



Reimagining Kidney Care: From Crisis to Opportunity

Executive Summary

In 1972, Congress extended Medicare coverage to individuals living with end-stage renal disease (ESRD), the final stage of chronic kidney disease (CKD) in which the kidneys are failing and can no longer filter waste and fluids from the blood.

This marked the first, and is still one of only two instances that individuals, regardless of age, may qualify for Medicare coverage on the basis of a specific medical condition, as people with ESRD are “deemed disabled” under the law for the purposes of Medicare Part A and Part B.¹ At the time, policymakers viewed the expansion of benefits as a moral obligation to enable broad access to life-saving treatment for the thousands of people living with ESRD who would die without regular dialysis.¹

This policy change was a critical step in saving lives of people with kidney failure, and it continues to provide this vulnerable population with vital health insurance coverage. Yet policymakers have historically missed the opportunity to incentivize the health care system to prioritize preventive care, disease management and treatment for earlier stages of CKD. As a result, we are facing a kidney disease public health crisis that places a significant societal and economic burden on our nation.

Data underscores just how urgent this public health crisis is: while the global age-adjusted death rate for CKD grew just 2.8% in the nearly three decades between 1990 and 2017, in the U.S., it rose by an alarming 63%.²

When the ESRD Medicare benefit was signed into law, there were 10,000 Americans on dialysis.³ In the 50 years since its passage, the number of individuals with ESRD has grown to over 800,000.⁴ Medicare covers the vast majority of these individuals, at a cost of over \$50 billion in ESRD-related expenditures alone.⁵ CKD prevalence has similarly skyrocketed; 37 million Americans have CKD and millions more are at risk of developing it. Most concerning, however, is that as many as 9 in 10 individuals are unaware that they have CKD.⁵

This means that while most people with CKD may not experience any signs or symptoms, their condition will likely be steadily progressing, resulting in diminished kidney function, as well as a greater chance of cardiovascular disease, stroke and death, with people of color at higher risk of poor outcomes.⁵ While kidney disease is not reversible, it is treatable, and when diagnosed and treated early, it is possible to slow or stop the progression of the disease to avoid these serious complications.⁵

Unfortunately, with Medicare responsible for most ESRD-related treatment costs, other payers, including employers, haven't been properly incentivized to prioritize the kind of upstream care (i.e., prevention and diagnosis) and early treatment necessary to delay progression to the later, more costly stages of kidney disease.

In this new analysis conducted in partnership with Health Capital Group and leveraging data from the United States Renal Data System (USRDS), we illustrate the significant opportunity for savings that Medicare, commercial payers and employers could realize if we evolve our current system to incentivize interventions that reduce the number of people that progress to the later stages of the disease.

We find that by reducing the share of people who progress to stages 4 or 5 (indicating severe kidney damage), as well as reducing the share of those who progress to stage 3 (indicating moderate kidney damage), by 25% each, Medicare could save an estimated \$9 billion each year. Commercial payers and employers could save an additional \$2.8 billion annually.

This analysis demonstrates that in addition to the significant societal opportunity to reduce a leading cause of illness and death in the U.S., there is also an equally significant economic benefit to prioritizing better kidney disease management. **By working together to advance policies that improve education for providers and people living with kidney disease, support earlier and more complete diagnosis and enable better access to treatment, we believe we can change the dire trajectory of CKD in the U.S.**



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Understanding Kidney Disease

Chronic kidney disease (CKD) occurs when kidneys are damaged and begin to lose their ability to filter waste and fluids out of the blood.⁶

Over time, this waste can build up in the body and lead to kidney failure and other dangerous complications. CKD is divided into five stages that indicate the extent of damage to the kidney and how well the kidneys still function.⁷ Kidney health is assessed with simple blood and urine tests. Urine tests are used to check for the presence of a protein called albumin. When detected above a certain level, the presence of albumin in urine can indicate kidney damage. The blood test allows a lab to calculate a person’s estimated glomerular filtration rate (eGFR), which measures how well the kidneys are working. Stage 1 CKD indicates mild damage to the kidneys and stage 5 indicates that the kidneys are very close to failure or have already failed. If the kidneys have failed, a person has developed end-stage renal disease (ESRD), which means they will need to start dialysis (a treatment to remove waste and fluid from the blood) or have a kidney transplant to live.⁷ Kidney failure is highly disruptive to an individual’s quality of life and their ability to work. Diabetes and high blood pressure are the leading causes of kidney disease, while other factors like genetics and inflammation in the body can cause more rare forms of the disease.

Prognosis of CKD by GFR and Albuminuria Categories: KDIGO 2012

- **Green:** low risk (if no other markers of kidney disease, no CKD)
- **Yellow:** moderately increased risk
- **Orange:** high risk
- **Red:** very high risk

				Persistent albuminuria categories, description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				<30 mg/g <3 mg/mmol	30-300 mg/g 3-30 mg/mmol	>300 mg/g >30 mg/mmol
GFR Categories (ml/min/1.73 m ²), description and range	Stage 1	Normal or high	≥90			
	Stage 2	Mildly decreased	60-89			
	Stage 3a	Mildly to moderately decreased	45-59			
	Stage 3b	Moderately to severely decreased	30-44			
	Stage 4	Severely decreased	15-29			
	Stage 5	Kidney Failure	<15			

Source: KDIGO CKD Staging Chart, Gomez, et al., 2019

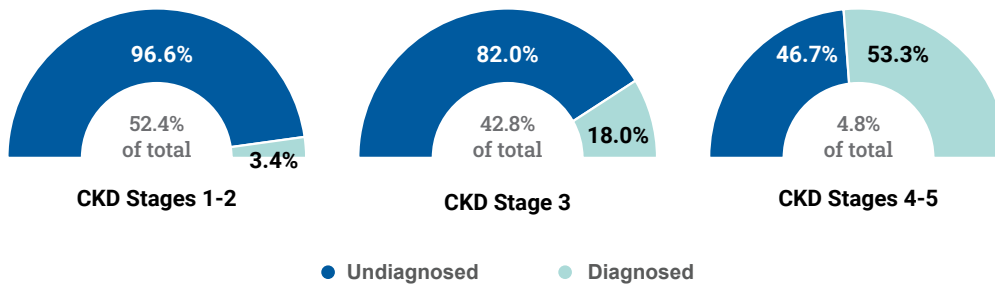


Diagnosed at Birth: Anel’s Story

Anel was born with one kidney that began failing when she was 12 years old. She started dialysis and was able to receive a kidney from a deceased donor that has now lasted her 27 years. She feels lucky her condition was treated early and properly managed.

Many people will not experience any symptoms until the late stages of the disease, when extensive damage to their kidneys puts them at risk for heart attack, stroke, kidney failure and death, resulting in costly care and treatment. Even when people do experience symptoms—which may include itching, muscle cramps and swelling in the feet and ankles, among others—their symptoms may not be taken seriously, or providers may not be aware that their symptoms are connected to kidney disease. As a result, kidney disease is often referred to as a “silent killer,” with nearly 9 in 10 people with the condition unaware that they have it.

Estimated Share of Undiagnosed People Living With Chronic Kidney Disease, by Stage⁸



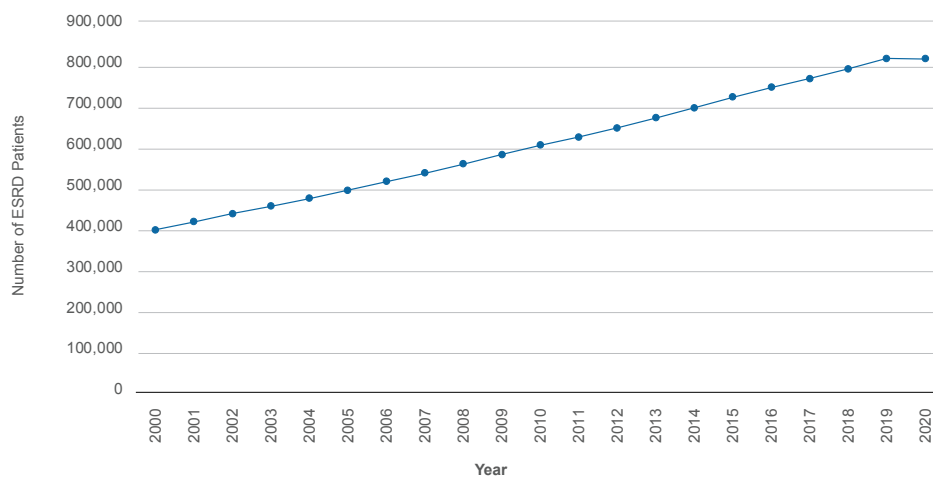
A Shocking Diagnosis: Kyle's Story

Kyle's kidney failure diagnosis came as a shock that left him feeling helpless, thinking that there was no life left to be lived. He regrets not knowing about his CKD earlier—knowledge that could have given him the opportunity to make the necessary changes to his diet and exercise that may have slowed the progress of the disease. Since his ESRD diagnosis, he has undergone years of dialysis and received a transplant from a deceased donor. While this transplant has greatly improved his quality of life, it is a treatment, not a cure for kidney failure.

THE SOCIETAL AND ECONOMIC BURDEN OF KIDNEY DISEASE

Today, 37 million Americans have CKD. It is now the fastest growing non-contagious disease in the U.S., affecting more than 1 in 7—or 15%—of American adults. One-third of adults with diabetes and one-fifth of adults with high blood pressure will eventually develop CKD.⁵ Even more alarming is the rate at which people are being newly diagnosed with ESRD—over 130,000 in 2020—which represents a nearly 40% increase in new cases from just 20 years ago.⁴

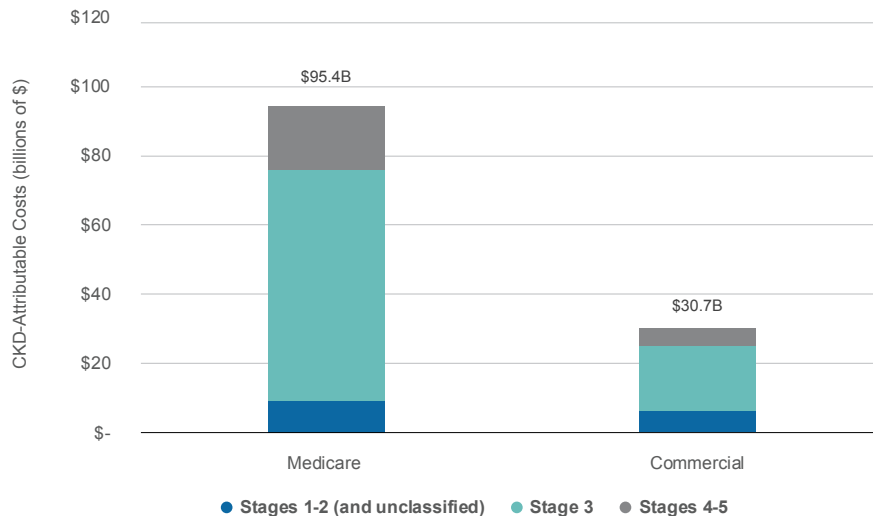
Prevalence of ESRD from 2000-2020



Source: 2022 USRDS Annual Data Report, 2022

The very sad reality is that many cases of CKD and ESRD are preventable through better control of underlying conditions like diabetes and high blood pressure. CKD can be managed, and its progression often slowed or stopped, with appropriate care and treatment once diagnosed. However, achieving earlier, equitable and optimal diagnosis and intervention still eludes us, resulting in over 800,000 Americans currently living with ESRD and placing kidney disease as one of the top 10 causes of death in the U.S.⁵ In fact, a study assessing the increase in kidney disease death rates around the world found that while the global age-adjusted death rate for the disease grew just 2.8% in the nearly three decades between 1990 and 2017, in the U.S., it rose by an alarming 63%.²

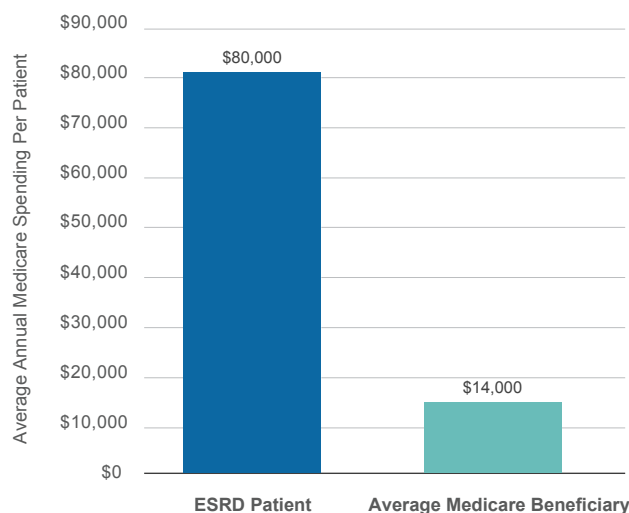
CKD Spending: Medicare vs. Commercial Markets



Source: Health Capital Group LLC analysis of data from USRDS 2022 Annual Report. Source data can be found in various tables at: <https://usrds-adr.niddk.nih.gov/2022/chronic-kidney-disease/6-healthcare-expenditures-for-persons-with-ckd>

In addition to its significant societal impact, CKD also places a massive burden on the U.S. health care system, resulting in an estimated \$126 billion in direct spending each year.⁹ This does not include the \$50 billion that Medicare spends on ESRD care, which translates to nearly \$80,000 in taxpayer dollars spent annually on each Medicare ESRD beneficiary, compared to just over \$14,000 in taxpayer dollars spent annually on the average Medicare beneficiary.^{10,11}

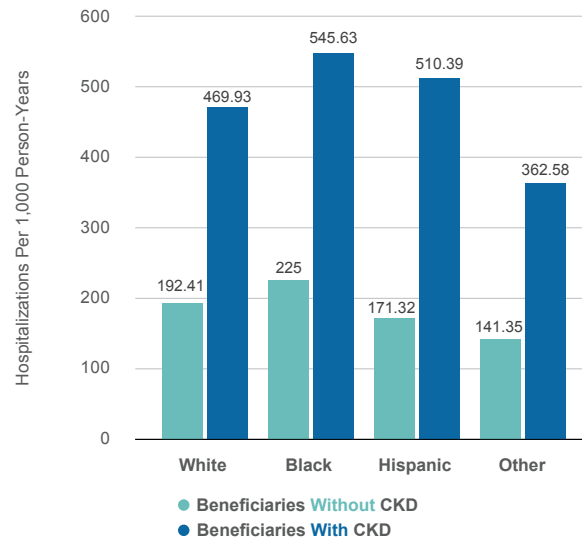
Average Annual Medicare Spending Per ESRD Patient vs. Average Medicare Beneficiary



Sources: 2020 USRDS data; USAFacts.org

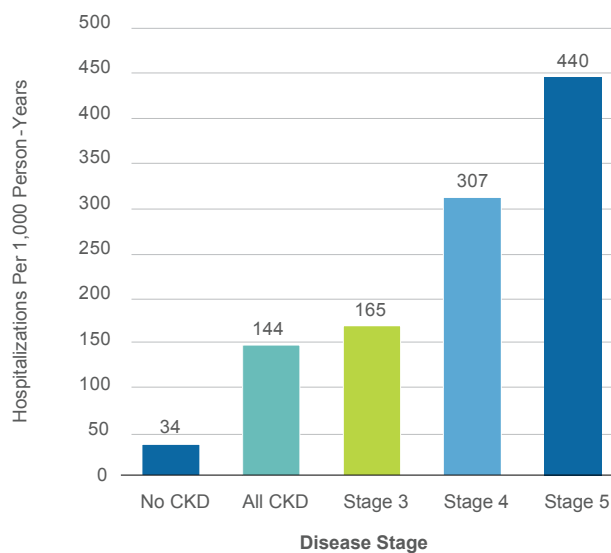
Excess hospitalizations are a key driver of spending for CKD. People with CKD face significantly higher hospitalization rates compared to those without the disease, which can affect Medicare, commercial payer and employer costs.^{9,12} Beyond the direct spending on care and treatment, kidney disease further strains the U.S. economy as it can significantly reduce the productivity of people living with the condition and their caregivers.¹³ One study estimated the employment rate for adults aged 18-54 with ESRD to be about 24% by the time they start dialysis, in contrast to an employment rate of 80% for similarly aged adults in the general population.¹⁴

Hospitalizations for Medicare Fee-for-Service Population, by Race/Ethnicity and CKD Status, 2020



Source: Health Capital Group LLC analysis of data available at: <https://usrhs-adr.niddk.nih.gov/2022/chronic-kidney-disease/3-morbidity-and-mortality-in-patients-with-ckd/>

Hospitalizations Among Younger, Commercially Insured Patients, 2020



Source: Health Capital Group LLC analysis of data available at: <https://usrhs-adr.niddk.nih.gov/2022/chronic-kidney-disease/3-morbidity-and-mortality-in-patients-with-ckd/>

CKD also has an outsized impact on traditionally underserved populations including members of racial and ethnic minority groups and rural Americans. Compared to white Americans, Black, Native and Asian Americans are, respectively, 4.2, 1.9 and 1.5 times more likely to develop kidney failure, and Americans of Hispanic ethnicity are 2.3 times more likely.⁵ While Black Americans represent 13% of the U.S. population, they account for 29% of adults with ESRD.¹⁵ And while every racial and ethnic group experienced increased ESRD prevalence between 2000 and 2019, the growth has been particularly sharp for Hispanic, Asian American and Native Hawaiian/Pacific Islander populations.¹⁶ Black Americans and Americans of Hispanic ethnicity also experienced higher rates of hospitalization compared to white Americans. Evidence also points to a significant mortality gap between urban and rural Americans, as rural Americans with ESRD suffer worse mortality rates than their urban counterparts.¹⁷

These rural and urban disparities will only continue to grow, with rural America experiencing explosive growth in many comorbidities, including diabetes and high blood pressure, that lead to CKD.¹⁸ Rural Americans can also face unique challenges obtaining timely diagnosis, which is often due to a lack of access to specialists or lack of adequate insurance coverage. The growing diversity in rural communities will further compound the disparities already facing members of racial and ethnic minority groups. Finally, for rural Americans diagnosed with ESRD, lack of access to dialysis centers poses even greater challenges, with research showing that individuals who live 100 miles away from a dialysis center are more likely to die than those who live 10 miles away, making it all the more urgent to address the underlying root causes of CKD to prevent kidney failure in these underserved populations.¹⁹

Social Determinants of Health and Kidney Disease

Social determinants of health (SDOH)—the environmental, physical and social factors that influence the onset or progression of disease—have a tremendous effect on underserved populations. SDOH add to the burden of kidney disease faced by these populations, who are already more likely to face challenging socioeconomic conditions throughout their life.²⁰ Factors that influence the risk and burden of kidney disease include:

- **Food insecurity**, such as living in “food deserts”^{21,22}
- **Chronic stress**, stemming from systemic oppression/discrimination or economic insecurity²⁰
- **Particulate air pollution**, exposed through a person’s occupation or living environment²³
- **Transportation insecurity**, including geographic barriers that can limit health care access²⁴
- **Insurance status**, such as being uninsured or underinsured²⁵



Uprooting Families: Michelle’s Story

By the time Michelle was aware that her health was in danger from kidney disease, she was headed to the hospital with signs of a stroke. At the hospital, she learned that weeks before, she had suffered a mild heart attack that went undetected. Michelle had to begin dialysis, and as a mother of five, she had to relocate her family from Pennsylvania to New Jersey to be closer to those who could help her while she was undergoing dialysis treatment three times a week.

Gaps in the Existing Kidney Care Delivery System

The expansion of Medicare coverage to individuals with ESRD in 1972—the first time Congress extended coverage based on a specific medical condition—was not accompanied by incentives for upstream kidney care across the U.S. health care system.

This has resulted in significant gaps in our current approach to kidney care delivery, leading to challenges with diagnosis, access to optimal care and access to treatment—which contribute to poor outcomes for individuals with CKD.

1. KEY CHALLENGES IMPACTING DIAGNOSIS

LIMITED PUBLIC AWARENESS OF RISK FACTORS

Over one-third of people newly beginning dialysis never received nephrology care prior to their diagnosis of kidney failure.²⁶ In fact, nearly 40% of people who begin dialysis do so on an emergency basis—meaning that they did not know they had kidney disease until their kidneys failed.²⁶ In addition to CKD itself, many people are unaware of its risk factors, such as high blood pressure, diabetes and a family history of the disease, which can lead to delays in diagnosis. This lack of awareness is particularly troublesome among marginalized and vulnerable communities, where individuals may not have access to adequate health care resources and are at a higher risk for developing conditions and comorbidities that may exacerbate CKD.

LACK OF SCREENING

The absence of a recommendation for kidney disease screening is a crucial challenge that affects early detection. The United States Preventive Services Task Force (USPSTF), which is charged with making preventive care recommendations for primary care clinicians, last made a recommendation on CKD screening in 2012,²⁷ but is currently reassessing the matter and set to update its recommendations in the near future. Without a current recommendation however, primary care providers may not include this screening as part of routine care, leading to delayed diagnosis.

GAPS IN CKD KNOWLEDGE AND UNDERSTANDING AMONG PRIMARY CARE PROVIDERS

CKD has been underrecognized and is often poorly diagnosed in primary care settings due in part to many providers lacking adequate knowledge and awareness of the condition and treatment guidelines.²⁸ One study found that nearly half of primary care providers do not follow CKD guidelines, meaning they are likely unaware of the importance of early detection and the impact that early intervention can have on health outcomes.²⁹ Additionally, a recent American Kidney Fund study found that 39% of health care providers surveyed are not aware of any medicines in development for kidney disease.³⁰ The majority of primary care providers surveyed also reported having limited awareness of rare kidney diseases.³⁰

LIMITED ACCESS TO GENETIC TESTING

While diabetes and hypertension are the underlying causes of CKD in the majority of patients, for some patients the underlying cause of their condition is unknown, which can contribute to poor disease management.²⁸ Genetic testing for these individuals can help identify the root cause of their condition and enable better treatment and delayed disease progression.²⁸ However, the lack of national guidelines for CKD genetic testing and limited coverage among payers has led to inadequate genetic testing among CKD patients.²⁸



Missed Signs: Crystal's Story

Crystal's kidney disease diagnosis came after she repeatedly expressed concerns—including hourly trips to the restroom and constant fatigue—to her primary care physician. Because her complaints went unchecked, by the time she was officially diagnosed with kidney disease, her kidneys were functioning at only 7% and she was in both heart and renal failure. She was struggling to do simple tasks, such as brushing her teeth. Today, she manages her condition with dialysis treatment and a change in diet.

2. KEY CHALLENGES IMPACTING ACCESS TO OPTIMAL CARE

REIMBURSEMENT NOT ORIENTED TOWARD UPSTREAM CKD CARE

Insurance plans have increasingly sought to address rising health care costs by expanding beneficiary cost-sharing arrangements, including deductibles and copays, while simultaneously carving out benefits which people being treated for CKD and kidney failure rely upon. Dialysis is currently one of these carve-outs. Historically, our health care system has not fully incentivized commercial payers and employers to prioritize upstream care. Without adequate coverage for screening, prevention and treatment, many Americans forego kidney care until their disease is at the point of quick progression and severe complications. Alternative payment models currently underway, such as the Kidney Care Choices model at the Center for Medicare & Medicaid Innovation (CMMI) of the Centers for Medicare & Medicaid Services (CMS), could help inform broader health system improvements by demonstrating to insurers and providers that strong financial incentives and effective care management can lead to better outcomes for people with CKD.

PROVIDER SHORTAGES

While provider shortages exist in nearly every specialty, these shortages are especially acute in nephrology, which has seen a steady decrease in residency applicants over the past decade.³¹ Currently, there is only one nephrology specialist for every 2,000 people with CKD.³² These specialists focus most of their efforts on the small share of people living with late-stage complications and kidney failure, leaving much of the early-stage care to primary care providers, who may lack training to appropriately diagnose and treat CKD.³²

LIMITED QUALITY MEASURES

National data systems do not sufficiently collect or highlight data on kidney disease. For example, the Healthcare Effectiveness Data and Information Set (HEDIS) is a collection of metrics used by most U.S. health plans to measure provider performance on important dimensions of care and service. More than 190 million Americans are enrolled in health plans that use HEDIS to report on quality.³³ However, of the 71 HEDIS quality measures, only one assesses kidney health, which can reduce incentives for screening and care for kidney disease.³⁴

THE COVID-19 PANDEMIC

The COVID-19 pandemic caused many Americans to forego routine screenings, vaccinations and yearly checkups. This led to an increase in preventable conditions, including kidney disease.³⁵ The effect of the pandemic on kidney disease is also multifaceted. In severe cases of COVID-19, the kidneys can be damaged, causing kidney disease in those without prior kidney conditions, or exacerbating existing kidney disease in those who already have it.³⁶ Studies show that more than 30% of patients hospitalized with COVID-19 developed kidney damage.³⁶

3. KEY CHALLENGES IMPACTING ACCESS TO TREATMENT

LIMITED COVERAGE FOR INNOVATIVE TREATMENTS

While providing Medicare benefits to people living with kidney failure is necessary to ensure broad access to life-saving dialysis and transplantation, there has been limited focus on incentivizing non-Medicare payers, including employers, to invest in care and treatment that slows the progression of CKD to prevent ESRD. And when commercial health plans do cover newer kidney disease treatments, access to these treatments is often limited due to high cost-sharing requirements imposed by insurers.³⁷

UTILIZATION MANAGEMENT

Utilization management strategies, or techniques used by health plans to manage health care costs by influencing patient care decision-making, can prevent access to treatments that may reduce kidney failure and the likelihood of dialysis. While these barriers to treatment impact the health of the people living with kidney disease the most, they can also have a downstream impact on the broader health care system, the Medicare program and the economy by speeding up disease progression and severity.

The Economic Opportunity of Evolving the Kidney Care Delivery System

In partnership with Health Capital Group, we conducted a new analysis to help policymakers and critical health care stakeholders understand the significant economic opportunity of evolving our current care delivery system to address the myriad gaps that hinder access to proper diagnosis, care and treatment for kidney disease.

Previous efforts to estimate potential improvements to kidney disease management have taken a careful approach when measuring the impact of specific, well-understood improvements for people living with the later stages of the condition.³⁸ While these approaches are quite useful in comparing potential opportunities to each other in terms of feasibility, implementation costs and so forth, we took a different approach. We used data from the United States Renal Data System (USRDS) Annual Report to examine the totality of extra costs associated when people are diagnosed with CKD, broke it up by stage, and compared to people without the disease and asked a simple question: what if we could slow down the transition of people to late-stage disease, such that 25% of those currently in stages 4 or 5 were in stage 3, and 25% of those in stage 3 were in stages 1 and 2? We did not specify which interventions or approaches would achieve such a goal, though there is plenty of opportunity, even with current technologies, to improve outcomes in CKD.

The USRDS estimated that CKD affects about 33% of seniors and 9% of commercially insured adults.³⁹ It also provided costs for such categories as CKD and non-CKD beneficiaries by age, disease stage and payer. At each stage, the extra costs associated with CKD grew, which we hereafter refer to as CKD-related costs. We developed a hypothetical scenario to show the possible savings from slowing down the progression of kidney disease. By aggregating these CKD-related costs across the different types of beneficiaries and payers, we were able to calculate a weighted average of CKD-related costs by payer (Medicare vs. commercial) and disease stage. We then recalculated the costs within each stage and for each payer under our assumption that 25% of people living with stage 4 and 5 of the disease moved to stage 3, and 25% of people living with stage 3 moved to the earlier stages. For this analysis, based on the available spending categories by stage in the USRDS reporting system, we combined average costs for stages 4 and 5 to estimate costs for people living with “late-stage” disease, kept data related to stage 3 costs as its own category, and combined data for stages 1 and 2 to estimate costs for people living with “early-stage” disease. For CKD patients whose disease stage was undetermined, we allocated them into stages 1 and 2.

We found that by reducing the share of people currently living with stage 4 or 5 disease and those living with stage 3 by 25% each, Medicare could save an estimated \$9 billion each year. Commercial payers and employers could save an additional \$2.8 billion annually.



Medicare Savings Opportunity

	Total Patients/ Costs	Stages 1-2 (and Unclassified)	Stage 3	Stages 4-5
Previous Medicare Patients by Stage	7,328,256	1,155,699	5,376,495	796,061
New Medicare Patients After Shifting 25% of Stage 4/5 into Stage 3 and 25% of Stage 3 into Stages 1/2	7,328,256	2,698,838	4,032,372	597,046
Previous CKD-Related Costs	\$95,430,422,785	\$9,377,883,822	\$67,697,066,897	\$18,355,472,066
New CKD-Related Costs	\$86,439,043,052	\$21,899,638,830	\$50,772,800,173	\$13,766,604,049
Potential Savings in CKD-Related Costs	\$8,991,379,733			

Commercial Savings Opportunity

	Total Patients/ Costs	Stages 1-2 (and Unclassified)	Stage 3	Stages 4-5
Previous Commercial Patients by Stage (<65)	1,358,150	456,116	784,175	117,859
New Commercial Patients After Shifting 25% of Stage 4/5 into Stage 3 and 25% of Stage 3 into Stages 1/2	1,358,150	681,625	588,131	88,393
Previous CKD-Related Costs	\$30,739,039,160	\$6,578,564,799	\$18,967,625,213	\$5,192,849,149
New CKD-Related Costs	\$27,951,428,206	\$9,831,072,436	\$14,225,718,910	\$3,894,636,862
Potential Savings in CKD-Related Costs	\$2,787,610,954			

Source: Health Capital Group LLC analysis of USRDS data

Our approach was conservative in several ways. First, we assumed the exact same number of total people diagnosed with CKD in both scenarios; certainly, there are opportunities to prevent CKD altogether, but we did not include those in our estimates. Second, we did not measure the likely impact of reductions in ESRD care that would naturally develop over time; ours was a point-in-time snapshot of what might be possible within the CKD-only population. Third, we did not consider potential reductions in comorbidities or other quality-of-life improvements that would likely go along with the changes we envisioned. Fourth, based on the data set, we know that we missed many people undiagnosed with kidney disease (who far outnumber those diagnosed). Finally, there are a subset of people living with CKD whose stage of disease is undetermined; by allocating these individuals to the earlier, less expensive disease stages, we likely underestimated the total potential cost savings associated with pushing them into those earlier stages, if they are in fact in the later stages already.

Our approach also had some important limitations. First, we did not specify the interventions or approaches that would make the reductions we envisioned achievable, though we noted from the global burden of disease study cited earlier that the U.S. appears to have a uniquely robust opportunity for improvement in diagnosing and treating CKD given our comparatively steep rise in death rates versus other countries. Second, we did not consider the costs of such potential interventions (e.g., the costs of investments in better detection, treatment or new technologies). Third, we did not assess whether the extra costs associated with kidney disease care are specifically due to the disease, or whether, if kidney disease progression is delayed but other underlying conditions advance anyway, the benefits of delay might be mitigated. Such considerations would require a complex economic analysis using individual-level data. Finally, we did not account for age-related factors that might impact the speed with which individuals can progress through the various stages of disease.

Despite these limitations, it is clear that the economic opportunity to better address kidney disease in the U.S. is robust.

Seizing on Progress in Kidney Disease Innovation and Policy Developments

Kidney disease has experienced an inflection point over the last several years. Innovative diagnostics and therapies and improvements in care delivery have enabled us to better address kidney disease prevention, diagnosis, progression and treatment.

However, we need a health care system that can fully align with and support our progress. Now is a critical time for key stakeholders, including government leaders, to seize the scientific and policy momentum and address the enormous burden of kidney disease.

Our kidney disease care infrastructure is changing. New treatments, including those that have recently been approved by the Food and Drug Administration and additional products in development,^{40,41} have the potential to modify disease progression and delay ESRD for the first time ever. Telenephrology, which was already being explored as a way to enhance care and improve health equity before the COVID-19 pandemic,⁴² became a critical service for at-risk individuals during the pandemic.⁴³ As demand for hybrid care models, including both in-person and telehealth care continues, kidney care delivery may be altered permanently.⁴⁴ Additionally, payers and providers are finding new ways to collaborate and provide integrated services to support personalized care for people living with kidney disease.⁴⁵

There has been recent policy momentum as well. In 2018, Kidney X was launched, which is a public-private partnership between the Department of Health and Human Services (HHS) and the American Society of Nephrology, to accelerate the pace of prevention, diagnosis, treatment and transplantation across all kidney diseases.⁴⁶ The following year in 2019, an executive order was released announcing the Advancing American Kidney Health (AAKH) Initiative, the goal of which is to reduce the health burdens and costs associated with kidney disease.⁴⁷ The AAKH initiative also introduced new value-based payments in partnership with CMMI to incentivize better care for people living with stages 4 and 5 CKD and prevent kidney failure.⁴⁷ The ESRD Treatment Choices model was also initiated to promote greater use of and enhanced care for people needing home dialysis and kidney transplants.⁴⁸

As part of a provision in the 21st Century Cures Act, Medicare beneficiaries with ESRD, regardless of age, are now allowed to enroll in Medicare Advantage plans, enabling enrollees to benefit from integrated, coordinated care and caps on out-of-pocket spending.⁴⁹ Beginning in January of 2022, and building on the AAKH model, the Kidney Care Choices alternative payment model was implemented in order to help providers improve care quality, reduce costs and delay the need for dialysis.⁵⁰ Finally, HHS and CMS are continuing to engage with the kidney community to make refinements to existing policies and ensure payment models are implemented appropriately.



Principles to Guide Policy Action

In the last 50 years since the ESRD Medicare benefit was established, enormous advances have been made in the prevention, diagnosis and treatment of kidney disease. While recent medical innovation and policy advances both share a goal of decreasing the societal, economic and personal burden of kidney disease, more needs to be done. We need to evolve our access paradigm to fully address the barriers people living with kidney disease face.

The American Kidney Fund encourages policymakers to explore provisions that can do the following:



Improve education for people living with kidney disease and their caregivers. In the wake of COVID-19, people living with kidney disease are facing an increasingly complex insurance coverage landscape in terms of plan changes, utilization management, specialty referrals, obtaining understandable coverage and information about CKD, etc. People with kidney disease are increasingly taking on the burden of managing their own care, which can cause a chilling effect in accessing necessary care, leading to preventable disease progression. Many people living with kidney disease and their caregivers do not fully understand the challenges associated with kidney disease diagnosis and treatment. It is critical that information be tailored to the recipient, keeping disease progression top of mind as the depth of information to be shared is determined.



Support earlier and complete diagnosis. People with kidney disease frequently face delays and difficulties in receiving a complete diagnosis. These issues are exacerbated when individuals face socioeconomic disparities. However, primary care providers can play an important role in identifying patients earlier on, particularly through urine testing. Greater education for these providers about kidney disease is needed, as is coverage for screening using urine tests. For patients who have already been diagnosed, genetic testing and counseling may provide important information about their disease and inform treatment approaches. Genetic testing should be routinely covered by all payers and employers, and the benefits of genetic testing should be clearly communicated, as it may be the key for people getting the most complete diagnosis possible.



Enable better access to kidney disease treatment. Policies are needed at every level of government to help eliminate barriers to kidney disease research, treatment access, reimbursement, etc. Policymakers should explore provisions that help reform utilization management; implement alternative payment models and expand them to include commercial insurers; ensure federal research agencies are funded appropriately; allow for appropriate regulatory expertise to encourage innovation by smaller manufacturers; and support provider education around new innovations to encourage uptake.

Innovation in kidney care is moving ahead, but unless our policies can keep up, people with kidney disease will be the ones left behind. This is the time for us to work together and shift our system from one that focuses on disease progression to one that prioritizes prevention, early diagnosis and disease management. It is time to put people with, and at-risk for, kidney disease at the center of our health care system.

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Endnotes

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The American Kidney Fund (AKF) fights kidney disease on all fronts as the nation's leading kidney nonprofit. AKF works on behalf of the 37 million Americans living with kidney disease, and the millions more at risk, with an unmatched scope of programs that support people wherever they are in their fight against kidney disease—from prevention through transplant. With programs that address early detection, disease management, financial assistance, clinical research, innovation and advocacy, no kidney organization impacts more lives than AKF. AKF is one of the nation's top-rated nonprofits, investing 97 cents of every donated dollar in programs, and holds the highest 4-Star rating from Charity Navigator for 20 consecutive years and the Platinum Seal of Transparency from GuideStar.