August 12, 2016

William N. Parham, III
Office of Strategic Operations and Regulatory Affairs
Division of Regulations Development
Attention: CMS-10105
Room C4-26-05
7500 Security Boulevard
Baltimore, Maryland 21244-1850

Dear Mr. Parham:

On behalf of the Nonprofit Kidney Care Alliance (NKCA), the only alliance exclusively representing only nonprofit providers, I write to offer our comments and recommendations regarding the Centers for Medicare and Medicaid Services' (CMS) National Implementation of In-Center Hemodialysis (ICH) CAHPS Survey (CMS-10105). NKCA represents five nonprofit dialysis providers: Centers for Dialysis Care; Dialysis Clinic, Inc.; Independent Dialysis Foundation, Inc.; Northwest Kidney Centers; and The Rogosin Institute. Collectively, we serve over 20,000 patients at more than 280 clinics in 30 states.

As you are aware, the ICH CAHPS Survey is used to: (1) provide a source of information from which selected measures can be publicly reported to beneficiaries as a decision aid for dialysis facility selection, (2) aid facilities with their internal quality-improvement efforts and external benchmarking with other facilities, (3) provide CMS with information for monitoring and public reporting purposes, and (4) support the end-stage renal disease value-based purchasing program.

We are writing to express our concern with the frequency of the administration of this survey and other related matters. **We urge CMS to consider reducing the frequency from biannually to annually and consider modifications to shorten the survey and the survey response options.**

Background

The ICH CAHPS Survey, administered either by phone or in writing, includes more than 60 questions over ten pages. CMS informs patients that "most patients find it takes less than 20 minutes to answer the survey questions."[1] However, perhaps because that estimate does not include the time involved in matters ancillary to the survey, including reading the pre-notification letter or returning the completed survey, CMS estimates that the average compliance time per respondent is actually approximately 32 minutes.

[1] See "ICH CAHPS Pre-notification letter (English) (051816)," available at https://www.cms.gov/Regulations-and-Guidance/Legislation/PaperworkReductionActof1995/PRA-Listing-Items/CMS-10105.html (accessed August 1, 2016).

The survey is administered twice per year. CMS reports a 27.3 percent response rate, with 109,328 responses per survey period and approximately 290,000 nonresponses. The total estimated burden is 59,037 hours per survey period,[2] though that estimate does not include the burden imposed on patients who begin but do not complete the survey nor those patients who receive letters and phone calls but do not chose to participate. Assuming an average hourly wage of $25.35, CMS estimates a compliance cost of approximately $1.5 million and a cost to the federal government of approximately $1.7 million.[3] CMS' estimated burden and compliance cost has declined but only because of a lower expected participation rate.

All of the questions are multiple choice, but 6 of the questions have 8 or more possible answers. There are 9 questions related to the patient's nephrologist, 23 questions regarding the facility staff, 3 questions about the dialysis center itself, 9 questions about the treatment received, and 17 questions related to the health and demographic characteristics of the patient.

Every Medicare-certified facility treating more than 30 patients annually is required to contract with an approved vendor to administer the ICH CAHPS Survey. As CMS has noted, approximately 200 survey responses are necessary to produce statistically significant survey results for a facility (that is, those with a confidence interval of +/– 0.07). Given that approximately 99 percent of all facilities treat fewer than 200 patients and that the expected facility response rate is less than 30 percent, the results from nearly all surveys are best considered suggestive, rather than conclusive.

Concerns and Recommendations Regarding ICH CAHPS Survey

The NKCA is concerned that the ICH CAHPS Survey is burdensome for our patients and has resulted in significant "survey fatigue" that has resulted in a lower response rate and an increasingly biased sample. At present, facilities are also required by CMS to administer the Kidney Disease Quality of Life Instrument (KDQOL-36) and to screen for pain and depression. Moreover, for facilities participating in the Comprehensive ESRD Care Model (CEC), an additional survey is also required. Because ESRD patients are more likely to be hospitalized than other Medicare patients, CMS should consider the cumulative effect on dialysis patients of these surveys and CMS-mandated surveys in other settings.

The NKCA makes the following recommendations to improve the ICH CAHPS Survey and make it less onerous for patients.

Annual instead of biannual survey. To reduce the burden on patients, which we believe will improve the survey response rate and result in a net improvement in data collection, the NKCA urges CMS to reduce the number of times a patient is surveyed to once per year. Because we suspect that there is a heterogeneous response across our patient population to the burden of the

[2] See "Supporting Statement Part A National Implementation of the In-Center Hemodialysis CAHPS Survey CMS-10105, OCN 0938-0926," available at https://www.cms.gov/Regulations-and-Guidance/Legislation/PaperworkReductionActof1995/PRA-Listing-Items/CMS-10105.html (accessed August 1, 2016).
[3] Ibid.

ICH CAHPS Survey, we are concerned that the decline in the response rate may be disproportionately distributed.

In addition, the cycle time associated with each ICH CAHPS survey is such that results from one survey often arrives to the facility at or after the time when the next survey cycle is beginning. As a result, it is impossible for providers to implement changes in response to one survey and measure the effects of that change in the next survey.

Fewer questions and shorter answers. CMS should reduce the number of questions and the number of possible answers. For example, the virtue of understanding a patient's ability to climb stairs and their ability to dress/bathe is likely limited, as both questions relate to physical mobility. Evidence from a leading survey purveyor suggests that surveys with fewer questions encourage respondents to answer more thoughtfully.[4]

In addition, questions that are scaled 1–10, should be reduced to a narrower scale of 1–5. There is substantial academic literature on optimal scale length indicating that a moderate scale is most effective.[5] Moreover, it is common practice in satisfaction surveys to employ "top box" techniques that summarize survey responses as the share of respondents with the top one or two responses. Converting responses to a top box metric yields a binary indicator and, given the observed distribution of most satisfaction survey responses, has proven a reliable metric in many circumstances. For questions likely to be interpreted using this technique, narrower scales are especially appropriate. In fact, this technique was employed by CMS contractor RTI International when evaluating the ICH CAHPS Survey for response bias.[6]

While demographic information is useful for many reasons, the fourteen unique race categories, four distinct Spanish/Hispanic/Latino categories, eight language categories, and eight educational attainment categories may be excessive. Narrowing these response categories could sacrifice little in content while improving both the response rate and respondents' satisfaction.

One strategy for CMS to consider taking comment on in future rulemaking to shorten the survey would be for facilities to provide third-party surveyors with demographic information about patients instead of requiring that information to be gathered from the survey every time the survey is administered. Alternatively, survey administrators could retain a patient's survey response from one survey period to the next for questions related to demographic information.

Web-based survey. NKCA urges CMS to pursue the development of lower-cost (and lower-burden) web-based surveys. A web-based survey could be both more efficient and implemented in a manner that would yield timelier responses, potentially even on a rolling basis. Timeliness

---

[4] See SurveyMonkey, "How Much Time Are Respondents Willing to Spend on Your Survey?" available at https://www.surveymonkey.com/blog/2011/02/14/survey_completion_times/ (accessed August 1, 2016).

[5] For an excellent survey of this evidence, see Jon A. Krosnick and Stanley Presser, "Question and Questionnaire Design," in *Handbook of Survey Research*, 2nd ed. (Bingley, UK: Emerald Group Publishing, 2010).

[6] See "ICH CAHPS Mode Experiment and Patient Mix Adjustment" available at https://www.cms.gov/Regulations-and-Guidance/Legislation/PaperworkReductionActof1995/PRA-Listing-Items/CMS-10105.html (accessed August 1, 2016).

would be extremely useful to facilities who currently receive one ICH CAHPS report just as the next survey is being administered.

Tracking responses over time. Valuable insights could be gained by applying a unique survey ID to each respondent and tracking individual patient satisfaction over time. For example, results could inform facilities about trends in satisfaction among a subset of consistent respondents and could inform surveyors about the probability of survey fatigue among patients of various sub-populations.

Potential Value from a Home Dialysis CAHPS Survey. NKCA also urges CMS to consider the development of a home dialysis CAHPS Survey. NKCA members are committed to encouraging patients to consider home dialysis and believe that a patient satisfaction survey, if well-constructed and not overly burdensome, could yield valuable insights for providers as well as the opportunity to track trends over time.

Other comments. We are surprised that gender is not a demographic question included in the survey. Its usefulness should be self-evident. In addition, we note that some dialysis patients may be unable to be surveyed either because of poor cognitive function or homelessness. In addition to current eligibility criteria – 18 years of age or older and three months or more of treatment at the current facility – we urge CMS to include cognitive function and suitable residence to be criteria for eligibility.

Thank you for the opportunity to comment. We would be glad to answer any questions. Please feel free to contact Martin Corry at 202-580-7707 or info@nonprofitkidneycare.org.

Sincerely,

Martin Corry
Executive Director