, emotional, financial issues, among others.</p>	3 minutes
	<p>c) Let's take a few minutes to discuss these thoughts that you've written down and see if we can create a common definition of health outcomes. Let's go around the table and you can each briefly share your thoughts. <i>(Allow participants time to share while assistant writes down themes and ideas.)</i></p>	8 minutes
	<p>d) Now that we've discussed what health outcomes are, and how they can be physical, mental, emotional, functional and financial, list a few specific outcomes that were important to you about your health from diagnosis and beyond. Which specific outcomes were or are most important to you? <i>(Allow participants a minute or two to write down specific outcomes.)</i></p>	
	8	<p>a) OK, that is great. Now, look at the outcomes you have listed and mark at least two of your most important outcomes. <i>(Allow participants one minute to mark down their most important outcomes.)</i></p>
9	<p>a) Now I want to go around the table, and I want each of you to tell me what you wrote down on your notepad. First, tell me what outcome you felt was most important, and then the second most important outcome and why. Remember, if it's important to you, it's probably important to other people, too, so feel free to share whatever it is you've written down. <i>(Second staff member will write down top two outcomes and note rank on flip chart.)</i></p> <p><i>(At end of discussion, assistant will underline the most popular outcomes as noted by rank for easy reference by facilitator.)</i></p>	5 minutes
	<p>b) We have this listing of outcomes, and as a group, let's go briefly through the most popular outcomes on this list and see if anyone has suggestions for how to measure any of these. For example, if I were trying to measure <u>outcome from list</u>, how would I do that? This is open for anyone to chime in. <i>(Facilitator will go through list of most popular, underlined outcomes for brief discussion.)</i></p>	3 minutes
10		5 minutes

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Is there any outcome we've missed or anything else about how we could help people measure these outcomes? *(Second staff member will list any additional outcomes.)*

### Break (15 minutes, 52 minutes total)

Thank you. Now we are going to take a brief break of about 10 minutes. The restrooms are \_\_\_\_\_. Please feel free to get another beverage or snack. When we come back together after the break we will talk about your ideas for how you would like to get these types of outcomes information 2 minutes

*BREAK for 10 minutes – Facilitators, come to back room and have quick huddle with study team members. In the huddle quickly determine if there are apparent categories of identified outcomes that should be used in part two of the focus group to structure discussion. Facilitators will also pass signed copies of informed consents to study team. Reconvene the focus group.* 12 minutes

### Health Information (37 minutes, 1 hour 29 minutes total)

#	Question	Estimated Time
	Now that we are starting to understand what you believe are important outcomes, we want to spend some time talking about how you might use information about these outcomes you have listed.	
11	As you look back and reflect, are there any outcomes listed up there that you wish you had known more about before making treatment decisions? Let's go around the table again quickly. <i>(Allow time to discuss. Assistant can mark outcomes pointed out here or make a second list.)</i>	5 minutes
12	Knowing what you know now, what would you have done with that information? For example, if you had more information about <u>(an outcome from the list)</u> , how would it have influenced your decisions? <i>(Allow time for discussion.)</i>	5 minutes
13	Were different outcomes important to you at different times or at different points in your treatment? <i>(Allow time for discussion.)</i>	10 minutes
14	a) What have been your primary sources of information for your top two outcomes you shared earlier? Where did you get the most information about them? <i>(Allow time for discussion.)</i>	5 minutes
	b) Do you feel like you got the information you needed? <i>(Allow time for discussion.)</i>	5 minutes
	Okay, this has been a terrific discussion.	
15	Are there any other comments about outcomes that you want to be sure we capture?	2 minutes

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### Health Information Delivery (25 minutes, 1 hour 54 minutes total)

For our final topic, we want to find out how your ideas and preferences for how best to get these types of outcomes information to you.

Let's look at some of the types of outcomes you have identified....

*(At this time point to some of the QOL type of outcomes; or survival outcomes, etc.)*

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| 16 | When would this information be most important for you to receive? At what point in your care would this information be useful, and how much information would you want?<br><i>(Probes: At what point would this information be useful (at time of initial diagnosis; as initial treatment decisions are being made; during treatment; at the conclusion of treatment?)<br/>(Second facilitator can make note of if patients want information at certain points in care)</i> | 10 minutes  |
|    | “How do you think would be the best way to receive this outcome information? “<br>(Probes if needed:  |             |
| 31 | - “For example, would it be useful if your clinical care providers talked about the outcomes?”  | 10 minutes+ |
| 7  | - What about information on paper you could take home?<br>- Would you find it useful if you could review this information in your own personal electronic health record?”   | 03          |
| 18 | “Would you like to have these outcomes information discussed or reviewed several times?”  | 5 minutes   |

### Conclusions (5 minutes, 1 hour 59 minutes total)

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| 19 | Is there any other information you would like us to know? | 5 minutes |
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### For first few focus groups

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| 20 | We just wanted to say thank you again for your help and participation; you've all given us a lot of really useful insight. We're going to do one more quick exercise and we're going to pass out a brief form about the focus group itself, just so that we can do these in the best way possible for participants. If you could please take a moment and fill out this form and just leave it as your place on your way out, it will help us out tremendously. You don't have to do it, but if you would, we would appreciate it. | 5 minutes |
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Thank you for your time and opinions. Please be sure to take your copy of the signed informed consent for your records and pick up the \$100 check.