

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

Appendix: Interview script for family members and friends

#	Question	Prompts
1.	Can you briefly tell me the story of your family member's (friend's) kidney disease?	How did you learn that your family member (friend) had a kidney problem? What kinds of treatments has your family member (friend) received for their kidney disease? How has their kidney disease impacted the rest of their life?
2.	What kinds of medical decisions have been related to their kidney disease or serious illness at different points of time?	Were there decisions about diagnostic tests or procedures? Were there decisions about different treatments? If you were NOT involved in these decisions, why not? Did you feel left out of the decision making process?
3.	Who did your family member (friend) with kidney disease rely on to make these decisions?	You? Other relatives? Healthcare providers?
4.	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 harder or easier for your family member (friend) with kidney disease to deal with these decisions related to serious illness?	
5.	What do you know now that you wished you had known earlier about your family member's (friend's) kidney disease that might have helped them make better medical decisions?	Symptoms? Changes in lifestyle? Life expectancy? Medications? Types of treatments such as dialysis? Impact of kidney disease on other aspects of your life or theirs?
6.	Looking back from the vantage point of today, are there any decisions that your family member (friend) made about tests or treatments that you think might have been made differently if they had known more about what would happen with their health in the future?	Decisions about medications? Diagnostic tests or procedures? Treatments like dialysis and kidney transplant?
7.	What would you most like to know now in making plans for the future for your family member (friend) with kidney disease?	What are your greatest concerns for your family member (friend) about their future health? Future medical treatments?

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<p>Have you heard of the term 'advance care planning' (also called Advance Directive or Living Will)?</p> <p>If yes: can you tell me what advance care planning means to you, in your own words?"</p> <p>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 the patient would want to help make decisions for them and the kind of care they would want if they became very ill and could not tell us what they wanted.</p> <p>Does this sound familiar now?</p> <p>Has <u>your family member (friend)</u> done any ACP (and what types: Living Will/AD, DPA)?</p> <p>Have <u>you</u> done any ACP (and what types: Living Will/AD, DPA)?</p>		
8.	Can you tell me whether you think advance care planning might be helpful or unhelpful for your family member (friend) with kidney disease? Why or why not?	Less stress about uncertainty? Fulfilling their wishes? Helped others in the family to make their own ACP? Scary? Not ready to think about end-of-life? How is ACP helpful or unhelpful for you?
9.	Reflecting on your family member's (friend's) experience, when during the course of their disease, do you think information about advance care planning would be important?	At the time of their diagnosis? When they need to make decisions about treatments? When they begin to feel ill as a result of your kidney disease? When they are facing a life threatening illness?
10.	One question we have about advance care planning is where might be the best place to discuss these matters. Can you tell us, where do you think ACP should be discussed?	At a clinic? At the Hospital? At home? In a church or religious setting?
11.	What kinds of formats do you think would be the best way to deliver information that might help your family member with advance care planning?	Conversations? One-on-one training? Written materials?

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		Video? Work book? Computer or online?
12.	Who do you think should be involved in discussing ACP with your family member (friend)?	Their doctor? Medical staff? (specify type) Family? Friends? Religious leader? Social Worker?
13.	Do you have anything else you want to share?	