

APPENDIX A Interview Guide

An investigation of the experiences and perspectives of family members of ICU patients who underwent organ donation decisions

Family Members Interview Guide

Participant ID: _____

Interviewers Name: _____

Date: _____

Time started: _____ Time completed: _____

1. Introduction

- a. Introduction of facilitator
- b. Thank participant for their participation
- c. Who we are?
- d. Purpose of the Needs Assessment
- e. Ethics approval and Informed Consent
- f. Strict confidentiality
- g. Taping of the interview for purpose of data collection

First of all, I would like to thank you for your participation and for sharing your experience and perspectives with our team. The results of this study will inform the development of an educational program for critical care residents, who will become ICU doctors in practice. We greatly value your opinions and thoughts. If at any time you feel uncomfortable or if the feelings these questions evoke are overwhelming, we can take a pause for you to collect your thoughts. Just let me know if you want to pause for a moment and please also note you may end this interview at any time.

2. Would it be ok if called ___ by their first name during our conversation?
3. Encourage them to tell their story (*Note for interviewer to be sure to probe more specifically to NDD vs DCD issues depending on case*)
 - a. Could you first start by telling me about your experience during this time in the ICU?
 - ii. *Probe: Can you tell me for what reason your loved one had to be admitted to the ICU? If Pre ICU experience: Can you tell me the event that still stands out in your mind prior to arriving at the ICU?*
 - b. Let's talk about your communication with the health care professionals (Doctors, Nurses, etc.) throughout this time?
 - i. When [name] was first admitted to the ICU?
 - ii. As his/her condition worsened or did not improve?

1. *Probe - How did you find out [name's] condition was getting worse?*
- iii. Can you describe how you learned that [name] was going to die / or may be brain dead?
 1. *[As appropriate] Was there any conversation about [Poor prognosis / end-of-life / Withdrawal of life sustaining therapy / Death]? Can you tell me what you recall about these discussions? Who discussed brain death with you? How was it discussed? Did they discuss what brain death meant? Or how the declaration was done? Were you given or did you seek any other information – i.e., website or booklets?*
 2. Can you recall if there were separate conversations about the fact that [name] was not going to make it and about organ donation?
- iv. Can you tell me about the care [name] received at the end of their life?
- v. Can you tell me how you came to thinking about organ donation?
 1. *Probes – Did yourself or family member request to discuss or was it brought up by the health care team?*
- c. Do you recall who first spoke with you about organ donation? When did this discussion occur?
 - i. *Probes - Physician? Nurse? Organ Donation Organization (ODO) Coordinator? What do you remember most about being asked about organ/tissue donation? Did the organ donation discussion occur separate from an end-of-life care discussion? Was what to expect during the donation process explained to you?*
- d. Is there something particular that stands out in your mind as to why you decided to donate / not donate [name's] organs?
 - i. *Probes - Do you recall if [name] had a registered donation decision? Did you know [name's] wishes regarding organ donation? What were your views on donation? Had you previously had previous open discussion on death or was this not discussed? If not discussed, why do you think it was not discussed? Do you feel any person / factors had an effect on your decision? Do you feel that religious or cultural beliefs influenced your decision? Do you have trust in the medical system? in the organ donation system? Did you feel pressured by medical personnel (MD, Nurse, OTDC) or family members either to donate or not donate? How did this impact your decision?*
- e. For those who consented: Do you recall completing the medical questionnaire for organ donation? If yes, what were your thoughts on this process?
 - i. *Probes - Do you recall discussing and then giving your consent for [name] to be an organ donor? If so with whom? How did you feel being*

asked the many questions about your loved one? I.e., their life, habits, health, sexual habits, drug use?

f. Following this, were there any more discussions about organ and tissue donation? Once [consented or declined] can you tell me about what happened next?

4. Receiving information

a. Can you tell me how different members of the health care team talked about or explained organ donation to you?

i. Probes - Doctors? Residents? Critical Care fellows? Nurses? ODO coordinator? Can you remember how they were different?

b. Did you ever have problems understanding what was being said to you?

i. About what was happening? Or what to expect? Was it difficult to remember information given to you?

c. Would you have wanted more information at this time? What about now, thinking back to those conversations, are there things you now think would have been good for you to know?

i. Probe: What other things would be useful to help support them at the time? Written materials to take away? Someone to stay with them? Having things explained in a different way?

d. Did you feel you were being listened to? Did you feel the team cared about you and [name/ your loved one]?

e. Do you recall any confusing or contradicting information or was the information consistent?

5. Conflicts

a. Do you recall if there were any differences in opinion between you and your family members (or amongst other family members) regarding organ donation?

i. If so, can you describe the nature of such conflict?

ii. Was the conflict resolved? If so, how?

1. Probe: Did any members of the health care team or ODO coordinator help you or give you any tools that helped?

6. Support / Emotional Support provided

a. Can you describe any support received during this time?

i. Probes: Who provided support (Let them tell you whether it was emotional or practical etc.) Do you feel you received an appropriate level of support? Did you have a support person with you?

ii. Do you wish you would have had more support? If so, can you describe what would be most helpful?

7. Critical Care Resident Training

- a. Do you remember the residents / trainees being present? If so, what was your impression of them? Were you introduced to them? Were they involved in the care of your loved one? Do they think that residents should be talking to families about donation?
 - b. Can you tell me about anything you wish your doctor had told you or done for you during this time? (time can be the whole spectrum of this experience)
 - c. Can you think about anything the doctors did or said at the time that if you could, you would want to tell the doctor to keep doing with other families?
8. Post-Donation Decision
- a. For those who consented to **DCD**, can you tell me about the withdrawal of life support process?
 - i. *Probes: Did the medical team prepare you for the withdrawal (e.g., [name] might gag, etc.?) Where did the withdrawal occur? Monitors on/off, privacy/private room, how quickly you had to say good bye? Did you feel this occurred too fast or too slow? How did this/or didn't it affect you? Did you want to see the body post donation? **Did someone stay with you at WLST or when [name's] body was taken away?***
 - b. For those who consented to **NDD**, can you tell me more about the organ donation process after your consented?
 - i. *Probes: How was the timing of the process? Was it too long or too fast? How did this/or didn't it affect you? Do you recall when your loved one was taken to the operating room for organ donation? **Was someone with you after?** Who was with you? How did you feel? Did have any feedback from the team following the organ retrieval? Did you want to see the body post donation?*
 - c. For all – Looking back on the entire process, would you make the same decision for [name]?
 - i. *Probe: If not then - why and what could have been done differently?*
 - ii. *If negative lasting impact, what do you think could help alleviate your angst?*
9. Post-ICU
- a. Can you tell me about how things were for you when you left the hospital?
 - b. Any particular supports that helped you?
 - c. Any suggestions on what would have helped you during this time?
 - i. Can you comment if you received follow up from your ODO?
 - d. For those who donated, did you learn anything about the recipients? If yes, what (e.g., letter from them or some info from the ODO?)
 - e. Overall, how has this experience impacted you? Any specific positive or negative lasting impressions?

Probe: Any negative impacts? Such as lingering unanswered question; regrets; depression; stress. Any impacts on your family life, between family members? If unanswered questions: what are they, how could they be addressed, and do these unanswered questions change your opinion about donation

10. Participation in Interviews
 - a. When do you think is the most appropriate time to call family members for an interview?
 - i. Probes: After 1, 2, 3 months or 1, 2, 3 years
 - b. How did you feel about being asked to participate in this interview?
 - i. Was the letter helpful? Was the call from the ODO helpful?
11. Additional comments?
 - a. That concludes my questions. Is there anything else that you would like to add?
12. Request for a follow up call
 - a. Would it be ok if I called you for a follow up?

If yes – what day / time would be best for you? _____
If no – thank for their time

13. Overall - Areas of Improvement / Strengths
 - a. What do you remember most about your time in the ICU?
 - b. Think about your time at the hospital, what (if anything) stands out in your mind that could have been improved If so, any potential solutions?
 - c. Any comments on what the team did particularly well?
14. Consented but not recovered
 - a. How did you find out that [pt.'s name] was not going to be able to donate?
 - a. Was this explained to you? If so, how? Were you able to speak to a doctor? If no, would you have wanted to?
 - b. Were you given information on why they could not donate their organs? Who answered your questions? Did you have any unanswered questions?
 - c. Were you given support?
 - d. How would you describe the care of your loved one after learning that they could not donate?
 - e. After this experience, are you still comfortable with your decision to donate?
 - a. Has this experience impacting your grieving? Has it exacerbated your grieving?

- f. Did you have any follow up after? With the ODO? If so, how did you feel about that? If not, would you have liked follow up? What kind of follow up? I.e., letter, meeting, call?
- g. Is there any advice you can give to the health care team looking after family members who also have consented but their loved one was not able to donate? Improvements?

Our sincerest thanks for your time and important contribution to this research