In-Center Hemodialysis CAHPS: Examining the Feasibility of Administering a CAHPS Survey of Home, Peritoneal, and Pediatric Dialysis Patients

**Summary of Discussions During the**

**Technical Expert Panel Telephone Conference**

List of Abbreviations and Acronyms

| Abbreviation/Acronym | Term/Phrase |
| --- | --- |
| AHRQ | Agency for Healthcare Research and Quality |
| ICH | In-center hemodialysis |
| ICH CAHPS | In-Center Hemodialysis CAHPS Survey |
| CAHPS | Consumer Assessment of Healthcare Providers and Systems |
| CMS | Centers for Medicare & Medicaid Services |
| CROWNWeb | Consolidated Renal Operations in a Web Enabled Network |
| HD | Hemodialysis |
| HCAHPS | Hospital CAHPS  |
| PD | Peritoneal dialysis |
| PEC | Patient Experience of Care (Survey) |
| QoL | Quality of Life (Surveys) |
| RRT | Renal replacement therapy |
| TEP | Technical Expert Panel |

## Overview

RTI International has been assisting the Centers for Medicare & Medicaid Services (CMS) with the national implementation of the In-center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS) Survey since its inception in 2014. The ICH CAHPS Survey is designed to obtain data from in-center hemodialysis (ICH) patients about their experience with and assessment of the quality of their dialysis care. To be eligible to participate in the ICH CAHPS Survey, patients must be 18 years old or older, be non-institutionalized, and have received ICH from their current dialysis facility for 3 months or longer. Adult dialysis patients who receive home hemodialysis (HD) and peritoneal dialysis (PD) and pediatric dialysis patients are not eligible to be included in the ICH CAHPS Survey.

Dialysis facilities and other stakeholders have recently expressed to CMS an interest in a CAHPS Survey for home HD, PD, and pediatric dialysis patients. CMS has asked RTI to examine the feasibility of conducting a CAHPS Survey of these patient populations. It should be noted that the primary focus of this task is to evaluate the feasibility of adapting or using some of the existing survey items in the ICH CAHPS Survey for one or more of these patient populations and to identify other domains or dimensions of care that might be of interest to these patients. This task does not include development of a questionnaire according to the CAHPS survey development process required by the Agency for Healthcare Research and Quality (AHRQ), which includes a call for measures, focus groups with the target populations, review and input from a TEP about the initial survey, a field test to examine the psychometric properties of the survey items, and revising the survey based on field test results.

RTI established a 10-member TEP, which consisted of nephrologists, dialysis nurses, dialysis social workers, and dialysis patients. We conducted a telephone conference with TEP members on March 16, 2018.

During the telephone conference, TEP members were asked to provide input on a number of issues, including domains of care that would be important to home, peritoneal, and pediatric dialysis patients. RTI project staff also sought input on domains of care and issues related to a possible CAHPS Survey of kidney transplant patients. In addition, we discussed issues related to survey sampling and administration. To expedite discussions during the telephone conference, 1 week prior to the TEP meeting, RTI project staff sent to each TEP member a “Pre-Meeting Review” package, which contained background information about the ICH CAHPS Survey, a copy of the ICH CAHPS Survey questionnaire, and a list of issues about which we would seek input during the telephone conference. The list of issues for discussion during the TEP telephone conference are included in ***Appendix A.*** This report summarizes the topics presented during the TEP telephone conference and the input and guidance that TEP members provided. It also includes issues and concerns that were raised by the TEP members. Information presented in this report is organized to follow the order of topics as they were presented and discussed during the telephone conference.

## Welcome, Introductions, and Overview of the CAHPS Surveys

RTI and CMS opened the meeting by welcoming TEP members and describing the purpose of the call. Judy Lynch, the RTI ICH CAHPS Project Director, explained the format that the telephone conference would follow. She then took a roll-call to identify participants who were on the call and asked each participant to say hello and state their name and affiliation. All 10 TEP members participated in the conference. Dr. Mark Graber, an RTI Fellow, served as the facilitator for the TEP conference call. Two CMS project team members and seven other RTI project team members also participated in the call. Judy provided background information about the family of CAHPS Surveys, reviewed the purpose and goals of the ICH CAHPS Survey, and described RTI’s role on the ICH CAHPS Survey. Judy then turned the meeting over to Dr. Graber, who facilitated the discussions during the remainder of the call.

## Description of the Populations of Interest

Before beginning a discussion of the issues related to conducting a CAHPS Survey of home HD, peritoneal, and pediatric dialysis patients, Dr. Graber described the study population and the choices available to end-stage renal disease (ESRD) patients as noted below.

***The study population***. The United States Renal Data System (USRDS) acquires and maintains data on chronic and end-stage kidney diseases. According to the USRDS, an estimated 30 million American adults have chronic kidney disease. These individuals are largely asymptomatic, but every year more than 100,000 patients will evolve to ESRD and require some form of renal replacement therapy (RRT). In 2015, 124,111 new cases of ESRD were documented. There is regional variance in ESRD incidence, with the Mountain states and New England states having the lowest incidence; rates that are 3-4 times higher are encountered in the South, mid-West, and mid-Atlantic regions.

At the present time, roughly 500,000 patients receive maintenance dialysis treatment. In round numbers, there are about 450,000 patients receiving ICH, 50,000 on home PD, and 10,000 on home HD. More than 200,000 are living with a kidney transplant, and another 80,000 are on transplantation waiting lists. Of the total ESRD population, approximately 10,000 are children on dialysis, and an additional 7,000 children are living with a kidney transplant. Roughly 125,000 patients will reach end-stage kidney disease every year.

***Choices ESRD patients face***. Patients with chronic kidney disease face two major decisions as they approach ESRD:

1. What type of RRT should they choose?

2. Where will they receive that treatment?

Both of these decisions are incredibly difficult, challenging, and unpleasant for ESRD patients. The decision these patients make will, to a great extent, determine the quality of their life for many years.

In regard to the first decision that ESRD patients must make (which treatment modality to choose), there are abundant resources available to patients to help make this choice, although we do not know to what extent patients are given this information, or seek it on their own. Choosing a treatment modality is not part of this task order. We are primarily focused on the second decision, choosing an ESRD treatment site and whether novel surveys on home dialysis, and possibly kidney transplantation centers, would supplement the value of the current ICH CAHPS Survey in helping patients make this selection.

Nationally, there are more than 6,000 ICH facilities, so depending on where a patient lives, there may be many possible choices. In terms of transplantation, the choices are substantially more constrained, but there are still approximately 250 accredited transplantation centers, and patients are very willing to travel to reach the transplantation center of their choice. Many patients are on waiting lists at more than one center. In regard to pediatric HD, we do not have good data, but it is probably safe to say that most children receive HD at an adult center because only a handful of centers specialize in providing dialysis care to children.

Developing new resources to meet these needs would help future patients in choosing the treatment center for their particular needs. There is a second benefit to having patient experience of care data: it provides both the motivation for centers to improve their services and the information they need to do so.

## Issues Discussed During the TEP Meeting

At this point during the telephone conference Dr. Graber reviewed and obtained input from TEP members about each of the issues included in the Pre-Meeting Review Package. Those issues, and TEP members’ input and questions, are provided in this section.

### General Issues

1. Facilities that serve only home, peritoneal, and pediatric dialysis and kidney transplant patients are not required by CMS’s Quality Incentive Program to administer a CAHPS Survey.

1a. If CMS made a CAHPS Survey available for these patient populations, about what percent of facilities would be willing to voluntarily administer a CAHPS Survey of these patient populations?

* One TEP member stated that some organizations are already conducting a patient experience of care (PEC) survey of these patients using home-grown instruments (i.e., not validated or standardized). This TEP member guessed that maybe a third to a half of organizations would be willing to administer a CAHPS Survey of these patient populations voluntarily.
* Another TEP member commented that he cannot comment on pediatric and transplant populations, but for home HD and PD, there is enthusiasm in facilities located in the Seattle, Washington, area for conducting a PEC survey of these patient populations.
* A TEP member noted that DaVita is also showing similar interest for this type of survey. If CMS goes ahead with such a survey, then DaVita would love to use what would be mandated.
* One TEP member stated that pediatric centers in general (transplant or dialysis) would be very interested in a uniform survey that could be used in facilities across the country, as long as survey results were compared to each other and not to adult centers. This same TEP member commented that “On the flipside, I’m not sure how many centers would be happy for this data to be in the public domain, as there is always a little reluctance from these centers to see their data out there.” This TEP member stated that overall, however, there would be an interest, but the added cost is the prohibitive factor. She pointed out that because facilities would be administering the surveys to a limited number of patients, and centers pay for these surveys to be conducted by contractors, the per patient costs would be high.
* Another TEP member agreed that facilities might be concerned that their survey results would be publicly available.
* A TEP member indicated that she is currently on a committee that is trying to get referral and wait list data. This TEP member indicated that facilities would want the aggregate data but would not want individual results published.

1b. If CMS made a CAHPS Survey available for these patient populations, about what percent of facilities would qualify for public reporting of data if they were required to obtain 30 or more completed surveys per reporting period?

* A TEP member commented that for home HD patients, it depends on what the definition of “facility” is. For example, there are home programs that are physically placed in the same building as an ICH program, but have a separate CMS provider ID number. This TEP member asked if we are considering the number of PD patients only, number of any home modality patients, or number of patients of any modality (including ICH). The TEP member stated that if we are only interested in number of patients on PD, we will have very few centers where the anticipated response rate would be more than 30 patients. Assuming the response rate is 30%-40%, being optimistic, probably less than 5% (of the facilities) would meet this requirement.
* Another TEP member concurred, adding that 10 years ago his organization looked at the sizes of PD programs across the country and asked (a) how big is the program and (b) what is the response rate? This TEP member pointed out that if 50% of patients are going to respond to a survey, you would have to have a program with 60 patients. There would be a handful of PD facilities in the country that would have 60 patients and home HD would be even smaller.
* One TEP member asked whether the USRDS can provide the number of patients served by each PD or home HD clinic, or the number of clinics with a certain number of patients. Judy Lynch responded that RTI has access to Consolidated Renal Operations in a Web Enabled Network (CROWNWeb) data and has created files that show the number of each type of patient served by all dialysis centers. Judy pointed out that it is hard to obtain a current patient size for each facility because some facilities close or switch owners.
* One TEP member noted that they downloaded data from Dialysis Facility Compare and saw 3,643 PD clinics and 1,871 home HD clinics.
* Another TEP member reported that the median number of PD patients in each center (10 years ago) was about 10. This TEP member pointed out that the number might be higher now, but he would anticipate maybe 5% of facilities would get more than 30 responses and thinks for home HD it would be closer to 1%-2%.
* A TEP member suggested that the number of completed surveys might be higher for transplant centers. She stated that given that transplant centers are typically affiliated with academic institutions and more centrally located, there is a smaller number of these centers, but they have a large number of patients. She estimated that perhaps 25%-30% of transplant centers would qualify for public reporting; that is, would be able to obtain 30 or more completed surveys.
* One TEP member asked if the survey or results reported would be based on year of transplant. For example, if you got a transplant 6 years ago, would you still be included (eligible for the survey)? Assuming that all transplant patients would be survey-eligible, the TEP member speculated that the number of transplant centers that would be able to obtain 30 or more completed surveys might be even higher, perhaps 55% or so given the limited number and volume of transplant centers.
* Another TEP member asked why 30 is the magic number, noting that USRDS looks at clinics with 11 or more. Judy noted on ICH CAHPS, a facility must have 30 or more completed surveys combined for two survey periods. She pointed out that for determining whether a facility must administer the survey to be compliant with CMS’s quality reporting requirements, a facility must have served 30 or more survey-eligible patients in the preceding calendar year. She also pointed out that for clinical measures, CMS requires that a facility serve 11 or more patients before clinical results are publicly reported.

2. According to information gleaned from the U.S. Renal Disease Report and some literature articles (specifically Chand H. Deepa et al., Dialysis in Children and Adolescents: The Pediatric Nephrology Perspective, American Journal of Kidney Diseases, 2017: 69(2):278-286) reviewed by project staff, “Dialysis units with pediatric designation make up <0.1% of the total number of dialysis facilities in the United States, with most located at or near pediatric tertiary-care centers in urban areas of the country.”

 With so few pediatric dialysis patients, many of whom receive dialysis care at adult dialysis facilities, protecting the identity and confidentiality of respondents becomes an issue during a survey. It should be noted that in the ICH CAHPS Survey, survey vendors cannot share survey responses with a facility, even if they have the patient’s consent, unless the facility has 11 or more respondents who provided an answer to each individual survey item. Do you have any suggestions as to how a survey organization can protect the privacy and identity of respondents to the survey?

* One TEP member asked how these surveys were being administered; are they handed to a patient in person and the patient turns it in? Online? Judy responded that ICH CAHPS and most other CAHPS surveys are administered by a third-party survey vendor. She pointed out that those vendors cannot share any patient responses unless they have the patient’s consent. For ICH CAHPS, however, survey vendors cannot share responses even with a patient’s consent. This TEP member then pointed out that unless you are dealing with a very small center, the aggregate responses should protect patients’ privacy because it would be difficult to point a finger at one person out of 20 or 30 respondents.
* Another TEP member commented on the current ICH CAHPS question about whether the patient has reported a problem to any agencies. The TEP member stated that if you had a similar question on one of these potential surveys, there is a good chance someone would know who said that.
* A TEP member acknowledged concern raised by patients who are worried about saying anything negative given that their lives are in the hands of the dialysis center staff. Two things to lessen these chances are not sharing the demographics tied to the responses and similarly to ICH CAHPS, conducting the survey semiannually so that the data are rolled up into a larger sample size with the potential for some patients to have left and new patients to have joined.
* Another TEP member added that using a third-party survey vendor helps as well. This TEP member indicated that, of the patients they have talked with, that was one of their patients’ main concerns. If the facility was the one administering a survey, patients would not complete the survey.

3. This same issue of protecting the identity and privacy of respondents also applies to home, peritoneal, and kidney transplant patients. Any suggestions for the minimum number of survey respondents a facility must have before de-identified survey response data can be shared with the facility?

* One TEP member suggested 10.
* Another suggested 11 based on USRDS but agreed that 10 would be fine too.
* Another TEP member was also fine with 10. That TEP member noted that the problem we would find is that this would exclude the majority of pediatric centers and quite a few home PD and home HD programs. Judy responded that some ICH facilities participating in ICH CAHPS are small as well, but on ICH CAHPS publicly reported results are based on combined data from two survey periods. The same TEP member agreed that that is a good approach, but still thinks some pediatric and home HD facilities would not be represented.
* Another TEP member commented that her organization’s pediatric transplant list is always fewer than 10 patients, and they have done 12 pediatric transplants total. She stated that she is not sure if a survey would be able to represent this population’s needs.
* One TEP member pointed out that home HD numbers being smaller would be true only if it is a standalone home HD center. If the facility services both home HD and home PD patients, then there is no reason to separate the survey by home PD and home HD; they (both types of patients) could be collectively represented.
* Another TEP member added that the definition of the facility should be a home program which would include both home PD and home HD. The issue remains for pediatric centers.

### Domains/Dimensions of Care That Would be Important to Patients

CAHPS Survey results are used by patients to inform their decisions about choice of a health care facility, by health care providers in their quality improvement efforts, and by CMS to monitor the quality of care provided by Medicare-certified health care facilities.

1. What are topics or dimensions of care that facilities would be interested in to improve the quality of care that they provide to their patients?

* One TEP member noted that having worked with these patient populations and looking at the culture of safety and safety issues, some issues that might need to be expanded are getting timely help, particularly at a home program (home HD and home PD). This TEP member stated that home dialysis patients need a timely response because they do not have face-to-face time in the clinic setting. The TEP member noted that with that comes communication with the appropriate players in those settings.
* Another TEP member concurred and noted that we could use different wording for some of the survey items about staff responding quickly and in a timely manner. This TEP member suggested adding questions to ask about the type of availability and support these patients have on a 24/7 basis. She also suggested asking a survey item to determine how well the center is providing that support.
* A TEP member added that timely response is also important to decrease the incidence of hospitalizations. She pointed out that an issue can be managed by bringing the patient into the clinic; that could avoid potential patient hospitalizations.
* One TEP member pointed out that to a certain degree, there is going to be a difference between what facilities might want to see [included in the survey] versus what patients want to see. This TEP member noted that patients:

care about safety and responsiveness and respect and the quality of time spent with staff;

worry about whether staff are really listening to them, because sometimes health care providers might seem rushed and not 100% attentive or focused; and

worry about the privacy of their discussions when in the clinic.

* That same TEP member suggested adding survey items to determine how easy it is to schedule a meeting with the facility, how easy it is to talk with someone [at the facility], and the quality of that meeting.
* Another TEP member stated that many transplant centers are set up differently in terms of follow-up care post-transplantation. This TEP member pointed out that some transplant patient patients only come visit the center once a year and asked whether there is any value or need to survey transplant patients more than once a year.
* This TEP member also pointed out that not all transplant centers provide data to CROWNWeb; he asked how we would identify and sample transplant patients who do not use CROWNWeb.

2. What are the domains of dialysis care that would be most important to home and peritoneal patients when choosing a dialysis facility?

* One TEP member commented that patients are concerned about the training they get and how quickly they get it after they have chosen a home treatment modality. This TEP member suggested including a question in the survey to ask if the training addressed all of the potential issues that could occur. He also suggested including a survey item to ask whether the facility accommodated the patient’s schedule.
* Another TEP member commented that he heard that some patients are concerned about transitions of care. This TEP member stated that if dialysis patients have to be hospitalized, they are concerned about whether the hospital will have all of the information about the patient it needs. Or conversely, if dialysis patients are discharged from a hospital, will the treating facility have all of the information it needs regarding the patient’s plan of care.
* This same TEP member suggested that patients will want to know how quickly patients being brought back into the office setting for a follow-up post hospitalization to ensure that they [the patients] are understanding any changes in treatment, medications, etc. The TEP member commented that “Things can easily fall through the cracks in those types of transitions.”

3. Would the dimensions of dialysis care that are important be the same for both home hemodialysis and peritoneal patients?

* One TEP member commented that the central elements for care are similar. However, technology and the skills taught are different, at least from the standpoint of a physician who has cared for a lot of patients.
* Another TEP member agreed that looking at ICH CAHPS, many domains would be the same for home HD and home PD, including physician communication and caring, center staff communication and caring, and providing information.
* Another TEP member added that there might be more specific questions for home dialysis patients and for transplant patients.
* One dimension of care that both HD and PD patients would likely be asked about is that of the staff who help care for them. One TEP member said that for home patients, doctors and nurses are appropriate to ask about, but we should specifically refer to those who are in charge of the home program. Sometimes they are the same people but other times they are not.

4. For peritoneal dialysis patients, would the dimensions of care that are important when choosing a dialysis facility differ based on whether the patient receives continuous ambulatory peritoneal dialysis or automated peritoneal dialysis?

* One TEP member stated that there is no need for a difference in questions, and most of the other TEP members agreed.
* Another TEP member pointed out that it would be important to know how the facility handles problems with a patient’s equipment or supplies.

5. What are dimensions of care that would be most important to parents/caregivers of pediatric dialysis patients?

* A TEP member commented that the domains for pediatric dialysis patients are essentially going to be very similar to those for adult patients. This TEP member stated that the ICH CAHPS domains, including the nephrologist’s communication and caring, dialysis center staff caring and operations, providing information, in this case to patients and caregivers, are very important. Providing information to patients, especially to adolescents, is very important.
* Another TEP member suggested that you cannot separate the patient from the caregiver. It does not matter if the patient or caregiver is responding, you have to be cognizant that you are talking to [asking about] both. One TEP member pointed out that for current quality of life (QoL) pediatric surveys, if the patient is aged 5-7 they are read the questions, and if they are 8 or older they (the children) can self-administer. The TEP member indicated that this can be done by phone or in-person interviews, although the QoL surveys are done in person. The TEP member indicated that in pediatric QoL surveys, children 8 and older are left alone (given some privacy) to complete the survey on their own. In addition, this TEP member stated that this is important to consider moving forward because a child’s point of view is going to be important.
* Some TEP members asked if someone could translate the survey for patients considering that in some locations 25% or more of the patients only speak Spanish. Another TEP member confirmed that someone can translate the survey.
* Another TEP member added that if you were going to allow proxy respondents, you must have an additional question about how the person helped with the survey. This is especially important with the pediatric population. This TEP member also indicated that her organization uses a proprietary survey that is based on ICH CAHPS and that they direct it toward both the parent and child, and they take children’s responses very seriously. In addition, this TEP member reported that the facilities in her organization administer the survey quarterly, which is likely too often because they get few responses. This TEP member also stated that it would be better if facilities use an outside agency [survey vendor] to collect the data.
* Dr. Graber stated that we know that children are different from adults in terms of medical, psychosocial, and behavioral support needs; he asked if it is important to survey on those dimensions.
* One TEP member replied yes, to make sure that facilities are meeting the needs of the family.
* Another TEP member added that a theme to consider is whether we will be surveying both adults and children.
* A TEP member noted she is concerned that Q18 in the ICH CAHPS, which asks if anyone in the facility has asked the patient how dialysis affects his or her life, is not included in one of the ICH CAHPS composites. She commented that it is important to collect and report this information for all patient populations. She also added that there are not enough psychosocial questions in the ICH CAHPS Survey.

6. If a patient experience of care survey were developed for kidney transplant patients, which type of providers/staff would the survey ask about? Are there dimensions of care that would be important to them? Should there be a separate series of questions that ask about each type of medical professional that comprise the patient’s kidney transplant care team?

* One TEP member indicated that from a transplant perspective, better terms would be doctor and coordinator.
* Another TEP member noted that ICH CAHPS groups all dialysis staff together, so if a patient is unhappy with a particular staff person, the rating of the staff could reflect poorly on everyone. This TEP member suggested using a matrix format, which would include all of the question in a table so as to not add too many survey items to the survey. She pointed out that the in a table all of the different types of dialysis staff could be listed separately including doctor, nurse, social worker, dietician, etc.
* One TEP member stated that for transplant patients, in addition to doctors and nurses, the survey should include questions about pharmacists and other mid-level practitioners such as nurse practitioners and physician assistants because they are a big part of the care of a transplant patient.
* Another TEP member indicated that for home dialysis patients, the home dialysis nurse is of the utmost importance, much more than ICH nurses. ICH nurses are shift nurses and patients do not always get the same nurse. This TEP member suggested that if the survey used a generic phrase “dialysis center staff,” the only person the patient would assess is the nurse. If you want to ask about dietician, social worker, etc., you need to call them out separately.

7. Considering that the questionnaire will have a maximum number of survey items, are there categories of staff (or members of the patient’s care team) that can be asked about in the same questions? For example, does there need to be separate sets of questions that ask about the nephrologist or transplant surgeon versus other members of the patient’s care team? The survey could have a statement such as “The next few questions ask about the care you receive from the social worker, nurses, dialysis technicians (etc.). When answering these questions, think about your experience with those facility staff members.”

* A TEP member confirmed that, in the home program, the nurse is the key individual who oversees the patient’s health, teaches the patient about the modality treatment, takes any phone calls from the patient, etc. Questions about the physician can be included in the survey, but when thinking of the home program and who is involved, other providers/staff are just as important as the nurses; they just might not be communicating with the patient as frequently. This TEP member noted that we should not remove questions about the patient’s care team.
* Some TEP members asked if it is feasible to have some type of skip logic in the questionnaire that would allow patients to skip questions that are not applicable to them, based on the type of team that was caring for them.
* One TEP member asked where CMS stands with administering a CAHPS survey electronically. One of the CMS project staff members on the call responded that CMS is currently testing web/Internet surveys with patients who received care in other provider settings. The CMS representative pointed out that CMS wants to make sure that using a web/internet mode would not preclude some patients from being able to participate in a CAHPS Survey.

8. Please review the survey items in the current ICH CAHPS Survey instrument. Which of the questions in the current survey would be applicable as worded or could be adapted for home and peritoneal patients?

* All TEP members agreed that almost all of the survey items in the current ICH CAHPS Survey are applicable to home and peritoneal patients.

9. Which survey items would be applicable as worded or could be adapted for pediatric dialysis patients?

* One TEP member noted that it is important to have survey items about support for families, parents, or caregivers. Another TEP member agreed and indicated that home dialysis patients should also receive similar survey items.
* All TEP members agreed that the current ICH CAHPS Survey items are relevant, but it might be necessary to develop new survey items that relate specifically to this patient population.

10. How feasible would it be to develop one survey that would be applicable to both adult home and peritoneal patients?

* All TEP members agreed that it is very feasible to develop one survey that would be applicable to both adult home and peritoneal patients.
* One TEP member stated that, for a pediatric survey, there would be a slight differentiation between questions that would involve the pediatric patient and the caregiver. Separate questions should be geared toward the caregiver, and the patient, so there would need some wording changes to make the survey items applicable to both the parent/caregiver and the child. All TEP members agreed that this would be doable for a pediatric survey.
* A TEP member commented that it is possible to develop any type of survey, but the time and effort that would be needed to develop a separate survey for all three of these populations may not be feasible.

11. The current ICH CAHPS Survey questionnaire has 60 survey items. What is the maximum number of survey items that should be included in a survey developed for each of these patient populations (home, peritoneal, pediatric dialysis, kidney transplant)?

* One TEP member recommended having no more than 10 survey items in the questionnaire.
* Another TEP member mentioned that if CMS anchors or models the survey after another CAHPS Survey, it would be the Hospital CAHPS (HCAHPS) Survey, which has 32 questions. This TEP member compared ICH CAHPS (60 questions) with HCAHPS and said that if 10 survey items are not enough to cover all domains, then an HD, PD, and Kidney Transplant CAHPS Survey should include 32 survey items, as does the HCAHPS.
* Another TEP member agreed that the survey should contain about the same number of survey items included in HCAHPS, saying that there should be an upper limit of 30 questions.
* A TEP member asked if it were possible to start with a larger tool (survey) and then do a factor analysis to see if the survey could be reduced to 20-25 questions while still hitting all the questions we are aiming for. Judy Lynch noted that, per AHRQ guidelines, steps are required in the survey development process to determine the internal validity and consistency of survey items, and analysis of field test data typically identifies survey items that can be removed from the survey.
* One TEP member noted that there is the potential for more patients to respond to the survey if it were shorter, and therefore the survey data would be more representative of the population.

### Patient Eligibility for the Survey

1. To be eligible for the ICH CAHPS Survey, ICH patients must be 18 years old or older by the date the sample is selected, be non-institutionalized, and have received dialysis care from their current ICH facility for 3 months or longer. What patient survey eligibility requirements do you recommend for adult home and peritoneal patients?

* All TEP members agreed that the patient eligibility criteria for adult home and peritoneal patients should be the same as the criteria for inclusion in the ICH CAHPS Survey.

2. In addition to having been served by their current facility for 3 months or longer, should patients have been receiving dialysis using their current modality for 3 months or longer, or would some shorter period of time suffice?

* One TEP member stated that it takes patients time to get acclimated and comfortable with their treatment, so 3 months is an appropriate amount of time.
* Most TEP members agreed that 3 months *after* the treatment modality training is a good amount of time. TEP members pointed out that home HD patients receive treatment training for up to 3 weeks, and home PD training can take at least a week.

3. Some pediatric health care providers will serve pediatric patients up to age 21. For a survey of pediatric patients, should the maximum age for receiving the pediatric version of the survey be under 18 or under 21?

* One TEP member noted that whatever the age limit may be, it is important to have a survey for both the patient and the caregiver.
* Another TEP member recommended keeping the age for pediatric surveys at 18 because that is the criteria in other CMS Surveys involving children.
* A TEP member asked a broader question: at what age do you start surveying a pediatric patient? Some facilities see a lot of patients under 5 years old. With that said, the decision would be to survey the patient’s parents before that age.

4. What if a pediatric patient has been seen in both a pediatric and an adult facility? Or if a peritoneal patient has received dialysis both at home and at a center? Which would take precedence so that we are not burdening the patient with multiple surveys?

* All TEP members agreed that patients should be included in the sample or survey based on the type of facility or treatment they received most recently.

5. What patient eligibility criteria do you recommend for kidney transplant patients? Is there a minimum amount of time after the kidney transplant takes place before a patient is eligible to be surveyed?

* Several TEP members recommended that the minimum amount of time after a patient receives a kidney transplant and being eligible to be surveyed should be 3 months post-transplant.
* One TEP member noted that it is hard to reflect back on the first 3 months after a kidney transplant to decide whether all of their questions and needs were met during the process.

6. RTI staff asked a general follow up question to the kidney transplant process: who would the kidney transplant patient be assessing if a survey were adapted for this population?

* One TEP member responded by saying that it would be best to assess the patient’s post-transplant support team. This TEP member pointed out that the patient usually has a coordinator and a doctor who help the coordinator. The patient would be rating the responsiveness of these staff.
* Another TEP member recommended asking “Where are you currently receiving your post-transplant care?” and then being able to assess the care team that way.

### Survey Administration

1. There are currently three approved modes of data collection for the ICH CAHPS Survey: mail only, telephone only, and mixed mode (mail with telephone follow-up of nonrespondents). Which of these three modes will dialysis facilities be more likely to use in administering surveys of home, peritoneal, and pediatric dialysis patients, and for kidney transplant patients?

* TEP members agreed that whichever mode receives the highest response rate would probably be the best data collection mode. One of RTI’s project staff members pointed out that on ICH CAHPS, the telephone-only mode has the lowest response rates, while mixed-mode surveys have yielded the highest response rates.
* One TEP member asked about the feasibility of an online survey, but another TEP member pointed out that, statistically, the dialysis population tends to be elderly patients who are unfamiliar with technology, and as a result, an online survey may negatively affect response rates.
* Another TEP member stated that mixed-mode data collection makes the most sense even if an online survey were offered. This TEP member pointed out that most people on dialysis have a lower socioeconomic status and education status; many do not have Internet access, and some are legally blind and have diabetic neuropathy.
* TEP members agreed that the more data collection modes offered, the better. The group indicated that we should not limit data collection to one mode.

2. The ICH CAHPS Survey is currently offered in English and Spanish, Traditional and Simplified Chinese, and Samoan for mail survey administration, and in English and Spanish for telephone survey administration. Are there other languages that should be offered for a survey for home, peritoneal, and pediatric dialysis patients, and for kidney transplant patients?

* Several TEP members agreed that the languages currently offered on the ICH CAHPS Survey are sufficient for a survey of home, peritoneal, and pediatric dialysis patients, and for kidney transplant patients.
* Judy Lynch noted that on ICH CAHPS, CMS will allow translation of the survey in up to two additional languages each year.

3. For pediatric patients, would the parent or caregiver always be the target for completing the survey? Should we consider surveying older children? If so, beginning at what age?

* A TEP member stated that the parent or caregiver should only be a *part* of the surveying; she stressed that the pediatric patient should also be included. She stated that some of the questions in the survey would need to be reworded so that one set would be completed by the parent/caregiver, and the other set would be completed by the child.

### Other Considerations

1. Are there other issues that CMS should consider when deciding whether to conduct a CAHPS Survey of these patient populations?

* One TEP member recommended considering a survey that targets pre-transplant patients. It was noted however, that pre-transplant patients still receive dialysis, so it is possible that they would be included in the ICH CAHPS Survey.
* Another TEP member recommended that pre-transplant patients could potentially be represented in a survey of post-transplant patients if there was a question similar to, “If you are within 6 months of receiving your transplant, skip to Question X,” where they would complete a section related to pre-transplant questions.
* A TEP member stated that to make sure the survey is clear, who the audience is, the results of the survey data, and the purpose of the survey must be clear.

2. Considering the universe of home, peritoneal, and pediatric dialysis patients, and that of kidney transplant patients, would you recommend that CMS move forward with development and implementation of a CAHPS Survey of these patient populations?

* All TEP members agreed that CMS should move forward with developing and implementing a survey for these targeted populations.

Appendix A
List of Issues for Discussion

### General Issues

1. Facilities that served only home, peritoneal, and pediatric dialysis and kidney transplant patients are not required by CMS’s Quality Incentive Program to administer a CAHPS Survey. If CMS made a CAHPS Survey available for these patient populations:

* about what percent of facilities would be willing to voluntarily administer a CAHPS survey of these patient populations?
* about what percent of facilities would qualify for public reporting of data if they were required to obtain 30 completed surveys per reporting period?

 According to information gleaned from the U.S. Renal Disease Report and some literature articles (specifically Chand H. Deepa et al., Dialysis in Children and Adolescents: The Pediatric Nephrology Perspective, American Journal of Kidney Diseases, 2017: 69(2):278-286) reviewed by project staff, “Dialysis units with pediatric designation make up <0.1% of the total number of dialysis facilities in the United States, with most located at or near pediatric tertiary-care centers in urban areas of the country.”

2. With so few pediatric dialysis patients, many of whom receive dialysis care at adult dialysis facilities, the issue of protecting the identity and confidentiality of respondents becomes an issue during a survey. It should be noted that in the ICH CAHPS Survey, survey vendors cannot share survey responses with a facility, even if they have the patient’s consent, unless the facility has 11 or more respondents who provided an answer to each individual survey item. Do you have any suggestions as to how a survey organization can protect the privacy and identity of respondents to the survey?

3. This same issue of protecting the identity and privacy of respondents also applies to home, peritoneal, and kidney transplant patients. Any suggestions for the minimum number of survey respondents a facility must have before de-identified survey response data can be shared with the facility?

### Questions About Domains/Dimensions of Care That Would be Important to Patients

CAHPS Survey results are used by patients to inform their decisions about choice of a health care facility, by health care providers in their quality improvement efforts, and by CMS to monitor the quality of care provided by Medicare-certified health care facilities.

1. What are topics or dimensions of care that facilities would be interested in to improve the quality of care that they provide to their patients?

2. What are the domains (dimensions) of dialysis care that would be most important to home and peritoneal patients when choosing a dialysis facility?

3. Would the dimensions of dialysis care that are important be the same for both home hemodialysis and peritoneal patients?

4. For peritoneal dialysis patients, would the dimensions of care that are important when choosing a dialysis facility differ based on whether the patient receives continuous ambulatory peritoneal dialysis or automated peritoneal dialysis?

5. What are dimensions of care that would be most important to parents/caregivers of pediatric dialysis patients?

6. If a patient experience of care survey were developed for kidney transplant patients, which type of providers/staff would the survey ask about? Are there dimensions of care that would be important to them? Should there be a separate series of questions that ask about each type of medical professional that comprise the patient’s kidney transplant care team?

7. Considering that the questionnaire will have a maximum number of survey items, are there categories of staff (or members of the patient’s care team) that can be asked about in the same questions? For example, does there need to be separate sets of questions that ask about the nephrologist or transplant surgeon versus other members of the patient’s care team? The survey could have a statement such as “The next few questions ask about the care you receive from the social worker, nurses, dialysis technicians (etc.). When answering these questions, think about your experience with those facility staff members.”

8. Please review the survey items in the current ICH CAHPS Survey instrument. Which of the questions in the current survey would be applicable as worded or could be adapted for home and peritoneal patients?

9. Which survey items would be applicable as worded or could be adapted for pediatric dialysis patients?

10. How feasible would it be to develop one survey that would be applicable to both adult home and peritoneal patients?

11. The current ICH CAHPS Survey questionnaire has 60 survey items. What is the maximum number of survey items that should be included in a survey developed for each of these patient populations (home, peritoneal, pediatric dialysis, kidney transplant)?

### Patient Eligibility for the Survey

1. To be eligible for the ICH CAHPS Survey, ICH patients must be 18 years old or older by the date the sample is selected, be non-institutionalized, and have received dialysis care from their current ICH facility for 3 months or longer. What patient survey eligibility requirements do you recommend for adult home and peritoneal patients?

2. In addition to having been served by their current facility for 3 months or longer, should patients have been receiving dialysis using their current modality for 3 months or longer, or would some shorter period of time suffice?

3. Some pediatric health care providers will serve pediatric patients up to age 21. For a survey of pediatric patients, should the maximum age for receiving the pediatric version of the survey be under 18 or under 21?

4. What if a pediatric patient has been seen in both a pediatric and an adult facility? Or if a peritoneal patient has received dialysis both at home and at a center? Which would take precedence so that we are not burdening the patient with multiple surveys?

5. What patient eligibility criteria do you recommend for kidney transplant patients? Is there a minimum amount of time after the kidney transplant takes place before a patient is eligible to be surveyed?

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