



Service to those affected by chronic kidney disease

August 15, 2024

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

RE: CMS-1805-P: End-Stage Renal Disease Prospective Payment System, Payment for Renal Dialysis Services Furnished to Individuals with Acute Kidney Injury, Conditions for Coverage for End-Stage Renal Disease Facilities, End-Stage Renal Disease Quality Incentive Program, and End-Stage Renal Disease Treatment Choices Model

Dear Administrator Brooks-LaSure,

Renal Support Network (RSN) empowers people with kidney disease to become proactive in their care and work with healthcare professionals and all stakeholders to achieve the best care and health outcomes possible. I have been dealing with kidney disease since the age of two (1968) and spent 13 years on dialysis experiencing home and peritoneal dialysis, and currently have a successful kidney transplant. I founded RSN in 1993 to provide hope to my peers and advocate for the best care. RSN reaches hundreds of thousands of people with kidney disease and their families through our patient engagement programs.

Providing access to Medicare for individuals with ESRD was a compassionate decision for those with chronic kidney failure. It was a significant step towards providing healthcare for those who were previously unable to afford or obtain life-saving treatment. We have come a long way since the 1960s, and I have personally benefited from numerous innovations in the kidney community since first being diagnosed. However, after 50 years, the system is under great pressure. Facilities will continue to close, reduce shifts, or have long wait times to start home therapies due to a lack of nurses. Furthermore, the reality is that ESRD disproportionately affects racial and ethnic minorities, and they will be hit the hardest.

In RSN's pursuit of progress in patient-centered kidney care, it is essential to recognize the vital role that access to innovation plays in providing hope to people battling kidney disease.

In our existing ESRD bundled payment healthcare system, payment policies are failing to align with patient-centered principles, destroying the prospect of innovation and compromising the well-being and future of those who need it most. These dire consequences arise from neglecting patient access to innovation in dialysis care and stress the significance of prioritizing hope and healing in healthcare.

ESRD Prospective Payment System Bundled payments, while aiming to streamline costs and improve efficiency, stifle access to cutting-edge therapies and new treatment options that can improve our well-being. By limiting reimbursement solely to a fixed bundled amount designed for the "average patient," this system discourages healthcare providers from pursuing individualized, innovative approaches, leaving patients devoid of hope and restricted to conventional treatments, even when breakthrough options are available.

We have already witnessed innovation that is no longer available to people who suffer from Pruritus, which can be debilitating, very painful, and irritating. The current prescribed treatment does not meet the needs of this intense itch, leaving people to suffer.

An illness is too demanding when you don't have hope!
– Lori Hartwell, RSN Founder and President

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In 2025, phosphate-lowering drugs are due to go into the bundle and will have dire consequences for us. People with kidney failure are prone to high levels of phosphate in their blood due to a lack of kidney function. Many foods are filled with phosphate as it is used as a preservative. It is impossible to avoid it and be able to eat.

When phosphate levels in the body are not properly controlled and remain high, it is a condition known as hyperphosphatemia. Hyperphosphatemia can lead to serious health complications and high phosphate levels that can disturb the balance of minerals like calcium in the body, leading to weakened bones, bone loss, and an increased risk of fractures.

The frequency and number of phosphate-lowering medications taken by people during each meal can vary based on their specific medical condition and treatment plan. These medications help to control and reduce the absorption of phosphate from the diet.

Leaving phosphate-lowering therapies out of the bundle system is important so doctors can prescribe the most effective treatment for their patients' needs. With current therapies you must take a handful of medication with each meal. With the innovation you take a small pill in the morning and night that can help with compliance and avoid the daunting feeling of taking a handful of pills when you're trying to enjoy a meal.

Also, there are no approved quality measures that can protect the patient from receiving the cheapest medication instead of the most effective one. Additionally, we are unsure how people receiving care in nursing homes will be able to get their medication.

These critical distinctions lead us to ask that phosphate-lowering medications not to be included in the bundle. We believe that doctors should have the freedom to prescribe the best treatment for their patients' specific situation, and that patients can pick up the medication from their pharmacy to speak with a pharmacist for instructions if necessary.

This is a Kidney Talk Podcast that explains this rationale in more detail. Innovative medications funds need to follow the patient, not the provider. (See Below)

By promoting innovation, it helps ensure equitable access to revolutionary therapies, healthcare providers can weave a tapestry of hope for patients that extends far beyond their present circumstances. It is our collective responsibility to bridge the gap between payment policies and patient-centered care, enabling a future filled with hope and better health for all.

Access to healthcare professionals

There is a huge staffing shortage that patients must navigate care every day due to the availability of lack of appointments. There is no room for error, and it is impacting the patient's ability to work and to maintain family commitments. This must be addressed so patients can get the care they need and not have to put their life on hold while doing so.

Payment drives practice, and the needle must be threaded very carefully to stitch a plan that does not hinder our quality and access to care. By addressing the challenges of the payment system inadequacies and the healthcare professional staffing pipeline, we can aim to provide better care, ensure access for those in need, and avoid situations where patients cannot even get through the door for treatment. We are worth saving.

ESRD Quality Incentive Program

ESRD Quality Incentive Program RSN supports the CAHPS survey with the strong recommendation that another measure providing more insight into and impact on patient outcomes be developed as soon as possible. RSN is concerned that the CAHPS survey is not providing meaningful information to improve patient care. The survey is implemented twice a year by a third party, and patients often experience survey fatigue. A once-a-year survey will allow facilities to react to the feedback and implement changes as necessary.

A critical area that the survey does not address is the plethora of day-to-day patient experiences during the entire period. These can range from various aspects of care, and the CAHPS survey does not capture the essence of what the patient is feeling regarding individual dialysis treatments or the general experience while on dialysis. Patients may also perceive the survey as onerous since it contains 52 questions and is administered by a third party they do not know. We often hear patients suffer from survey fatigue and not sure how the survey improves their well-being.

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CMS should consider adopting a patient reporting measure to ensure that the patient has a voice during every dialysis treatment. For example, after each treatment, patients could be asked a simple question, such as whether they were (a) not at all bothered, (b) somewhat bothered, (c) moderately bothered, (d) very much bothered, or (e) extremely bothered during a treatment.

If the patient is bothered, a series of additional questions could be asked to qualify their response based on the common difficulties patients' experience, such as access problems, low blood pressure, crashing, cramping, or other pertinent indicators.

Collecting this information might help providers understand why patients do not stay for the entire treatment or why they miss treatments. A brief, structured conversation with the patient can also provide the physician and the facility manager with insights on whether a patient is tolerating treatment or not, and on the potential need for adjustments before a major problem emerges.

In addition, this approach could be used to assess quality of care for home dialysis patients, an area of focus that is greatly needed.

ESRD Treatment Choices (ETC)

The ESRD Treatment Choices (ETC) Model is designed to promote increased utilization of home dialysis and kidney transplants for Medicare beneficiaries with ESRD. The goal is to cut Medicare expenses while maintaining or improving the quality of care provided to beneficiaries with ESRD.

CMS and the community have several initiatives to encourage more people to undergo home dialysis. However, the number of people choosing home dialysis remains relatively stagnant as new patients enter while others choose to go back to the dialysis center or get a transplant. With the current percentage of people doing home dialysis (low 20%), there is room for growth in this area.

The National Kidney Foundation has proposed a bill to have paid caregivers perform the treatments for the patient at home. While this can be helpful, especially when the patient isn't feeling well, it also means relying on other people's schedules and we simply do not have enough health care professionals choosing dialysis care as a profession. Respite care is needed.

In our opinion, one of the best ways to increase the number of individuals opting for home dialysis is by recognizing and valuing the time and energy people with kidney failure dedicate to their treatment regimen. This requires a deep understanding of the daily challenges and commitment involved in managing home dialysis. Kristin Rice and Rachel Cluthe's video, which provides a condensed but impactful portrayal of their home dialysis experience, is a powerful example of how sharing firsthand experiences can help decision-makers understand the reality of this treatment method and the commitment needed by the patient. By highlighting individuals like Rachel & Kristin who have dedicated extensive time and effort to do their own home dialysis, it offers valuable insights into the true nature of this treatment. This video showcases the dedication and resilience required to provide your care. (See below).

As the government and various organizations within the dialysis community continue to advocate for home dialysis, implementing a system to help people transition to home dialysis with greater confidence and ease would be beneficial. This system may include in-center self-care with the goal of eventually the person transitioning to home treatment.

Recognizing the tremendous effort put forth by people who diligently manage their dialysis treatments every day, especially during periods of poor health, is crucial. Motivating and retaining individuals on home dialysis is essential, given the high number of people who discontinue this form of treatment after just a few months. Efforts to address this issue could involve providing tangible benefits and support to home dialysis patients, thereby acknowledging and valuing their dedication to self-care.

One potential approach to incentivizing home dialysis and attention is to design and establish a pilot program that offers specific benefits or rewards aimed at recognizing and appreciating the commitment it takes to do one's treatment. For

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instance, waiving Medicare copayments for home dialysis patients could be a meaningful step in demonstrating recognition and support for their efforts. A task force should be created to work with CMS to evaluate options.

Humans are wired to respond to rewards. When we receive a reward, our brain releases a feel-good chemical called dopamine. Rewards motivate us to work harder, learn new things, and strive for success. Rewards give us a sense of achievement, validation, show progress, boost our self-esteem, and make us feel valued. Also, reward systems can have an impact on patients' family dynamics and may help them feel less burdened and more willing to accept and support home dialysis.

By acknowledging and valuing the energy and dedication required by people to do their home dialysis, we can foster a more supportive environment that encourages people to choose and persevere with this form of treatment. We believe this approach can help motivate and retain people on home dialysis. Also, with the shortage of renal care professionals, drastic changes are needed in how we provide care to meet the needs of people requiring dialysis to live.

My experience with both home hemodialysis and peritoneal dialysis gave me the ability to take control of my treatment at home, positively impacting my overall well-being. I am grateful to have a kidney transplant that is doing well.

The goal is to empower people with kidney failure to choose home dialysis as their treatment option. By fostering a deeper appreciation for the efforts of those engaged in home dialysis, we can work towards increasing the percentage of people benefiting from this valuable form of treatment.

Healthcare systems should be unwavering in their commitment to a patient-centered approach, acknowledging the necessity of hope and access to innovation for people battling kidney disease. The current ESRD bundled payment program has no sustainable means to incentivize and improve kidney care. Innovation in healthcare can help attract doctors to choose nephrology as their specialty. It provides doctors with access to advanced technology, advanced medical treatments, and opportunities for research and development. Additionally, healthcare professionals who are passionate about improving patient care and outcomes are more likely to be attracted to disease states that focus on innovation and offer cutting-edge advancements in healthcare. Misaligned payment policies risk perpetuating a cycle of limited options, denying patients the chance to explore cutting-edge treatments and stifling the potential for improved outcomes.

We thank you for the opportunity to comment on the proposed ESRD payment policies. We need meaningful payment policy to support Innovation, quality of care, and most importantly, hope. We thank you for the opportunity to comment. Please let me know if you have any questions or need additional information.

Sincerely,



Lori Hartwell
President & Founder

KidneyTalk Podcasts
Embracing Independence with Kidney Disease
<https://www.rsnhope.org/rsn-blog/embracing-independence-with-kidney-disease-2/>

Access to Innovation in Dialysis care has its Ups and Downs
<https://www.rsnhope.org/kidneytalk/access-to-innovation-in-dialysis-care-has-its-ups-and-downs/>

