

## Appendix A. Interview Guides for Patient and Clinician Stakeholders

### *Patient Interview Guide:*

Thank you so much for meeting with me today. My name is [state name]. As you know, we are here as part of a research study to help understand the kind of information people think is important when making breast reconstruction decisions after a mastectomy. We really appreciate your time and insights. We want to hear about the concerns that people have, and the challenges they may face when making a decision. We're here to learn from you, so anything you have to share is welcome. There are no right or wrong answers to any of today's questions. As was mentioned in the consent form, the information you provide is kept in strict confidence. The transcript that results from today's interview will not in any way identify you. Before we begin, it's important that you understand the context for our questions. Best practice in health care suggests that doctors engage in a process called shared decision making with patients.

**Have you ever heard of the term “shared decision making?”**

**What have you heard about shared decision making?**

[Read after they answer] Shared decision making is a way for patients and their clinicians to work together to reach agreement about a health decision. Often times, there is no clear “best” option for a patient's health condition. Instead, the choice depends on patient values and preferences. For example, for women that are considering a mastectomy with breast reconstruction, choices involve **whether** to have reconstruction, **when** to have reconstruction, and **what type** of reconstruction to have. **Now let's talk more about your experience.**

1. What was your experience with your breast reconstruction decision? How did you make your decision [to undergo breast reconstruction/to not undergo breast reconstruction]?
  - a. What kinds of issues were important to you as you made your decision [to undergo breast reconstruction/to not undergo breast reconstruction]?

- i. Probes: how you felt about your body, how your partner felt about your body, whether you wanted to have extra surgery, worry about whether it would change your cancer treatment, pain, worry about getting an infection or other complications
  - b. Which of these issues were **most** important to you?
  - c. How did you talk about your concerns with your doctors?
  - d. What was the hardest part about deciding [to undergo breast reconstruction/to not undergo breast reconstruction]?
  - e. Who else besides you and your surgeon was involved in making this decision?
    - i. Probes: partner, friends, family members, surgeon(s), oncologist(s)
    - ii. Did you ask anyone else for help making this choice?
  - f. How did those people work with your [breast/plastic & reconstructive] surgeon?
2. Imagine you're in your visit with your doctor, discussing your breast reconstruction decision. What helped you talk about the decision with your doctor?
3. What made it hard for you to talk about the decision with your doctor?
4. Now imagine that your surgeon makes a recommendation about reconstructive surgery, but you disagree with his or her recommendation. What things come to mind when thinking about disagreeing with his or her doctor's recommendation?
  - a. How would you approach the discussion with your surgeon if you disagree with what he or she recommends?
5. Thinking back to your choice, how did your doctors feel about your choice?
  - a. How do you feel about your decision now?
  - b. What information could have helped you during the decision-making process?
  - c. Is there anything you know now that you wish you had known when you were making your decision?
6. **Have you ever heard of the term "patient decision aids"?**

## 7. What have you heard about patient decision aids?

[Read after they answer] Decision aids are tools that help people think about their health choices. They provide information about options, help people think about what matters to them, and help them make a step by step decision. They come in various formats. For example, on paper, online, on video. Some even allow patients or clinicians to personalize information and add their own thoughts or any relevant health information.

8. How would you feel about using a patient decision aid to help make a breast reconstruction decision?
9. When would you have liked to use a patient decision aid during your decision process?
10. What do you think is the best format for these tools? Probe: paper based, online, on video
11. Where else did you look when you were making your decision?

**Wrap-up:** We really appreciate your time and insights. Before we wrap up, is there anything we didn't cover that you think is important for us to know about people making this decision?

### *Clinician Interview Guide:*

Thank you so much for talking with me today. My name is [state name]. As you know, we are here as part of a research study to help understand the kind of information people think is important when making breast reconstruction decisions after a mastectomy. We want to hear about the concerns that people have, and the challenges they may face when making a breast reconstruction decision. We're here to learn from you, so anything you have to share is welcome. There are no right or wrong answers to any of today's questions. As was mentioned in the consent form, the information you provide is kept in strict confidence. The transcript that results from today's interview will not in any way identify you. Before we begin, it's important that you understand the context for our questions. As you know, current guidelines for many medical conditions suggest that you engage in a process called shared decision making with patients.

**Have you ever heard of the term “shared decision making?”**

## What have you heard about shared decision making?

[Read after they answer] Shared decision making is a way for patients and their clinicians to work together to reach agreement about a health decision involving multiple medically appropriate treatment options. Often times, there is no clear “best” option for a patient’s health condition. Instead, the choice depends on patient values and preferences. For example, for women that are considering a mastectomy with breast reconstruction, choices involve **whether** to have reconstruction, **when** to have reconstruction, and **what type** of reconstruction to have. **Now let’s talk more about your experience.**

1. How do you generally counsel women about this decision? How do you tell the patient that there is no clear best option, and that the patient has a decision to make?
  - a. What kinds of issues do you make sure patients understand about the options?
    - i. Probes: how the patient feels about her body, number of procedures, whether it will change cancer treatment, pain, risk of complications
  - b. Which of these issues are the **most** important to discuss?
  - c. How do you generally communicate risks and benefits of options? How do you communicate numbers?
  - d. When you provide patients with potential risks and benefits for different treatment options, what information is this based on? Probes: Literature? Prior Experience?
  - e. How do you generally elicit patients’ values and preferences for options?
  - f. How do you work with other clinicians such as the patients’ breast surgeon to talk about options?
  - g. How do you work with the patients’ family members, if relevant?
2. Imagine you’re in the visit with the patient, discussing their breast reconstruction decision. What factors or circumstances enable you to engage in shared decision making with the patient?
3. What factors or circumstances would make it difficult for you to engage in shared decision making with the patient?

4. Now imagine that even though you know there is no clear best option from an evidence standpoint, based on what you know, you recommend one option for your patient because you think it is the best option for that person. But your patient disagrees with what you recommend and tells you that.
  - a. What things come to mind when thinking about your patient disagreeing with your recommendation?
  - b. How would you feel if your patient told you that he or she disagrees with your recommendation?
  - c. How would you approach the discussion with your patient if your patient disagrees with what you recommend?
5. **Have you ever heard of the term “patient decision aids?”**
6. **What have you heard about patient decision aids?**

[Read after they answer] Decision aids are tools that help people think about their health choices. They provide information about options, help people think about what matters to them, and help them make a step by step decision. They come in various formats. For example, on paper, online, on video. Some even allow patients or clinicians to personalize information and add their own thoughts or add any relevant health information.

7. How would you feel about using a patient decision aid for breast reconstruction decisions with your patients?
8. When is the best time to give patients a patient decision aid?
  - a. When could you use a decision aid with your patients?
9. What do you think is the best format for these tools? Probe: paper based, online, on video

**Wrap-up:** We really appreciate your time and insights. Before we wrap up, is there anything we didn't cover that you think is important for us to know about people making this decision?