



National
Kidney
Foundation™

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January 15, 2016

The Honorable Sylvia Mathews Burwell
Secretary
Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Re: Draft 2017 Letter to Issuers in the Federally-facilitated Marketplaces

Dear Secretary Burwell:

The National Kidney Foundation (NKF) appreciates the opportunity to comment on the Patient Protection and Affordable Care Act: Draft 2017 Letter to Issuers. NKF is America's largest and oldest health organization dedicated to the awareness, prevention, and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of people at risk. NKF has a network of 40,000 patient and family members as part of our constituent council membership and reaches tens of thousands more patients through our programs and education materials. In addition, NKF has provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD), including transplantation since 1997 through the NKF Kidney Disease Outcomes Quality Initiative (NKF KDOQI). We work with volunteers to offer the scientific, clinical and kidney patient perspective on what needs to be done to prevent kidney disease, delay progression, and better treat kidney disease and kidney failure. NKF has local division and affiliate offices serving our constituents in all 50 states.

NKF appreciates the commitment and progress HHS has made in issuing guidance to reduce discrimination against individuals with chronic conditions, including those with kidney disease. We believe many of the proposals in the Notice of Benefits and Payment Parameters (NBPP) and the Letter to Issuers will improve patient protections and access to care. We appreciate that the Letter includes additional clarification of some of those

proposals and we offer additional comments on how to ensure better patient protections moving forward.

Network Adequacy Standards

NKF supports the HHS proposal to ensure provider network adequacy using the following metrics:

- Prospective time and distance standards at least as stringent as the FFE standard; and
- Prospective minimum provider-covered person ratios for the specialties with the highest utilization rate for its State.

NKF particularly appreciates the additional detail on the proposed Federal time and distance standards. However, we note that organ transplant centers are not identified in the standards and we are concerned that the standards deviate from the Medicare Advantage (MA) standards and permit longer drive times and distances for patients to access a dialysis facility. As stated in our NBPP comments, given that dialysis patients typically receive treatment in an outpatient facility three times per week for four hours a day, it is important that patients are not required to commute a significant distance for treatment. Shorter travel times and distance to dialysis clinics have been associated with improved patient outcomes and a higher health-related quality of life.¹ Dialysis patients encountering burdensome transit demands, are more likely to miss or shorten treatments. Compared with other dialysis patients, those who *missed* one or more dialysis sessions in a month had a 25% higher risk of death. Patients who *shortened* three or more dialysis treatments in a month had a 20% higher risk of death than those who received the prescribed treatment.² Additionally, patients who miss dialysis treatments are more likely to end up needing expensive care in hospital emergency departments.

To help protect patients from having to commute further to a dialysis facility, we strongly encourage HHS to adopt the MA standards, which are much more reasonable. In addition,

¹ M. J. Diamant, et al. A Comparison of Quality of Life and Travel-Related Factors between In-center and Satellite-Based Hemodialysis Patients *Clin J Am Soc Nephrol* 5: 268–274, 2010.

² J.E. Leggat, et al, Noncompliance in Hemodialysis: Predictors and Survival Analysis, *Am J. Kidney Dis.* 1998 Jul;32(1):139-45.

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we encourage HHS to adopt MA standards for transplant centers and to provide Federal oversight to ensure that plans in the FFMs are meeting those standards.

Continuity of Care

NKF appreciates HHS addressing the need for individuals with chronic conditions to maintain access to their healthcare providers when they are undergoing active treatment. We echo our comments from the NBPP here and urge HHS to finalize its proposal to ensure that individuals undergoing active treatment maintain access to their provider for 90 days when the provider is terminated by the plan without cause and that the provider still be considered an in network provider in terms of cost-sharing to the patients. We also encourage HHS to extend this proposal to ensure patients undergoing active treatment, with a provider whose contract is non-renewed as termination without cause, are able to continue seeing that provider. While patients with ESRD meet the proposed definitions and criteria for "active treatment," we request HHS specifically include ESRD patients on dialysis in the list of examples for "a serious acute condition as a disease or condition requiring complex on-going care which the covered person is currently receiving."

Discriminatory Benefit Design

ESRD

NKF appreciates the reminder that ESRD patients are not required to enroll in Medicare and are eligible for Marketplace coverage when they are not enrolled in Medicare (should they meet the standard eligibility requirements). Per our comments on the NBPP, we request that HHS clarify that issuers are not able to terminate coverage, limit benefits, or use non-negotiated rates subjecting patients to balance billing charges that do not count towards the patient's out-of-pocket maximum based on a patient's eligibility for Medicare due to ESRD. Doing so discriminates against a patient with ESRD and could cause them to feel they have no other option but to enroll in Medicare. While nearly 80 percent of ESRD patients do elect to enroll in Medicare there are some patients who prefer to have private insurance coverage and patients should have the right to make that choice. Given that issuers in some states continue to have policies with this discriminatory language, we request that HHS also review plans for discriminatory benefit design language that coerces, requires, or imposes

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penalties for ESRD patients who do not enroll in Medicare and enforce with the issuers that this language is prohibited.

Prescription Drugs

NKF is pleased that HHS will conduct formulary reviews and look at high cost-sharing and tier placement across medications used to treat certain chronic conditions. However, we caution against complete reliance on clinical guidelines to determine appropriate access. These guidelines are important to give healthcare practitioners a starting point in the care of patients, but ultimately it is up to the physician who knows the medical history of the individual patient to tailor treatments that will result in the best outcomes for that patient. This is particularly the case for organ transplant recipients as individual patients respond differently to various immunosuppressive drug combinations and many of the reasons are not understood.

Limited formularies and high cost sharing on certain medications can limit options for patients and reduce practitioners' abilities to deliver care that addresses individual patients' needs, goals and outcomes. Timely access to immunosuppressive drugs for organ transplant recipients is the difference between organ rejection (or potentially death) and maintaining the transplant. NKF commissioned a study which identified that 19 to 32 percent of Silver plans are using coinsurance with the average amount being 36 percent and outliers charging as high as 60 percent for certain drugs. This poses a substantial barrier to organ transplant patients accessing their medications. While we appreciate the agency's attention for prescription drug access across certain chronic conditions, NKF urges HHS to review formularies for discriminatory tier placement and cost sharing for all medications used to treat chronic conditions, including immunosuppressive drugs and enforce prohibition of such activities. In addition, it is highly important that these reviews be supplemented by the timely appeals process that allows those with life-threatening conditions to have appeal decisions issued within 24 hours.

Third Party Payments

With regard to required acceptance by issuers of third party premium assistance payments, we reiterate our comments from the NBPP that the proposed requirements also extend to non-profit entities even when the patient population may be eligible for other credible

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coverage. As highlighted above, ESRD patients are not required to enroll in Medicare and while it is considered credible coverage, there are certain circumstances where Medicare results in patients having greater out-of-pocket costs than the maximums established for the Marketplace and additional reasons some patients desire maintaining private coverage.

The American Kidney Fund (AKF) has provided premium and cost-sharing assistance to dialysis patients for many years – affording them the option to maintain health insurance coverage of their choice. The AKF program helps protect dialysis patients' choice in insurance coverage and makes accessing healthcare services and dialysis services more affordable for patients whether they choose Medicare (with Medigap coverage), Medicaid, or private coverage. The HHS Office of the Inspector General has approved arrangements such as AKF's Health Insurance Premium Program (HIPPP) and stated that it is a program that "will expand, rather than limit, beneficiaries' freedom of choice."³ NKF urges HHS to notify issuers that plans must accept third party payments from non-profit charitable organizations that existed prior to the enactment of the ACA, have been reviewed favorably by the OIG, and offers assistance for the purchase of any coverage option.

Decision Support Tools

Decision support tools are vitally important to help consumers pick plans that best meet their healthcare needs and we appreciate the agency's development and deployment of such tools. As a result patients will be able to select plans based on network status of their healthcare providers, coverage of their medications, and an estimate of their annual out-of-pocket costs. NKF encourages further refinement of these tools, particularly in the out-of-pocket costs and echoes the recommendations of the National Health Council, which has experience in developing and maintaining an out-of-pocket cost calculator. The Marketplace calculator should provide cost estimates based on the exact medications patients enter and types of providers they expect to use. Integration of the provider and formulary tools into the cost calculator would simplify consumers' shopping experience by allowing them to enter their providers and medications and identify plans based on this information as well as compare those plans by costs. Patients could then make adjustments on this selection criteria based on the number of results they receive.

³ HHS OIG, Advisory Opinion No. 97-1, June 11, 1997.

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In sum, NKF appreciates the progress made over the years to protect individuals with kidney disease access to health care services and coverage of their choice. We look forward to partnering with HHS on strengthening these protections and ensuring that patients with kidney disease have affordable access to coverage and care.

If you have any questions please contact Tonya Saffer, Senior Health Policy Director at tonya.saffer@kidney.org or at 202.244.7900 extension 717.

Sincerely,

Kevin Longino

Kevin Longino
CEO and Kidney Patient