DPC
DIALYSIS PATIENT CITIZENS

*Improving Life Through Empowerment*

January 31, 2012

Steve Larsen
Director, Center for Consumer Information and Insurance Oversight
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244-1850

**Re: Essential Health Benefits Bulletin**

Dear Director Larsen:

Dialysis Patient Citizens (DPC) appreciates the opportunity to comment on the Center for Consumer Information and Insurance Oversight's (CCIIO) December 16, 2011 bulletin on the proposed regulatory approach to defining essential health benefits under section 1302 of the Affordable Care Act (ACA). As America's largest patient-led organization representing dialysis patients, we are committed to improving the quality of life for all dialysis patients by engaging policy makers, providers and the public. To that end, there are several important protections for dialysis patients that we respectfully urge you to consider as you work to develop the framework on Essential Health Benefits (EHB).

Overall, we have significant concerns that the proposed approach of comparing coverage to benchmark plans does not provide the details and clarity necessary to ensure that consumers with chronic diseases, especially those with kidney disease, will have the coverage and protections they need to receive full coverage and high-quality care.

## I. Include Coverage of End Stage Renal Disease as an Essential Benefit

First and foremost, we urge CCIIO to ensure that coverage for end stage renal disease (ESRD), which includes dialysis and transplant services, is considered an essential health benefit in the new exchanges, whether the package is defined on a Federal or State level.

Each year in the United States, more than 100,000 Americans are diagnosed with end stage renal disease (ESRD), an irreversible condition which is fatal without a kidney transplant or lifesaving dialysis treatments. Currently, more than 485,000 Americans suffer from ESRD and 340,000 are on dialysis, a number that is expected to double over the next decade. This dramatic rise is attributable to the increased prevalence of diabetes and hypertension, two skyrocketing chronic diseases and the leading risk factors for ESRD.

When defining essential benefits for the health exchange plans, we find it difficult to imagine the exclusion of dialysis and transplantation, as both are absolutely essential to the survival of an ESRD patient. In fact, these life-preserving treatments allow hundreds of thousands of Americans to live high quality and fulfilling lives. Mandating coverage of ESRD as an essential benefit will enable thousands of Americans to take advantage of new coverage opportunities the exchanges create.

## II. Reconsider State Flexibility

We have serious reservations regarding CCIIO's decision to allow each state to create its own package of EHB. While we recognize the desire to provide each state with the flexibility to create a package that best caters to the health needs of its residents, we are concerned that this flexibility will lead to confused consumers and wide discrepancies in care across states.

The EHB provision of the ACA was created with the intent to ensure a consistent, minimum level of benefits across all plans in the individual and small group insurance markets. This benefits package will allow easier comparisons of plans for consumers and prevent insurers from manipulating health plans to "cherry pick" enrollees. We believe moving the determination of these benefits to the states undermines the intent of the law and could be detrimental to consumers.

By permitting each state to create its own individual EHB packages, CCIIO is leaving too much to interpretation. The original 10 benefit categories outlined in the ACA are very broad, and different states could interpret those categories to encompass very different things. Categories such as "preventive and wellness services and chronic disease management" could be interpreted to mean a very different set of benefits by individual states. By providing no additional federal guidance on which benefits are deemed essential, there is a strong possibility of wide discrepancies in coverage across the country. This could lead to residents of certain states receiving a set of services well below that of others who reside in a neighboring state, which could disproportionately impact the most vulnerable patients.

Having separate packages will also create confusion for individuals who relocate across state lines, especially for those who have chronic illnesses that require continuous care. Having to navigate a new system and determine what services and benefits are offered in their new location could lead to a gap in care and could put beneficiaries' health at risk.

We encourage CCIIO to put in place strong oversight rules and monitoring practices, including regular reviews and updates, to ensure that the most vulnerable patients in this country do not suffer due to EHB package discrepancies.

## III. Remove Benefit Design Flexibility

We are also deeply troubled by CCIIO's decision to allow health plans to offer benefits that are "substantially equal" to the benefits offered by the benchmark plans selected by each State. Permitting insurance carriers to deviate from the set benchmark benefits would be a huge disservice to consumers and significantly weaken the intent of the ACA's EHB provision.

The EHB standard is intended to ensure a consistent, minimum level of benefits across all plans in the individual and small group insurance markets so that consumers can make an "apples-to-apples"

comparison of plan options. The benefits standard is also in place to prevent insurers from adopting benefit designs intended to attract healthier people and deter enrollment by those in poorer health.

If insurers can substantially vary the details of the benefits they cover from a state's chosen benchmark benefits standard, consumers will have a difficult time comparing the features of different plan options and making informed decisions about coverage. In addition, some insurers would likely exercise this flexibility to impose problematic benefit restrictions (such as visit limits) that would shift costs to people with significant or rare health care needs. Insurers would thus be able to construct their plans in ways that discourage enrollment by high-cost individuals or attract enrollment by people who are less costly to cover. Dialysis patients are among the sickest, and therefore costliest, patient populations in the American health care system, and could suffer significantly from these types of deviations.

The allowance of such flexibility would significantly undermine the original goals and intent of the EHB package, and final guidance and regulations should prohibit such flexibility and require insurers to adhere to the applicable benchmark benefits in a given state.

## IV. Ensure Strong Consumer Protections

Additionally, we are concerned about each State's ability to place benefit limits on coverage for dialysis and other treatments in its EHB packages. Individuals who are diagnosed with ESRD require dialysis treatments at least three times a week for their lifetime, or until they receive a transplant. Because of the nature of the treatment, any plan that places benefit limits on dialysis will severely impact the health and well-being of ESRD patients.

We are troubled by the potential for States to choose benchmark plans that place limits on the number of visits, frequency of treatment, length or dollar values of coverage. The implications of such limitations are significant. If an enrollee exceeds the plan's limit on the number of dialysis treatments, the beneficiary would be responsible for paying the full cost of those services. This could lead to skipped treatments, avoidable hospital visits, and in the case of ESRD patients, even death.

For example, among the possible plans identified by HHS, a state may choose "the largest plan by enrollment in any of the three largest small group insurance products in the state's small group market." Existing small group plans—even those with substantial enrollment in a state—may provide benefits with problematic benefit limits and may not be appropriate to serve as a state's essential health benefits standard. In the existing small group market, benefit limitations are often used to limit coverage of particular items or services. Because HHS has not clearly indicated whether the ACA's prohibition on annual and lifetime dollar value limits would apply to service-based dollar limits, we are very concerned about the potentially negative impact this will have on beneficiaries. Such "de facto" annual/lifetime limits should be prohibited for all plans, whether inside exchanges or not.

Beginning in 2014, the ACA requires insurers to take all applicants, prohibits insurers from charging people higher premiums due to health status, sex, and other characteristics, and limits the impact that a person's age can have on their premiums. When this occurs, the incentive for insurance companies to find other ways to restrict access will be amplified. With these requirements in place, insurers who can no longer reject high-cost enrollees or charge more for people with pre-existing conditions are likely to adopt other methods to reduce their exposure to large or certain types of health claims. This could be

the case even though the ACA includes provisions that are intended to reduce the incentive for plans to "cherry pick."

In particular, if this flexibility is allowed, it is likely that insurers will increase their use of "internal plan limits," such as restrictions on the number of visits for a particular service, in order to reduce their costs. Insurers could scale back coverage in one area (perhaps by placing stricter limits than the benchmark on a service more likely to be used by people with greater health care needs) and make up for it by increasing coverage in another benefit. Even if insurers must show each category of their benefits is equal in actuarial terms to each of the 10 benefit categories in the benchmark, there would still be significant room for insurers to design that benefit category in problematic ways.

These consumer protections should also extend to adequate choice of providers and reasonable coverage areas for patients. For such a time-intensive treatment as dialysis, it is especially important that patients are in close proximity to the dialysis provider of their choice.

If HHS proceeds with its intended approach, stakeholders—particularly those representing consumers — should have ample opportunity to review the details of benefits covered by each of the potential benchmark plans in each state and to weigh in through a public comment process on the tradeoffs of selecting one plan over another.

Additionally, the Bulletin does not address what protections will be in place, at either the Federal or State level, to assure benchmark plans are subject to strong, enforceable standards to protect consumers. While the ACA explicitly prohibits discrimination against various protected classes, many of the plan and benefit flexibility examples listed above could lead to potential discrimination against individuals the bill is designed to protect. We urge CCIIO to develop a strong evaluation process to ensure States are complying with all requirements of the ACA.

## V. Protect Prescription Drug Coverage

Like many other patient advocates, we are also troubled by the current plan for prescription drug coverage outlined in the Bulletin. The Bulletin details a proposed standard of coverage that falls far below current standards, including private plans and Medicare Part D, by only requiring plans to cover one drug per category or class. This threatens to undermine care for all those suffering from chronic conditions.

Typical dialysis patients take more than a dozen medications each day to manage their kidney failure, its effects on other organs and to manage other comorbidities common in dialysis patients. If the standard is to only cover one drug per category or class, medically necessary medications will not be covered for many patients. This will have a serious impact on the quality of care patients receive and the quality of life they are able to enjoy.

CCIIO should look to current standards of coverage when designing the prescription drug coverage guidelines. It would be a disservice to patients for CCIIO to develop new coverage rules that diminish patient choice and reduce access to life saving medicines. We also urge CCIIIO to consider including Medicare Part D's protected class policy for all medications in specific categories in order to protect vulnerable individuals. Prescription medication is a critical tool in the management of chronic diseases, the prevention of disease progression and costly complications, and we encourage CCIIO to consider

redesigning the standard to provide more comprehensive prescription drug coverage through the exchanges.

## VI. Conclusion

With more than 31 million Americans suffering from chronic kidney disease (CKD), which very often leads to kidney failure, it is absolutely critical that the CCIIO not forget this growing segment of the population when considering future guidance on essential health benefits. We appreciate your consideration and stand ready to assist in ensuring that all patients are protected as you move forward with outlining the future of essential health benefits.

Sincerely,

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