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**Comment on Information Collection "National Implementation of the In-Center Hemodialysis CAHPS Survey"**
**Form Number: CMS-10105**
**OMB control number: 0938-0926**

## Necessity and utility

The In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS) provides a measure of patients' experience of care with in-center hemodialysis. It was created to allow:

- consumers and patients to make comparisons among dialysis facilities;
- dialysis facilities to benchmark their performance;
- CMS to monitor facility performance; and
- facilities to gather information for internal quality improvement purposes

We believe it is critically important to evaluate patients' experiences when receiving dialysis and support the ICH CAHPS measure conceptually. However, we feel that ICH CAHPS as currently implemented has two major shortcomings:

1. The survey is long and burdensome for patients to complete. This leads to low response rates, which results in random outcomes lacking sufficient statistical power. These concerns have also been echoed by KCP and members of the CMS Patient-Report Outcomes Technical Expert Panel (TEP).
2. ICH CAHPS is limited to adult patients treated with in-center hemodialysis. Given that approximately 11 percent of dialysis patients have selected home dialysis,[1] a significant group of patients have been excluded. This segment will continue to grow and will continue to cut into the number of responses on the ICH CAHPS survey.

## Estimated burden

At 62 questions long, the survey is far too lengthy to effectively engage patients and places a significant burden on those patients and family members who choose to complete it. As a comparison, the ICH CAHPS is almost twice as long as the Hospital CAHPS (HCAHPS), which only has 32 questions, despite the fact that hospitals are treating a variety of patient conditions and ESRD facilities only kidney failure. This variance is due both to the number of patient perspective questions and demographic questions. Additionally, the ICH CAHPS administration occurs in the context of numerous other surveys that patients are asked to complete (eg. Kidney Disease Quality of Life [KDQoL], provider-specific questionnaires), and thus raises concerns about survey fatigue.

The burden is further exacerbated by the current administration methods. An editorial in the American Journal of Kidney Diseases, highlighted the severity of this problem:

> *[I]n its current form, the ICH CAHPS survey is long and its administration imposes a substantial respondent burden. Patients are the only data source and it is vital to minimize their burden. In addition, mailing cost limits the number of pages over which the survey can be spread; this leads to a small font size that makes the survey inaccessible to patients whose comorbid conditions and/or age reduce their vision. CMS allows for telephone interviews in this circumstance; however, in our experience, hemodialysis patient telephone interviews are fraught with problems. CMS requires that the interview occur while the patient is outside the facility, but acceptable call hours are limited and many don't answer unless they recognize the number on caller ID. Furthermore, even well-conducted telephone interviews frustrate patients: the necessary scripting is stilted, response choices can be confusing, questions are perceived as repetitive, and calls are lengthy, on average 30 minutes.*[2]

From a provider perspective, the lengthy timeline for which the survey is open means that results are delayed and providers are restricted in ability to act on results in real-time. In comparison to HCAHPS, which provides data on a rolling basis so that providers are receiving data within several weeks of survey completion, results are much more lagged for ICH CAHPS (up to 3 months) due to the long survey period.

Similarly, the rules around black-out dates and on-going and real-time patient feedback are excessively restrictive. On-going feedback is a demonstrated best practice throughout the healthcare industry as a primary means to understand and improve the patient experience. The restrictions around utilizing this best practice impairs the ability of dialysis providers to improve delivery of care.

## <u>Recommendations on information collected</u>

1. CMS should validate and implement a shorter version of the ICH CAHPS. This should be done through a collaborative process led by recognized experts in psychometrics, working closely with patients and clinicians to ensure information relevance and feasibility of implementation. The goal should be to focus on a few questions that are leading indicators of overall patient experience. In addition, the demographic questions should be reassessed with the goal of reducing them significantly. This recommendation is consistent with comments made by the dialysis CAHPS TEP. When asked the optimal number of questions for individual CAHPS surveys for home and pediatric patients, some participants suggested no more than 10, while others indicated there should be no more than 30.[3]

2. We also ask that CMS expedite the process for establishing a home dialysis CAHPS, as well as a pediatric CAHPS. We appreciate that CMS has established a process for developing these instruments. We understand that the current survey was established for in-center patients, but according to the recent ICH CAHPS TEP, the vast majority of the ICH CAHPS questions are applicable to these populations, especially home dialysis patients. We urge AHRQ and CMS to act quickly by continuing to work with the community, in particular the University of Washington, to ensure home and pediatric surveys are available sooner, rather than later.

## Recommendations on collection methods

1. It is critically important to have a mechanism, which does not appear to exist currently, for facilities to ensure that patients' contact information is as accurate and up-to-date as possible. Because response rates necessarily depend on accurate contact information, we recommend inclusion of an opportunity for facilities to ensure that the primary survey and/or any follow-up is delivered to the most current contact (phone or mail) given the consequence to validity that results from non-responsiveness.
2. Similarly, CMS should review the lingual translations of the surveys to ensure that they are accurate. Several translation errors have been reported to us, and the Agency has a responsibility to ensure that the information gleaned from all foreign-language speakers is accurate and meaningful.
3. Moreover, as the ICH CAHPS TEP participants emphasized, allowing patients to respond to ICH CAHPS on mobile devices is critically important. Sixty percent of ESRD patients are under the age of 65.[4] This means that, contrary to some assumptions, they are not too old to understand electronic devices. In fact, CMS seems to have recognized that even those 65 years and older are electronically savvy by creating online tools, such as the Medicare consumer guides, blogs from the Administrator, and even email tips for seniors. According to the Pew Research Center, 91 percent of Americans 65 years and older own a cellphone and approximately 60 percent of those cellphones are smart phones. Even Americans struggling with poverty are likely to own a smart phone as well; Pew found that approximately 95 percent of Americans making $49,999 or less a year own a cell phone and, of those, more than 75 percent are smartphones.[5] A web-based survey would also allow for patients to easily select their preferred language (which is not possible via mail). If CMS makes it easier for patients to respond to ICH CAHPS through a modern survey delivery mode, the likelihood of an improved response rate may increase substantially.

## Recommendation on ICH CAHPS restrictions

We ask CMS to reduce restrictions around black-out dates and real-time feedback. This would give providers the opportunity to employ industry best practices to more rapidly respond to patient feedback and improve patients' experience.

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[1] MedPAC, Report to the Congress 158 (2017).

[2] Richardson MM, Grobert ME. *Am J Kidney Dis*. 2014;64(5):670-672.

[3] RTI International, 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 13 (2018).

[4] United States Renal Data System. 2017 USRDS Annual Data Report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2017. Reference Table B.1.

[5] Pew Research Center, Mobile Fact Sheet: https://www.pewinternet.org/fact-sheet/mobile/. Accessed July 10, 2019.