

CREATING A CULTURE OF QUALITY

WEBINAR #1 ~ SEPTEMBER 14, 2016

THE PATIENT PERSPECTIVE:

What is the experience of care? Are we asking the right questions?

QUESTIONS & ANSWERS DOCUMENT

The Q&A below represents general questions to the presenters.

Questions on pages 1-5 were answered by the webinar co-chairs and planning committee representatives.

Questions to the Patient Panel (page 6) were answered by members of the Forum of ESRD Network's Kidney Patient Advisory Council (KPAC)

Questions to CMS (page 7-11) will be answered by webinar presenter Ms. Jeneen Iwugo.

BASIC QUESTIONS REGARDING ICH-CAHPS

(In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems)

1	Is the PSS (Patient Satisfaction Survey) that is to home patients the same as ICHCAHPS since the home patients do not get this survey? Is the analyzing of the PSS that same as ICH-CAHPS?	No, the ICH-CAHPS survey is for eligible patients on in-center hemodialysis for 3 months or longer. (Eligible = adult, not in hospice, on in-center hemodialysis for 3 months or more). Patient satisfaction surveys of home dialysis patients are different than experience of care surveys. Experience of care surveys are thought to provide more objective reflection of the quality of care from the perspective of what patients consider important.
2a	Are the surveys sent in all languages? Many patients are non-English speaking.	No, the surveys are not sent in all languages. Written questionnaires are administered in English, Spanish, Samoan, Simplified Chinese and Traditional Chinese. Telephone surveys are administered in English and Spanish. Requests for other languages can be made by email ichcahps@rti.org It is the responsibility of the dialysis clinic to inform the vendor that administers the survey about the language preferences of its patients. Each dialysis clinic or organization has a contract with a vendor.
2b	Are these surveys in Spanish? Most of our population is Spanish speaking but they've stated that they receive these in English.	
2c	Is the survey available in multiple languages and how can a patient specify which language would be best for them?	
3	Is it possible to combine surveys as I receive comments from patients that they are asked to complete too many surveys?	No. Surveys cannot be combined. CMS (Centers for Medicare and Medicaid Services) requires that the ICH CAHPS survey is administered to eligible adult in-center hemodialysis patients twice annually. The results of ICHCAHPS are used for public reporting via Dialysis Facility Compare and for payments to clinics under the Medicare End Stage Renal Disease (ESRD) Quality Incentive Program (QIP). Other surveys may not be combined with or substituted for ICH CAHPS.

**BASIC QUESTIONS REGARDING ICH-CAHPS
(In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems)**

<p>4a</p> <p>4b</p>	<p>How are surveys administered to patients? (Mail, phone, email, etc.)? I don't think I ever got surveyed when I was a dialysis patient. Whose responsibility is it to contact patients (dialysis, CMS)?</p> <p>These surveys are mailed to the Patient's home?</p>	<p>The clinic, or the corporation with which the clinic is affiliated, contracts with a vendor, a company that is not affiliated with the dialysis clinic or corporation, to administer the survey. The vendor sends a pre-notification letter to the patient's address. It is followed by the written survey. If there is no response to the written survey, the vendor contacts the patient by telephone. The dialysis clinic is prohibited from administering the survey or assisting patients in any way to respond to the survey.</p> <p>CMS has required clinics to contract with outside vendors to administer ICH CAHPS since 2014. Clinics with fewer than 30 eligible patients are exempt. Homeless patients are not exempt.</p>
<p>5</p>	<p>How are address changes dealt with?</p>	<p>Vendors obtain the addresses from the CMS data base CROWNWeb and are expected to use a commercially available address update service if the CROWNWeb address is incomplete or incorrect.</p>
<p>6a</p> <p>6b</p> <p>6c</p> <p>6d</p> <p>6e</p> <p>6f</p>	<p>Many patients have disabilities and need assistance to complete these surveys. Many times they don't have a caregiver or family member to assist them. What options do they have?</p> <p>What happens when patients who cannot read bring the survey to dialysis staff to help complete it? Many patients in rural areas cannot have confidentiality when completing the survey if bringing it to staff to assist in the completion, especially when they may not trust the staff or health care professional?</p> <p>How can patients of lower literacy participate?</p> <p>Where can one receive training on how to engage patient's around the survey?</p> <p>Is there a 1-800 for patient at home to call?</p> <p>Can the facility have a volunteer to assist completion of the survey?</p>	<p>If patients need help with the survey they are instructed to reach out to friends or family. If patients have questions about the survey they are instructed to contact the vendor at the 800 number provided in the mail survey cover letters. Patients can also respond to the telephone survey rather than the written survey.</p> <p>The dialysis clinic is not allowed to "coach" or otherwise influence patient responses. It cannot tell the patients that the facility hopes or expects their patients to give them a high rating. Clinic staff are not allowed to assist patients with the survey even if asked. The Forum is querying CMS about whether a volunteer at the clinic can assist patients. Clinic staff are allowed to tell patients that they may be contacted to respond to a survey.</p> <p>The clinic cannot use the same questions in ICH-CAHPS to conduct surveys of their own and cannot "coach" patients about the survey or give them details of the survey.</p>
<p>7</p>	<p>How do we get our patients to fill out the survey?</p>	<p>Clinic staff can tell patients that they may be contacted to respond to a survey. Some clinics provide flyers to inform patients that a survey is being sent out and encourage them to complete it. The clinic can tell patients that the survey results are confidential and that no individual patient answers are shared with the clinic staff or doctors.</p> <p>The clinic can also tell the patients that the clinic results are reported on the Dialysis Facility Compare website and that the clinic uses the results to improve patient care.</p>

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8a	What is the percentage of patient surveys given to any given dialysis clinic?	<p>The average statewide response rate in 2015 was 33%. The response rate by state can be found on this website: https://ichcahps.org/ICHCAHPS_2015_NatlStateAvgs.pdf</p> <p>Information about how many patients in a specific facility complete the survey is not publicly available.</p> <p>Clinics can tell patients that they will receive a survey. They can post or provide flyers to inform patients that they will receive a survey. The clinic can also tell patients that the survey results are confidential and that no individual patient answers are shared with the clinic staff or doctors. They can tell patients that the survey results are posted on Dialysis Facility Compare website and that the clinic uses the results to improve care.</p> <p>It is important to encourage patients to complete the survey. If a clinic has fewer than 30 completed surveys from its patients, the results <u>may</u> not be reported either to the clinic or on Dialysis Facility Compare.</p>
8b	How do you propose that we increase patients' responses to the survey?	
8c	How can we get more patients to fill out the survey? We have such a small number of patients filling out the survey, in our clinics, that the results are not real accurate.	
8d	How do we get our patients to fill out the survey?	
9a	Please provide the timeline of the ICH-CAHPS survey- most specifically the best time frames to educate the patients on the timeframes of when to respond.	<p>The surveys are administered twice annually, in the spring and in the fall. The fall 2016 data collection window is October 21, 2016 to January 13, 2017. The vendors have strict rules about when to send out the surveys and when to make telephone contacts. Clinics are only allowed to tell patients that they may be contacted to respond to a survey.</p> <p>When a clinic receives its results will depend on the clinic's contract with the vendor and/or on the policies of the corporation with which the clinic is affiliated. The corporation may wish to review the results first then distribute them to the clinics.</p> <p>Clinics receive their results twice annually. Survey results from the two survey periods of the previous year are reported on Dialysis Facility Compare annually.</p>
9b	When was the survey conducted this year? And when will the clinics get the results?	
9c	Do dialysis facilities even get the results from the Spring survey before the administration of the Fall survey?	
9d	How often will Dialysis Facility Compare be updated?	
10	How does a facility access the results of the facility-specific ICH-CAHPS?	<p>Survey results are sent to the clinic and/or the dialysis corporation by the vendor. The amount of detail provided to the clinic about the results is determined by the contract with the vendor and/or by the dialysis corporation's policies.</p> <p>ESRD Networks also receive ICH-CAHPS reports. If a clinic needs more detailed information about its ICH-CAHPS results, it can call the Network for assistance. The Network <u>may</u> be able to provide more detail.</p>
11	Does the National Patient and Family Engagement-Learning and Action Network (NPFE-LAN) provide supportive materials to use in our facilities?	<p>The organization that sponsors the NPFE-LAN is the ESRD National Coordinating Center (NCC). CMS contracts with the NCC on many projects including the NPFE-LAN. The NCC does not have any responsibilities with regard to administering ICH-CAHPS and at this time does not have specific ICH-CAHPS materials available for clinics.</p>

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12	Will the center's score after the survey play a role in whether the center will continue to provide services or will the center be asked to close down based on a very poor score after the survey?	No. However, CMS may direct the ESRD Network to provide assistance to the clinic so that the clinic can improve.
13	Do the ICH CAHPS results affect a facility's 5 Star Rating?	The ICH CAHPS results are not a part of the 5 Star Rating. However, the results are reported on Dialysis Facility Compare semi-annually if the facility has at least 30 completed surveys for reporting.

DIALYSIS CLINIC RESPONSE TO ICH-CAHPS

1	Is it not up to the companies that run the centers to be more vigilant with circulating information? I don't believe that is what is happening!	If you are referring to circulating information about the administration of ICH CAHPS, see above. However, if you are referring to whether clinics discuss the responses to ICH CAHPS with patients, the Forum is asking CMS about whether there are guidelines about how much the clinic is allowed to share with patients. In general, we encourage clinics to collaborate with patients to identify areas in which care can be improved and we will discuss this further in the 2 nd and 3 rd webinars of this series.
2	Facilities have a way to make sure that staff is professional and polite with patients, however how can facilities make doctors take more time with patients and be polite and caring?	Most doctors are not employees of the facility. However, the Governing Body of the facility has the responsibility to make decisions about which doctors are allowed to see patients in the clinic. The Governing Body includes the Medical Director, the Administrator of the clinic and other personnel. There are questions about doctors in the ICH-CAHPS survey, similar to the questions about the clinic staff. Each Governing Body should have mechanisms to respond to concerns from patients and/or facility staff about the behavior of doctors and other professionals.
3	Will the ESRD clinics be mandated to make changes based on what the patients ask for?	No. CMS contracts with ESRD Networks to assist certain facilities on issues identified by the survey. Clinics are expected to review the responses to the survey and determine which areas require additional evaluation and improvement at the local level. Survey responses are anonymous, and the report that a clinic receives depends on the contract it (or its parent corporation) has with the vendor that administered the survey, so clinics may be quite challenged to identify specific problems. If a clinic needs more detail, see #9 in the previous section.
4	I have gotten the same comments from patients at my clinic as the patients speaking today. My question is: how do I continue to encourage them to complete the survey if they feel no-one is really taking the survey seriously in relation to them? Because the feedback would show that someone is listening.	See #7 in the section above this one. Results are publicly reported on Dialysis Facility Compare. Presenters, including quality experts, clinic administrators, patients and educators, will discuss how clinics can assess the experience of care and respond to patient concerns in Webinars 2 and 3.

OTHER QUESTIONS AND COMMENTS

1	What would be the best way to let patients know what they should expect from a dialysis clinic? For example, some patients think that all of their needs should be met at the clinic rather than just the needs that are ESRD related. This would affect their comments if their expectations are not accurate to start with.	The dialysis clinic should have a mechanism for communicating what the clinic can and cannot provide to its patients. Patient satisfaction surveys can be very subjective; the results are often highly variable due to different patient expectations. Experience of care surveys are designed to lessen the problem of different expectations. They provide more objective ways of assessing how a clinic is doing in terms of specific activities, e.g., whether a patient feels that the dialysis center staff explained things in a way that was easy to understand.
2	I have been on dialysis for 15 years and now mentor patients for the past five years. Patients are not receiving information from their centers!	We will address “closing the loop” on patient concerns in the next two webinars. Thank you for bringing this up.
3	I have patients who are extremely difficult to engage, no matter how I try, how do I deal or work with them. Most of them are angry being on dialysis.	There are patients who are not engaged whether by choice or by the inability to engage. Some of the ways that other clinics have encouraged patient engagement will be addressed in the next two of the three Forum of ESRD Networks webinars. We recognize that engaging an angry patient is a challenge. That said, it is a focus of multiple organizations including CMS and the ESRD Networks.
4	I love Ms. Dixon's comment about posting patient survey report in the dialysis center for patients	

Helpful online references:

<https://www.dialysisdata.org/sites/default/files/content/Methodology/DFCReportGuide.pdf>

<https://ichcahps.org/SurveyandProtocols.aspx>

https://ichcahps.org/Portals/o/ICH_SurveyAdminManual.pdf

QUESTIONS AND COMMENTS FOR PATIENTS

The Forum of ESRD Network's Kidney Patient Advisory Council (KPAC) provided answers and comments to these questions.

1a	Explain thinking for separating surveys or questions by staff type.	We feel that grading staff as a whole does a disservice to those departments that are doing a good job. For example, a patient may feel their Dietician is doing an exemplary job but the techs need additional training and/or coaching. It would be unfair to give a poor rating based on one staff department.
1b	I heard two of the patient speakers say that they'd like to have separate questions about RD and MSW care. What question(s) would you like to see on the survey to assess whether you're getting the high quality care from the RD and MSW?	
2	Do we think the patients truly understand the impact of the survey?	Certainly not. Actually, other than the weight CMS puts on the survey in the new SOW, what IS the impact? Does anyone know?
3a	<p>SURVEY LENGTH AND TIMING</p> <p>Do patients perceive it to be a disincentive to have over 50 questions on the survey?</p> <p>Do patients feel the survey is too lengthy or is length just right?</p> <p>How do the patient representatives feel about the survey done 2x a year? Are they more or less likely to respond related to frequency of survey?</p>	<p>a. and b. Mixed answer on this one. As in all things, some patients are intimidated by the length and some are not. Those patients who are engaged and comfortable with language are less apt to be intimidated the length.</p> <p>c. less likely because many patients feel that "we already took this survey". Because results are not normally shared, it is often perceived to be the same survey they already took.</p>
3b		
3c		
4	I am 5 months post living donor, paired exchange, transplant. No dialysis. My new kidney is doing well, and I have no other illnesses. The side effects of the immunosuppressant's have given me diminished executive function, both long and short term memory loss, tremors, high cholesterol, GI issues, exhaustion and hair loss. I can no longer work as a result. The quality of my life is significantly lower than it was pre transplant. I question whether the tradeoff of a longer life is worth feeling like I am but half alive. I'm leaning towards "no." It is ironic to go through the pain and expense of major surgery to end up regretting have had it.	I know this does not ask for an answer, but my heart aches for this individual. My personal suggestion would be to explore other immunosuppressant therapies. There are a lot of options out there and I have NEVER experienced any of the symptoms or side effects mentioned above. This just seems wrong to me and possibly very correctable.
5	Just a comment: Good work to the KPAC members and AAKP member. The patient voice IS important and thank you for your explaining it so eloquently!	
6	Thank you to the panel for their sincere and honest comments!	

QUESTIONS AND COMMENTS FOR CMS

Webinar presenter Ms. Jeneen Iwugo provided answers and comments to these questions.

1	<u>Dialysis Personnel</u>	
1a	On the survey it refers to "Physicians" but many facilities also utilize Nurse Practitioners' or Physician Assistants. Patients may not realize these practitioners are part of practitioner care team. Is there any thought of rewording those questions to include practitioners other than Nephrologists?	
1b	Questions on floor staff should not be in the same section with dietician and social worker.	
2	<u>Administration of CAHPS</u>	
2a	Can the facility have a volunteer to assist completion of the survey?	
2b	Are patients and/or patient mentors allowed to help other patients with the survey?	

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3	<u>Literacy/Language</u>	
3a	What is the literacy level of the survey? How can patients of lower literacy participate?	
3b	Any consideration to simplifying the language? For example, the word "modality" is not commonly known (or recalled even when we educate) and other patients do not accurately understand the questions. Language is medical-centric, not everyday language and the level should be about 3rd, 4th grade.	
3c	Perhaps the letter that goes out needs to be simplified so that patients with limited education can understand it.	
3d	Is it possible for the "general government letter" sent with the survey to be written at a somewhat more approachable level? Perhaps a lower reading level? Several of our patients throw it away because they don't understand the cover letter.	
3e	The item stating "peritoneal dialysis" usually gets a negative response while at the same time the one about "Did you have as much input as you wanted in your choice of the type of dialysis you received" they respond positively. This wording is problematic for understanding the question in this area. If you ask about "the modality where you use the fluid in your belly" they understand that.	
3f	Patients report that "the not eligible for transplant" question is confusing.	
3g	Many patients do not understand the word "grievance" no matter how many times I provide education. If you would please change the wording to "complaint" then they immediately remember they have been educated!	
4	Is it possible to increase the education provided to clinic staff on the results of the surveys? (Forum comment: I believe this is a request for guidance in the interpretation and evaluation of the survey results)	

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5	<p>The biggest issue with the delay in resulting is that when people complain about something, they want to see results more or less immediately. Is it possible to explain the lag time in the intro letter? Or perhaps make some kind of mention that if people have an issue it should be addressed to their facility administration?</p>	
6a	<p><u>Future Changes in ICH CAHPS</u></p> <p>Will the NPFE-LAN be utilized to advise on the relevance of ICH CAHPS questions and propose changes?</p>	
6b	<p>Have there been any changes made in response to the surveys returned by the patients? (Forum note: it is unclear whether the question is about changes made by a facility or about changes in the CAHPS survey itself).</p>	
6c	<p>My clinic has 85% Vietnamese patient population. Is there any plan for creating a survey in Vietnamese to assist patients with language barrier?</p>	
6d	<p>A whole category has been left out in discussions today. Home Hemodialysis has not been addressed and it's not clearly addressed in the survey. A separate survey should be developed, one for in-center and another survey for home styles of dialysis.</p>	
6e	<p>Jeneen, is it really circling around? New pts are answering the CAHPS and don't know what changes have been made. (Forum comment: I believe this question was related to this section of her presentation shown on slide 26 which briefly presented the ICH CAHPS pilot projects. She was discussing the commitment of CMS to pilot a project for change following receipt of initial survey results, then to circle back with a re-survey to see if there was any change.)</p>	
7	<p>What about surveying caregivers (spouses/sons or daughters who are caregivers)? Many caregivers have opinions on the communication and care their loved ones receive.</p>	

QUESTIONS AND COMMENTS FOR CMS

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8a	Are the patients that respond to CAHPS representative of the population that are dialyzing?	
8b	Comment: The patients who are on the panel today are not representative of the dialysis patients I see daily in my clinics as a social worker.	
	<u>Timing of Survey and Reporting</u>	
9a	Why is it twice a year? The timing of all of this takes about 6 months in total. I see overlap.	
9b	We have had concerns at our facilities about the timing of the surveys. We often don't get results from one survey until another one rolls out...that makes it impossible to make changes and see the improvement of those changes by the next survey period.	
9c	Clinics are not getting results from the survey until after the next survey has been sent out, not giving the clinics time to make changes before the next survey is out.	
10	Can the survey questions be different for each survey?	
11	Please comment on how the clinic can share ICH CAHPS results, and the clinic's response to the results, with patients without affecting the patient responses to the next CAHPS survey considering the problem that the clinic may not receive the report of the previous survey until the subsequent survey either underway or very close. Sharing the clinic's response to the previous survey may be perceived as an attempt to influence the responses to the next survey.	

COMMENTS FOR CMS

1	I have been on dialysis for 15 years and now mentor patients for the past five years. Patients are not receiving information from their centers!	
2	Patients report not being comfortable with the person who is calling to follow up and do not like to give out information over the phone.	
3	<u>Survey Fatigue</u>	
3a	To follow up on the survey fatigue...in Maine, each person who visits a doctor's office or the hospital receives a survey shortly after their visit. If they have been to three appointments and then the CA-HPS survey comes out, the patient is tired of completing surveys. Surveys do look similar and patients don't want to complete more surveys. I don't know if that happens in other states, but it happens here.	
3b	Comment...one of the reasons patients tell me they do not complete the survey is that they are inundated with surveys from healthcare providers and they have survey fatigue.	
	<p>This is a comment: If the survey is going to separate out Social Workers and Dietitians CMS needs to be prepared to address staffing in these areas. It is easy for a PCT or Nurse to provide attentive care when the ratio is 4:1. SW and Dietitian ratios are much lower and they often have to go to multiple clinics making them less available to patients.</p> <p>As a social worker - I agree with the comments being expressed. Separate questions for different disciplines</p> <p>When SW is assigned to a clinic one day a week--to care for 40 pts-it is bound to be reflected in survey and doesn't reflect on corp. but on SW!</p>	
	Patients do not understand the nature and relevance of the survey	