

## Appendix A

### Interview Guide: Shared Decision Making in Renal Supportive Care

#### Moderator:

- Introduce self and other research team member(s).
- Express appreciation for participation in study.
- Explain overall study purpose/goal of today's interview.
- Note that we are recording answers so we don't miss any details and that no identifying information will be included in written transcripts so none of what is shared can be traced back to participants.
- Remind there are no right answers; we want to find out what people really think and feel about this subject.
- Acknowledge that patients and families may have different opinions about the topics we are discussing and we hope everyone is able to respect those differences.
- Remind participants may decline to answer any question and may stop their participation at any time.
- Provide a reminder to please let whomever is speaking finish his or her thoughts before we move on to the next person's input.
- Let us know if they would like a break and we can pause at any time.
- Ask if there are any questions before starting,

#### Interview:

1. I would like to start by having you tell me a little bit about yourself/yourselves.  
(Warm-up)
2. Thank you. Now I would like to ask what your understanding is about where you are with your kidney disease.
3. Now could you tell me a little bit about what living with kidney disease has been like for you and your family. (Prompt memories of first being told about the diagnosis, changes in work, activity, relationships)

Ask family (if present) for their thoughts after patient for each question.

4. Thank you. Now, I'd like to ask how you feel about the communication between you and your dialysis team. (Prompt positive/negative, what has made it good or needing improvement )
5. Now if you could tell me a little about how much you want to know about what likely lies ahead with your illness. (What could be good about talking about this? What might be difficult?)
6. Have you had a chance to discuss what likely lies ahead with your team?

(If yes) Please tell us about this discussion. (Probe who/where/when/what worked/what didn't/what would be better)

(If no) Do you feel this is something you would like to have the opportunity to discuss or might you prefer not to? (probe why or why not/why do they think it hasn't been discussed yet)

7. Have you had a chance to think about what your most important goals are if your health situation worsens?

(If yes) Can you share your thoughts about this? (Probe any actions taken to make wishes known)

8. Thank you. Now I'd like to know whether you have had a chance to discuss your goals of care (define) with your dialysis team?

(If yes) Could you tell me about that experience? (Probe who/where/when/what worked/what didn't, what options were discussed such as hospice, DNR, DNH/how could do better)

(If no) Do you feel that you would like to have the opportunity to discuss your goals? (If yes) How would you prefer these discussions be carried out? (Prompt timing, who would initiate, with whom discussions occur, whether the option of hospice should be part of discussion).

9. Thank you, this is very helpful. Now I would like to get your feedback on the plan for the intervention part of this study that will take place later this year.

All patients who participate in the second part of this study will have an opportunity to meet with a member of the social work team to discuss the status of their kidney disease and their goals if their health situation worsens.

What should the social worker know about the patient before the meeting?

Who else should be there?

Where should it take place?

How should the research team follow up after the first discussion?

10. Thank you. Do you have any other thoughts you'd like to share that you think may help dialysis care teams do the best job possible talking to patients about what likely lies ahead with their kidney disease and their goals of care if their health situation worsens?