

Supplemental Appendix to:

Development and Content Validity of a Patient-Reported Experience Measure for Home Dialysis

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SUPPLEMENTAL TABLE 1. COREQ 32-item checklist for focus group reporting¹

Topic	Item number	Description
Domain 1: Research team and reflexivity		
Interviewer/facilitator	1	Matthew Rivara (MR), Todd Edwards (TE), Donald Patrick (DP)
Credentials	2	MD (MR); PhD (TE); PhD (DP)
Occupation	3	Nephrologist and Assistant Professor (MR); Health Services Research and Associate Professor (TE); Health Services Researcher and Professor (DP)
Gender	4	Male (MR, TE, DP)
Experience and training	5	Dr. Rivara has taken care of patients with chronic kidney failure on dialysis for over 8 years, and has conducted previous studies of patients undergoing peritoneal dialysis and home hemodialysis. Drs. Edwards and Patrick have an extensive background in developing and applying patient-centered outcomes measures, including conducting qualitative research with patients.
Relationship established	6	None
Participant knowledge of the interviewer	7	None
Interviewer characteristics	8	Facilitators introduced themselves at the beginning of the focus groups as health services researchers trying to understand patients' priorities around home dialysis care experience. MR identified that he is a nephrologist with an interest in home dialysis care.
Domain 2: Study design		
Methodological orientation and theory	9	Phenomenology/lived experience
Sampling	10	Purposive sampling to recruit patients of varying ages, sex, and home dialysis modality; purposing sampling was also used to recruit providers of various home dialysis modality expertise and duration of practice
Method of approach	11	For nephrologists and nurses, we recruited participants from the medical and nursing staffs of three dialysis organizations in Washington. Participants were approached by email. Patients and caregivers were recruited via informational signs and telephone or in-person contact by study personnel.
Sample size	12	Focus groups included a total of 56 participants, including 27 registered nurses, 24 home dialysis patients, 3 caregivers/care partners, and 8 nephrologists with expertise in home dialysis (15 approached, 7 could not be scheduled). Following completion of the focus groups, we conducted 6 additional telephone-based semi-structured interviews. Cognitive debriefing interviews were done with 8 patients.
Non-participation	13	Focus groups: Registered nurses: 33 approached, 6 couldn't be scheduled. Home dialysis patients: 34 approached, 6 declined, 4 couldn't be scheduled. Caregivers/care partners: 7 approached, 4 declined. Nephrologists with expertise in home dialysis: 15 approached, 7 could not be scheduled
Setting of data collection	14	Focus groups were conducted in dialysis clinic conference rooms in Seattle, WA. Conference room doors were closed to protect patient privacy. Participants sat at a conference table and were served light refreshments or dinner depending on the time of day. Cognitive

		interviewers were conducted in patients' homes or workplaces in private settings.
Presence of non-participants	15	One note-taker
Description of sample	16	See Supplemental Table 2
Interview guide	17	See Supplemental Appendix
Repeat interviews	18	None
Audio/visual recording	19	Audi-recorded
Field notes	20	The note-taker and interviewer/facilitator took notes on patient priorities and non-verbal cues
Duration	21	Focus groups were 90 minutes. Cognitive interviews were 60 minutes.
Data saturation	22	Discussed in Results
Transcripts returned	23	N/A
Domain 3: Analysis and findings		
Number of data coders	24	2
Description of the coding tree	25	See Supplemental Figure 1
Derivation of themes	26	The investigator team created codebook descriptions initially based on an overall read through of transcripts in addition to utilizing the results of the literature review. Codes and definitions were refined as needed iteratively throughout transcript/content analysis. Transcripts were systematically coded based on the refined coding scheme. Code application frequency and coding clusters were identified. Lists of top-reported domains and aspects of home dialysis care were determined based on focus group mentions as reported in table 3. Code application was confirmed by consensus via discussion between the two coders.
Software	27	Dedoose (www.dedoose.com)
Participant checking	28	At the end of each moderator guide section, the moderator probed for additional comments and checked understanding by providing summary statements and asking for clarifying feedback. At conclusion of each focus group, the moderator asked for final thoughts so participants could comment on the focus group content as a whole.
Quotations presented	29	N/A
Data and findings consistent	30	Consistent
Clarity of major themes	31	Presented in the Results
Clarity of minor themes	32	N/A

SUPPLEMENTAL TABLE 2. Patient and care partner focus group participant characteristics

Characteristic ^a	Focus group Participants ^b (n = 24)
Age, yr	52 ± 14
Sex	
Male	12 (50)
Female	12 (50)
Education	
Less than high school	0 (0)
High school graduate or GED	3 (12)
Some college or 2-year degree	8 (33)
4-year college degree	5 (21)
More than a 4-year college degree	3 (13)
Unknown	5 (21)
Home dialysis modality^c	
Peritoneal dialysis	10 (48)
Home hemodialysis	11 (52)
Unknown	0 (0)
Time on home dialysis^c	
Less than 6 months	1 (5)
6 to 11 months	4 (19)
1 to 5 years	13 (62)
More than 5 years	3 (12)

^a Data presented as *n* (%) or mean ± standard deviation, as appropriate

^b Column percentages may not add to 100% due to missing data. Age and education data were missing for all focus group caregiver participants and 2 patient focus group participants.

^c Column percentages for modality and time on home dialysis calculated among patient participants only

SUPPLEMENTAL TABLE 3. Demographic characteristics for point prevalent PD and home HD populations in the United States, 2018 – Source: 2020 United States Renal Data System (USRDS) Annual Data Report

Characteristic	PD (n = 58,558)	Home HD (n = 10,350)
Age, years		
0-17	864 (1)	0 (0)
18-34	4130 (7)	640 (6)
35-54	16,867 (29)	3639 (35)
55-74	28,211 (48)	4870 (47)
75 or older	8569 (15)	1183 (11)
Sex		
Male	33,105 (57)	6343 (61)
Female	25,453 (43)	4007 (39)
Race		
White	39,025 (67)	6494 (63)
Black/African American	13,829 (24)	3365 (33)
Asian	4133 (7)	311 (3)
Other	1564 (3)	174 (2)

Data presented as n (%); PD data includes CAPD and CCPD, excludes “Other PD” category in USRDS data. Abbreviations: PD, peritoneal dialysis; HD, hemodialysis

The data reported here have been supplied by the United States Renal Data System (USRDS). The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy or interpretation of the U.S. Government.

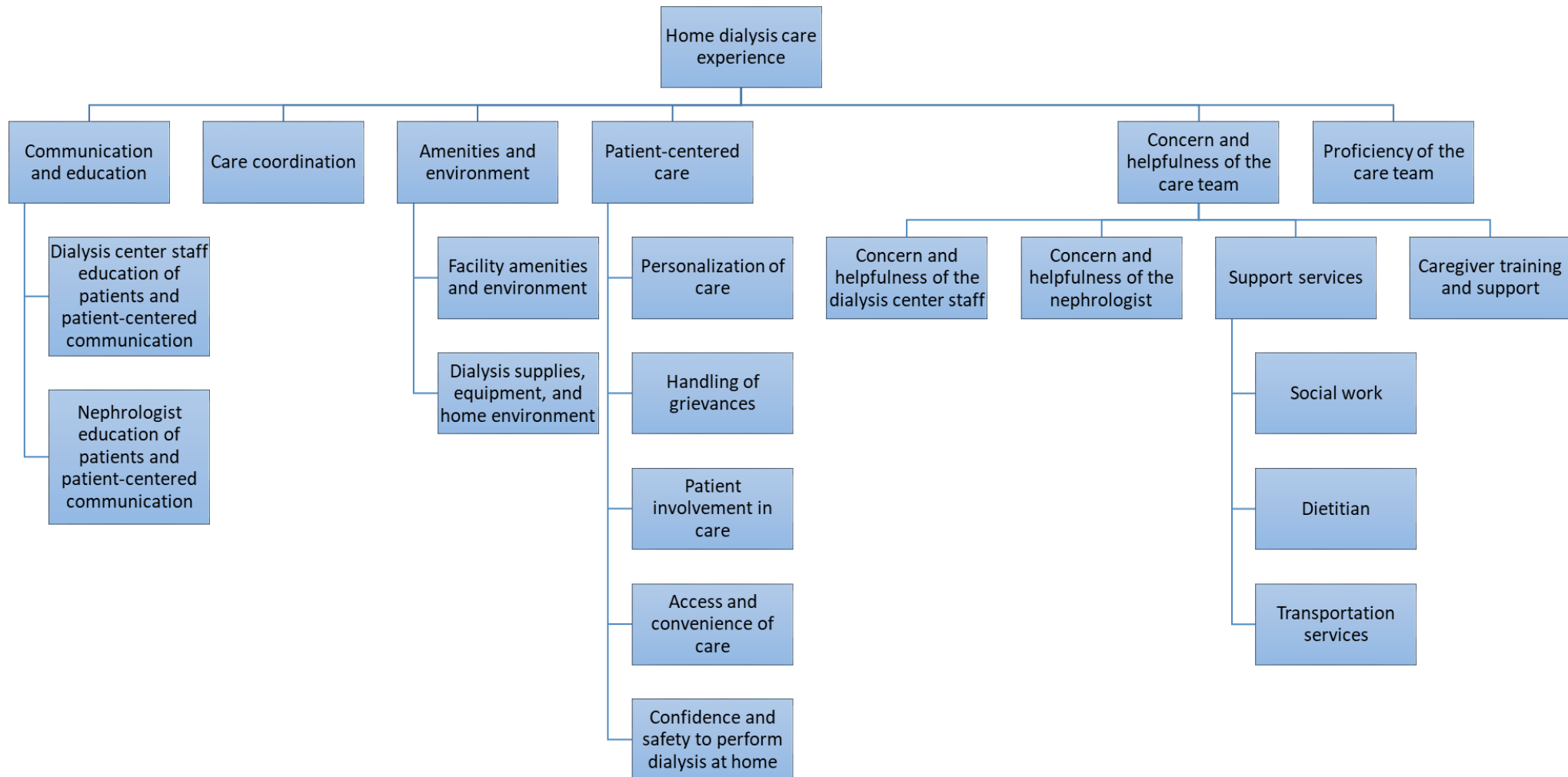
SUPPLEMENTAL TABLE 4. Patient-reported experience instruments and measures identified in literature review and environmental scan

Instrument Name	Reference
In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Survey	Wood et al (2014) ²
Customer Satisfaction Questionnaire (CSQ) for Peritoneal Dialysis Patients	Kirchgessner et al (2006) ³
Home Health (HH) Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Survey	Smith et al (2015) ⁴
Dialysis Clinic Incorporated Clinic Report Card	Richardson et al (2015) ⁵
Renal Treatment Satisfaction Questionnaire (RTSQ)	Barendse, et al (2005) ⁶
Consumer Quality index for in-center hemodialysis (CQi-CHD)	Van der Veer et al (2012) ⁷
Consumer Quality index for peritoneal dialysis and home hemodialysis (CQi-PHHD)	Van der Veer et al (2012) ⁷
Dialysis Patient Satisfaction Survey (DPSS)	RAND ⁸
Questionnaire for Patients' Expectations of Healthcare	Bowling et al (2012) ⁹

SUPPLEMENTAL TABLE 5. Key cognitive interview findings and instrument changes

Interview round	Instrument area	Cognitive interview finding	Instrument update
Round 1 (<i>n</i> = 3)	Instructions	Participants suggested that receptionists are important dialysis center staff	Added receptionists to instructions
	Instructions	Participants suggested that it is important to call dialysis staff “home dialysis staff” for clarity	Changed text in instructions and items to specify “home dialysis staff”
	Recall period	All participants thought that 3 month recall period was too short to capture sufficient experiences	Changed recall period in instructions and items to 6 months
	Global ratings	Participants had trouble distinguishing global ratings of facilities and staff due to wording similarities	Added underlining for emphasis in item text
	Order effect	Participants interpreted item regarding spending enough time with staff as time on the telephone due to item order effect	Switched order of 2 items
	Recall period	For items regarding patient involvement in treatment, 6 month recall was felt to be too short	Recall period removed 2 items
	Item understanding	Participants were unclear as to what “treatment” meant in item regarding treatment options.	Reorganized preamble for 2 items to specifically indicated that “treatment” includes dialysis at a center, dialysis at home, and kidney transplant
Round 2 (<i>n</i> = 3)	Item understanding	Participants noted that a number of items include similar wording, and thus understanding would be enhanced by underlining distinct item elements	Underlined distinct item elements in sequential items containing similar wording
	Survey title	Some participants felt that the instrument title did not encourage them to continue – suggested making more personal	Revised instrument title
	Instructions	Some participants felt it important to highlight in numerous places that dialysis center staff does not refer to the doctor	Add underling for emphasis in instructions and section preamble
	Recall period	Some participants felt that it was important to add the word “ever” in items asking about staff education about equipment or health problems at home, as no recall period was listed	Added “ever” to relevant items without recall period
	Item understanding	Some participants felt that items mentioning caregivers were confusing and redundant	Removed mention of caregiver from items 9 and 22

SUPPLEMENTAL FIGURE 1. Coding tree for qualitative thematic analysis



CONCEPT ELICITATION FOCUS GROUP MODERATOR GUIDE FOR PROVIDERS

HOME DIALYSIS AREAS OF CARE PROVIDER FOCUS GROUP GUIDE (APPROX. 60-90 MINUTES)

BACKGROUND

Materials needed:

- Study Information Statement
- Cards where people can write their names on
- Whiteboard markers
- Refreshments

Meeting preparation

Write on available whiteboard the following areas of care:

1. Communication & Education
2. Concern & Helpfulness of the Care Team
3. Proficiency of the Care Team
4. Patient-Centered Care
5. Care Coordination
6. Amenities & Environment

Interviewer Script: Focus Group facilitator will paraphrase below.

INTRODUCTION

- Good (morning/afternoon/evening) and welcome to our session. [hand out information statement]
- Thank you for taking the time to join our study activity today. Everyone here today was invited for this group because you have at least one year of experience taking care of patients undergoing (peritoneal dialysis or home hemodialysis).
- Before I explain what the goal and purpose of the focus groups today is, I wanted to give an introduction to the goals and process of the research study of which this focus group is a part.
- The study is called the ASPIRED study, which stands for Assessing Patient-Reported Experience of Care in Home Dialysis.
- Goal of the study is to develop a short new survey questionnaire for home dialysis patients that will be completed by the patients themselves, and will assess patients' experience of their dialysis care.
- An existing survey, called the ICH-CAHPS survey, is currently available for use in patients undergoing in-center hemodialysis, and is administered twice a year by all dialysis providers

in the U.S. However, peritoneal dialysis and home hemodialysis patients are not currently included.

- Currently, the ICH-CAHPS is completed directly by patients, and ratings by patients of their experience of care are used by the government as part of a pay-for-performance program called the ESRD Quality Incentive Program or QIP.
- We hope that development of surveys for use by patients undergoing home dialysis will lead to an enhanced voice for home dialysis patients and better quality improvement efforts. Additionally, it is possible that such a survey will be adopted by CMS for use in parallel with the ICH-CAHPS survey.
- A key and critical component of this study is engagement with providers with training and experience in home dialysis therapy.

FOCUS GROUP OVERVIEW/DESCRIPTION

- The focus group today will last a total of 60-90 minutes.
- First, we will describe 6 areas of home dialysis care that are likely to be important when assessing the overall quality of care provided to patients. We have identified these areas through a literature review and in previous focus groups. I've written these areas up on the white board.
- We will ask you during a group discussion to think about what are the key specific aspects or indicators for each area of care that would be important to capture in a survey of home dialysis care quality. In other words, if you were evaluating another home dialysis program, how would you know that quality care is being delivered in each of the care areas? Importantly, we would like you to focus on aspects that are specific and unique to home dialysis.
- Importantly, in considering indicators of high quality home dialysis care, please remember we are not asking about the your home dialysis program specifically, but rather more broadly about what we be important in evaluating care at any dialysis provider.

FOCUS GROUP GUIDELINES

Everything that you share in the focus group will be treated as confidential. We will be audio-recording parts of the activity when we are having group discussion about the issues that are important to you. The audio recordings will be transcribed by a company called Verbalink transcription services. They will not know who you are or who is talking.

Note to Focus Group facilitator

Facilitator, if after these assurances, any participants are still uncomfortable and wish to withdraw from the focus group, the moderator should respectfully acknowledge and support their right to do so and thank them for their time and effort.

DISCUSSION GROUP RULES

Before we begin, let me review some guidelines that will make our discussion more productive.

- Please speak up and speak slowly because we don't want to miss any comments, and also want to make sure that the conversation is recorded accurately.
- I may ask to have you hold a thought or may ask to move the discussion along so that everyone has a chance to participate or because we are short of time.
- Following the conclusion of the group, we may contact you by email to complete a follow-up survey, and there will be an opportunity at that point to contribute additional comments.
- Please write your first name on the card tent in front of you. This will be used by the moderators to facilitate the discussion only.
- Any questions before we begin?

FIRST ACTIVITY

As I've already mentioned, we've identified some very broad areas or domains of care that are likely to be important in a survey of home dialysis patients about their experience of dialysis care. I've listed these areas on the board.

These areas also correspond to many of the questions on the ICH-CAHPS survey for in-center hemodialysis patients. They may be more or less relevant to the home dialysis population, but we're using them as a starting point for discussion.

1. Communication & Education
2. Concern & Helpfulness of the Care Team
3. Proficiency of the Care Team
4. Patient-Centered Care
5. Care Coordination
6. Amenities and Environment

I'd like to ask you as a group to consider whether there are any other broad areas of care that are not listed here that would be important to evaluating the quality of home dialysis care from the patient's perspective.

Note to Focus Group facilitator

Facilitator, if participants mention other more specific aspects of care at this point, the moderator should ask the group whether these aspects fit into one of the larger areas of care, or whether the newly mentioned aspect should be considered its own area.

SECOND ACTIVITY

[After note-taker captures list of any additional areas of care listed on, moderator erases the board]

[Moderator writes each area of care in turn on the board to facilitate discussion of that area.]

We will now review each of the broad areas of home dialysis care, and have a group discussion what are the key specific aspects or indicators for each area of care that would be important to capture in a survey of home dialysis care quality. In other words, **how would you know that quality care is being delivered in each of the care areas?** Importantly, we would like you to focus on aspects that are specific and unique to home dialysis.

[Prompts used only if no spontaneous discussion.]

1. Communication & Education

[Prompts:

- a) Clarity of communication between nephrologist (or staff), patient, caregiver
- b) Accuracy and completeness of information provided by nephrologist (or staff)
- c) Patient perception of quality of ongoing education and training
- d) Patient feels comfortable asking questions of nephrologist or staff
- e) Understandability of educational materials]

2. Concern & Helpfulness of the Care Team

[Prompts:

- a) Perception by the patient that the nephrologist or staff are caring
- b) Perception by the patient that the nephrologist or staff are respectful
- c) Perception by the patient that the nephrologist or staff are helpful
- d) Perception by the patient that the nephrologist or staff spent enough time with the patient
- e) Degree to which patient/caregivers feel supported by dialysis center staff]

3. Proficiency of the Care Team

[Prompts:

- a) Patient perception of the ability of the dialysis facility staff to manage problems encountered at home
- b) Patient perception of the ability of the dialysis facility staff to deliver timely care
- c) Patient perception of the ability of the dialysis facility staff to help patients troubleshoot medical emergencies at home
- d) Adherence of nephrologist and staff care to national/international guidelines]

4. Patient-Centered Care

[Prompts:

- a) How well the nephrologist or staff take patients' values and schedules into account in treatment and prescription decisions
- b) Inclusion of patients in making dialysis-related decisions
- c) Inclusion of caregivers in making dialysis-related decisions
- d) Ease of contacting nephrologist
- e) Ease of contacting home dialysis nurse
- f) Accessibility of help by telephone for problems or emergencies encountered at home
- g) Patient's perception of preparedness to handle dialysis-related emergencies at home
- h) Patient's knowledge/preparedness for disasters
- i) Responsiveness of dialysis center staff or nephrologist to patient complaints
- j) Comfort of patients/caregivers in raising complaints
- k) Length of time to wait for appointments with dialysis center staff]

5. Care coordination

[Prompts:

- a) Patient perception of the coordination of health information among providers and staff

- b) Staff and nephrologist keep health information private
- c) Patient perception of cooperation among healthcare providers
- d) Convenience and accessibility of home dialysis supplies and delivery
- e) Quality of nephrologists relationships with patients and other dialysis center staff
- f) Was dietitian education or social work services provided to patient

6. Amenities and Environment

[Prompts:

- a) Cleanliness and convenience of the home dialysis hub
- b) Quality of home dialysis hub equipment]

Before we conclude, does anyone have anything else they'd like to contribute?

CONCLUSION

Thank you all for participating in the focus group today!

CONCEPT ELICITATION FOCUS GROUP MODERATOR GUIDE FOR PATIENTS

HOME DIALYSIS AREAS OF CARE PATIENT FOCUS GROUP GUIDE (APPROX. 60-90 MINUTES)

BACKGROUND

Materials needed:

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- Cards where people can write their names on
- Whiteboard markers
- Refreshments

Meeting preparation

Write on available whiteboard the following areas of care:

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2. Concern & Helpfulness of the Care Team
3. Proficiency of the Care Team
4. Patient-Centered Care
5. Care Coordination
6. Amenities & Environment

Interviewer Script: Focus Group facilitator will paraphrase below.

INTRODUCTION

- Good (morning/afternoon/evening) and welcome to our session. [hand out information statement]
- Thank you for taking the time to join our study activity today. Everyone here today was invited for this group because you have at least 6 months of experience undergoing peritoneal dialysis or home hemodialysis.
- Before I explain what the goal and purpose of the focus groups today is, I wanted to give an introduction to the goals and process of the research study of which this focus group is a part.
- The study is called the ASPIRED study, which stands for Assessing Patient-Reported Experience of Care in Home Dialysis.
- Goal of the study is to develop a short new survey questionnaire for home dialysis patients that will be completed by the patients themselves, and will assess patients' experience of their dialysis care.
- An existing survey, called the ICH-CAHPS survey, is currently available for use in patients undergoing in-center hemodialysis, and is administered twice a year by all dialysis providers

in the U.S. However, peritoneal dialysis and home hemodialysis patients are not currently included.

- Currently, the ICH-CAHPS is completed directly by patients, and ratings by patients of their experience of care are used by the government as part of a pay-for-performance program called the ESRD Quality Incentive Program or QIP.
- We hope that development of surveys for use by patients undergoing home dialysis will lead to an enhanced voice for home dialysis patients and better quality improvement efforts. Additionally, it is possible that such a survey will be adopted by CMS for use in parallel with the ICH-CAHPS survey.
- A key and critical component of this study is engagement with patients like you who have experience with home dialysis therapy.

FOCUS GROUP OVERVIEW/DESCRIPTION

- The focus group today will last a total of 90 minutes. We will hand out gift cards as a thank you at the end of the group.
- First, we will describe 6 areas of home dialysis care that are likely to be important when assessing the overall quality of care. We have identified these areas through a literature review and in previous focus groups with care providers. I've written these areas up on the white board.
- After we have reviewed brief descriptions of these important areas of care, we will ask you again during a group discussion to think about what are the key specific aspects or indicators for each area of care that would be important to capture in a survey of home dialysis care quality. In other words, if you were evaluating another home dialysis program, how would you know that quality care is being delivered in each of the care areas? Importantly, we would like you to focus on aspects that are specific and unique to home dialysis.
- At the end of each section corresponding to each of the areas I've written on the board, we will have you all write down on the worksheet in front of you the top 3 specific aspects or items that you think are the most important elements within that area that you think should be included on a survey of home dialysis care.

FOCUS GROUP GUIDELINES

Everything that you share in the focus group will be treated as confidential. We will be audio-recording parts of the activity when we are having group discussion about the issues that are important to you. The audio recordings will be transcribed by a company called Verbalink transcription services. They will not know who you are or who is talking.

Note to Moderator

Facilitator, if after these assurances, any participants are still uncomfortable and wish to withdraw from the focus group, the moderator should respectfully acknowledge and support their right to do so and thank them for their time and effort.

DISCUSSION GROUP RULES

Before we begin, let me review some guidelines that will make our discussion more productive.

- Please speak up and speak slowly because we don't want to miss any comments, and also want to make sure that the conversation is recorded accurately.
- I may ask to have you hold a thought or may ask to move the discussion along so that everyone has a chance to participate or because we are short of time.
- Following the conclusion of the group, we may contact you by email to complete a follow-up survey, and there will be an opportunity at that point to contribute additional comments.
- Please write your first name on the card tent in front of you. This will be used by the moderators to facilitate the discussion only.
- Any questions before we begin?

FIRST ACTIVITY

As I've already mentioned, we've identified some very broad areas or domains of care that are likely to be important in a survey of home dialysis patients about their experience of dialysis care. I've listed these areas on the board.

These areas also correspond to many of the questions on the ICH-CAHPS survey for in-center hemodialysis patients. They may be more or less relevant to the home dialysis population, but we're using them as a starting point for discussion. I'd like to give a brief description of each area as an initial step:

7. Communication & Education
8. Concern & Helpfulness of the Care Team
9. Proficiency of the Care Team
10. Patient-Centered Care
11. Care Coordination
12. Amenities and Environment

Any initial reactions?

SECOND ACTIVITY

[Moderator erases the board and writes each area of care in turn on the board to facilitate discussion of that area. Throughout second activity, moderator writes individual elements discussed on the board for easy viewing by participants]

We will now review each of the broad areas of home dialysis care, and have a group discussion what are the key specific aspects or indicators for each area of care that would be important to capture in a survey of home dialysis care quality. In other words, **how would you know that quality care is being delivered in each of the care areas?** Importantly, we would like you to focus on aspects that are specific and unique to home dialysis. I will also mention throughout the discussion certain aspects that were brought up during previous focus groups with nephrologists and home dialysis nurses.

[Moderator uses prompts if no spontaneous discussion.]

7. Communication & Education

[Prompts from provider groups:

- f) Quality of initial home dialysis training provided by staff to patients
- g) Quality of ongoing education provided by staff to patients
- h) Quality of communication between staff and patients
- i) Flexibility of staff communication style and materials/tailoring to patient preferences/needs
- j) Accuracy of information about dialysis provided by dialysis center staff]

Note to Moderator

Review list of elements discussed, including those cited by providers, and ask patients to individually list their top three.

8. Concern & Helpfulness of the Care Team

[Prompts from provider groups:

- f) Perception of how much dialysis center staff and nephrologists care about patients' lives and experiences
- g) Quantity of time spent by staff with the patient
- h) Availability of backup and respite care
- i) Are home visits by dialysis center staff a part of your care?
- j) Availability of social work and dietitian services]

Note to Moderator

Review list of elements discussed, including those cited by providers, and ask patients to individually list their top three.

9. Proficiency of the Care Team

[Prompts from provider groups:

- e) Were problems effectively managed remotely by dialysis center staff?
- f) How timely did you feel the staff communication and response was?
- g) How knowledgeable was your nurse about home dialysis?
- h) Quality of nurse phlebotomy skills]

Note to Moderator

Review list of elements discussed, including those cited by providers, and ask patients to individually list their top three.

10. Patient-Centered Care

[Prompts from provider groups:

- l) 24-hour and weekend availability of staff assistance
- m) Flexibility and convenience of clinic appointments

- n) Did your dialysis center consider your lifestyle and expectations in designing a care plan for you?
- o) Do you feel safe dialyzing at home?
- p) Do you know what do to in case of an emergency at home?]

Note to Moderator

Review list of elements discussed, including those cited by providers, and ask patients to individually list their top three.

11. Care coordination

[Prompts from provider groups:

- g) Quality of communication among nephrologist, nurse, and other dialysis center staff
- h) Coordination of visits to different providers (physician, nurse, lab draw)
- i) Consistency of communication between different dialysis center staff members]

Note to Moderator

Review list of elements discussed, including those cited by providers, and ask patients to individually list their top three.

12. Amenities and Environment

[Prompts from provider groups:

- c) Do you routinely have the supplies that you need to dialyze at home?
- d) Is the company that delivers supplies responsive to your needs?
- e) Is the home dialysis hub a good space for education and communication?]

Note to Moderator

Review list of elements discussed, including those cited by providers, and ask patients to individually list their top three.

Before we conclude, does anyone have anything else they'd like to contribute?

WEB-BASED PRIORITIZATION SURVEY

ASPIRED Patient and Caregiver Home Dialysis Prioritization Survey

PART 1: QUESTION PRIORITIZATION

The home dialysis experience of care questionnaire will have a variety of items on different areas of home dialysis. Based on your responses today and those of other patients, caregivers, dialysis nurses, and physicians, researchers will prioritize the top-ranked items to include in the final questionnaire.

For each potential survey item, please tell us how important you think each item would be in judging how good your home dialysis care is.

We have divided the items into different categories for organization purposes.

ACCESS AND CONVENIENCE OF CARE

This area includes accessibility of the home dialysis center, ease of contacting nephrologist and dialysis center staff, and convenience of center/monthly visits with dialysis center staff.

How important is it that...	Check one box that indicates how important this is for judging how good your home dialysis care is.		
	Not important	Moderately important	Extremely important
You or your caregiver receive help as soon as you ask for it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You are seen by dialysis center staff within 15 minutes of your appointment time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

CARE COORDINATION

This area includes cooperation among healthcare providers, and coordination of health information at the dialysis center.

How important is it that...	Check one box that indicates how important this is for judging how good your home dialysis care is.		
	Not important	Moderately Helpful	Extremely important

Your kidney doctor and the dialysis center staff work well together as a team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is good communication among the dialysis center staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You know who to call if you have a problem with your home dialysis equipment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dialysis center staff help you solve problems with receiving dialysis supplies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

CONCERN AND HELPFULLNESS OF THE DIALYSIS CENTER STAFF

This area includes the perception by the patient that dialysis center staff are caring, informed, respectful, and helpful.

How important is it that...	Check one box that indicates how important this is for judging how good your home dialysis care is.		
	Not important	Moderately important	Extremely important
The dialysis center staff really care about you as a person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The dialysis center staff ask if you have concerns or questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The dialysis center staff listen carefully to you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The dialysis center staff show respect for what you have to say	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You feel supported when you call the dialysis center staff for help	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The dialysis center staff spend enough time with you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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KNOWLEDGE AND SAFETY TO PERFORM DIALYSIS AT HOME

This area includes confidence and training to perform dialysis at home, and knowing how to respond to complications and emergencies.

How important is it that...	Check one box that indicates how important this is for judging how good your home dialysis care is.		
	Not important	Moderately important	Extremely important
You know how to take care of your dialysis access (either PD catheter, hemodialysis catheter, fistula or graft)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You are told by dialysis center staff what to do if there is a problem with your dialysis equipment at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You are told by dialysis center staff what to do if you experience a health problem at home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You feel confident in the ability of you or your caregiver to perform dialysis at home safely.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

DIALYSIS CENTER STAFF PROFICIENCY

This area includes patient perception of the ability of the dialysis center staff to manage problems and deliver timely care

How important is it that...	Check one box that indicates how important this is for judging how good your home dialysis care is.
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	Not important	Moderately important	Extremely important
The dialysis center staff are able to help you solve problems that you encounter with your home dialysis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

HANDLING OF GRIEVANCES AND COMPLAINTS

This area includes response by dialysis center staff to patient complaints and problems brought up by patients, and comfort of patients and caregivers in raising complaints.

How important is it that...	Check one box that indicates how important this is for judging how good your home dialysis care is.		
	Not important	Moderately important	Extremely important
You are able to talk to someone on the dialysis center staff about being unhappy with the care you receive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You are satisfied with the way dialysis center staff address any concerns you raise about your care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PATIENT INVOLVEMENT IN CARE DECISIONS

This area includes inclusion of patients in decision-making regarding dialysis therapy

How important is it that...	Check one box that indicates how important this is for judging how good your home dialysis care is.		
	Not important	Moderately important	Extremely important
You are involved as much as you want in choosing the treatment for your kidney disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PERSONALIZATION OF CARE

This area includes patient perception of the degree to which dialysis center staff take patients' preferences and lifestyle into account in treatment decisions.

How important is it that...	Check one box that indicates how important this is for judging how good your home dialysis care is.		
	Not important	Moderately important	Extremely important
Your home dialysis care is adjusted to your individual schedule and lifestyle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The dialysis center staff and your nephrologist help to find a home dialysis treatment plan that works for you at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

EDUCATION OF PATIENTS AND PATIENT-CENTERED COMMUNICATION

This area includes the clarity and quality of communication between the dialysis center staff, patient and caregiver, as well as the accuracy and completeness of information provided by the dialysis center staff.

How important is it that...	Check one box that indicates how important this is for judging how good your home dialysis care is.		
	Not important	Moderately important	Extremely important
The dialysis center staff explain things in a way that is easy for you to understand	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You receive laboratory results from the dialysis center in a timely fashion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You receive teaching or education related to your dialysis care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The dialysis center staff listen carefully to you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The dialysis center staff tell you what to do if you are unable to do dialysis at home due to an emergency or disaster	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The dialysis center staff or your kidney doctor talk to you as much as you want about options for treatment, including center dialysis, home dialysis and kidney transplant.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

SUPPORT SERVICES

This area include whether support resources are made available, including home visits, dietitian, and social work services.

How important is it that...	Check one box that indicates how important this is for judging how good your home dialysis care is.		
	Not important	Moderately important	Extremely important
The dialysis center staff talk to you about what you should eat and drink	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You are able to meet with the social worker if you want to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The dialysis center staff conducts a home visit to assess your home dialysis environment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PART 2 - DEMOGRAPHIC QUESTIONS ("ABOUT YOU")

1. What is your age?

1 ☐ 18-34 years old

2 ☐ 35-54 years old

- 3 ☐ 55-74 years old
- 4 ☐ 75 years old or older

2. What is your gender?

- 1 ☐ Female
 - 2 ☐ Male
 - 3 ☐ Other (specify)
-

3. What is the highest grade or level of school that you have completed?

- 1 ☐ Less than high school
- 2 ☐ High school graduate or GED
- 3 ☐ Some college or 2-year degree
- 4 ☐ 4-year college graduate
- 5 ☐ More than 4-year college degree

4. What is your employment status?

- 1 ☐ Employed full time
- 2 ☐ Employed part time
- 3 ☐ Unemployed
- 4 ☐ Homemaker
- 5 ☐ Full-time student
- 6 ☐ Retired
- 7 ☐ Disabled or cannot work because of health reasons
- 8 ☐ Other

5. What is your race? (One or more categories may be selected)

- 1 ☐ White
- 2 ☐ Black or African American
- 3 ☐ American Indian or Alaska Native
- 4 ☐ Native Hawaiian or other Pacific Islander
- 5 ☐ Asian
- 6 ☐ Some other race

6. Are you of Spanish, Hispanic, or Latino origin or descent?

- 1 ☐ No
- 2 ☐ Yes

7. What region of the United States do you live in?

- 1 ☐ West
- 2 ☐ Midwest

- 3 ☐ South
- 4 ☐ Northeast

8. Are you currently:

- 1 ☐ Being treated with home dialysis → **Go to question 9**
- 2 ☐ Caring for someone treated with home dialysis → **Please submit survey. Do not answer the remainder of the questions.**

9. How long have you been treated with any form of dialysis?

- 1 ☐ Less than 6 months
- 2 ☐ 6 to 11 months
- 3 ☐ 1 to 5 years
- 4 ☐ More than 5 years

10. How long have you been treated with dialysis at home?

- 1 ☐ Less than 6 months
- 2 ☐ 6 to 11 months
- 3 ☐ 1 to 5 years
- 4 ☐ More than 5 years

11. Do you live alone?

- 1 ☐ Yes
- 2 ☐ No

12. In general, how would you rate your overall health?

- 1 ☐ Excellent
- 2 ☐ Very good
- 3 ☐ Good
- 4 ☐ Fair
- 5 ☐ Poor

13. Are you being treated for high blood pressure?

- 1 ☐ Yes
- 2 ☐ No

14. Are you being treated for diabetes or high blood sugar?

- 1 ☐ Yes
- 2 ☐ No

15. Are you being treated for heart disease or heart problems?

- 1 ☐ Yes
- 2 ☐ No

COGNITIVE DEBRIEFING INTERVIEWER GUIDE

[INTERVIEWER PARAPHRASE THE FOLLOWING BEFORE QUESTIONNAIRE IS COMPLETED] -- “The purpose of this interview is to assess the wording and clarity of the questionnaire we just developed. We need you to help us improve the questionnaire. After you complete the questionnaire I will ask you some questions about areas where the questionnaire can be improved, so please think about this as you are completing it. Feel free to make notes to yourself on the questionnaire as you are completing it.”

[GIVE RESPONDENT TIME TO COMPLETE THE QUESTIONNAIRE]

[AFTER THE QUESTIONNAIRE IS COMPLETED, GO OVER IT WITH THEM SIDE BY SIDE AS YOU BOTH LOOK AT THE QUESTIONNAIRE] -- First, I would like to ask:

1. Overall, how easy or difficult was this for you to complete the questionnaire? What was easy? What was difficult?
2. Did you read the instructions? Were the instructions clear? Would you please tell me in your own words what the instructions mean?
3. **[FOR EACH ITEM]** -- Was the wording clear? Would you please paraphrase the question for me in your own words? What were you thinking of, recalling, or picturing when you answered this question? Do you have suggestions for how the question could be re-worded to make it more clear?
4. **[IN MOST CASES, FOR FIRST FEW ITEMS ONLY]** -- Did the response options make sense to you? Were the response options useful to you?
5. Were there any questions that did not think were applicable to you?

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Your Home Dialysis Care Experience

March 2020

Funding for development of this questionnaire was provided by Satellite Healthcare,
a not-for-profit renal care provider.

Survey Instructions

This survey is about your experiences with home dialysis care through [SAMPLE FACILITY NAME].

For this survey, 'home dialysis staff' includes the nurses, social workers, technicians, dietitians, receptionists and other individuals at your home dialysis center who support you doing your dialysis at home. *'Home dialysis staff' does not include your doctors.*

In this survey, some questions ask about your care in the last 6 months. As you answer these questions, think only about your experience at [SAMPLE FACILITY NAME], *even if you have not been receiving care there for the entire 6 months.*

Answer each question by marking the box to the left of your answer that best describes how you feel.

1. **Where do you currently get your dialysis treatments?**
 - 1 ☐ At home
 - 2 ☐ At a dialysis center → **If at a dialysis center, Go to Question 27**
 - 3 ☐ I do not currently receive dialysis → **If you do not currently receive dialysis, Go to Question 27**
2. **What type of dialysis do you currently do at home?**
 - 1 ☐ Peritoneal dialysis
 - 2 ☐ Home hemodialysis
3. **How long have you been getting home dialysis through your current dialysis center?**
 - 1 ☐ Less than 3 months → **If Less than 3 months, go to Question 27**
 - 2 ☐ At least 3 months but less than 1 year
 - 3 ☐ At least 1 year but less than 5 years
 - 4 ☐ 5 years or more
 - 5 ☐ I do not currently receive dialysis through this dialysis center → **if you do not currently receive dialysis through this dialysis center, Go to Question 27**

THE HOME DIALYSIS STAFF

For the next questions, “home dialysis staff” means nurses, social workers, technicians, dietitians, and receptionists at this dialysis center who support your home dialysis. “Home dialysis staff” does not include your doctors.

4. **In the last 6 months, how often did the home dialysis staff listen carefully to you?**
 - 1 ☐ Never
 - 2 ☐ Sometimes
 - 3 ☐ Usually
 - 4 ☐ Always
5. **In the last 6 months, how often did the home dialysis staff explain things in a way that was easy for you to understand?**
 - 1 ☐ Never
 - 2 ☐ Sometimes
 - 3 ☐ Usually
 - 4 ☐ Always
6. **In the last 6 months, how often did the home dialysis staff show respect for what you had to say?**
 - 1 ☐ Never
 - 2 ☐ Sometimes
 - 3 ☐ Usually
 - 4 ☐ Always

7. In the last 6 months, how often did the home dialysis staff spend enough time with you?

- 1 ☐ Never
- 2 ☐ Sometimes
- 3 ☐ Usually
- 4 ☐ Always

8. In the last 6 months, how often did you feel supported when you called the home dialysis staff for help?

- 1 ☐ Never
- 2 ☐ Sometimes
- 3 ☐ Usually
- 4 ☐ Always
- 5 ☐ I did not call the dialysis center staff for help

9. In the last 6 months, if you asked for help from the home dialysis staff, how often did you get help as soon as you needed it?

- 1 ☐ Never
- 2 ☐ Sometimes
- 3 ☐ Usually
- 4 ☐ Always
- 5 ☐ I did not ask the dialysis staff for help

10. In the last 6 months, how often did you notice problems with communication among the home dialysis staff?

- 1 ☐ Never
- 2 ☐ Sometimes
- 3 ☐ Usually
- 4 ☐ Always

11. In the last 6 months, how often did the home dialysis staff and your kidney doctor work well together as a team?

- 1 ☐ Never
- 2 ☐ Sometimes
- 3 ☐ Usually
- 4 ☐ Always

12. In the last 6 months, how often were the home dialysis staff able to help you deal with problems that you encountered with your home dialysis?

- 1 ☐ Never
- 2 ☐ Sometimes
- 3 ☐ Usually
- 4 ☐ Always
- 5 ☐ I did not encounter problems with my home dialysis

13. In the last 6 months, did the home dialysis staff talk to you about what you should eat and drink?

- 1 ☐ Yes
- 2 ☐ No

14. Has the home dialysis staff ever told you what to do if there is a problem with your dialysis equipment at home?

1 ☐ Yes

2 ☐ No

15. Has the home dialysis staff ever told you what to do if you experience a health problem at home?

1 ☐ Yes

2 ☐ No

16. Has the home dialysis staff ever told you what to do if you are unable to do your dialysis at home in the event of an emergency or disaster?

1 ☐ Yes

2 ☐ No

17. Using a number from 1 to 10, where 1 is the worst home dialysis staff possible and 10 is the best home dialysis staff possible, what number would you use to rate your current dialysis staff?

1 ☐ 1 (Worst staff possible)

2 ☐ 2

3 ☐ 3

4 ☐ 4

5 ☐ 5

6 ☐ 6

7 ☐ 7

8 ☐ 8

9 ☐ 9

10 ☐ 10 (Best staff possible)

TREATMENT

18. In the last 6 months, did the home dialysis staff and your kidney doctor make sure that your home dialysis treatment plan works for you?

1 ☐ Yes

2 ☐ No

For the next two questions, 'treatment for your kidney disease' includes dialysis at a center, dialysis at home, or a kidney transplant.

19. In the last 6 months, did your kidney doctors or home dialysis staff talk to you as much as you wanted about which treatment for your kidney disease is right for you?

1 ☐ Yes

2 ☐ No

20. In the last 6 months, have you been involved as much as you wanted in choosing the treatment for your kidney disease that is right for you?

1 ☐ Yes

2 ☐ No

For the next question, your 'Dialysis Access' means either your peritoneal dialysis catheter, fistula, graft, or hemodialysis catheter.

21. Do you know how to take care of your dialysis access?

- 1 ☐ Yes
2 ☐ No

22. How confident are you in your ability to perform your dialysis safely at home?

- 1 ☐ Very confident
2 ☐ Somewhat confident
3 ☐ Only slightly confident
4 ☐ Not at all confident

THE HOME DIALYSIS CENTER

23. In the last 6 months, were you ever unhappy with the care you received at the home dialysis center?

- 1 ☐ Yes → If Yes, Go to Question 24
2 ☐ No → If No, Go to Question 26

24. In the last 6 months, did you ever talk to someone on the home dialysis center staff about this?

- 1 ☐ Yes → If Yes, Go to Question 25
2 ☐ No → If No, Go to Question 26

25. In the last 6 months, how often were you satisfied with the way they handled these concerns?

- 1 ☐ Never
2 ☐ Sometimes
3 ☐ Usually
4 ☐ Always

26. Using a number from 1 to 10, where 1 is the worst home dialysis center possible and 10 is the best home dialysis center possible, what number would you use to rate your current dialysis center?

- 1 ☐ 1 (Worst home dialysis center possible)
2 ☐ 2
3 ☐ 3
4 ☐ 4
5 ☐ 5
6 ☐ 6
7 ☐ 7
8 ☐ 8
9 ☐ 9
10 ☐ 10 (Best home dialysis center possible)

DEMOGRAPHIC QUESTIONS ("ABOUT YOU")

27. In general, how would you rate your overall health?

- 1 ☐ Excellent
2 ☐ Very good
3 ☐ Good
4 ☐ Fair
5 ☐ Poor

28. In general, how would you rate your overall mental or emotional health?

- 1 ☐ Excellent
- 2 ☐ Very good
- 3 ☐ Good
- 4 ☐ Fair
- 5 ☐ Poor

29. Are you being treated for high blood pressure?

- 1 ☐ Yes
- 2 ☐ No

30. Are you being treated for diabetes or high blood sugar?

- 1 ☐ Yes
- 2 ☐ No

31. Are you being treated for heart disease or heart problems?

- 1 ☐ Yes
- 2 ☐ No

32. Are you deaf or do you have serious difficulty hearing?

- 1 ☐ Yes
- 2 ☐ No

33. Are you blind or do you have serious difficulty seeing, even when wearing glasses?

- 1 ☐ Yes
- 2 ☐ No

34. Because of a physical, mental or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

- 1 ☐ Yes
- 2 ☐ No

35. Do you have serious difficulty walking or climbing stairs?

- 1 ☐ Yes
- 2 ☐ No

36. Do you have difficulty dressing or bathing?

- 1 ☐ Yes
- 2 ☐ No

37. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone, such as visiting a doctor's office or shopping?

- 1 ☐ Yes
- 2 ☐ No

38. What is your age?

- 1 ☐ 18 to 24
- 2 ☐ 25 to 34
- 3 ☐ 35 to 44
- 4 ☐ 45 to 54
- 5 ☐ 55 to 64
- 6 ☐ 65 to 74
- 7 ☐ 75 to 84
- 8 ☐ 85 or older

39. Are you male or female?

- 1 ☐ Male
- 2 ☐ Female
- 3 ☐ Neither male nor female

40. What is the highest grade or level of school that you have completed?

- 1 ☐ No formal education
- 2 ☐ 5th grade or less
- 3 ☐ 6th, 7th, or 8th grade
- 4 ☐ Some high school but did not graduate
- 5 ☐ High school graduate or GED
- 6 ☐ Some college or 2-year degree
- 7 ☐ 4-year college graduate
- 8 ☐ More than 4-year college degree

41. What language do you mainly speak at home?

- 1 ☐ English
 - 2 ☐ Spanish
 - 3 ☐ Chinese
 - 4 ☐ Samoan
 - 5 ☐ Russian
 - 6 ☐ Vietnamese
 - 7 ☐ Portuguese
 - 8 ☐ Some other language (please identify):
-

42. Are you of Spanish, Hispanic, or Latino origin or descent?

- 1 ☐ No, not Spanish/Hispanic/Latino
- 2 ☐ Yes, Puerto Rican
- 3 ☐ Yes, Mexican, Mexican American, Chicano
- 4 ☐ Yes, Cuban
- 5 ☐ Yes, other Spanish/Hispanic/Latino

43. What is your race? (One or more categories may be selected)

- 1 ☐ White
- 2 ☐ Black or African American
- 3 ☐ American Indian or Alaska Native
- 4 ☐ Asian Indian
- 5 ☐ Chinese
- 6 ☐ Filipino
- 7 ☐ Japanese
- 8 ☐ Korean
- 9 ☐ Vietnamese
- 10 ☐ Other Asian
- 11 ☐ Native Hawaiian
- 12 ☐ Gaumanian or Chamorro
- 13 ☐ Samoan
- 14 ☐ Other Pacific Islander

44. Did someone help you complete this survey?

- 1 ☐ Yes → If Yes, Go to Question 45
- 2 ☐ No → If No, please return completed survey to the vendor

45. Who helped you complete this survey?

- 1 ☐ A family member
- 2 ☐ A friend
- 3 ☐ A staff member at the dialysis center
- 4 ☐ Someone else (please identify):

**46. How did that person help you?
Check all that apply.**

- 1 ☐ Read the questions to me
- 2 ☐ Wrote down the answers I gave
- 3 ☐ Answered the questions for me
- 4 ☐ Translated the questions into my language
- 5 ☐ Helped in some other way (please print):

Thank you. Please return the survey in the enclosed envelope to:

**VENDOR'S NAME
STREET ADDRESS 1
STREET ADDRESS 2
CITY, STATE, ZIP**

Su experiencia con el cuidado de diálisis en casa

Marzo 2020

La financiación para el desarrollo de este cuestionario fue proporcionada por Satellite
Healthcare, un proveedor de atención renal sin fines de lucro.

Instrucciones para el cuestionario

Esta encuesta trata de sus experiencias con el cuidado de diálisis en casa a través de [SAMPLE FACILITY NAME].

Para esta encuesta, “personal de diálisis en casa” incluye enfermeros, trabajadores sociales, técnicos, nutricionistas, recepcionistas y otras personas de su centro de diálisis en casa que lo apoyan al realizarla en casa. El “personal de diálisis en casa” no incluye a sus doctores.

En esta encuesta, algunas preguntas se refieren a su cuidado en los últimos 6 meses. Al contestar estas preguntas, piense solamente en su experiencia en [SAMPLE FACILITY NAME], *incluso si no ha recibido cuidado allí durante los 6 meses completos*.

Conteste cada pregunta marcando el cuadrito que aparece a la izquierda de la respuesta que mejor describa cómo se siente.

1. ¿En dónde le hacen los tratamientos de diálisis actualmente?
 - 1 ☐ En casa
 - 2 ☐ En un centro de diálisis → Si contestó “En un centro de diálisis”, pase a la pregunta 27
 - 3 ☐ Actualmente no recibo diálisis → Si actualmente no recibe diálisis, pase a la pregunta 27
2. ¿Qué tipo de diálisis realiza actualmente en casa?
 - 1 ☐ Diálisis peritoneal
 - 2 ☐ Hemodiálisis en casa
3. ¿Cuánto tiempo ha estado recibiendo tratamiento de diálisis en casa a través de su actual centro de diálisis?
 - 1 ☐ Menos de 3 meses → Si contestó “Menos de 3 meses”, pase a la pregunta 27
 - 2 ☐ Al menos 3 meses pero menos de 1 año
 - 3 ☐ Al menos 1 año pero menos de 5 años
 - 4 ☐ 5 años o más
 - 5 ☐ Actualmente no recibo diálisis a través de este centro de diálisis → Si actualmente no recibe diálisis a través de este centro de diálisis, pase a la pregunta 27

EL PERSONAL DE DIÁLISIS EN CASA

Para las siguientes preguntas, el “personal de diálisis en casa” se refiere a los enfermeros, trabajadores sociales, técnicos, nutricionistas y recepcionistas de este centro de diálisis que lo apoyan para su diálisis en casa. El “personal de diálisis en casa” no incluye a sus doctores.

4. En los últimos 6 meses, ¿con qué frecuencia el personal de diálisis en casa le escuchaba con atención?
 - 1 ☐ Nunca
 - 2 ☐ A veces
 - 3 ☐ La mayoría de las veces
 - 4 ☐ Siempre
5. En los últimos 6 meses, ¿con qué frecuencia el personal de diálisis en casa le explicaba las cosas en una forma fácil de entender?
 - 1 ☐ Nunca
 - 2 ☐ A veces
 - 3 ☐ La mayoría de las veces
 - 4 ☐ Siempre
6. En los últimos 6 meses, ¿con qué frecuencia el personal de diálisis en casa le mostraba respeto a lo que usted decía?
 - 1 ☐ Nunca
 - 2 ☐ A veces
 - 3 ☐ La mayoría de las veces
 - 4 ☐ Siempre

7. En los últimos 6 meses, ¿con qué frecuencia el personal de diálisis en casa pasó suficiente tiempo con usted?

- 1 ☐ Nunca
- 2 ☐ A veces
- 3 ☐ La mayoría de las veces
- 4 ☐ Siempre

8. En los últimos 6 meses, ¿con qué frecuencia se sintió apoyado cuando llamaba al personal de diálisis en casa para pedir ayuda?

- 1 ☐ Nunca
- 2 ☐ A veces
- 3 ☐ La mayoría de las veces
- 4 ☐ Siempre
- 5 ☐ No llamé al personal del centro de diálisis para pedir ayuda

9. En los últimos 6 meses, si pidió ayuda al personal de diálisis en casa, ¿con qué frecuencia recibió ayuda tan pronto como la necesitaba?

- 1 ☐ Nunca
- 2 ☐ A veces
- 3 ☐ La mayoría de las veces
- 4 ☐ Siempre
- 5 ☐ No pedí ayuda al personal de diálisis

10. En los últimos 6 meses, ¿con qué frecuencia notó problemas de comunicación entre el personal de diálisis en casa?

- 1 ☐ Nunca
- 2 ☐ A veces
- 3 ☐ La mayoría de las veces
- 4 ☐ Siempre

11. En los últimos 6 meses, ¿con qué frecuencia trabajaron bien como equipo el personal de diálisis en casa y su doctor de los riñones?

- 1 ☐ Nunca
- 2 ☐ A veces
- 3 ☐ La mayoría de las veces
- 4 ☐ Siempre

12. En los últimos 6 meses, ¿con qué frecuencia logró el personal de diálisis en casa ayudarle a lidiar con los problemas que tuvo con la diálisis en casa?

- 1 ☐ Nunca
- 2 ☐ A veces
- 3 ☐ La mayoría de las veces
- 4 ☐ Siempre
- 5 ☐ No tuve problemas con la diálisis en casa

13. En los últimos 6 meses, ¿el personal de diálisis en casa habló con usted acerca de lo que debería comer y beber?

- 1 ☐ Sí
- 2 ☐ No

14. ¿Alguna vez el personal de diálisis en casa le ha dicho qué hacer si tiene un problema con el equipamiento de diálisis en casa?

- 1 ☐ Sí
2 ☐ No

15. ¿Alguna vez el personal de diálisis en casa le ha dicho qué debe hacer si tiene un problema de salud cuando está en casa?

- 1 ☐ Sí
2 ☐ No

16. ¿Alguna vez el personal de diálisis en casa le ha dicho qué hacer si usted no puede realizar la diálisis en casa en caso de una emergencia o un desastre?

- 1 ☐ Sí
2 ☐ No

17. Usando un número del 1 al 10, donde 1 es el peor personal de diálisis en casa posible y 10 es el mejor personal de diálisis en casa posible, ¿qué número usaría para calificar a su personal de diálisis actual?

- 1 ☐ 1 (El peor personal posible)
2 ☐ 2
3 ☐ 3
4 ☐ 4
5 ☐ 5
6 ☐ 6
7 ☐ 7
8 ☐ 8
9 ☐ 9
10 ☐ 10 (El mejor personal posible)

TRATAMIENTO

18. En los últimos 6 meses, ¿el personal de diálisis en casa y su doctor de los riñones se aseguraron de que su plan de tratamiento de diálisis en casa funcione para usted?

- 1 ☐ Sí
2 ☐ No

Para las siguientes dos preguntas, el “tratamiento para su enfermedad de los riñones” incluye diálisis en el centro, diálisis en casa o un trasplante de riñón.

- 19. En los últimos 6 meses, ¿sus doctores de los riñones o el personal de diálisis en casa hablaron con usted tanto como usted lo deseaba sobre cuál era el tratamiento para su enfermedad de los riñones más adecuado para usted?**

1 ☐ Sí
2 ☐ No

- 20. En los últimos 6 meses, ¿ha estado usted tan involucrado como quería en escoger el tratamiento para su enfermedad de los riñones más adecuado para usted?**

1 ☐ Sí
2 ☐ No

Para la siguiente pregunta, su “acceso para diálisis” significa su catéter de diálisis peritoneal, fístula, injerto o catéter de hemodiálisis.

- 21. ¿Sabe cómo cuidar su acceso para diálisis?**

1 ☐ Sí
2 ☐ No

- 22. ¿Cuán seguro se siente de su capacidad para realizar la diálisis en casa de forma segura?**

1 ☐ Muy seguro
2 ☐ Algo seguro
3 ☐ Solo un poco seguro
4 ☐ Para nada seguro

EL CENTRO DE DIÁLISIS EN CASA

- 23. En los últimos 6 meses, ¿alguna vez estuvo descontento con el cuidado que recibió en el centro de diálisis en casa?**

1 ☐ Sí → Si contestó “Sí”, pase a la pregunta 24
2 ☐ No → Si contestó “No”, pase a la pregunta 26

- 24. En los últimos 6 meses, ¿alguna vez habló con alguien del personal del centro de diálisis en casa sobre esto?**

1 ☐ Sí → Si contestó “Sí”, pase a la pregunta 25
2 ☐ No → Si contestó “No”, pase a la pregunta 26

- 25. En los últimos 6 meses, ¿con qué frecuencia estuvo satisfecho con la manera en la que manejaron esas inquietudes?**

1 ☐ Nunca
2 ☐ A veces
3 ☐ La mayoría de las veces
4 ☐ Siempre

26. Usando un número del 1 al 10, donde 1 es el peor centro de diálisis en casa posible y 10 es el mejor centro de diálisis en casa posible, ¿qué número usaría para calificar su actual centro de diálisis?

- 1 ☐ 1 (El peor centro de diálisis en casa posible)
2 ☐ 2
3 ☐ 3
4 ☐ 4
5 ☐ 5
6 ☐ 6
7 ☐ 7
8 ☐ 8
9 ☐ 9
10 ☐ 10 (El mejor centro de diálisis en casa posible)

**PREGUNTAS DEMOGRÁFICAS
("ACERCA DE USTED")**

27. En general, ¿cómo calificaría su estado de salud?

- 1 ☐ Excelente
2 ☐ Muy bueno
3 ☐ Bueno
4 ☐ Regular
5 ☐ Malo

28. En general, ¿cómo calificaría su estado de salud mental o emocional?

- 1 ☐ Excelente
2 ☐ Muy bueno
3 ☐ Bueno
4 ☐ Regular
5 ☐ Malo

29. ¿Está en tratamiento por tener la presión alta?

- 1 ☐ Sí
2 ☐ No

30. ¿Está en tratamiento porque tiene diabetes o el nivel de azúcar en la sangre alto?

- 1 ☐ Sí
2 ☐ No

31. ¿Está en tratamiento porque tiene una enfermedad cardíaca o problemas del corazón?

- 1 ☐ Sí
2 ☐ No

32. ¿Es usted sordo o tiene mucha dificultad para oír?

- 1 ☐ Sí
2 ☐ No

33. ¿Es usted ciego o tiene mucha dificultad para ver, aunque use lentes/anteojos?

- 1 ☐ Sí
2 ☐ No

34. Debido a una condición física, mental o emocional, ¿tiene mucha dificultad para concentrarse, recordar o tomar decisiones?

- 1 ☐ Sí
2 ☐ No

35. ¿Tiene mucha dificultad para caminar o subir escaleras?

- 1 ☐ Sí
- 2 ☐ No

36. ¿Tiene dificultad para vestirse o bañarse?

- 1 ☐ Sí
- 2 ☐ No

37. Debido a una condición física, mental o emocional, ¿tiene dificultad para hacer mandados por sí mismo, como ir al consultorio de un doctor o ir de compras?

- 1 ☐ Sí
- 2 ☐ No

38. ¿Qué edad tiene?

- 1 ☐ 18 a 24
- 2 ☐ 25 a 34
- 3 ☐ 35 a 44
- 4 ☐ 45 a 54
- 5 ☐ 55 a 64
- 6 ☐ 65 a 74
- 7 ☐ 75 a 84
- 8 ☐ 85 o más

39. ¿Es usted hombre o mujer?

- 1 ☐ Hombre
- 2 ☐ Mujer
- 3 ☐ Ni hombre ni mujer

40. ¿Cuál es el grado o nivel escolar más alto que ha completado?

- 1 ☐ Sin educación formal
- 2 ☐ 5° grado o menos
- 3 ☐ 6°, 7° u 8° grado
- 4 ☐ Algo de preparatoria o 'high school' pero sin graduarse
- 5 ☐ Graduado de la escuela preparatoria o 'high school' o GED
- 6 ☐ Algunos cursos universitarios o un título universitario de un programa de 2 años
- 7 ☐ Título universitario de 4 años
- 8 ☐ Título universitario de más de 4 años

41. ¿Qué idioma habla usted principalmente en el hogar?

- 1 ☐ Inglés
- 2 ☐ Español
- 3 ☐ Chino
- 4 ☐ Samoano
- 5 ☐ Ruso
- 6 ☐ Vietnamita
- 7 ☐ Portugués
- 8 ☐ Algún otro idioma (por favor, especifique):

42. ¿Es usted de origen español, hispano o latino?

- 1 ☐ No, no soy de origen español, hispano o latino
- 2 ☐ Sí, puertorriqueño
- 3 ☐ Sí, mexicano, mexicano americano, chicano
- 4 ☐ Sí, cubano
- 5 ☐ Sí, de otro origen español, hispano o latino

43. ¿Cuál es su raza? (Puede seleccionar una o más categorías.)

- 1 ☐ Blanca
- 2 ☐ Negra o africana americana
- 3 ☐ India americana o nativa de Alaska
- 4 ☐ India asiática
- 5 ☐ China
- 6 ☐ Filipina
- 7 ☐ Japonesa
- 8 ☐ Coreana
- 9 ☐ Vietnamita
- 10 ☐ Otra raza asiática
- 11 ☐ Nativa de Hawái
- 12 ☐ Guameña o Chamorro
- 13 ☐ Samoana
- 14 ☐ Otra de las islas del Pacífico

44. ¿Le ayudó alguien a llenar esta encuesta?

- 1 ☐ Sí → Si contestó “Sí”, pase a la pregunta 45
- 2 ☐ No → Si contestó “No”, devuelva la encuesta con sus respuestas al proveedor

45. ¿Quién le ayudó a llenar la encuesta?

- 1 ☐ Un miembro de su familia
- 2 ☐ Un amigo
- 3 ☐ Un miembro del personal del centro de diálisis
- 4 ☐ Otra persona (Por favor, especifique):

46. ¿Cómo le ayudó esa persona? Por favor, marque todas las respuestas que correspondan.

- 1 ☐ Me leyó las preguntas
- 2 ☐ Escribió las respuestas que yo le di
- 3 ☐ Contestó las preguntas por mí
- 4 ☐ Tradujo las preguntas a mi idioma
- 5 ☐ Me ayudó de alguna otra manera (Por favor escriba en letra tipo imprenta):

Gracias. Por favor, devuelva la encuesta en el sobre adjunto a:

**VENDOR'S NAME
STREET ADDRESS 1
STREET ADDRESS 2
CITY, STATE, ZIP**