

Appendix A: Patient Interview Protocol

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Introduction (5 minutes)

Hello. My name is *[interviewer name]* from Insight Policy Research, and I want to thank each of you for taking the time to talk to me today about your experiences learning about and accessing care for your kidney disease. I'm joined on the call by *[note taker name]* from Insight, who will be taking notes during the call.

Insight was hired by the Centers for Medicare & Medicaid Services, the agency that handles Medicare and Medicaid, to learn about the care patients with kidney disease receive.

Informed Consent

Before we get started, I would like to go over some information about how we will handle the information you share with me today:

- ▶ Your participation today is voluntary. You don't have to answer any questions you don't want to answer. After the call, you will receive \$50 as a thank-you for your time.
- ▶ What you say on this call will be considered private. We will summarize what we talk about today and put it together with information we will gather from other calls just like this.
- ▶ Nothing you say will ever be linked to your name, and nothing you say will affect your Medicaid or Medicare benefits if you currently receive them.
- ▶ We will use the information you share with us for research purposes only.
- ▶ All information identifying you is stored securely and will be destroyed at the end of the study.
- ▶ We expect that this call will take about 60 minutes.

You should have received an attachment to the email confirmation for the interview that covers this information. That document also includes contact information for the project director if you have questions about the study. Do you recall seeing that document?

[If no] We'll send you that document again so you have a written copy of this information.

With your permission, we'd like to audio record the interview to ensure we capture and analyze your remarks accurately. Only the research team will have access to the recording, and it will be destroyed at the end of the project. Would it be okay to audio record the interview?

Do you have any questions before we begin?

Introduction of Interviewee(s)

1. Before we start our discussion, I'd like to learn a bit about how your kidney disease journey started. Did you start dialysis after years of care for chronic kidney disease or quickly after a hospitalization that showed you had kidney failure?

Dialysis Quality (20 minutes)

My first set of questions has to do with the quality of care you've received related to your kidney disease and dialysis.

1. Thinking about your dialysis care overall, what are some aspects of your care experience that are the most important to you?
 - a. [Probe: time spent with nephrologist, care provided by nurses and techs, cleanliness of the facility, care provided by dieticians or social workers, facility amenities, cost of care, health outcomes and feeling comfortable]
2. Please tell me about the support you receive from the nurses and techs at the dialysis facility. What is helpful or not so helpful about their support with your care experience?
 - a. [Probe: sensitivity to needs, caring, responsiveness, availability in an emergency]
 - b. What, if anything, could they do better to support you with your dialysis treatment?
3. Please tell me about the support you receive from the social worker at the dialysis facility. What is helpful or not so helpful about their support with your care experience?
 - a. [Probe: sensitivity to needs, caring, responsiveness]
 - b. What, if anything, could they do better to support you with your dialysis treatment?
4. Please tell me about the support you receive from the nephrologist who works with you at the facility. What is helpful or not so helpful about their support with your care experience?
 - a. [Probe: sensitivity to needs, caring, responsiveness, amount of time spent]
 - b. Is this your regular nephrologist or a different one who works with your facility?
 - c. What, if anything, could they do better to support you with your dialysis treatment?
5. Of all the providers you interact with during dialysis, whom do you trust the most when discussing your treatment options and reviewing your care plan? Please explain.

6. Would you recommend your dialysis center to a friend or relative who needs dialysis? Why or why not?

Access to Care & Health Equity (15 minutes)

Thank you for sharing that with me. I'm going to shift gears a little bit and ask you about some experiences you may or may not have had with regard to access to kidney care.

1. Think back to when you first found out you needed dialysis. Tell me about how your doctor explained your treatment options.
 - a. Did someone give you educational materials or invite you to an educational session? If so, which materials or sessions were most helpful to you and why?
 - b. [Probe: Do you recall discussing treatment modalities for your kidney disease (e.g., in-center hemodialysis, peritoneal dialysis, home dialysis)?]
2. As you reflect on your experience, what supports would you recommend for someone just starting dialysis?
3. [FOR HOME PATIENTS ONLY] Have you ever tried in-center hemodialysis?
 - a. [If yes,] How long ago and for how many years or months?
 - b. [If no, skip to Q6]
4. [If yes to Q3] For these next questions, please think back to when you would go to a facility for your dialysis. I'm interested in hearing about the location of the facility you went to relative to your home or work. How did you typically travel to the facility, and how long did the trip take?
 - a. Did you experience challenges when traveling to the dialysis facility? If so, please describe those challenges.
5. [If yes to Q3] Please tell me about your decision to receive treatment from that facility. Who or what factors helped you select this facility?
 - a. [Probe: nephrologist recommendation, internet search, Star rating online, social worker, closest facility to home, closest facility to work, accessible with public transportation]
6. Have you ever had difficulty accessing foods that are good for you, given the kidney disease diagnosis? If yes, were you able to access supports to help you with this challenge? If not, what support do you think would be most helpful to you and others in a similar situation?
7. Have you ever felt like you couldn't get the kidney care you needed because of the cost? If so, were you able to access supports to help with this challenge? If not, what support do you think would be the most helpful to you and others in a similar situation?
 - a. [Probe: Cost of copays and coinsurance, now knowing how much it would cost ahead of time]
 - b. [Probe: Other challenges around accessing health insurance]

8. [FOR ICHD PATIENTS] Have you tried home dialysis in the past? *[If no, skip to Q11]*
9. *[If yes to Q8]* Did you try home hemodialysis or peritoneal dialysis (known as PD)?
10. *[If yes to Q8]* What factors led you to try home dialysis in the first place?
 - a. [Probe: COVID-19 pandemic, wanting more independence, family support enabled home dialysis, increased ability to work]
11. *[If no to Q8]* What are some reasons you have not tried home dialysis?
 - a. [Probe: Lack of a good space at home, concern about burden on family, discomfort treating self, concern about emergency situations]
12. Have you noticed a change in the past 5 years in the way your healthcare providers talk to you about home dialysis as an option? Please explain.
 - a. [Probe: Frequency in asking about interest in trying home dialysis]
13. I'm interested in hearing about the location of your facility relative to your home or work. How do you typically travel to the facility, and how long does the trip take?
14. Please tell me about your decision to receive treatment from your current facility. Who or what factors helped you select this facility?
 - a. [Probe: Nephrologist recommendation, internet search, Star rating online, social worker, closest facility to home, closest facility to work, accessible with public transportation]
15. Have you ever had difficulty accessing foods that are good for you, given the kidney disease diagnosis? If yes, were you able to access supports to help you with this challenge? If not, what support do you think would be most helpful to you and others in a similar situation?
16. Have you ever felt like you couldn't get the kidney care you needed because of the cost? If so, were you able to access supports to help with this challenge? If not, what support do you think would be the most helpful to you and others in a similar situation?
 - a. [Probe: Cost of copays and coinsurance; now knowing how much it would cost ahead of time]
 - b. [Probe: Other challenges around accessing health insurance]
17. My next set of questions has to do with transplant as a treatment option for kidney disease. Have you ever had a kidney transplant?
 - a. *[If no]* Was transplantation discussed as an option with any of your providers?
 - b. Have you discussed transplantation as an option with your providers more than once?
18. *[If yes to Q17 or Q17a]* Can you describe what information you received from your healthcare providers about transplant as a treatment option?

19. Are you currently on a waitlist and/or interested in pursuing kidney transplant? *[If yes, go to Q19a; if no, skip to Q20]*
 - a. *[If yes]* Who has been most helpful in supporting you through the process of assessment and getting on the waitlist? What did they do that was particularly helpful?
 - i. *[Probe: nephrologist, nurse at dialysis facility family]*
20. *[If no to Q19]* What are some of the reasons you are not interested or able to pursue getting on the kidney transplant waitlist?
 - a. *[Probe: burdensome assessment process, not an eligible candidate, difficulty finding donor, cost, concerns about risk]*
21. Have you noticed a change in the past 5 years in the way your healthcare providers talk to you about transplant as an option? Please explain.

Thank you for sharing your responses with me. Before I move on to asking some questions about quality of life, was there anything else you wanted to share about accessing kidney disease treatment?

Quality of Life (20 minutes)

As part of this research, we are trying to understand what is important to individuals with kidney disease and what you feel contributes to a higher quality of life.

1. In your view, what are some aspects of everyday life for someone living with kidney disease to aim for in order to have a high quality of life?
 - a. *[Probe: Having more energy, feeling independent, accessing healthy foods that you enjoy, getting good sleep, having time to work and see friends/family]*
2. What are the sources of support in your life that helped you achieve high quality of life?
 - a. *[Probe: Supportive family and friends, strong relationship with social workers and other providers, comfortable living situation that accommodates home dialysis, ability to drive, not having to travel far to get dialysis, physical and financial access to donor kidney or transplant, straightforward transplant assessment process]*
3. What are some of the challenges individuals living with kidney disease face when trying to obtain a higher quality of life?
 - a. *[Probe: Difficulty finding a job that can accommodate the dialysis schedule, the way you feel after a dialysis session, the amount of time needed to dialyze (including transportation to and from the facility), dietary restrictions]*
4. Have your healthcare providers, including those outside your kidney disease-related care, helped you achieve your quality of life goals? What have they done?
 - a. *[Probe: Social workers arranging transportation, nephrologists helping them transition to home dialysis, improved coordination with transplant centers]*

5. *[For patients who have lived with ESRD for over 3 years]* How, if at all, do you feel your quality of life has changed while living with kidney disease? In what ways?

Closing

Thank you for taking the time to answer all of my questions! Those are all the questions we have for today. Before we finish, is there anything you would like to share that I haven't asked about or anything you would like to explain more that you didn't get to about your experience?

Thank you for taking the time to speak with me today. Your input is helpful, and we look forward to summarizing all the information we hear from stakeholders. If you have questions after the call or wish to offer additional feedback, please feel free to reach out to me or [INSERT RECRUITMENT FIRM NAME].