

July 5, 2012

Ms. Marilyn Tavenner
Acting Administrator
Centers for Medicare and Medicaid Services
Department of Health and Human Services
Room 445-G
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Re: CMS-9965-P: Patient Protection and Affordable Care Act; Data Collection to Support Standards Related to Essential Health Benefits; Recognition of Entities for the Accreditation of Qualified Health Plans.

Dear Acting Administrator Tavenner:

Dialysis Patient Citizens (DPC) appreciates the opportunity to comment to the Centers for Medicare and Medicaid Services (CMS) on the *Patient Protection and Affordable Care Act; Data Collection to Support Standards Related to Essential Health Benefits; Recognition of Entities for the Accreditation of Qualified Health Plans* Proposed Rule.

As America's largest patient-led dialysis organization, DPC represents more than 23,000 dialysis and pre-dialysis patients and their families. DPC's mission is to improve the quality of life of dialysis patients by engaging policy makers, providers and the public. Through patient education, empowerment and advocacy, we work to increase awareness about kidney disease and promote favorable public policy.

We would like to thank the Centers for Medicare and Medicaid Services (CMS) for issuing this Proposed Rule regarding data collection, intended to support the standards related to Essential Health Benefits (EHB). Robust data on the potential benchmark plans is vital to better understanding how the Agency's intended approach to defining the EHB package would impact kidney disease patients across the country. However, upon reviewing CMS-9965-P, there are several key areas we would like to highlight for your consideration when preparing the final rule on this critical issue.

I. Data Collection for Dialysis and Kidney Disease Services

We encourage CMS to ensure that coverage of dialysis, transplantation and other kidney disease treatments are included in the data collection protocols for state benchmark plans. For individuals with

end stage renal disease (ESRD), dialysis services and treatments are essential benefits. Dialysis can restore productive, high-quality and sustainable life to ESRD patients. Not including kidney dialysis and kidney related care in the benefit categories in which data will be collected could severely limit kidney disease patients from receiving these critical treatments. As these services save and sustain lives, it is vital that they be included in the final rule for data collection.

However, DPC would like to provide one caveat to the data collection on dialysis, transplantation and other kidney disease treatments. When data is collected, please note that there is a risk of underreporting of dialysis coverage in private insurance policies that could significantly skew the data. Specifically, a report released by the Department of Labor in 2011 highlighted the lack of available data regarding these services. The report noted that dialysis is only mentioned in 27 percent of private health insurance plans, indicating that almost three-quarters of private insurance plans do not mention dialysis as a plan benefit.¹ However, DPC knows from anecdotal evidence that a majority of kidney disease patients are not denied coverage of dialysis services from their private insurance plans. This leads DPC to believe that dialysis and other kidney related services are actually covered by far more plans than is indicated by the aforementioned report. DPC cautions the Agency to look more closely at dialysis and other similar services that might not be clearly mentioned in plan benefit summaries but are essentially part of benefit packages.

If the Agency hopes to collect accurate data on insurance plan benefits, DPC suggests it find a way to capture those benefits and services that, while perhaps not mentioned, are at the end of the day covered when individuals need them. Therefore, DPC recommends that these benefits and services should be included in the EHB packages as determined by the states and we also hope that the Agency will work to secure methods for ensuring this information is accurately captured.

II. Data Gathering on Plan Limits

We appreciate CMS's desire to collect data on limits in the potential benchmark plans that could impede access to care. However, DPC wants to make certain that the collection of this data is not an indication that these limits will be incorporated wholesale into the final EHB packages. These often arbitrary and unreasonable limits can be used to restrict needed care or steer consumers into or away from certain plans. It is DPC's belief that the intention of the Affordable Care Act (ACA) is to guarantee coverage of services within the 10 benefit categories, and incorporating these service limits will be inconsistent with this goal.

When it comes to dialysis services, this issue becomes even more important. There is no more essential a benefit than dialysis for someone with ESRD. Dialysis treatments are usually required three days a week for a minimum of several hours a session for the lifetime of a patient, or until an individual receives a transplant. Placing any service limits on these patients could truly mean the difference between life and death.

We are troubled by the potential for states to include these benchmark plan limits in their EHB packages. The implication of limits on the number of visits, frequency of treatment and length or dollar values of coverage for dialysis patients is extremely significant. If an enrollee exceeds the plan's limit on

¹ "Selected Medical Benefits: A Report from the Department of Labor to the Department of Health and Human Services," April 15, 2011, <http://www.bls.gov/ncs/ebs/sp/selmedbensreport.pdf>, page 18.

the number of dialysis treatments, the beneficiary would be responsible for paying the full cost of these essential, yet costly, services. This could lead to skipped treatments, avoidable hospital visits, and in the case of ESRD patients, even death.

While we support efforts by CMS to collect data on potential service limits included in the plans, we strongly urge that the Agency prohibits some limits or exclusions if they are found in a proposed state benchmark plan.

With more than 31 million Americans currently suffering from chronic kidney disease (CKD), it is critical for patients to have access to kidney treatments, especially dialysis and transplants, in the new health insurance exchanges. Each year in the United States, more than 100,000 Americans are diagnosed ESRD and that number that is expected to double over the next decade. It is critical that CMS take the necessary steps now to ensure that some of the most vulnerable patients are able to take full advantage of the reforms laid out in the ACA. We thank you for your consideration and welcome the opportunity to work with you on this and other important issues in the future.

Sincerely,

A handwritten signature in black ink, appearing to read "Hrant Jamgochian". The signature is fluid and cursive, with a long horizontal stroke at the end.

Hrant Jamgochian, J.D., LL.M
Executive Director