**Interview Guide – Patients and Caregivers**

**Hospice Decision Aid**

**2017**

Ground Rules

Before we begin, let me mention a few things about how we usually run these groups.

1. NAME and I will be facilitating the group discussion. My role is to ask questions of the group and to encourage everyone to participate. This should be a conversation with me doing very little talking
   1. So, at times, it might seem as though I am cutting you off, and this is not meant to be rude but rather to make sure that we have time for complete discussion of each question.
2. It’s really important that everyone know this: there are no right or wrong answers! Everyone comments are valid and important. It is ok to disagree but please be respectful.
3. Sometimes participants bring up sensitive issues during these discussions, and we want to be sure that everyone agrees that anything of a personal nature that is mentioned in this room will NOT be repeated to others outside of this discussion group.
4. We are using 2 recorders to record our discussion. To ensure your privacy. We’ll be using only first names in the group discussion, and when we put together the results from all the groups, we won’t include any names at all.
   1. It is very important that we speak one at a time, so that the recorder picks up everything that is said.
   2. Please try to limit side conversations.
   3. If anyone is not willing to give their consent to being recorded, they may be excused from the group.
5. We also have note cards for each of you. I will collect these at the end of the session. If there is any feedback that you would prefer not to share out loud, that you prefer not to be recorded, or that you didn’t have a chance to say, please write it down on these cards and then give them to us after the focus group is over. *(Pass out notecards.)*
6. Once the discussion has ended, you will receive a $25Target gift card as our thank-you for participating in the group. We will need to get your signature to show that you received the gift card.

Questions

Does anyone have any questions about anything I’ve just said? *(Wait for responses.)*  
Are you ready to get started? *(Wait for affirmation.)* Okay, great. Here we go!

**(Start recording)**

State “Patient/Caregiver Hospice Focus Group # [date]

Question Guide

**Research question:**

**What information about hospice care is important to patients, caregivers, and providers and should be included in a hospice decision aid?**

Before we begin, I want to tell you how we are defining “hospice” so we are all on the same page. I’ve written it up here so you can refer to it as needed: “DEFINITION.”

“Hospice is a treatment philosophy. Its goal is to provide care that focuses on providing comfort to seriously ill patients. Hospice does not cure disease but provides pain and symptom management and emotional and spiritual support to patients and loved ones.”

**MAIN TOPIC-Feelings/Opinions**

1. Introductions/experience with hospice.

1. Briefly, 1 to 2 minutes, tell me about your experience with hospice
   1. Who, When, Where, How long

**MAIN TOPIC-Learning about hospice**

2. How did you learn about hospice as a treatment option? How did you feel about hospice as a treatment option?

**MAIN TOPIC-Making the decision**

3. How did you make the decision?

4. What information do families need to know before they make a decision about hospice? Please give me 2 or 3 things

5. Where there any assumptions you had about hospice that you later found not to be true?

**MAIN TOPIC-Informational material**

6. How does this compare to other materials you have seen?

Conclusion

Thank you so much for your time today.