

Subject #: \_\_\_\_\_

**Script for innovations of organ donation interviews:**

Introduction: My name is \_\_\_\_\_, and I am a researcher. Thanks so much for joining me here today. First, I would like you to know that while I help to study organ donor families like yours, I am not a transplant surgeon or a nurse. I also want you to know that I do not know anything about your loved one's donation history or your background other than what you tell me today.

You have been asked to participate in this survey because your [insert X-relationship here (son/mother etc.)] attempted to donate his (or her) organs but was not able to. Our research team is interested in finding out about your experience and what you think about current and future organ donation practices. We recognize that this can be a sensitive subject and some family members may feel uncomfortable discussing these topics. Please let me know if you are uncomfortable or would prefer not to talk about these subjects, either now, or anytime during the interview. This isn't a quiz; there is no right or wrong answer, we would just like to hear your thoughts and feelings. If our conversation today does bring up specific questions about organ donation that I cannot address, I will help you get in contact with the appropriate people who can answer your questions.

I'd like to record our discussion so that I don't miss anything. Your name will not appear in any reports or publications. Your comments here today are strictly confidential. I'll start the recorder now.

Is it OK if we get started? Please let me know if you have any questions or concerns, now or during the interview.

[INTERVIEWER STARTS RECORDING]

**DOMAIN #1: Story of attempted organ donation**

**Question 1:**

To understand more about the organ donation process, we are interviewing people to learn about their experiences. Everyone we are interviewing has had a similar experience to you, where their loved one tried to donate but was unable to.

Am I correct that it was your [RELATIONSHIP – e.g. son, grandmother] who attempted to donate his/her organs?

[AFTER CONFIRMATION] I'd like to talk about your [RELATIONSHIP] today. How should I refer to your [RELATIONSHIP] in our conversation? [e.g., "Alan," "your grandmother," etc.]

1.1 To start, could you tell me about what was happening at the end of [X's] life that led up to him/her becoming a potential organ donor.

**PROBES IF NOT COVERED IN THE STORY OF ATTEMPTED ORGAN DONATION**

PROBE 1.1a How did you come to decide to have X become an organ donor?

PROBE 1.1b Who helped you come to a decision about organ donation for X?

PROBE 1.1c How did your other family members feel about the decision to have X become an organ donor?

**Question 2:**

2.1 Thinking back to that time, what was important to your X about donating organs?

2.2 What was important to you about donating your X's organs?

2.3 Some family members have told us that donating their loved one's organs was a way to help remember him or her. Was that part of your experience? Why or why not?

**Question 3:**

The next questions ask about things that happened after your X was not able to donate his/her organs.

INTERVIEWER NOTE: THE OBJECTIVE OF QUESTIONS 3.1 AND THE PROBES THAT FOLLOW IS TO ACKNOWLEDGE THE EMOTIONS AND THEN TO GO BEYOND THE EMOTIONS TO DISCOVER IMPACTS/HARMS (E.G, ORGANS WASTED, NO GOOD CAME FROM IT, ETC.)

3.1 How did it impact you when it became clear that your X could not donate his/her organs?

PROBE 3.1a: How did you feel when it became clear that your X could not donate his/her organs?

PROBE 3.1b: It was clearly very upsetting when your X was not able to donate his/her organs – What other harms, if any, came from your X not being able to donate?

3.2 When your X was not able to donate his/her organs, how did this impact other family members?

**DOMAIN #2: Knowledge about the process and what was understood at the time of donation**

For the next few questions, I'd like to find out more about how you understood the process of organ recovery at the time of X's donation. I want to emphasize that there are no right or wrong answers to these questions – we're just interested in what your understanding was when you were going through this experience. And I recognize that time has passed and some things may be difficult to recall, so whatever you want to say here is fine.

1.1 My first question is this: At the time of X's organ donation, what was your understanding about when and how people can donate organs?

PROBE 1.1a: Do you recall there being any medical limitations on when and how organs could be donated?

IF YES: What were those limitations?

PROBE 1.1b: Do you recall discussing anything with the medical staff about having to wait until X's heart stopped before recovering his/her organs?

IF YES: What did you discuss?

I'd like to clarify a little about what I mean when I am talking about when and how people can donate organs, so I can be sure we are on the same page. There are 2 ways.

In the first way, the brain is determined to be dead based on technical measures and the organs are removed when the heart is still beating.

In the second way, the brain has not met all the criteria for "official brain death" so doctors stop the life support and wait until the heart stops beating before they remove the organs. Because doctors have to wait for the heart to stop beating, they cannot use all of the organs, for example they cannot use heart and lungs, like they can when the person is "officially brain dead." Also, when they have to wait for the heart to stop, the organs that the doctors can remove and give to other people are not as strong because they get damaged during the time it takes for the heart to stop. And, when it takes too long for the heart to stop, doctors cannot use the organs in someone else at all because they are too damaged.

1.3 Do you recall being aware of these 2 ways to donate organs?

IF YES: In the case of X, he/she was not officially brain-dead, so he/she attempted to donate in the second way I described. How did you feel about X being a donor who was not officially brain dead?

IF NO: GO TO 1.4. (AND SKIP 1.5)

1.4 Do you recall being aware that patients who are not "officially brain dead" cannot donate all of their organs?

IF YES: How did you feel about the fact that X was not officially brain dead and was therefore unable to donate all of his/her organs?

IF NO: How do you feel now about the fact , that patients who are not “officially brain dead” cannot donate all of their organs?

1.5 Do you recall being aware that waiting for the heart to stop can harm the strength or quality of the organs from the donor?

IF YES: How did you feel about the possibility that the strength and quality of X's organs could be harmed by waiting for his/her heart to stop, because he/she was not officially brain dead?

DELIBERATIVE BRIEFING: Before we get to our next set of questions I would like to recap these details about organ donation, because it's pretty complicated. First, I'd like to give you this card, which shows 2 different ways of organ donation. [INTERVIEWER: HAND OVER THE

Donation after Brain Death

- Brain has died but the heart is still beating
- Organs from brain-dead donors are removed while the heart is beating
- Donation after brain death is more common than donation after circulatory death
- Donors can typically give all organs including heart, lungs, liver, and kidneys

Donation after Circulatory Death

- Brain has not died completely
- Doctors wait until the heart stops beating to recover organs
- Organ donation not always possible because the heart keeps beating for a long time after life support is stopped
- Donors can typically only give liver and kidneys, not heart or lungs
- The liver and kidneys are not as strong as when provided from brain-dead donors

SHOWCARD NOW]

As the card notes, there are 2 ways organ donation can happen: donation after brain death and donation after circulatory death.

Donation after brain death means that the person's brain has died, and is officially declared dead, but the heart is still beating. The organs from brain dead donors are removed while the heart is still beating. Donation after brain death is a more common method for organ donation and donors can typically give all organs including heart, lungs, liver, and kidneys.

Donation after circulatory death means that doctors will need to wait until the heart stops beating to recover the organs. This happens when people want to donate, but the person who is dying does not have official brain death. In this case donation is not always possible because the heart

keeps beating for a long time after life support is stopped. The dying person's organs cannot be given to another person because they get damaged during this process. Even when the heart stops in time to allow donation, doctors can only use liver and kidneys, not heart or lungs, and the liver and kidneys are not as strong as the organs from brain dead donors. This scenario, where willing donors are unable to donate, does not occur when the donor is officially "brain dead."

Does this make sense to you? Do you have any questions about this?

*IF KEN CANNOT ANSWER THE QUESTIONS:*

Unfortunately, because I am not a doctor or a nurse, I cannot answer all of your questions on this topic. If you want more information about this I am happy to connect you with people who can help you learn more.

INTERVIEWER: IF R FULLY UNDERSTOOD DOMAIN 2 Qs 1.4 AND 1.5, SKIP THE FOLLOWING TWO QUESTIONS:

**Question 2:**

2.1 As I mentioned earlier, the organs recovered from donation after circulatory death are not as strong as organs recovered from donation after official brain death. How do you feel about the fact that organs recovered after circulatory death are not as strong?

2.2 I also mentioned earlier that donors after official brain death can give all their organs – heart, lungs, liver and kidneys – but donors after circulatory death can usually only give their liver and kidneys, not their heart and lungs. How do you feel about the fact that a donor after circulatory death cannot donate as many of their organs?

**DOMAIN #3: opinions about innovations in organ recovery**

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Next, we would like to ask you about some new ideas to recover organs from people who are dying. These are not things that are currently being done in Wisconsin, or in any other state, in fact they are subject to debate. We are simply trying to understand your views on potential changes to the organ donation process, given the experiences you have had.

I am going to start by describing a scenario about a hypothetical patient. [INTERVIEWER: CHOOSE GENDER AND ILLNESS DIFFERENT FROM X'S] This is about a woman (man) named Jamie. She (he) (was in a serious accident and had a terrible head injury)/(had a horrible stroke that caused very serious brain damage). It is clear her (his) brain will never recover but she (he) does not meet the official criteria for brain death. Her (his) family feels it is very important for her (him) to donate her (his) organs. Because Jaime is not officially brain dead, the doctors are required to wait until Jamie's heart stops beating before they can begin to recover her (his) organs. The doctors are worried that Jamie's heart will not stop in time for her (his) organs to be recovered successfully, and that even if her (his) heart did stop in time, the organs will not be as good.

**Question 1:**

Now I have some questions about Jaime:

- 1.1 What would you think about removing a kidney from Jamie, who is not officially brain dead, before her (his) heart stops?

PROBE: What would you think about this morally?

PROBE: As I mentioned, the current practice is that doctors wait until the heart stops beating to recover organs because they are concerned about the morality of removing organs from someone whose heart is still beating but who has not been declared

officially brain dead. If Jaime's kidney were removed while her (his) heart was still beating, what would you think about this morally?

1.2 If your X were here today, what would he/she say about removing Jamie's kidney before Jamie's heart stopped?

1.3 How do you think your family would have felt about your X donating a single kidney before the doctors stopped life support?

1.4 If Jamie died during the surgery to remove her (his) kidney, how would you view this morally?

**Question 2:**

I am now going to ask about another possibility for Jamie. All of her (his) organs are healthy and would help sick people who need them if they can be removed while the heart is still beating. It is clear that Jamie's brain will never recover, but she (he) does not meet the official criteria for brain death. The doctors think her heart will not stop in time for her organs to be used in other people. Hypothetically, the doctors could remove all of her organs before her (his) heart stops. Because they will remove her heart, she will be dead after they do this.

2.1 Knowing that removing all of Jamie's organs would lead to her (his) death, how would you feel about that?

PROBE: What would you think about this morally?

2.3 How do you think your family or people in general would think about having all of Jamie's organs removed even though this would lead to her (his) death?

PROBE: How would they think about it morally?

ONE FINAL QUESTION:

1. I have one last question for you: From your perspective as a family member, what could be done to improve the organ donation process?

Thank you for taking the time to meet and discuss your thoughts and feelings with us. We recognize that this interview may have brought up some new questions about organ donation. Is there anything I might be able to answer for you now?

I cannot answer that question, would you like me to have someone contact you about this to help get your questions answered? Record: YES/NO

Your participation is greatly appreciated and we want to give you a gift for your time (hand out gift card). If you have any questions or concerns after you leave today, please do not hesitate to contact either your surgeon or me or any member of the study staff (hand out post-interview contact sheet). You can call or email us at any time.