Appendix C: Dialysis Facility Social Worker Interview Protocol

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-XXXX (Expires XX/XX/XXXX). This is a voluntary information collection. The time required to complete this information collection is estimated to average one hour per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850. Please do not send applications, claims, payments, medical records or any documents containing sensitive information to the PRA Reports Clearance Office. Please note that any correspondence not pertaining to the information collection burden approved under the associated OMB control number listed on this form will not be reviewed, forwarded, or retained. If you have questions or concerns regarding where to submit your documents, please contact Christopher King at Christopher.King@cms.hhs.gov or (410) 786-6972.

Introduction

Hello. My name is [*interviewer name*] from Insight Policy Research, and I want to thank you again for agreeing to speak with me today about your involvement in activities related to dialysis care. I'm joined today by [*note taker name*] from Insight, who will be taking notes for the interview.

We were hired by the Centers for Medicare & Medicaid Services, otherwise known as CMS, to conduct an evaluation of the ESRD Quality Incentive Program (QIP). CMS is interested in learning how this initiative may have affected dialysis patients' health, outcomes, satisfaction, access to care, quality of care, and healthcare spending. CMS has also asked us to learn about other topics that are less directly related to the QIP.

This year we are focusing on the following topics related to ESRD care and will be asking you about them today:

- Quality of dialysis care
- Health Equity and access to ESRD care
- Factors associated with access to home dialysis
- Factors associated with access to transplant
- Quality of life for individuals with ESRD

Informed Consent

Let me also take a minute to review the informed consent for the interview and how we'll handle the information you provide:

- We will use the information you share with us for research purposes only.
- All your responses will be kept confidential. No one except the Insight research team will have access to the information you provide.

- We will use your answers to produce summaries from our collective set of interviews.
- We will not report information in any way that identifies you or the organization you are affiliated with to anyone outside the research team, except with your permission or as required by law. CMS will not see your name or your organization's name connected to your individual responses.
- All information identifying you is stored securely and will be destroyed at the end of the study.
- We'd also like to emphasize that your participation is completely voluntary:
 - Your participation or nonparticipation will not be reported to anyone.
 - You can stop the interview at any time for any reason, and you can decline to discuss any topic we raise.
- We expect that this call will take about 45 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)

[If there are several interviewees on the phone, call out each one individually and ask them the same introductory question below.]

- 1. Before we start our discussion, would you please share with me your job title and your role at [facility name]? How long have you been working in the ESRD field?
- 2. Can you please describe the area where your facility is located?
 - a. Probe: Urban, rural, suburban

Dialysis Quality

My first set of questions has to do with the quality of care dialysis patients receive. We understand that the role of social workers in dialysis facilities varies from facility to facility – so if any of my questions are not relevant to your role, please let me know and I will skip to the next question.

- 1. From your perspective, what are the highest priorities for patients when selecting a dialysis facility for treatment?
 - a. [Probe: How clean the facility is? How often they see the nephrologist in the clinic? How easy it is to reach staff in an emergency?]

- 2. How does your facility measure the quality of care provided to your patients? (i.e., which methods do you use to measure quality)?
 - a. [Probe: ICH-CAHPS? QIP? Five Star?]
 - b. Does the facility use data analyses on quality of care to inform care delivery processes or policies? If so, can you describe an example of how a measure or survey led to change in care delivery?

Access to Care

Next, I'm going shift gears a little and ask about patient access to ESRD care.

- 1. What are the characteristics of your facility's overall patient population?
 - a. [Probe: High percentage of low-income patients; Multiple comorbidities; High/low access to transportation.]
- 2. What do you see as the most significant challenges your patients face in accessing treatment for their ESRD?
 - a. [Probe: Access to financial resources, adequate facilities to choose from, transportation, specialists, social support, distance to treatment.]
- 3. Have you noticed a change in the degree to which patients have access to ESRD care over the past five years? If yes, can you explain why you think this is the case?
 - a. Do you think QIP has had any impact on access? Please explain.
- 4. Focusing on improving access to care for underserved populations, what are some improvement strategies that you have implemented or seen implemented by facilities or providers?
 - a. What are some barriers, if any, that have hindered the implementation of these strategies?
 - b. What resources or incentives are facilitating or supporting implementation of these improvement strategies?
- 5. Does your facility collect data on patients' health-related social needs? If so, which needs are most common?
 - a. [Probe: Food insecurity, stable housing, mobility impairment, transportation barriers]
- 6. [*If they do collect data on patients' health related social needs*] What does your facility do with the information they collect related to these needs?
 - a. [Probe: Make note in patient chart; Referral for social needs programs; Additional screening]
- 7. Do you feel that you are able to engage patients and their caregivers in conversations about the social determinants of health and their affects on health outcomes?
 - a. What are the challenges limiting those conversations?
- 8. If you identify a social determinant of health need for a given patient at the facility, what is the process to update the care team?
 - a. What is the process to make referrals to community-based organizations?

- b. Do you see opportunities for improvement in either care team communications or referral processes?
- 9. What strategies, if any, has your facility adopted to address other issues that may affect health, such as housing, food security, transportation, access to social workers, financial security to pay for health care?
- 10. In your opinion, what are the factors in patients' choice of treatment modality (e.g., home, incenter, transplant)?
 - a. [Probe: Nephrologist recommendation; Crashing into dialysis vs managing CKD for a while; Cost; Health literacy]
- 11. How do patients' social needs, (like housing, transportation, food security, etc) affect their access to home dialysis?

Access to Transplant

As you may know, over the past several years there has been a push to get more dialysis patients access to transplants because of the quality of life benefits associated with it.

- 1. What are your facility's approaches to patient engagement related to transplantation as a treatment option?
 - a. [Probe: patient education about finding a donor and referral for assessment for transplant viability.]
 - b. Has the patient engagement approach changed in the past five years? If so, why and what was the change?
- 2. How do patients' social needs affect their access to transplant? Including transplant assessment.
- 3. Can you please describe how your facility's location affects patients' transplant options?
 - a. [Probe: State/local requirements, distance to nearest transplant centers, number of transplant centers available]

Quality of Life

As part of this research, we are trying to understand the quality of life that individuals with ESRD experience and what can be done at the policy level to ensure the highest possible quality of life for this patient population.

- 1. From your perspective, what are some aspects of everyday life that you would consider signs of a higher quality of life for someone living with ESRD?
 - a. [Probe: Having more energy; Feeling independent; Accessing healthy foods that are enjoyable; Getting good sleep]
- 2. Are there interventions that dialysis providers (including dialysis facilities and nephrology practices) have been able to implement to improve the quality of life for individuals living with ESRD?

- a. [Probe: Help arranging transportation; Nephrologists helping them transition to home dialysis; Improved coordination with transplant centers; Peer-to-peer support; Streamlining screenings for depression]
- 3. How, if at all, does your facility measure patient quality of life? Why did your facility select these measures or data collection tools?
 - a. [If KDQoL not mentioned] Do you administer the Kidney Disease Quality of Life instrument otherwise known as the KDQOL questionnaire or the Health-Related Quality of Life (or the HRQOL)?
 - b. What does your facility do with quality-of-life data once it is collected?
- 4. In your experience, have you noticed the quality of life for individuals living with ESRD changed over time? What is the reason for the change?
 - a. [Probe: access to social services, screening of SDOH need, patient interest or eligibility for home dialysis and/or transplant]

Closing

Before we finish, is there anything you would like to share that I haven't asked about or anything you would like to elaborate on that you didn't get a chance to discuss providing care to dialysis patients?

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.