

# US Renal Data System 2023 Annual Data Report: Epidemiology of Kidney Disease in the United States



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The United States Renal Data System 2023 Annual Data Report (ADR) contains updated information about the chronic kidney disease (CKD) and end-stage renal disease (ESRD) populations in the United States through the end of 2021. As such, it offers information about ESRD incidence, prevalence, and outcomes during the second year of the COVID-19 pandemic, in which the more transmissible delta variant became dominant, and during the first year of implementation of the ESRD Treatment Choices (ETC) payment model.

## New Data in This Year's ADR

This year's ADR contains data from medical claims through 2021 and for some ESRD-related metrics through 2022. In addition to updating data from Medicare, we now present new data for beneficiaries with ESRD covered by Medicare Advantage (MA) about hospitalization and mortality (CKD Volume, Chapter 3 and ESRD Volume, Chapter 5). Given the growing percentage of incident dialysis patients with MA and the first-ever opportunity for prevalent ESRD patients to switch to MA in 2021 (ESRD Volume, Chapter 9), we have been requesting and receiving MA data for the ESRD population for the last several years. However, our method of ascertaining which patients have comorbidities relevant in adjusted models requires a 1-year "look-back" period. Furthermore, MA data lag Medicare Fee-for-Service (FFS) claims data by an additional year because of additional required processing time. Thus, it is only this year that data are available to begin to show (very) short-term trends (2019-2020) in the MA population. We continue our use of Medicaid claims data to examine outcomes in patients with CKD.

New in this year's ADR, we introduce a cohort of patients with CKD obtained from electronic health records of the M Health Fairview system. M Health Fairview is an academic health system in Minnesota that comprises 10 hospitals, 48 primary care clinics, and numerous specialty clinics. The electronic health record database contains data on more than 4.5 million patients since 2011. We use data from this cohort in the Transitions of Care in Chronic Kidney Disease chapter to examine the treatment of anemia, vascular access placement, and dialysis initiation.

Although we have presented data from the USRDS Study of Treatment Preferences, conducted by a USRDS Special Studies Center, in previous ADRs, this year we move

beyond presentation of survey data to direct presentation of patient narratives. We believe that hearing directly from patients about their experiences of the care we provide can help the nephrology community identify areas of success as well as areas that need improvement in our quest to provide high-quality, patient-centered care for individuals with kidney disease. This year, we highlight the experiences of patients receiving in-center hemodialysis (HD), but we envision that this approach can be applied to patients performing dialysis at home, navigating the kidney transplant process, or living with a functioning kidney transplant in future ADRs.

## Key Findings in the 2023 ADR

### COVID-19

The epidemiologic implications of the COVID-19 pandemic continue to be a major theme of the ADR. ADRs published prior to 2022 reported gradual but consistent improvements in hospitalization and mortality over the preceding decade for people with CKD and ESRD. However, 2020 proved to be a watershed year that witnessed a reversal of many long-term improvements for patients with CKD and ESRD, as reported in the 2022 ADR. The 2023 ADR reports on 2021 events that occurred as the pandemic continued to unfold. The most alarming development was continued high mortality rates. Although adjusted mortality decreased among FFS beneficiaries with CKD in 2021 (CKD Volume, Fig 3.1a), it did not return to pre-pandemic levels. Worse, mortality did not improve among Medicaid enrollees with CKD (CKD Volume, Fig 3.1b), who are much younger than Medicare beneficiaries. Graver still, the mortality rate was higher in 2021 than in 2020 among patients with ESRD (ESRD Volume, Fig 6.1). The HD population was hit particularly hard, to the extent that the prevalent HD population decreased in 2021 for the second year in a row (ESRD Volume, Fig 1.6). Overall and COVID-19 related mortality also increased substantially in 2021 for kidney transplant recipients.

This year's ADR also examined treatment of COVID-19 and outcomes following COVID-19 infection. Despite being more likely to be diagnosed with COVID-19 and substantially more likely to be hospitalized and to die after a COVID-19 diagnosis, patients with CKD and ESRD were less likely to receive remdesivir than those without CKD

(CKD Volume, Fig 7.17; ESRD Volume, Fig 10.16). Patients with kidney disease were also less likely to receive monoclonal antibody therapy than individuals without (CKD Volume, Fig 7.18; ESRD Volume, Fig 10.17).

In the first 4 months of availability of a new ICD-10-CM code for long COVID (October to December 2021), the incidence of long COVID diagnosis was twice as high among Medicare beneficiaries with CKD as among those without; the incidence was two-and-a-half times as high among beneficiaries treated with dialysis and more than 3 times as high among kidney transplant recipients. It is possible that the short period during which patients could be diagnosed with long COVID in 2021 could have led to higher rates among patients receiving more frequent medical care—warranting close monitoring going forward. Nevertheless, it is extremely concerning that patients with kidney disease were simultaneously more vulnerable to COVID-19 diagnosis, hospitalization, and mortality and also less likely to receive effective treatments. Undertreatment of COVID-19 may have contributed to initially high rates of long COVID diagnoses as well. Although there may have been some concern in 2021 about the safety of remdesivir among patients with CKD, the US Food and Drug Administration (FDA) recently approved the use of remdesivir for patients with severe kidney impairment, including those receiving dialysis.<sup>1</sup> The USRDS and the nephrology community must continue to monitor treatment for COVID-19 among patients with kidney disease and to advocate for appropriate and adequate access for our patients if we are to combat the high rates of mortality and possibly high rates of long COVID among survivors.

## CKD Population

Aside from the ongoing impact of the COVID-19 pandemic, there were several new findings in the CKD population that deserve emphasis.

### Anemia Management

We built on the observation in the 2022 ADR that fewer than 10% of Medicare FFS beneficiaries with stage 4 or 5 CKD (based on claims data) received erythropoiesis-stimulating agents (ESAs) and only 5% received intravenous (IV) iron to delve further into anemia treatment. Examining ESA use by stage of CKD revealed that although ESA use remained <10% in 2021 among beneficiaries with stage 4 CKD, it was slightly higher (14.4%) among those with stage 5 CKD. IV iron use was also higher among those with stage 5 than among those with stage 4 CKD. Remarkably, blood transfusions were more common than ESA therapy among patients with stage 4 CKD in 2021; for individuals with stage 5 CKD, the rate of blood transfusion was similar to that of ESA use. These findings suggest that anemia management appears to be suboptimal, but without laboratory results for the Medicare population, it is not possible to derive a full picture of whether indicated treatments are being delivered and whether transfusions could be avoided.

Inclusion of data from the M Health Fairview system this year allowed us to examine receipt of treatment for anemia and iron deficiency based on relevant laboratory data. Some key takeaways were:

- About 1 in 5 patients with stage 4 CKD and almost 2 in 5 with stage 5 CKD had Hb <10 g/dL (CKD Volume, Fig 8.3a). Just over half of patients with stage 4 CKD and 43% of those with stage 5 CKD had iron deficiency, as indicated by transferrin saturation  $\leq 20\%$  or ferritin  $\leq 100$  ng/mL.
- A minority of patients received relevant treatment. Specifically, fewer than 20% of patients with stages 4–5 CKD who had Hb <9 g/dL and fewer than 15% of those with Hb 9 to <10 g/dL received ESAs (CKD Volume, Fig 8.3b). Just over 10% of those with iron deficiency received IV iron, and fewer than half received any iron at all.
- These results are important because more than 15% of individuals with Hb <9 g/dL received a blood transfusion, whereas only 1.2% of those with Hb  $\geq 10$  g/dL did (CKD Volume, Fig 8.4b).

These results indicate that patients with anemia are being undertreated and that undertreatment with medications may be contributing to use of red blood cell transfusion. This is concerning, particularly for younger patients, because receipt of even a single red blood cell transfusion can lead to sensitization to HLA antigens.<sup>2</sup> Sensitization, in turn, can reduce access to kidney transplantation, particularly to living donor transplantation, as patients are more likely to react to a limited pool of available donors. Sensitized patients then receive dialysis for longer while awaiting a deceased donor transplant, during which time they are exposed to a higher risk of mortality than after transplant. Sensitization can also lead to exposure to higher levels of immunosuppression because many transplant center protocols call for more aggressive induction therapy among recipients with high panel reactive antibody levels, thereby increasing the risk of infections and malignancies.

### Racial Differences in Outpatient Dialysis for AKI

The number of Medicare FFS beneficiaries who initiated outpatient HD with AKI has grown since 2017 to almost 12,000 individuals each year over the last three years, constituting almost 10% of the total new in-center HD starts in 2021. For the first time this year, we examined the demographic characteristics and some comorbidities (CKD and heart failure) of these beneficiaries (CKD Volume, Fig 4.9). Not surprisingly, almost all had a prior diagnosis of CKD. However, the distribution of race and ethnicity was very different among these beneficiaries compared with those initiating in-center HD for ESRD. In 2021, about 74% of beneficiaries initiating dialysis with acute kidney injury (AKI) was White, a substantially higher proportion than among those initiating HD for ESRD (~58%). Correspondingly, a smaller percentage of beneficiaries

initiating HD for AKI were Black (~16%) compared with the incident ESRD population treated with dialysis (~24%). This is surprising given the higher rates of hospitalization with AKI and AKI requiring dialysis among Black beneficiaries. In contrast to their underrepresentation among beneficiaries initiating outpatient dialysis for AKI, Black beneficiaries were more likely to receive dialysis for ESRD within 1 week of discharge from a hospitalization with AKI than their White counterparts (CKD Volume, Fig 4.3c). The reasons for this apparent difference in the perceived likelihood of recovery of kidney function (versus designation as having ESRD) for Black and White beneficiaries with dialysis-requiring AKI—and any associated differences in outcomes—deserve exploration.

## ESRD Population

Several new developments in the ESRD population also deserve emphasis. Some of these developments may be directly or indirectly related to the COVID-19 pandemic, whereas others are related to changes in practices, policies, or payment models.

### Increase in Posthospitalization Mortality

Mortality following discharge from a hospitalization increased in 2020 relative to 2019 and then worsened further in 2021 among Medicare beneficiaries with ESRD (ESRD Volume, Figs 5.9 and 5.11a). Furthermore, the percentage of patients with ESRD who died without rehospitalization increased from 7.5% in 2019 to 9.4% in 2021—a prodigious relative increase of more than 25% (ESRD Volume, Fig 5.9). That over 1 in 11 live discharges among patients with ESRD in 2021 resulted in death (without rehospitalization) in the subsequent 30 days raises several non-mutually exclusive possible explanations: that hospitalization avoidance (in this case following an initial hospitalization) occurred, that patients were discharged prematurely from their index hospitalization, that COVID-19 hospitalization conferred a higher risk of mortality that extended beyond the period of hospitalization,<sup>3</sup> or that patients had difficulty receiving postdischarge outpatient care.

### Vascular Access Among Incident Hemodialysis Patients

In 2021, more than 85% of individuals who initiated HD did so with a catheter. Further, almost three-quarters of individuals had no permanent access in place when initiating HD, a striking increase from about 65% in 2018. This dramatic shift in clinical practice over a very short time warrants further scrutiny because it is unclear whether it was driven by pandemic-related limitations in the capacity to perform vascular access procedures, a response to new clinical practice guidelines suggesting that some patients may be better served with an arteriovenous graft or catheter than an arteriovenous fistula,<sup>4</sup> or both. Continued monitoring of trends in vascular access use and of outcomes among patients with different types of

vascular access will be needed to clarify the reasons for the shift away from arteriovenous fistulas and toward catheters and the effects of this shift on the HD population.

## Examination of Medicaid Expansion and ESRD Incidence

Medicaid expansion under the Patient Protection and Affordable Care Act provided a natural experiment of sorts. Numerous states expanded Medicaid access to all individuals with incomes up to 138% of the federal poverty level beginning in 2014, but many others delayed implementation or never implemented this expansion. Thus, in some states, all low-income individuals have had access to Medicaid since 2014, while in others, many low-income individuals remain uninsured. Given that outcome data are now available for several years, we examined whether there were differences in ESRD incidence between states that expanded Medicaid access in 2014 and those that did not. We reasoned that access to care in expansion states might lead to lower rates of ESRD onset (or, more likely, less of an increase) than in non-expansion states, particularly for individuals under 65 years of age who are (mostly) not covered by Medicare before developing kidney failure.

We found that ESRD incidence was higher among younger individuals (aged <65 years) in non-expansion states even before 2014, which could be related to the location of several of these states in the Deep South, which has a larger Black population and higher poverty rates than other parts of the country. In addition, there may have been more stringent Medicaid eligibility requirements in these states even before other states expanded eligibility. After Medicaid expansion, ESRD incidence increased in non-expansion and expansion states but increased more in non-expansion states, widening the gap in incidence by about 10 cases per million population. Interestingly, however, this divergence in ESRD incidence after 2014 was driven almost entirely by changes among White individuals. Whereas ESRD incidence among White individuals had been increasing in both non-expansion and expansion states from 2011 to 2014, it flattened in expansion states and continued to rise through 2018 in non-expansion states. Both expansion and non-expansion states saw steep decreases in ESRD incidence in 2020, and it remains to be determined whether these were the result of a delay in onset of ESRD during the COVID-19 pandemic or higher death rates among individuals with advanced kidney disease.

## Effects of Payment Models

Data presented in the first 2 chapters of the ESRD Volume of the ADR demonstrate that expansion of home dialysis occurred during the entire period from 2011 to 2021—even during the initial 2 years of the COVID-19 pandemic. However, it is still important to examine

whether current payment models, such as the ETC model and the Kidney Care Choices model, are succeeding in increasing the use of home dialysis and increasing access to kidney transplantation. This year's ADR presents evidence that home dialysis use among incident dialysis patients increased in early 2021 in areas participating in ETC (ESRD Volume, Fig 2.2). Whereas rates had been lower in ETC markets prior to 2021, they were similar in ETC and non-ETC markets in 2021, indicating a small increase in ETC relative to non-ETC markets. A more detailed investigation of trends in home dialysis utilization among incident patients (including both Medicare FFS beneficiaries and non-FFS beneficiaries) over the first 18 months of the implementation of ETC found that the overall growth in home dialysis among patients new to dialysis (that is, incident patients with ESRD) nearly doubled compared to the period prior to ETC implementation.<sup>5</sup> Furthermore, the increase was not confined to ETC markets or even to Medicare FFS beneficiaries. However, a recent evaluation commissioned by the Centers for Medicare & Medicaid Services (CMS) reported no significant increase in the uptake of home dialysis among prevalent Medicare FFS beneficiaries.<sup>6</sup> Taken together, published evidence suggests that ETC may eventually prove more effective at increasing uptake in home-based dialysis modalities in incident, rather than prevalent, ESRD patients. Unfortunately, however, growth in the use of home dialysis among incident patients has not resulted in an appreciable increase in the prevalent home dialysis population and is insufficient to meet ambitious targets established by the Executive Order.

The effect of ETC on home dialysis growth (and growth in kidney transplantation) will be a focus of ongoing USRDS surveillance. Future reports should also evaluate differences in the use of home dialysis in prevalent dialysis populations and differences in rates of kidney transplantation among participants in various payment models. However, it is important to recognize that it may prove difficult to separate the effects of new payment models from the effects of the COVID-19 pandemic, given that they coincided. COVID-19 mortality was higher among patients receiving in-center HD than among patients performing dialysis at home in 2020 and 2021,<sup>7</sup> resulting in a shrinkage in the prevalent in-center HD population in both years (ESRD Volume, Fig 1.6). A larger reduction in the in-center HD population than in the home dialysis population would be expected to increase the percentage of prevalent dialysis patients treated with home dialysis even if payment models have had no effect. Thus, it will be important to focus on differences in rates of home dialysis use between model participants and non-participants rather than solely on overall changes in dialysis modality during this tumultuous period.

### **Implementation of the 21st Century Cures Act**

Prior to 2021, Medicare FFS beneficiaries with CKD were precluded from switching to MA plans, but those with pre-existing MA coverage were allowed to continue it. As

a result, the number of patients with ESRD with MA coverage was growing only slowly. However, with the implementation of the 21st Century Cures Act, all Medicare beneficiaries with ESRD became eligible to enroll in MA plans beginning in the 2021 open enrollment period. As a result, MA enrollment in the prevalent ESRD population grew by a remarkable one-third in 2021 in relative terms (and from 18.3% in 2020 to 24.5% in absolute terms; ESRD Volume, Fig 9.4b). As a result, MA spending for ESRD increased by a prodigious 46.4% in a single year (ESRD Volume, Fig 9.1), and Medicare FFS spending decreased correspondingly. Future ADRs should track the influence of this shift on Medicare spending for patients with ESRD and should also compare outcomes among those insured under FFS and MA programs.

### **Racial and Ethnic Disparities in Access to Home Dialysis and Living Donor Kidney Transplantation**

Large racial, ethnic, and socioeconomic disparities in access to home dialysis were evident (Fig 14.12). Black and Hispanic patients were much less likely to start dialysis at home than White patients; this was true across all levels of neighborhood deprivation. However, outcomes did not mirror these differences in access. Conversion to in-center HD within 1 year varied little by race and ethnicity or neighborhood deprivation, and mortality was higher among White patients. Thus, although prior studies suggested that Black patients were more likely to convert to in-center HD than White patients,<sup>8</sup> in the modern era, Black and Hispanic patients were more likely to remain on home dialysis after 1 year than White patients regardless of neighborhood deprivation.

Considering access to preemptive kidney transplantation, Black race, Hispanic ethnicity, and higher neighborhood deprivation were all associated with lower rates of preemptive waitlisting for a kidney transplant and of receiving a kidney transplant from a living donor in 2021. These disparities are important because outcomes are superior for preemptive and living donor kidney transplantation compared with deceased donor kidney transplantation after ESRD onset. In addition, these disparities lead to longer waiting times for a kidney transplant among disadvantaged groups. There has been some reduction in disparities in access to deceased donor kidney transplantation among patients with ESRD in recent years. Differences in the rate of deceased donor transplantation by race and ethnicity were small in 2021 after considering neighborhood deprivation. However, patients living in more deprived neighborhoods had lower rates of receipt of deceased donor kidney transplants. Thus, important disparities in access to kidney transplantation remain for patients with ESRD, compounding the large disparities in the incidence of ESRD.



### Racial and Ethnic Disparities Among Children With ESRD

Racial disparities in children deserve particular attention. Noticeable disparities are present despite a very different distribution of causes of ESRD and a shorter time horizon to develop ESRD (prior to age 18) than among adults. Incident ESRD was 42% higher among Black children, at 14.8 cases per million population, than among White children, for whom the rate of incident ESRD was 10.4 per million population (ESRD Volume, Fig 8.2). Although some of this difference may be due to more glomerulonephritis (ESRD Volume, Table 8.1) among Black children and a worse prognosis among patients with glomerulonephritis than among those with other causes of CKD, disparities in access to care may also contribute. The disparity in ESRD incidence is compounded by a large disparity in access to preemptive kidney transplantation. Rates of preemptive kidney transplantation among Black children (12.0%) were less than half those of White children (27.9%). Examining and addressing these disparities is critical, as the combination of more ESRD and less access to transplantation as the initial kidney replacement therapy adds an enormous burden of morbidity and mortality to Black children with kidney disease.

### Patient Experience Chapter

In this year's Patient Experience chapter, we present interviews with patients about their experiences undergoing in-center hemodialysis. The patients had started dialysis under varied circumstances and with differing levels of preparation and involvement in decision-making. Most experienced dialysis as a major disruption to the lives they had been living and the futures they had hoped for. They saw dialysis as something they had to do if they wanted to continue living, and this understanding of dialysis as a lifeline in the face of existential threat was instrumental in helping them tolerate a time-consuming and sometimes uncomfortable and painful treatment that had seriously disrupted their lives. Our interviews also shed light on patients' interactions with nephrologists and dialysis facility staff members as well as with other patients receiving dialysis care.

Clinicians and staff working in dialysis facilities should recognize that many of the patients under their care have experienced substantial trauma and loss, see dialysis as a lifeline in the face of existential threat, have a limited sense of community with other patients dialyzing alongside them, and often feel vulnerable and powerless in their relationships with staff and clinicians. Collectively, these interviews highlight the critical importance of care that is "careful and kind"<sup>9</sup> and person-centered<sup>10</sup> for people with kidney failure, which includes taking time to get to know patients as people, building relationships and establishing trust, and caring for patients in ways that uphold their personhood, support their goals, and improve their

experiences of illness and care. The insights shared by the patients we interviewed offer a powerful illustration of why patients and families must have a voice in shaping efforts to improve dialysis care.

### Conclusion

The 2023 ADR presents critical information about the state of the CKD and ESRD populations after the first 2 years of the COVID-19 pandemic and the initial years of implementation of new payment models for advanced CKD and ESRD. In the coming years, we can expect to continue to track these developments as well as to further examine the impact of new treatments for CKD and ESRD.

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