Appendix: Interview script

Question	Probes
Can you briefly tell me the story of your kidney disease?	How did you learn that you had a kidney problem? What kinds of treatments have you received for your kidney disease? How has your kidney disease impacted the rest of your life?
What kinds of medical decisions have been made about your kidney disease at different points in time?	Decisions about diagnostic tests, procedures, different treatments?
In making these decisions, did you rely on family members or health care providers or both?	Spouse, friends, caregivers, physicians?
We'd like to understand what could be changed to provide better support for people facing tough decisions about tests and treatments. Can you tell us about anything that, in your experience, made it easier or harder for you to deal with these decisions?	
What do you know *now* that you wish you knew *earlier* about your kidney disease?	Life expectancy, symptoms, medications, changes in lifestyle, types of treatments (dialysis)?
Looking back from the vantage point of today, are there any decisions you made about tests or treatments that you might have made differently if you had known more about what would happen with your health?	Decisions about medications, diagnostic tests or procedures, treatments like dialysis or kidney transplant?
What would you most like to know *now* to help you make plans for the future?	Concerns about your future health, future medical treatments, life expectancy?
Have you heard of the term 'Advance Care Planning' (also called Advance Directives or a Living Will)?	If yes: "can you tell me what you know about advance care planning?" If no: "advance care planning is a term that describes an approach to medical decision making. It involves talking with family, friends and providers about who you would want to help make decisions for you and the kind of care you would want if you became very ill and could not tell us what you wanted." Does this sound familiar now? The rest of the questions will be about advance care planning.
***What type* of advance care planning have you done?**	Nothing done yet (if so why not), Living Will, Advance Directives, Appointing Durable Power of Attorney?
***Who* helped you with this planning?** *(if not done yet, skip to next question)*	Medical staff (your doctors), family/caretakers, social workers, church or others?
***Who* do you think *should be* involved in advance care planning? Why do you think this person (these people) should be involved?**	Primary care provider, nephrologist, nurse, social worker, family/caretakers, friends, church or others?
Have any of your family members, caregivers or friends done advance care planning?	Did their experience with advance care planning prompt you to do advance care planning for yourself? When you did your advance care planning did others do it too?

Can you tell me how you think 'advance care planning' might be *helpful* for you, or why it might not be helpful for you?	
Reflecting on your own experience, *when* during the course of your disease do you think information about advance care planning would have been important?	At the time of diagnosis, when you need to make decisions about treatments, when you begin to feel ill, when you are facing a life threating event?
***Where* do you think advance care planning should be discussed?**	At the hospital/clinic, at home, at church?
***How* would you like to receive information about advance care planning?**	Conversations with providers, one-on-one training, written materials (work-books, brochures, etc.), videos (DVDs), computer or on-line websites?
Now, this is your chance to tell us anything else about advance care planning that you think is important or we have not covered.	