

June 16, 2025

The Partnership for Quality Measure Development c/o Battelle 901 D Street SW Suite 900 Washington, D.C., 20024

Dear PQM Development Staff,

## RE: Comments on Selected Measures in the Spring 2025 Measure Cycle

On behalf of the more than 37,000,000 Americans living with kidney diseases and the 22,000 nephrologists, scientists, and other kidney health care professionals who comprise the American Society of Nephrology (ASN), thank you for the opportunity to provide comments on Selected Measures in the Spring 2025 Endorsement and Maintenance (E&M) Measure Cycle. Currently, more than 800,000 Americans have kidney failure from ESRD, including more than 550,000 receiving dialysis and more than 200,000 living with a kidney transplant. We greatly appreciate the Partnership for Quality Measure (PQM) undertaking this important work and offer the following general comments regarding the four measures that make up the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH-CAHPS) Survey.

## Concerns About Low Response Rates and Patient Engagement

ASN remains encouraged by Centers for Medicare and Medicaid Service's (CMS) efforts to refine the ICH-CAHPS survey by shortening the instrument in response to well-documented concerns about its length. However, survey response rates continue to be low, underscoring the need for additional strategies to enhance patient engagement and improve the representativeness of the data. Despite the survey's growing role in dialysis facility reimbursement, response rates have shown no meaningful improvement since its implementation in 2016. In fact, recent data indicate that post-pandemic response rates remain comparable to pre-pandemic levels, averaging around 30 percent, a fact acknowledged in the measure specifications<sup>i</sup>.

Low response rates not only limit the utility of the measure but may also signal that the length and frequency of survey administration may lead to patient survey fatigue. The burden of survey may furthermore affect certain populations disproportionally. Evidence cited in literature as well as the most recent ICH-CHAPHS Survey results demonstrate that non-responders are more likely to be men, individuals from non-white racial and ethnic backgrounds, younger, single, dually eligible for Medicare and Medicaid, less educated, non-English speaking, and not active on the transplant list<sup>ii</sup>. These disparities

raise serious concerns that the current tool may not be fully representative of the U.S. dialysis population, limiting the generalizability of the data it produces.

For example, in a 2018 cross-sectional analysis of 11,055 eligible in-center hemodialysis patients across the U.S., Dad et al. found that non-responders, comprising 59 percent (6,541) of the sample, differed significantly from responders<sup>iii</sup>. Non-responding people were more likely to face socioeconomic disadvantages and a higher burden of illness, underscoring the challenge of capturing an accurate picture of patient experience across the full spectrum of the dialysis population.

Furthermore, high non-response rates prevent many dialysis facilities from meeting the required threshold of 30 completed surveys over two administration periods, thereby excluding them from public reporting of facility-level data. According to 2023 data cited in the measure specifications, only approximately 26 percent of facilities met this minimum reporting threshold<sup>iv</sup>.

Administering the ICH CAHPS survey presents both financial and operational challenges for dialysis facilities. Medicare-certified facilities are mandated to participate and must contract with a CMS-approved vendor to administer the survey twice annually. In addition to the direct costs, facilities must allocate staff time to encourage patient participation. The twice-yearly administration schedule also limits opportunities for facilities to analyze results and implement meaningful improvements before the next survey cycle begins.

## The Growing Need for a Home Dialysis Equivalent to ICH-CAHPS

Despite multiple federal policy initiatives aimed at incentivizing and increasing home dialysis usage, there is currently no equivalent to the ICH-CAHPS survey specifically designed to evaluate patient-reported experiences with home dialysis. Several dialysis facilities have successfully adapted the ICH-CAHPS instrument for home dialysis providers. Notably, a recent study by Rivara et al. led to the development of the Home Dialysis Care Experience instrument, which is the first rigorously developed, content-valid, English-language tool designed to measure patient experiences in home dialysis. If CMS intends to continue prioritizing patient-centered care, developing a validated patient-reported experience measure tailored to home dialysis is essential.

Looking at home dialysis, in the Kidney Care Choices model, recently released evaluation data showed that in 2023, the model increased the rates of home dialysis by 10% and decreased in-center dialysis use by 1% and increased home dialysis training, a necessary step before beginning home dialysis, by 22%. Therefore, the home dialysis population is growing, and a standardized survey is needed to evaluate and compare patient experiences across the modalities of in-center and home dialysis.

## Conclusion

ASN appreciates the work of both the Partnership for Quality Measure Developments and CMS. We stand ready to work through the details of any of these comments. To discuss this letter further, please contact David Whie, ASN Senior Regulatory and Quality Officer, at <a href="mailto:dwhite@asn-online.org">dwhite@asn-online.org</a>.

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<sup>&</sup>lt;sup>i</sup> <u>ICHCAHPS PublicRptCoeffOct202</u>4.pdf

<sup>&</sup>quot;ICHCAHPS\_PublicRptCoeffOct2024.pdf

Evaluation of non-response to the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS) survey | BMC Health Services Research | Full Text

iv <u>ICH CAHPS: Rating of Dialysis Center Staff | Partnership for Quality Measurement</u> (under "Use & Usability tab, under "Use")

<sup>&</sup>lt;sup>v</sup> <u>Development and Content Validity of a Patient-Reported Exper...</u>: <u>Clinical Journal of the American Society of Nephrology</u>