



National
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November 27, 2017

Seema Verma
Administrator
Centers for Medicare & Medicaid Services
200 Independence Avenue, SW
Washington, DC 20201

Re: CMS-9930-P – Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2019

Dear Administrator Verma,

The National Kidney Foundation appreciates the opportunity to comment on the proposed Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters (NBPP) for 2019. The National Kidney Foundation is the largest, most comprehensive and longstanding, patient centric organization dedicated to the awareness, prevention and treatment of kidney disease in the US. In addition, the National Kidney Foundation has provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD), including transplantation since 1997 through the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (KDOQI). Our comments reflect our request that CMS provide additional clarification to states and plans that will protect people with CKD from discriminatory benefit designs that put patients' lives at risk and result in unnecessary, additional Federal spending.

I. Clarify and protect ESRD patients from coverage limitations

The National Kidney Foundation urges the Centers for Medicare & Medicaid Services (CMS) to ensure patients with chronic conditions, like CKD, are protected from discrimination in plan design as the agency moves towards allowing for greater state flexibility in benefit design and oversight. Specifically, we are aware of challenges patients with end-stage renal disease (ESRD), who rely on either dialysis or transplant to survive, have faced in accessing care and maintaining coverage because of insurer attempts over the past several years to (1) limit coverage for ESRD patients, (2) significantly limit access to care by designing narrow networks. and (3) charge significant coinsurance on immunosuppressive medications even when they are generics. We believe that even with greater state flexibility that CMS

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has a key role to play in establishing parameters and guidance to states to ensure that patients with chronic conditions are protected from discriminatory benefit designs.

Patients with CKD have a unique relationship with the Medicare program as most patients who progress to ESRD will be eligible for Medicare coverage. However, enrollment in Medicare is not a requirement for ESRD patients and eligibility cannot be determined unless a patient chooses to enroll. While most patients with ESRD will choose to enroll in Medicare, there are some patients who, for a variety of reasons, prefer to maintain private coverage. The Federal Government has noted ESRD patients' ability to choose coverage in the Exchanges over Medicare, but additional guidance to states and plans is necessary to ensure clarity and understanding by health plans and state governments.^{1,2}

The National Kidney Foundation requests that CMS clarify to states that health plans cannot place limitations on coverage of ESRD patients solely because of their eligibility for ESRD. In addition, we are very concerned about the flexibility provided to states in determining benchmark plans and substituting essential health benefits. Ensuring benefits typically covered by an employer plan is critical to protecting people with chronic conditions, particularly ESRD patients for which there is no substitute for a kidney transplant or dialysis. Specifically, we ask that CMS provide affirmative notification in this final notice and in the subsequent Letter to Issuers that dialysis and kidney transplants should continue to be covered, without waiting periods, for patients with ESRD.

Affordable access to immunosuppressive drugs, which kidney transplant recipients must take to prevent organ rejection for the life of their transplant, are critical for kidney transplant recipients. Kidney transplant recipients, if they are under age 65 and not otherwise disabled, lose Medicare coverage 36 months after receiving a kidney transplant. The Exchanges have helped these patients maintain access to insurance and their medications. However, some plans require deductibles to be met before the plan will pay for any costs of the medications. There are also plans that place even generic immunosuppressive medications on high cost-sharing tiers with coinsurance of 20% or more while allowing other generic drugs to have fixed copayment or coinsurance. To accomplish this disparate policy, some plans label immunosuppressive drugs erroneously as "specialty" and have them accessible only through specialty pharmacy. We urge CMS to encourage states to adopt first dollar coverage of all prescription medications so that patients do not have to first meet deductibles and experience high out-of-pocket costs before their drug coverage starts. In addition, if plans have policies that incentivize

¹Medicare and the Marketplace: The Relationship between Medicare and the Health Insurance Marketplace
<https://www.cms.gov/Medicare/Eligibility-and-Enrollment/Medicare-and-the-Marketplace/Overview1.html>.

² IRS, "Eligibility for Minimum Essential Coverage for Purposes of the Premium Tax Credit"

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generic drug use through flat copays or fixed coinsurance amounts then those policies should apply to all generic medications regardless of whether the patient receives those medications at their local brick and mortar pharmacy or through a specialty pharmacy.

While this notice proposes to provide states with flexibility in developing network adequacy standards, we believe CMS has a role in establishing minimum parameters to protect patients from discrimination by narrow networks. Kidney patients need to access to primary care practitioners, nephrologists, dialysis centers, palliative care specialists, and transplant centers in addition to providers who take care of their other health needs. However, without quantifiable metrics for the number of nephrologists, dialysis facilities, palliative care specialists, and transplant centers that should be included in the network, patients will find their options for plans that encompass the health care services they need very limited. For example, we are aware of one plan in Idaho that had only one dialysis facility in network for the entire state in 2016. NKF urges CMS to work with states and provide guidance on network adequacy standards.

While most ESRD patients will choose to enroll in Medicare over remaining in an Exchange plan this is not and should not be a one size fits all policy. CMS needs to clarify to states and plans that ESRD patients cannot be forced to enroll in Medicare by plans limiting coverage or access to dialysis and transplant. In addition, patients who receive a kidney transplant and leave or do not enroll in the Medicare program need to have affordable access to their medications or they risk requiring a new kidney transplant or dialysis, which would make them re-eligible for Medicare – an unnecessary added risk to their lives and additional Government spending that could have been avoided.

The National Kidney Foundation appreciates the opportunity to provide comments. Please contact Tonya Saffer, Senior Health Policy Director at 202.244.7900 x 717 or tonya.saffer@kidney.org with any questions.

Sincerely,

Kevin Longino

Kevin Longino
CEO and Transplant Recipient

Michael Choi

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