

Appendix G: Patient Advocacy Organization Interview Protocol

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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 dialysis quality and patient quality of life and will be asking you about them today:

- ▶ Access to and disparities in 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. That being said, there are only a few organizations out there, so be mindful that CMS may be able to determine which organization is affiliated with certain remarks.
- ▶ 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 30-45 minutes.

If you would like this information in writing, let me know, and I will send you a copy to your email.

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 [organization name]? And what the overall mission of [organization name] is?

I'm going to ask you some questions about a variety of topics related to ESRD care, but since we are talking to many different stakeholder organizations, some of the questions may not fall within your purview of expertise. If that is the case, please let me know and I can move on to another set of questions.

Organization-level Activities

1. What are the most common concerns or challenges that your organization hears from individuals with ESRD and their caregivers?
2. Are there changes in dialysis facility delivery that your organization is actively encouraging?
 - a. [Probe: Change in transplant center processes?]
 - b. [Probe: Changes in regulation or legislation, either at the Federal or State level?]

Access to Care

First, I'd like to ask about patient access to ESRD care.

1. In your opinion, what are some of the most significant challenges that patients face when trying to access dialysis for their ESRD ?
 - a. [Probe: Access to financial resources, adequate facilities to choose from, transportation, specialist, social support, distance to treatment]
 - b. Are there other challenges or barriers specific to patient access to home dialysis?
 - c. Are there other challenges or barriers specific to patient access to transplantation?
2. Have you noticed a change in patient access to ESRD care over the past few years?
 - a. [Probe: change in transportation options; change in available dialysis facilities]
3. Does your organization collect information from individuals with ESRD on challenges they experience related to health-related social needs (e.g., food insecurity, stable housing, mobility impairment, transportation barriers)? If so, what does your organization do with the information collected related to those needs?
4. What are some improvement strategies that you have implemented or seen implemented in recent years to address issues that may affect health, such as housing, food security, transportation, access to social workers, financial security to pay for health care?
 - a. Who led the implementation of these strategies? [Probe: advocacy organizations, dialysis facilities]
 - b. What are some challenges, if any, that limit the implementation of these strategies?
 - c. What resources or incentives help or support the implementation of these strategies?
5. In your opinion, what are the factors in patients' choice of treatment modality (e.g., home, in-center, transplant)?
 - a. [Probe: Nephrologist recommendation; Crashing into dialysis vs managing CKD for a while; Cost; Health literacy]
6. How do patients' social needs, (like housing, transportation, food security, etc) affect their access to home dialysis?
7. How do patients' social needs affect their access to transplant? Including transplant assessment.
8. In your opinion, what can be done at the policy level to improve health equity among individuals with ESRD?

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, has the quality of life for individuals living with ESRD changed over time?
 - a. [Probe: What do you think contributed to this change?]
 - b. [Probe: More patients interested in home dialysis and/or transplant; More patients eligible 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 about access to ESRD care?

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.