

## In-Depth Interview Guide

### Introduction

My name is \_\_\_\_\_. Thank you so much for helping us today. I would like to ask you a few questions about your thoughts and experiences as the family member (or friend) of a patient in the intensive care unit who is not able to make decisions for him/herself. We are trying to develop a support tool for family members facing decisions for a loved one in the ICU. Thus, our goal is to come up with ways to support family members in this difficult time. There is no right answer to these questions, and your responses will be completely confidential. This interview will in no way affect your loved one's care. As you recall, you gave us permission to audio-record this conversation. We can stop the interview at any point if you feel uncomfortable or do not wish to continue. Also, feel free not to answer any question that you would prefer not to.

### 1. General Experience

To begin, tell me a little bit about how the experience of having a loved one in the ICU has been for you.

What has been hardest for you?

Probes: Can you give me an example?

Tell me more about that.

Can you tell me about a specific decision you have faced for your loved one?

- Can you walk me through that process?
- Can you tell me about a decision you anticipate facing for your loved one in the near future?
- Tell me more about that decision you anticipate facing.
- What [particular] decision are you most worried about coming up in the future?
- How did the doctors talk to you about that decision? What was happening?
- Did you ever think of any alternatives?
- Did the doctors present any other options?

*Not making decisions:*

- Why didn't that feel like a real decision?
- Why did you want that? Why do you think that's best [for  X  ]?

### 2. Support/Resources

Tell me about how you are coping during this time.

What challenges or barriers do (did) you face in making  [mentioned]  decision for your loved one?

- Tell me more about that.

What do you think would make this experience easier for you?

What special sources of support have you found in making decisions for your loved one?

- Tell me more about that.
- What else has been helpful? (providing support)

### 3. Surrogate Role

How do you see your role in making decisions as a family member?

How have the doctors described your role in decision making (making the decision to  X )?

- Tell me more about that.

How comfortable do you feel in your role making decisions as a family member (or friend)?

- What makes you feel comfortable (or uncomfortable) in this role?

### 4. Knowledge

Tell me about the information you have to make decisions for your loved one.

What kinds of information would you like to have?

- Can you elaborate on that?

Where have you turned to learn the information you feel you need to best help your loved one?

Tell me about how you decide what information to trust or believe.

### 5. Values

When making decisions for your loved one, are there certain values or beliefs that are important to you?

- Tell me more about that.
- What does  X  mean to you?

How do you think your values/beliefs are influencing your decision making?

- Is it ever challenging to be clear about your values/beliefs?
- Why do you think you might feel this way?

What do you think is most important to your loved one?

- *Why* do you think  [mentioned item]  is most important to him/her?

How clear do you feel about what is most important to your loved one?

- Why do you feel this way?
- What would help you to feel clearer?

## 6. Other Aspects:

As you know, we are trying to develop a support tool for family members facing decisions for a loved one in the ICU. What do you think might be most helpful for that purpose?

If you could make one recommendation to the hospital, doctors, or staff to improve your experience as the family member of a loved one who is unable to make decisions for him/herself, what would it be?

Is there anything else that you think we should know about your experience?

Thank you so much for your time.

### Supplement – Probes useful for several question areas:

*Participant upset by line of discussion:*

- That sounds like it's complicated, but can you tell me more ...?
- I know that this can be difficult, but can you tell me more about ...?
- I can see this is hard for you, but can you tell me more about ...?

*Participant referring to patient dying, but not openly discussing:*

- What if [patient] doesn't get better?
- What makes you think that [patient] will get better?

*Clarification (of vague, "understood" term):*

- Tell me what you mean by that.
- Help me understand what you mean when you say XX.