2021 Annual Data Report

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End Stage Renal Disease: Chapter 1

Incidence, Prevalence, Patient Characteristics, and Treatment Modalities

Highlights

- In 2019, 134,608 individuals were newly diagnosed with end-stage renal disease (ESRD), representing an increase of 2.7% from the previous year and 15.8% from a decade ago (Figure 1.1). However, the adjusted incidence fell from a peak of 431 per million population (pmp) in 2006 to 386 pmp in 2019.
- In 2019, 85% of those with incident ESRD initiated in-center hemodialysis (HD) (Figure 1.2). This represents a decrease from 91% in 2009. Over the past decade, the percentage initiating kidney replacement therapy with peritoneal dialysis (PD) nearly doubled, from 6% to 11%. The percentage who received a preemptive kidney transplant remained unchanged over the decade at about 3%.
- Adjusted ESRD incidence increased as age increased: among individuals aged 0-17 years, the adjusted incidence in 2019 was 12 pmp; among individuals aged 65-74 years, 1,307 pmp; and among individuals aged ≥75 years 1,587 pmp (Figure 1.4).
- Between 2009 and 2019, adjusted ESRD incidence in Black individuals decreased by 17.5%, in Native American individuals by 14.1%, in Hispanic individuals by 12.1%, in Asian individuals by 5.2%, and in White individuals by 2.4% (Figure 1.4). However, in all individuals except for Whites, adjusted incidence increased between 2018 and 2019.
- The prevalent count of individuals with ESRD reached 809,103 in 2019, an increase of 41.0% from 2009 (Figure 1.5). Adjusted ESRD prevalence also increased to an all-time high of 2302 cases pmp in 2019.
- At the end of 2019, 492,096 individuals were receiving in-center HD, up 1.7% from 2018 and 34.5% from 2009 (Figure 1.6). There were 12,243 patients performing home HD at year's end, an increase of 20.1% over the preceding year. The number of individuals receiving PD increased to 62,275, representing 8.5% growth in a single year.
- Adjusted ESRD prevalence in Black individuals was far higher, at 6423 pmp, than in other racial and ethnic groups; adjusted prevalence in Black individuals was 78.6% higher than in the next-highest group, Native Americans, and more than fourfold higher than in White individuals (Figure 1.8).
- The percentage of patients with prevalent ESRD who had a functioning kidney transplant was highest among White (36%) and lowest among Native Hawaiian and Pacific Islander (18%) individuals. Conversely, White individuals had the lowest percentage receiving in-center HD (54%), and Native Hawaiian and Pacific Islander individuals had the highest (73%) (Figure 1.10).
- White (73%), Asian (72%), and Native American (72%) individuals were much more likely to have received pre-ESRD care compared with Black (64%), Native Hawaiian/Pacific Islander (62%), and Hispanic (61%) individuals (Figure 1.11).
- In 2019, 39% of patients had an estimated glomerular filtration rate (eGFR) ≥10 mL/min/1.73 m² at ESRD onset (Figure 1.14). The mean eGFR at initiation of kidney replacement therapy was 9.6 mL/min/1.73m^2 (Table 1.3). Overall, 60.6% of incident patients with ESRD had diabetes mellitus (DM), 28.4% heart failure (HF), and 20.8% other cardiac disease (Figure 1.18). Fully 77.5% of Native American individuals had DM, compared with 57.8% of White individuals.
- Cardiovascular disease (CVD) was present in 77.3% of patients receiving HD, 66.4% of patients receiving PD, and 54.8% of patients with a kidney transplant.

Introduction

In the first chapter of the ESRD Volume of the Annual Data Report, we describe the incidence and prevalence of ESRD in the U.S. as of the end of 2019 (the most recent year for which complete data are available). We begin by describing the incidence of registered ESRD, including counts of patients with newly diagnosed (incident) ESRD, unadjusted and adjusted rates of ESRD incidence, and variation in ESRD incidence among subgroups defined by demographic characteristics and geography. We then present similar information for prevalent ESRD.

The next section focuses on modalities of kidney replacement therapy. We examine modality among incident and prevalent patients with ESRD over time, by geographic region, and by demographic characteristics. The Executive Order on Advancing American Kidney Health, which was released in July 2019 (U.S. Department of Health and Human Services, 2019), sets forth a target for utilization of home dialysis and preemptive transplantation that is much higher than current practice in the U.S.

We next report on the prevalence of nephrology care before the onset of ESRD and its correlates among patients with incident ESRD. These correlates include eGFR at the time of initiation of kidney replacement therapy (with a focus on how eGFR at initiation differs by strata of age, sex, and race/ethnicity) as well as other biochemical parameters reported on the ESRD Medical Evidence Report, which is completed at the time that kidney replacement therapy is initiated. Finally, we show data on comorbid conditions among patients with ESRD.

Methods

Throughout this chapter, we rely heavily on the enumeration of incident and prevalent ESRD patients and their kidney replacement therapy history in the USRDS database. Estimates of incidence are primarily informed by validated submissions of the ESRD Medical Evidence Report (form CMS 2728), which by rule must be submitted whenever a patient is newly treated for ESRD. This form establishes the date of ESRD onset, which might more properly be termed the date of initiation of kidney replacement therapy because the USRDS tracks treated ESRD and not ESRD overall (the latter encompassing use of conservative care).

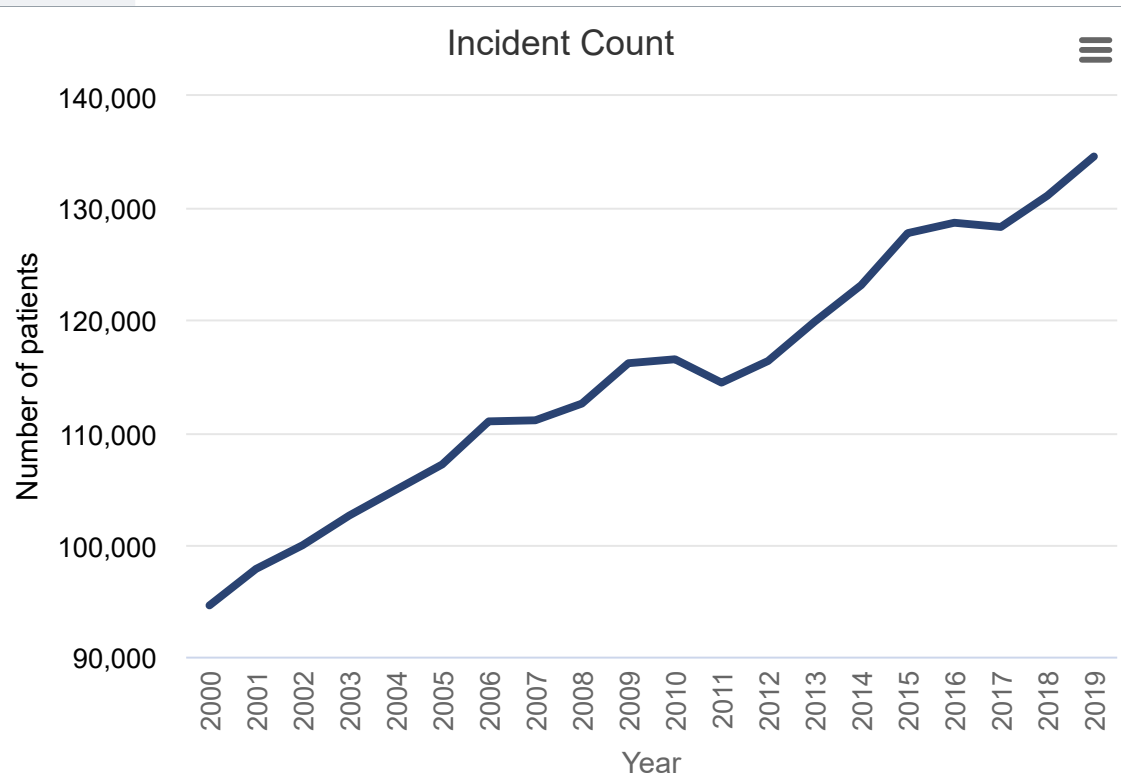
The unadjusted incidence of ESRD is derived by dividing the annual number of patients with incident ESRD by the size of the U.S. population, as reported by the U.S. Census Bureau (Centers for Disease Control and Prevention, 2019). The adjusted incidence of ESRD is standardized to the age, sex, race, and Hispanic ethnicity distribution of the 2015 U.S. population. Considering the gradual aging of the population, adjustment for age is relatively influential.

The prevalence of ESRD is derived in the same manner; adjustment factors are the same as for incidence. The mixture of dialysis modalities and presence of a functioning kidney transplant in the prevalent ESRD population reflects the treatment history constructed by the USRDS. Of note, home HD in the ESRD database reflects an uncertain mixture of patients dialyzing in private residences and in skilled nursing facilities.

Receipt of from a nephrologist or dietician prior to ESRD as well as eGFR and hemoglobin level at initiation of kidney replacement therapy are ascertained from the ESRD Medical Evidence Report. Using the Chronic Kidney Disease Epidemiology Collaboration (CKD-EPI) equation (Levey et al., 2009), GFR is estimated from the serum creatinine measurement that must be recorded on the Medical Evidence Report.

Figure 1.1 Incidence of ESRD

Incident Count | Incidence Rate | % Change

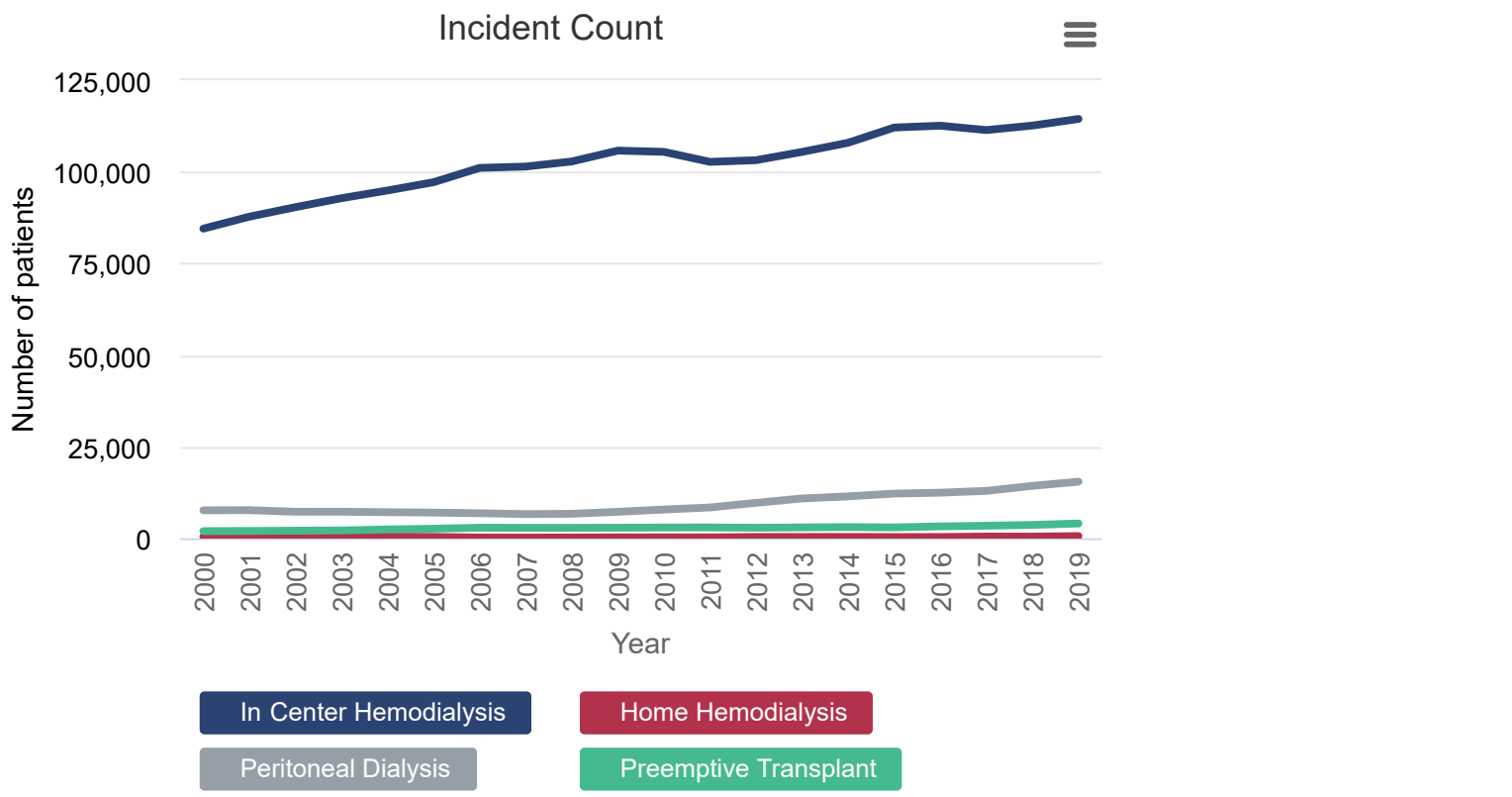


Data Source: USRDS ESRD Database. All U.S. ESRD incident patients were included for Incident Count; unknown sex and other or unknown race/ethnicity were excluded for Incidence Rate (adjusted and unadjusted). Adjusted rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

In 2019, 134,608 individuals were newly registered as having treated ESRD, which represented an increase of 2.7% from the previous year and 15.8% from a decade ago (Figure 1.1). However, the adjusted incidence fell from a peak of 431 cases pmp in 2006 to 386 cases pmp in 2017, or by 10.4%; the rate remained virtually unchanged between 2017 and 2019. From 2012 onwards, year-over-year adjusted percent change has oscillated between approximately -2% and +2%. Much of the apparent discordance between trends in unadjusted and adjusted ESRD incidence can be explained by the aging of the U.S. population.

Figure 1.2 Incident ESRD by modality

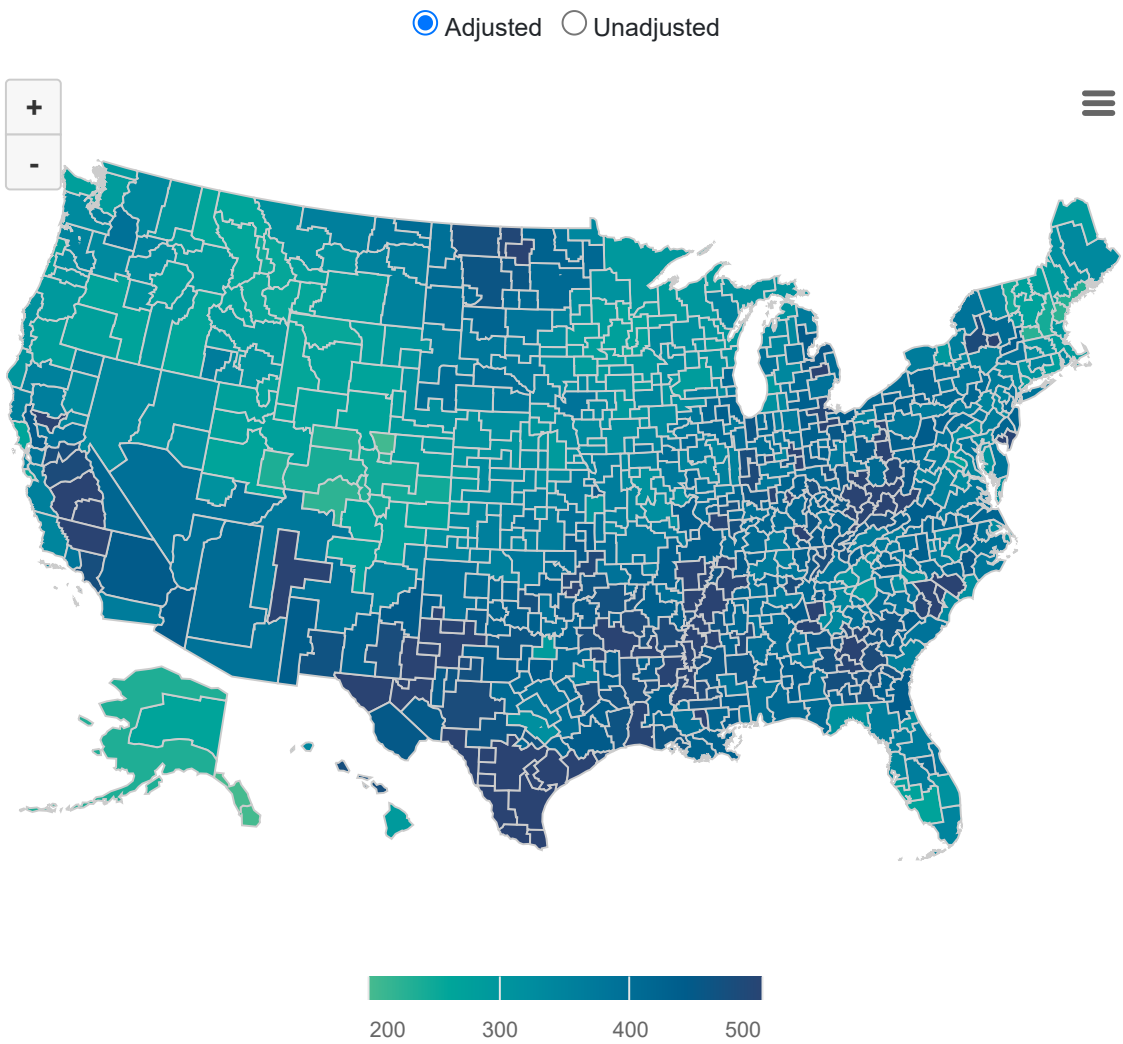
Incident Count | Percentage



Data Source: USRDS ESRD Database. U.S. and U.S. territories ESRD patients. Persons with “Uncertain Dialysis” type were excluded.

Annual incident counts by initial modality of kidney replacement therapy and the percentage starting on each modality are shown in Figure 1.2. In 2019, 114,432 individuals initiated in-center HD, representing 85.1% of individuals with incident ESRD. This percentage decreased from 91.1% in 2009. Over the past decade, the percentage who initiated PD nearly doubled, increasing from 6.2% to 11.5% (total count, 15,433 in 2019). The percentage who received a preemptive kidney transplant remained essentially unchanged over the decade at about 3% (total count, 4022 in 2019). Although individuals initiating home HD in 2019 represented <1% of the total ESRD incident count, the percentage initiating home HD nevertheless increased by more than one third (34.5%) between 2018 and 2019.

Figure 1.3 Incidence of ESRD by Health Service Area



Data Source: USRDS ESRD Database. U.S. ESRD patients, unknown sex, and other and unknown race/ethnicity excluded. Adjusted incidence rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

ESRD incidence from 2018 to 2019 is shown in Figure 1.3 by Health Service Areas (HSAs). Higher adjusted ESRD incidence was apparent in several areas, including southeastern Ohio and West Virginia; the coastal plains of South Carolina and southern Georgia; the border of Illinois and Indiana; the southern Mississippi River Valley; western Arkansas and eastern Oklahoma; much of southern Texas, from Houston to El Paso; sparse areas in the western Dakotas; the Four Corners region in the Southwest; and the Central Valley in California. Relatively low ESRD incidence was apparent in New England; much of Minnesota, Wisconsin, and the Upper Peninsula of Michigan; the Rocky Mountains; and much of the Pacific Northwest.

Table 1.1 Incidence of ESRD and distribution of modality at incidence by ESRD network

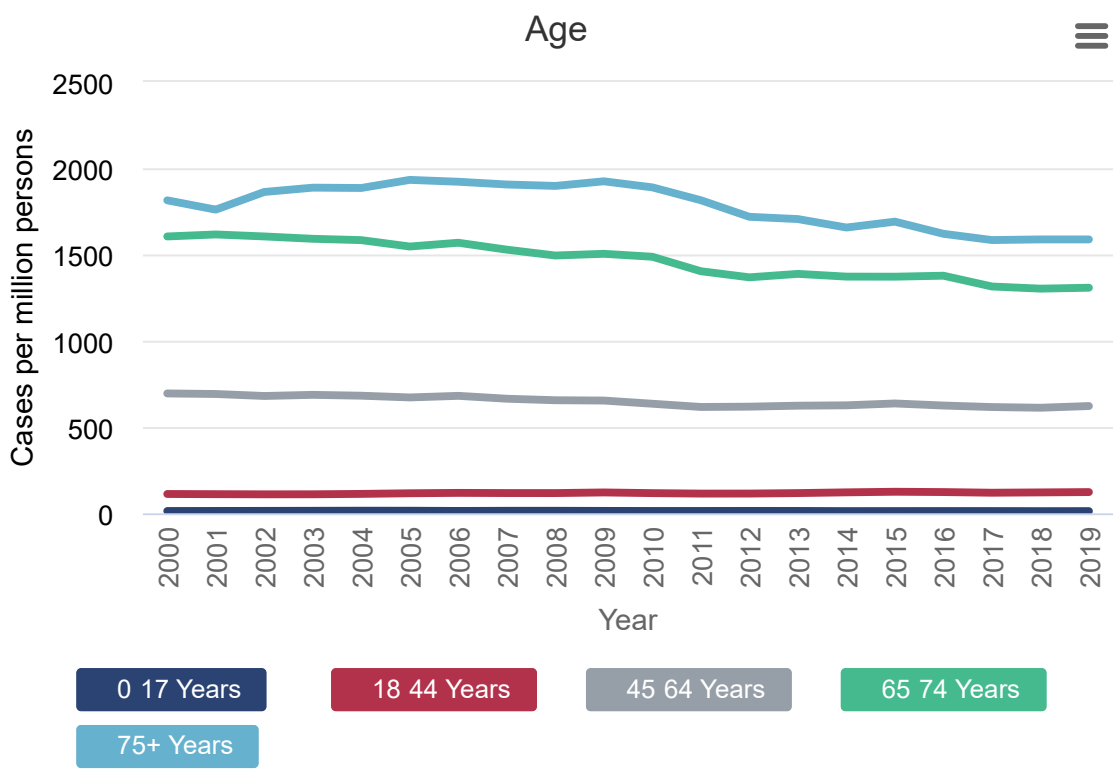
	All ESRD			In-Center Hemodialysis		Home Hemodialysis		Peritoneal Dialysis		Preemptive Transplant	
Network	N	Unadjusted Incidence Rate	Adjusted Incidence Rate	N	% of Network	N	% of Network	N	% of Network	N	% of Network
1 CT, MA, ME, NH, RI, VT	20,457	273.9	288.3	17,624	86.2	37	0.2	1,905	9.3	858	4.2
2 NY	39,820	401.6	367.0	36,102	90.7	199	0.5	2,133	5.4	1,351	3.4
3 NJ, PR, VI	26,671	431.8	411.5	24,011	90.0	33	0.1	1,957	7.3	640	2.4
4 DE, PA	26,797	387.7	369.6	23,378	87.2	163	0.6	2,492	9.3	747	2.8
5 MD, DC, VA, WV	36,073	421.8	364.0	31,301	86.8	121	0.3	3,387	9.4	1,107	3.1
6 NC, SC, GA	56,925	440.9	357.5	49,073	86.2	192	0.3	6,431	11.3	1,151	2.0
7 FL	44,260	418.4	345.6	38,707	87.5	197	0.4	4,221	9.5	977	2.2
8 AL, MS, TN	34,833	476.8	392.8	29,745	85.4	87	0.2	4,386	12.6	583	1.7
9 IN, KY, OH	46,723	408.5	409.4	40,637	87.0	244	0.5	4,591	9.8	1,184	2.5
10 IL	27,363	423.2	407.9	23,029	84.2	196	0.7	3,377	12.3	717	2.6
11 MI, MN, ND, SD, WI	38,702	335.7	363.3	33,581	86.8	77	0.2	3,411	8.8	1,598	4.1
12 IA, KS, MO, NE	23,745	334.0	369.6	19,785	83.3	54	0.2	3,110	13.1	775	3.3
13 AR, LA, OK	26,487	453.9	413.7	22,962	86.7	49	0.2	2,979	11.2	489	1.8
14 TX	62,074	436.6	437.0	54,605	88.0	279	0.4	5,628	9.1	1,354	2.2
15 AZ, CO, NV, NM, UT, WY	33,087	305.7	315.6	28,052	84.8	41	0.1	3,816	11.5	1,085	3.3
16 AK, ID, MT, OR, WA	19,882	262.6	299.3	16,550	83.2	18	0.1	2,684	13.5	628	3.2
17 N. CA, HI, GUAM, AS	33,391	392.0	382.7	27,954	83.7	69	0.2	4,606	13.8	665	2.0
18 S. CA	53,078	431.9	418.2	45,959	86.6	71	0.1	6,142	11.6	888	1.7
All Networks	650,917	403.1	390.6	563,116	86.5	2,127	0.3	67,261	10.3	17,239	2.6

Data Source: USRDS ESRD Database. U.S. and US territories ESRD patients. Persons with “Uncertain Dialysis” type were included in the total count of incident ESRD cases but are not represented separately. Adjusted rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

There is substantial variability in ESRD incidence and distribution of kidney replacement therapy modalities utilized in patients with incident ESRD across ESRD Networks (Table 1.1). In 2015-2019, adjusted ESRD incidence ranged from a low of 288.3 pmp in New England to a high of 437.0 pmp in Texas, a one-and-half-fold difference. Although in-center HD was the most common modality among patients with incident ESRD across all Networks, utilization of other therapies varied widely. The percentage of patients who initiated PD varied by more than two-and-a-half fold across networks, from 5.4% in New York to 13.8% in Northern California, Hawaii, and the U.S. Pacific Territories. Similarly, the percentage of patients who received a preemptive kidney transplant varied by two-and-half-fold by network, from 1.7% in Southern California and the Alabama/Mississippi/Tennessee region to 4.2% in New England. The percentage of patients who initiated home HD varied even more dramatically, from 0.1% in many areas of the country to 0.6% in Delaware and Pennsylvania and 0.7% in Illinois, although it is important to note that home HD sometimes represents individuals who receive hemodialysis in a skilled nursing facility (SNF).

Figure 1.4 Adjusted incidence of ESRD by patient characteristics

Age | Sex | Race/Ethnicity



Data Source: USRDS ESRD Database. U.S. ESRD patients, unknown sex and other or unknown race/ethnicity excluded. Rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

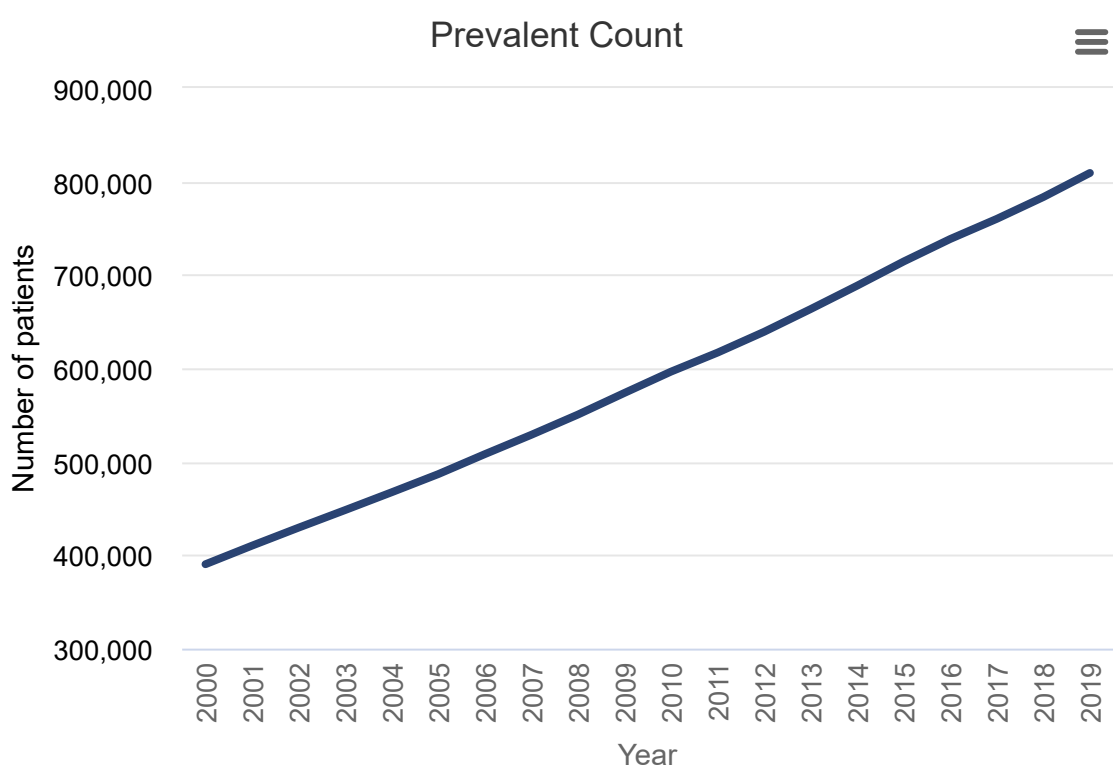
Adjusted ESRD incidence from 2000-2018 is displayed in Figure 1.4, stratified by age, sex, and race/ethnicity. Adjusted ESRD incidence was higher among older age groups. Among individuals aged 0-17 years, the adjusted incidence of ESRD in 2019 was 12 pmp but was 1307 pmp among individuals aged 65-74 years and 1587 pmp among individuals aged ≥75 years. In the decade between 2009 and 2019, adjusted ESRD incidence declined by 13.1% among individuals aged 65-74 years and by 17.5% among individuals aged ≥75 years. Among the youngest individuals, adjusted incidence decreased by 14.3%. In contrast, adjusted incidence was virtually unchanged over this period in individuals aged 18-44 years.

Between 2009 and 2019, adjusted ESRD incidence in Black individuals decreased by 17.5%, in Native American individuals by 14.1%, in Hispanic individuals by 12.1%, in Asian individuals by 5.2%, and in White individuals by 2.4%. However, between 2018 and 2019, adjusted incidence increased in all race groups except Whites.

Men have always had a higher incidence of ESRD than women, and despite declines in adjusted incidence in men and women since 2009, the relative difference continues to increase: adjusted ESRD incidence was 57.8% higher among men in 2009 but 63.9% higher in 2019.

Figure 1.5 Prevalence of ESRD

Prevalent Count | Prevalence Rate | % Change

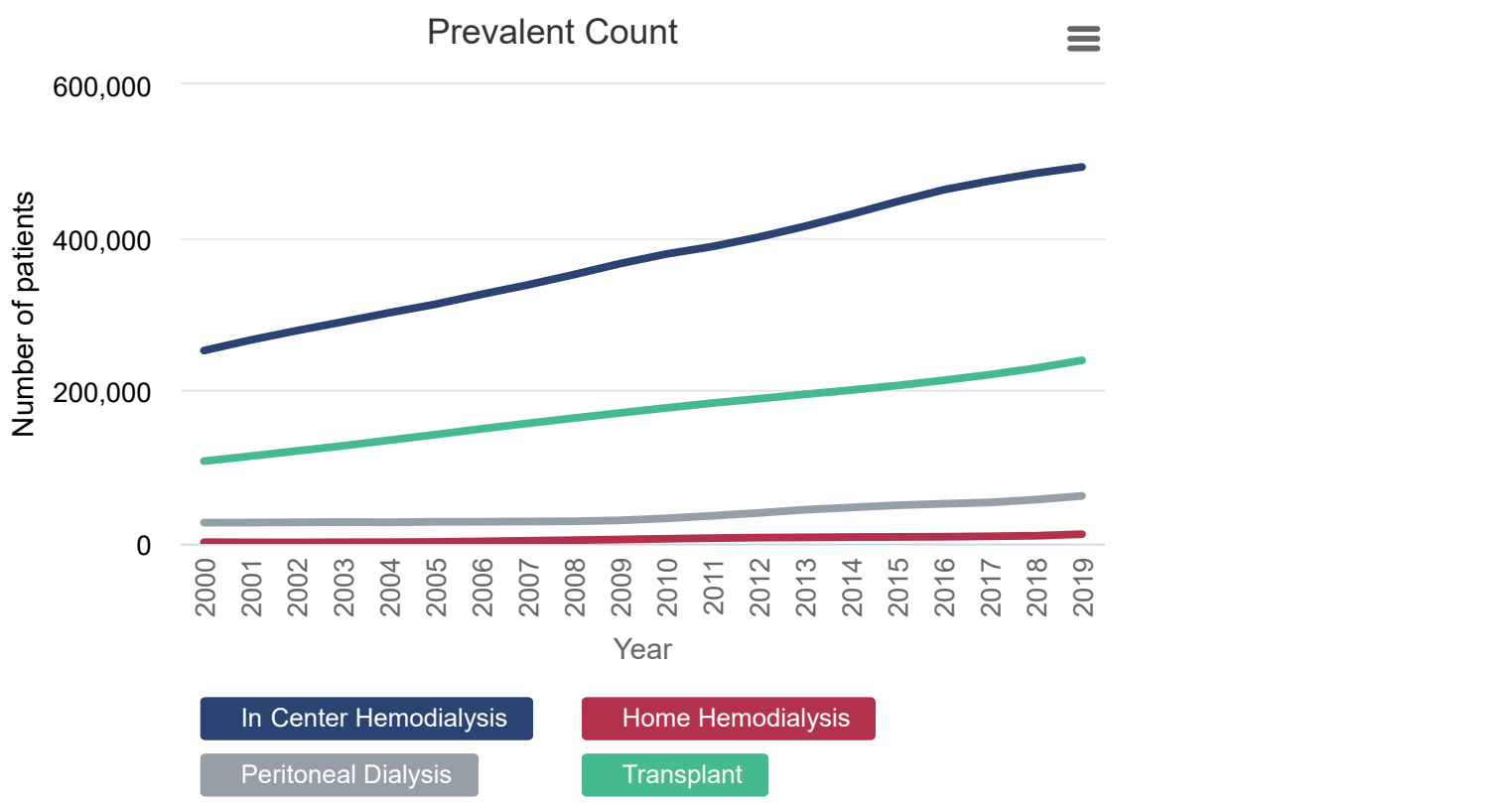


Data Source: USRDS ESRD Database. All U.S. ESRD prevalent patients were included for Prevalent Count; unknown sex and other or unknown race/ethnicity were excluded for Prevalence Rate (adjusted and unadjusted). Adjusted rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

The number of individuals with prevalent ESRD reached 809,103 in 2019, an increase of 41.0% from 2009. After adjustments for age, sex, and race/ethnicity, adjusted ESRD prevalence also increased to an all-time high of 2302 pmp in 2019, representing an increase of 1.4% from 2018. Year-over-year increases in adjusted ESRD prevalence have been at or below 2% since 2009.

Figure 1.6 Prevalent ESRD by modality

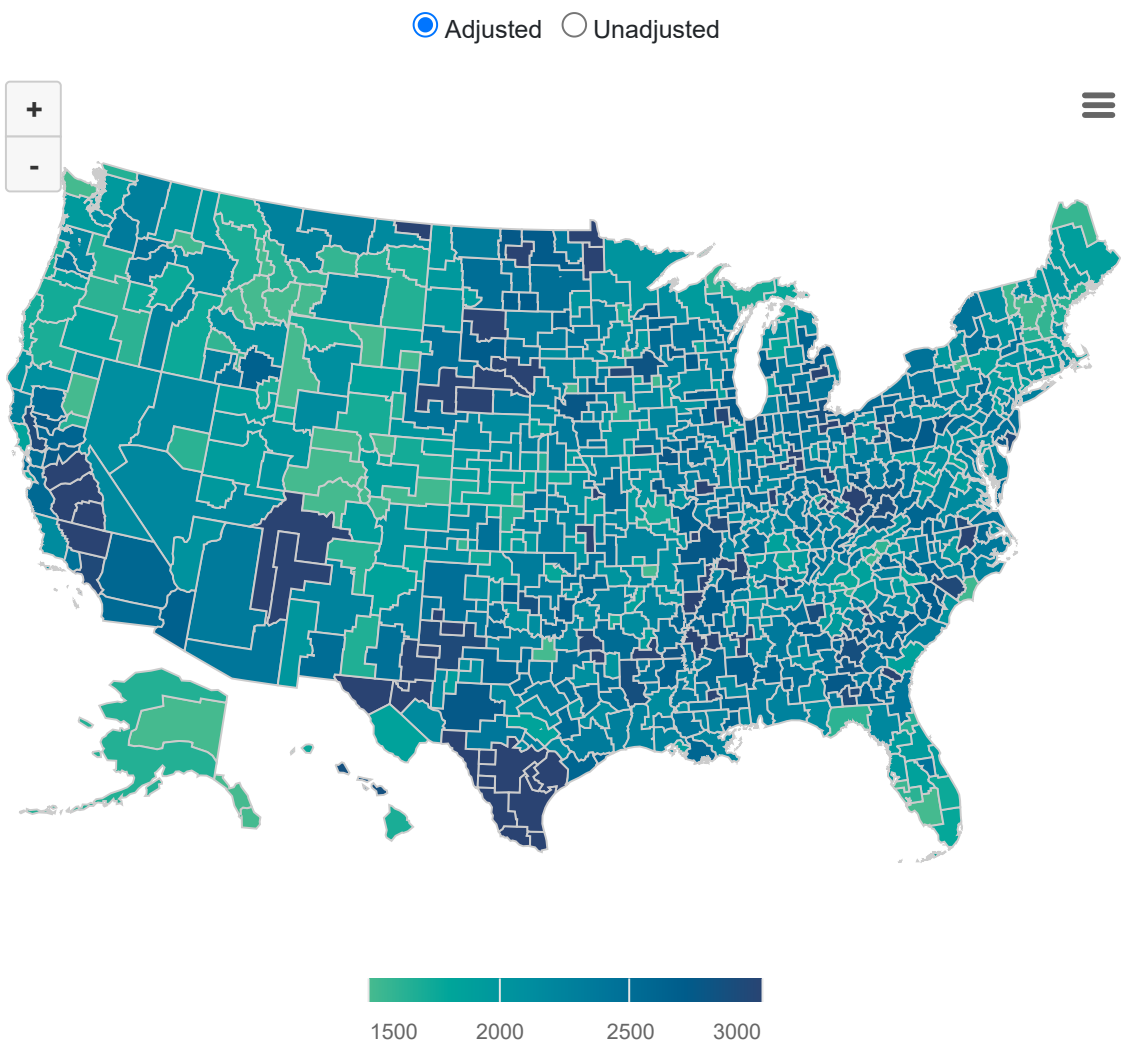
Prevalent Count | Percentage



Data Source: USRDS ESRD Database. U.S. and US territories ESRD patients. Persons with “Uncertain Dialysis” type were excluded.

At the end of 2019, 492,096 individuals were receiving in-center HD, up 1.7% from 2018 and 34.5% from 2009. There were 12,243 patients receiving home HD at year’s end, an increase of 20.1% over the preceding year. The number of patients receiving PD increased to 62,275, representing 8.5% growth in a single year. Finally, the number of prevalent patients with a functioning kidney transplant increased from 229,181 in 2018 to 239,413 in 2019, a year-over-year increase of 4.5% and an increase of 34.3% from the previous decade. Overall, 61.1% of patients with ESRD received in-center HD, down from 63.9% in 2009; patients receiving PD increased from 5.3% of the prevalent ESRD population in 2009 to 7.7% in 2019. Individuals living with a functioning kidney transplant have consistently represented approximately 30% of the prevalent ESRD population over the decade.

Figure 1.7 Prevalence of ESRD by Health Service Area



Data Source: USRDS ESRD Database. U.S. ESRD patients, unknown sex, and other and unknown race/ethnicity excluded. Adjusted rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

The map of adjusted ESRD prevalence by HSA (Figure 1.7) shows that contiguous areas with elevated prevalence in 2018-2019 included the coastal plains of South Carolina and southern Georgia; the shores of Lake Michigan, from Gary, Indiana to Chicago to Milwaukee; the Mississippi River Valley from roughly St. Louis to Memphis; southern Texas; the western Dakotas; and the Central Valley of California.

Table 1.2 Prevalence of ESRD and distribution of modality at prevalence by ESRD network

	All ESRD			In-Center Hemodialysis		Home Hemodialysis		Peritoneal Dialysis		Transplant	
ESRD Network	N	Adjusted Prevalence Rate	Unadjusted Prevalence Rate	N	% of Network	N	% of Network	N	% of Network	N	% of Network
1 CT, MA, ME, NH, RI, VT	26,853	1,875.8	1,740.2	14,229	53.0	311	1.2	1,679	6.3	10,540	39.3
2 NY	51,596	2,231.1	2,556.2	32,777	63.5	558	1.1	1,994	3.9	16,151	31.3
3 NJ, PR, VI	31,639	2,365.2	2,567.1	20,773	65.7	150	0.5	1,745	5.5	8,888	28.1
4 DE, PA	32,775	2,268.4	2,336.6	18,873	57.6	507	1.5	2,247	6.9	11,046	33.7
5 MD, DC, VA, WV	45,591	2,124.4	2,612.4	27,141	59.5	894	2.0	3,186	7.0	14,176	31.1
6 NC, SC, GA	71,220	2,010.2	2,660.5	46,469	65.2	1,268	1.8	6,066	8.5	17,169	24.1
7 FL	50,227	1,897.4	2,289.7	31,233	62.2	931	1.9	3,722	7.4	14,142	28.2
8 AL, MS, TN	40,444	2,114.6	2,708.4	26,198	64.8	719	1.8	3,452	8.5	9,903	24.5
9 IN, KY, OH	51,595	2,258.6	2,210.9	30,561	59.2	957	1.9	4,318	8.4	15,528	30.1
10 IL	35,233	2,541.4	2,711.3	19,384	55.0	1,612	4.6	2,857	8.1	11,267	32.0
11 MI, MN, ND, SD, WI	50,030	2,338.7	2,106.4	26,845	53.7	779	1.6	3,276	6.5	18,928	37.8
12 IA, KS, MO, NE	28,547	2,289.8	1,990.0	14,935	52.3	478	1.7	2,638	9.2	10,345	36.2
13 AR, LA, OK	29,471	2,232.6	2,518.4	18,960	64.3	528	1.8	2,703	9.2	7,168	24.3
14 TX	75,396	2,352.7	2,557.6	49,755	66.0	895	1.2	5,733	7.6	18,653	24.7
15 AZ, CO, NV, NM, UT, WY	43,148	1,931.9	1,926.3	24,705	57.3	402	0.9	3,447	8.0	14,435	33.5
16 AK, ID, MT, OR, WA	26,181	1,928.2	1,645.5	13,922	53.2	359	1.4	2,397	9.2	9,396	35.9
17 N. CA, HI, GUAM, AS	45,682	2,502.2	2,675.1	28,090	61.5	430	0.9	4,199	9.2	12,759	27.9
18 S. CA	71,481	2,566.1	2,894.7	46,970	65.7	464	0.6	6,601	9.2	17,225	24.1
All Networks	809,103	2,316.6	2,450.6	492,096	60.8	12,243	1.5	62,275	7.7	239,413	29.6

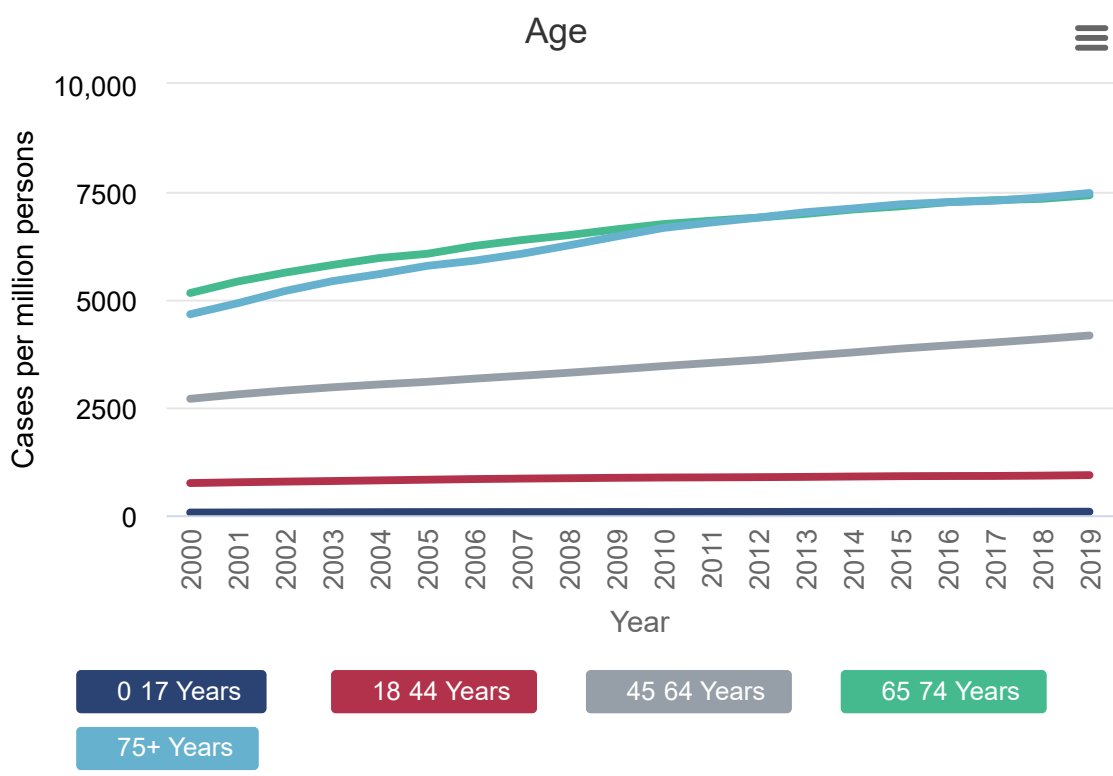
Data Source: USRDS ESRD Database. US and US territories ESRD patients. Persons with “Uncertain Dialysis” were included in the total count of prevalence ESRD cases but are not represented separately. Prevalence rates are calculated for US ESRD patients with unknown sex and other or unknown race/ethnicity dropped. Adjusted rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

There was substantial variability in ESRD prevalence and utilization of kidney replacement therapy modalities across ESRD Networks (Table 1.2). In 2019, adjusted ESRD prevalence ranged from a low of 1,875.8 pmp in New England to a high of 2,566.1 pmp in Southern California. In-center HD was the most frequently utilized kidney replacement therapy across all Networks, although in five Networks spanning 21 states, fewer than 55% of patients utilized in-center HD.

Network-specific percentages of ESRD patients who received home HD varied between 0.5% and 2.0%, except for Illinois, where 4.6% of prevalent patients with ESRD utilized home HD. (This outlying value is likely attributable to a large population of skilled nursing facility residents utilizing on-site hemodialysis, which is indistinguishable from home dialysis in claims.) Network-specific percentages of ESRD patients who received PD varied by more than twofold, ranging from 3.9% in New York to 9.2% in many states across five Networks. Network-specific percentages of patients with a functioning kidney transplant varied between 24.1% (North and South Carolina, Georgia, and Southern California) and 39.3% (New England).

Figure 1.8 Adjusted prevalence of ESRD by patient characteristics

Age | Race/Ethnicity

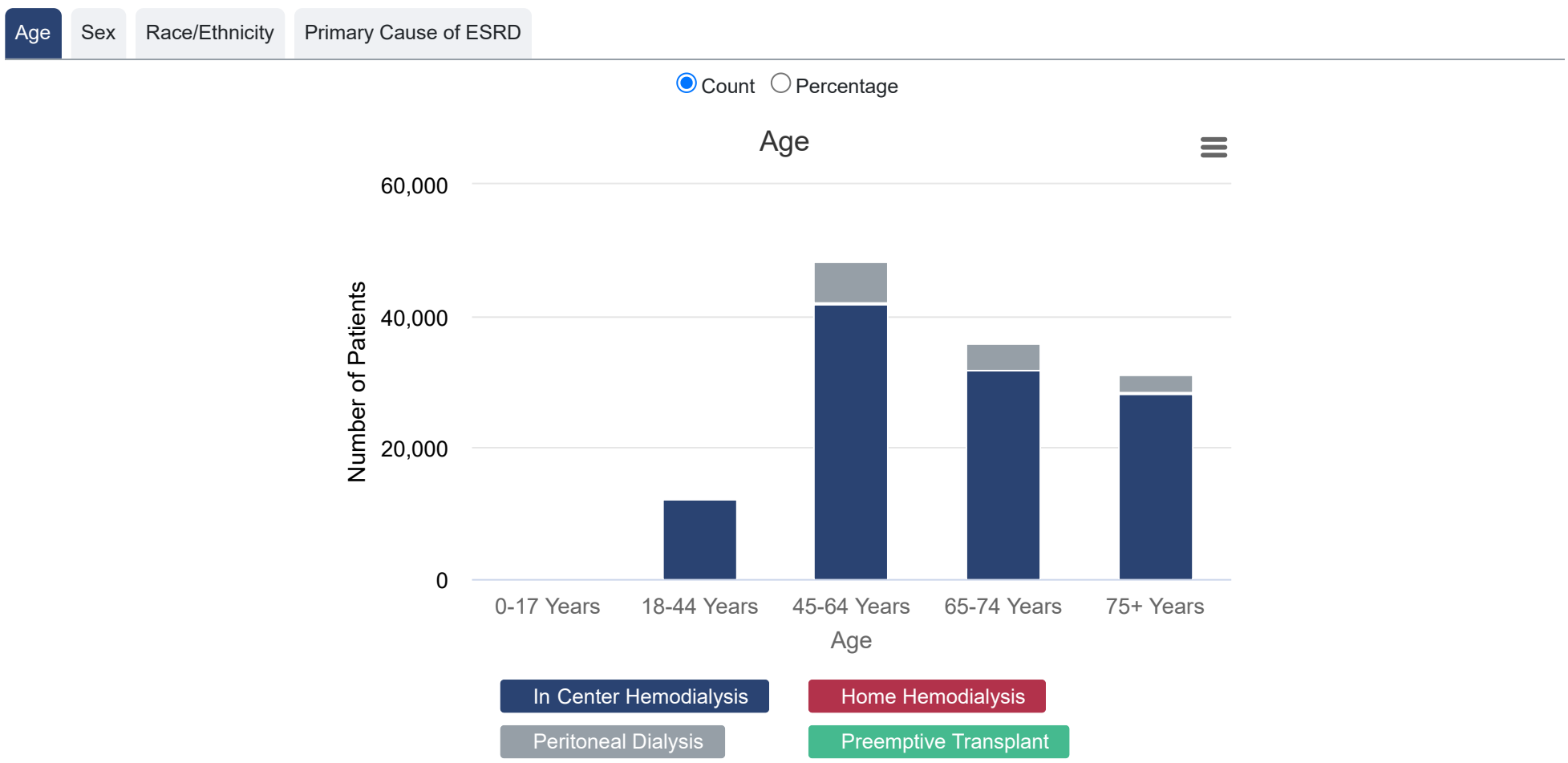


Data Source: USRDS ESRD Database. U.S. ESRD patients, unknown sex and other or unknown race/ethnicity excluded. Rates are standardized to the age, sex, and race/ethnicity distribution of the 2015 US population.

Figure 1.8 displays adjusted ESRD prevalence from 2000-2019 stratified by age and race/ethnicity. Adjusted ESRD prevalence was higher among older individuals, with 7473 cases pmp among individuals aged ≥75 years (an increase of 15.6% since 2009) and 7419 cases pmp among individuals aged 65-74 years in 2019 (an increase of 11.9% since 2009). Even among the youngest individuals (those aged 0-17 years), the adjusted prevalence of ESRD in 2019 was 7.9% higher than in 2009, at 82 cases pmp.

Adjusted ESRD prevalence in Black individuals increased by 0.6% between 2018 and 2019 but remained far higher, at 6423 cases pmp, than in other racial and ethnic groups. For example, adjusted prevalence in Black individuals was 78.6% higher than in the next-highest group, Native Americans (3596 cases pmp), and more than four-fold higher than in White individuals (1500 cases pmp). Between 2018 and 2019, adjusted prevalence increased by 2.1% in Asian, 1.6% in Native American, 1.6% in Hispanic, and 1.7% in White individuals.

Figure 1.9 Modality at incidence of ESRD by patient characteristics

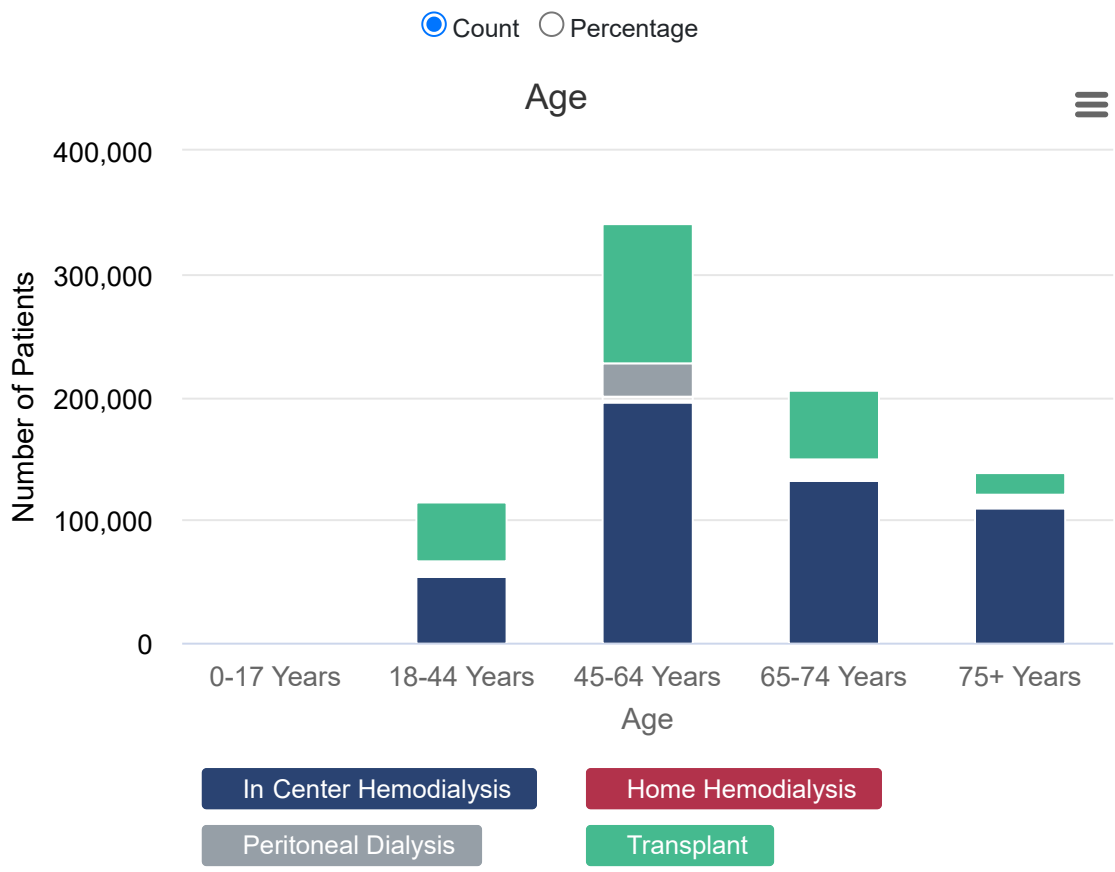


Data Source: USRDS ESRD Database. U.S. and U.S. territories ESRD patients. Persons with “Uncertain Dialysis” type were excluded.

The Executive Order on Advancing American Kidney Health envisions increased utilization of preemptive transplantation and home dialysis in patients with incident ESRD. Figure 1.9 displays the modality of kidney replacement therapy at incidence of ESRD in 2019. As age increased, the percentage initiating kidney replacement therapy with in-center HD increased, and the percentage initiating with PD or a preemptive kidney transplant decreased. There were no salient differences between men and women. Compared with Black individuals, a higher percentage of White individuals initiated kidney replacement therapy with PD or a preemptive kidney transplant. Individuals with glomerulonephritis (GN) or cystic kidney disease as their cause of ESRD more commonly initiated kidney replacement therapy with PD or a preemptive kidney transplant than did individuals with DM or HTN as their cause of ESRD.

Figure 1.10 Distribution of modality in prevalent ESRD

Age | Sex | Race/Ethnicity | Primary Cause of ESRD



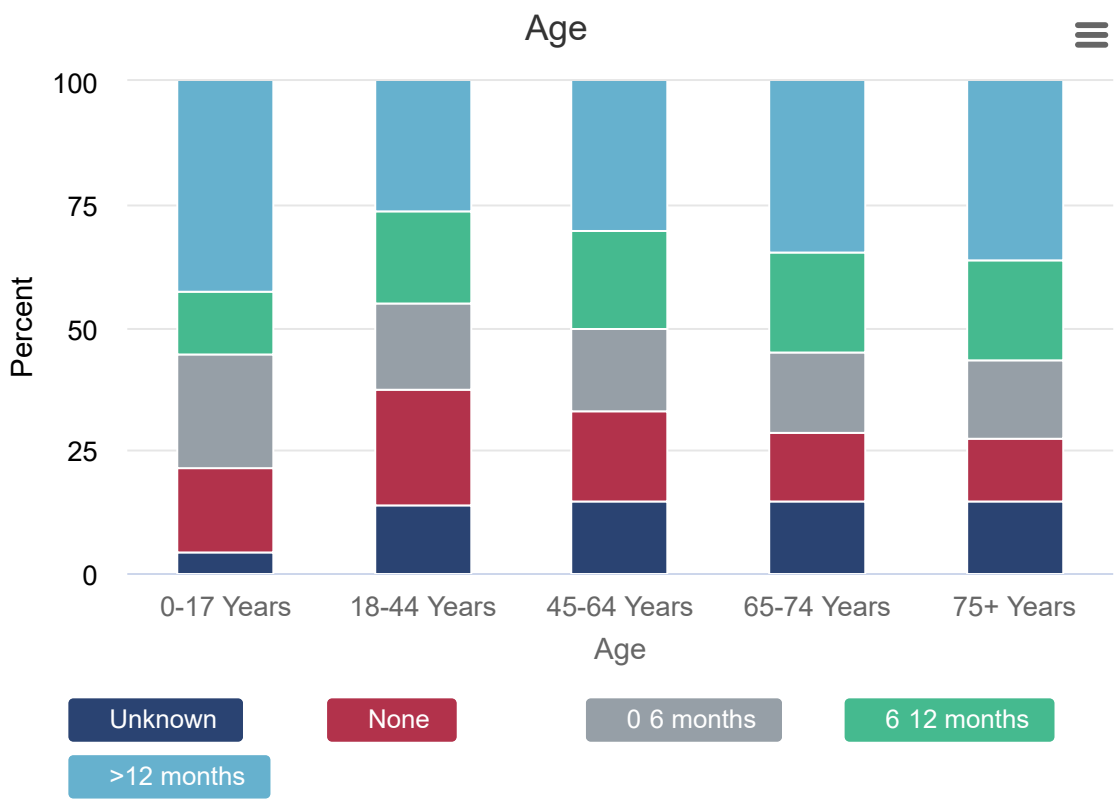
Data Source: USRDS ESRD Database. U.S. and U.S. territories ESRD patients. Persons with "Uncertain Dialysis" type were excluded.

The distribution of kidney replacement therapy modality utilized in prevalent patients with ESRD in 2019 is shown in Figure 1.10 by age, sex, race/ethnicity, and cause of ESRD. The percentage with a functioning kidney transplant was lower among older individuals. For example, among pediatric patients, 74% had a functioning kidney transplant, compared with 33% of individuals aged 45-64 years (the largest single age group) and just 13% of individuals aged ≥75 years. Correspondingly, the percentage receiving in-center HD was higher among older individuals (e.g., 57% of individuals aged 45-64 years, 65% of individuals aged 65-74 years, and 79% of individuals aged ≥75 years). The percentage receiving PD was slightly lower among older individuals. About 2% of prevalent patients aged 18-64 years received home HD, compared with about 1% of those aged ≥65 years. There is little difference in modality use between men and women.

White patients had the highest percentage with a transplant (36%) and the lowest receiving in-center HD (54%); Native Hawaiian and Pacific Islander patients had the lowest percentage with a transplant (18%) and the highest receiving in-center HD (73%), followed closely by Native American (20% transplant and 72% in-center HD) and Black (21% transplant and 71% in-center HD) patients. Individuals with ESRD attributed to GN or cystic kidney disease were much more likely to have a functioning kidney transplant (and, correspondingly, much less likely to be receiving in-center HD) than individuals with DM or HTN as their ESRD cause.

Figure 1.11 Duration of pre-ESRD nephrology care among incident ESRD patients by patient characteristics

Age | Sex | Race/Ethnicity | Primary Cause of ESRD | ESRD Network | Employment Status | Insurance Status

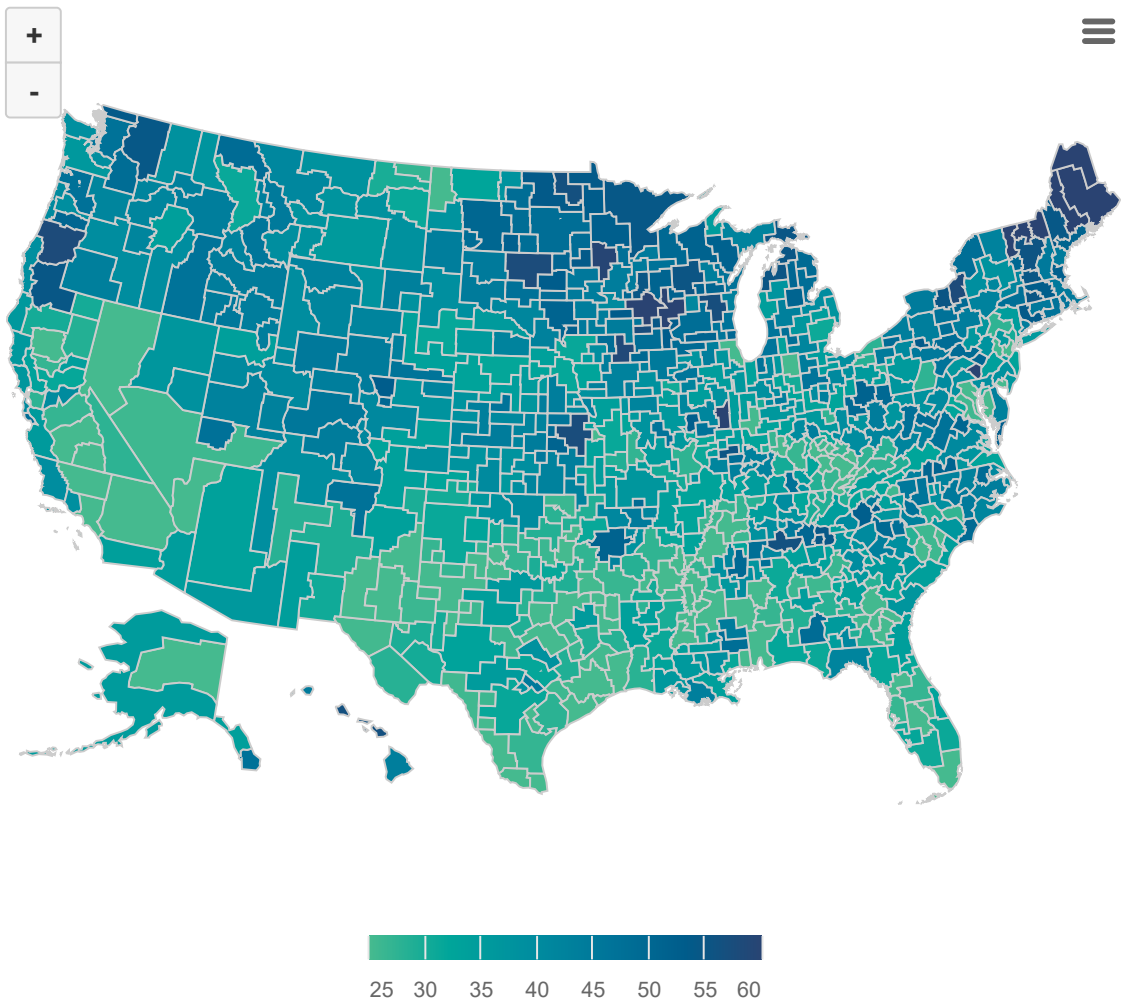


Data Source: USRDS ESRD Database. U.S. and U.S. territories ESRD patients with a Medical Evidence Report (form CMS 2728).

Receipt and duration of pre-ESRD nephrology care among patients with incident ESRD in 2019 is displayed in Figure 1.11. Overall, about 30% of patients had unknown or no nephrology care prior to ESRD. Children were most likely to have received pre-ESRD care (79%), and young adults (aged 18-44 years) were least likely (62%). White (73%), Asian (72%), and Native American (72%) individuals were much more likely to have received pre-ESRD nephrology care than were Black (64%), Native Hawaiian/Pacific Islander (62%), or Hispanic (61%) individuals. Among those with a known cause of ESRD, patients with cystic kidney disease as their cause of ESRD were most likely to have received care prior to ESRD and those with HTN least likely. Patients with cystic kidney disease and GN were particularly likely to receive pre-ESRD care extending for at least 12 months prior to ESRD (cystic kidney disease, 56%; GN, 42%).

Pre-ESRD care varied widely by ESRD Network and was highest in New England, at 82%, and lowest in Texas, at only 61%. The percentage of unemployed individuals who did not receive pre-ESRD care (43%) was substantially higher than the percentage of employed individuals or students who did not (24%). As expected, those without insurance or who were in the waiting period for Medicare eligibility were substantially less likely to receive care than those who were insured by a Medicare program.

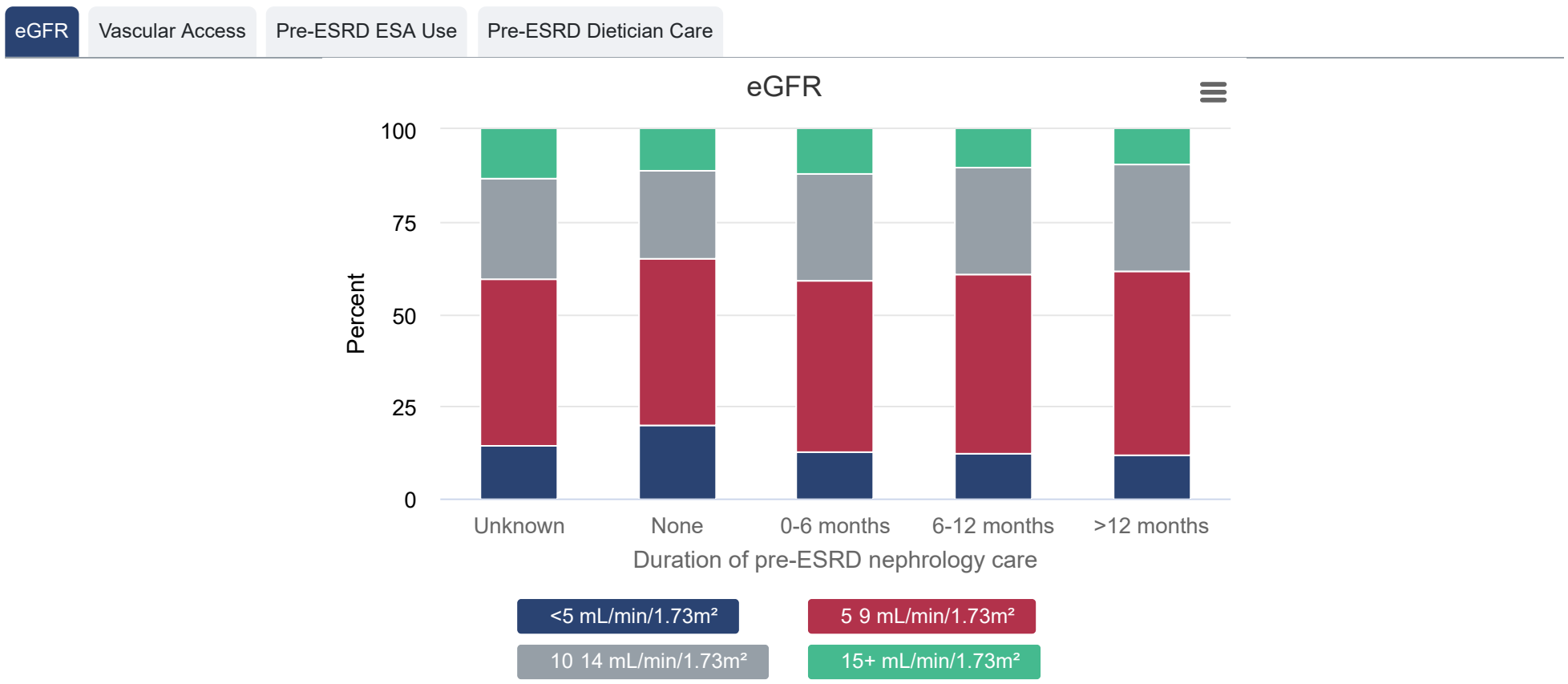
Figure 1.12 Prevalence (%) of >12 months of pre-ESRD nephrology care among incident ESRD patients by Health Service Area



Data Source: USRDS ESRD Database. U.S. ESRD patients with a Medical Evidence Report (form CMS 2728).

The percentage of patients with incident ESRD who received at least 12 months of pre-ESRD nephrology care is depicted in Figure 1.12. Areas with the highest percentage included New England and upstate New York, the Upper Midwest, and parts of the Pacific Northwest. In the southern part of the U.S., there were relatively few areas where a high percentage of patients received at least 12 months of pre-ESRD nephrology care.

Figure 1.13 Clinical characteristics and care of incident ESRD patients by duration of pre-ESRD nephrology care

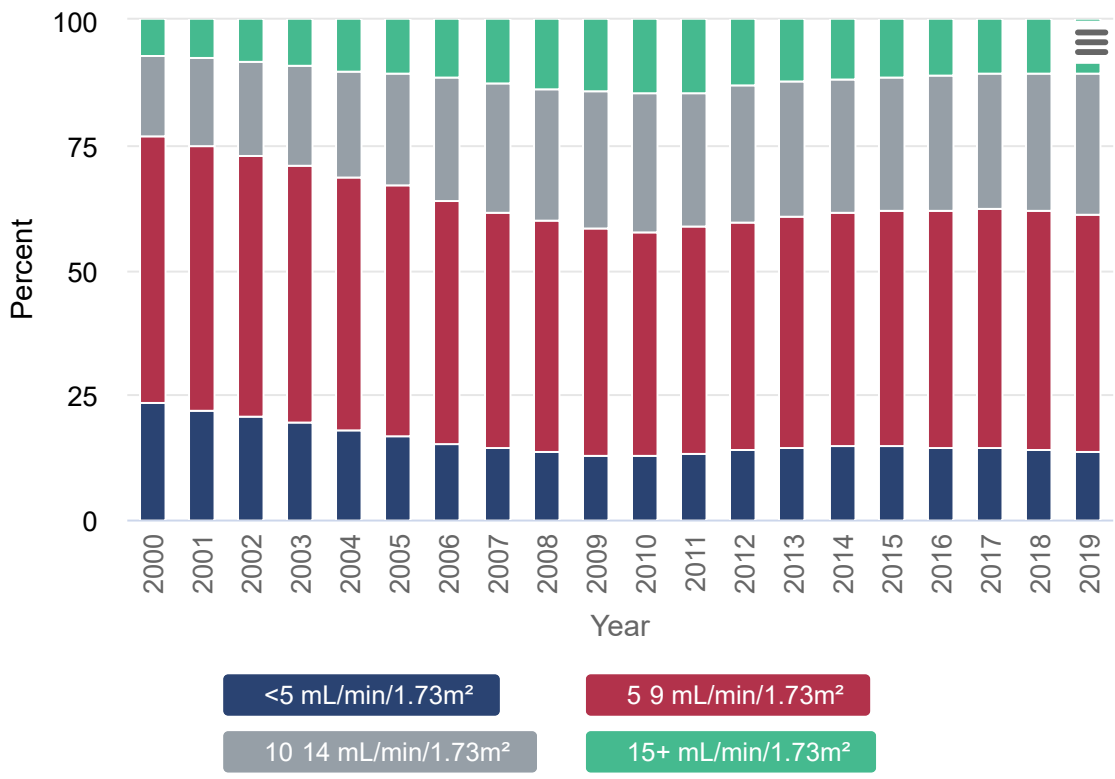


Data Source: USRDS ESRD Database. U.S. and U.S. territories ESRD patients with a Medical Evidence Report (form CMS 2728). eGFR calculated using the CKD-EPI equation for those aged ≥18 years and the Bedside Schwartz equation for those aged <18 years.

The distribution of clinical characteristics and care in patients with incident ESRD in 2019 are displayed in Figure 1.13, stratified by duration of pre-ESRD nephrology care. Less than 1% of patients without any pre-ESRD nephrology care had received pre-ESRD care from a dietician, but unexpectedly, the percentage receiving dietician care did not increase as the duration of pre-ESRD nephrology care increased. Only about 2% of patients without pre-ESRD nephrology care had received an erythropoiesis-stimulating agent (ESA), whereas the corresponding percentage in patients with 0-6 months, 6-12 months, and >12 months of pre-ESRD nephrology care were 26%, 20%, and 21%, respectively. There was little difference in eGFR at ESRD onset; in contrast, there was a clear association between duration of pre-ESRD nephrology care and catheter use at ESRD onset.

More than one quarter of patients who initiated HD with >12 months of pre-ESRD nephrology care did so with an arteriovenous fistula or graft, compared with only 18% of patients with 6-12 months of pre-ESRD nephrology care, 10% of patients with 0-6 months of nephrology care, and 4.0% of patients with no known pre-ESRD nephrology care.

Figure 1.14 Estimated glomerular filtration rate among incident ESRD patients

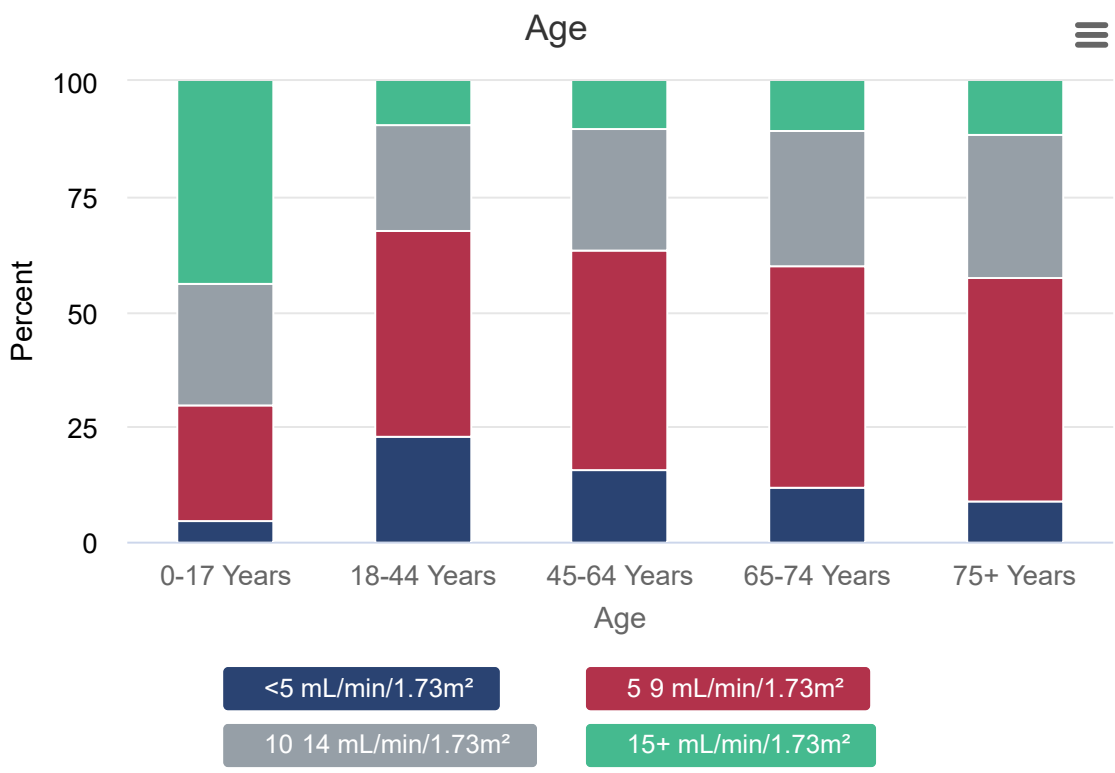


Data Source: USRDS ESRD Database. U.S. and U.S. territories ESRD patients with a Medical Evidence Report (form CMS 2728). eGFR calculated using the CKD-EPI equation for those aged ≥18 years and the Bedside Schwartz equation for those aged <18 years.

Figure 1.14 shows the distribution of eGFR at ESRD onset from 2000-2019. After a substantial increase in the percentage of patients initiating kidney replacement therapy with an eGFR ≥10 ml/min/1.73m^2 between 2000 and 2010 from 23% to 43%, there has been little change in this percentage since 2010. In 2019, eGFR at onset of kidney replacement therapy was between 5 and 10 mL/min/1.73 m^2 in 48% of patients and was between 10 and 15 mL/min/1.73 m^2 in 28%; in only 11% of patients was eGFR ≥15 mL/min/1.73m^2.

Figure 1.15 Estimated glomerular filtration rate among incident ESRD patients by patient characteristics

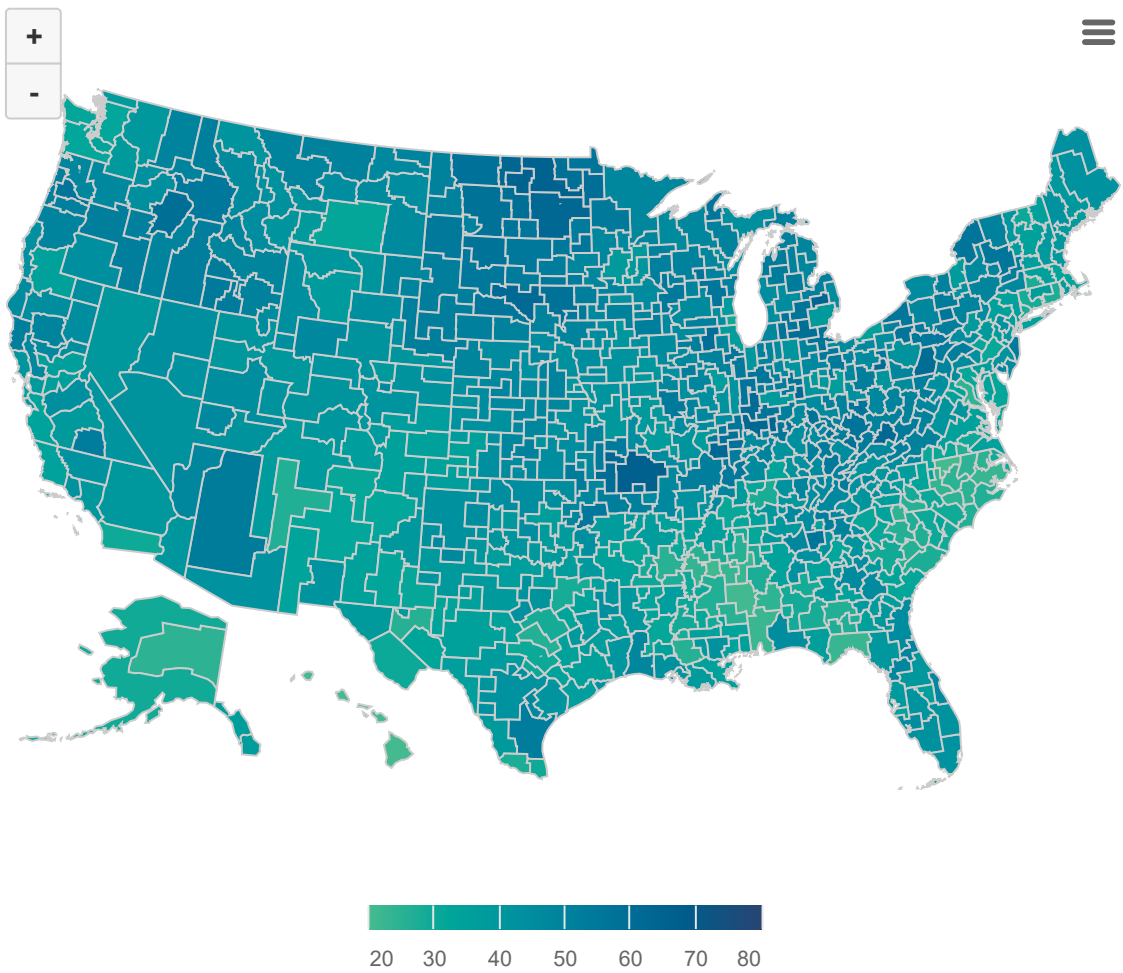
Age | Sex | Race/Ethnicity



Data Source: USRDS ESRD Database. U.S. and U.S. territories with a Medical Evidence Report (form CMS 2728). eGFR calculated using the CKD-EPI equation for those aged ≥18 years and the Bedside Schwartz equation for those aged <18 years.

Figure 1.15 displays the distribution of eGFR at initiation of kidney replacement therapy by age, sex, and race/ethnicity. Among pediatric patients, 44% had eGFR ≥15 mL/min/1.73 m^2 at initiation of kidney replacement therapy, which may be the result of high use of preemptive kidney transplantation in children. Among adults, the percentage whose eGFR was <10 mL/min/1.73 m^2 at initiation of kidney replacement therapy was lower among older individuals, driven almost entirely by a smaller percentage initiating at an eGFR <5 mL/min/1.73m^2. Men (59%) were less likely than women (64%) to initiate kidney replacement therapy with eGFR of <10 mL/min/1.73 m^2. Approximately 21% of Black, 20% of Asian, and 22% of Native Hawaiian/Pacific Islander individuals had an eGFR <5 mL/min/1.73 m^2 at initiation of kidney replacement therapy, whereas the corresponding percentages were 9% for White and 11% for Native American individuals.

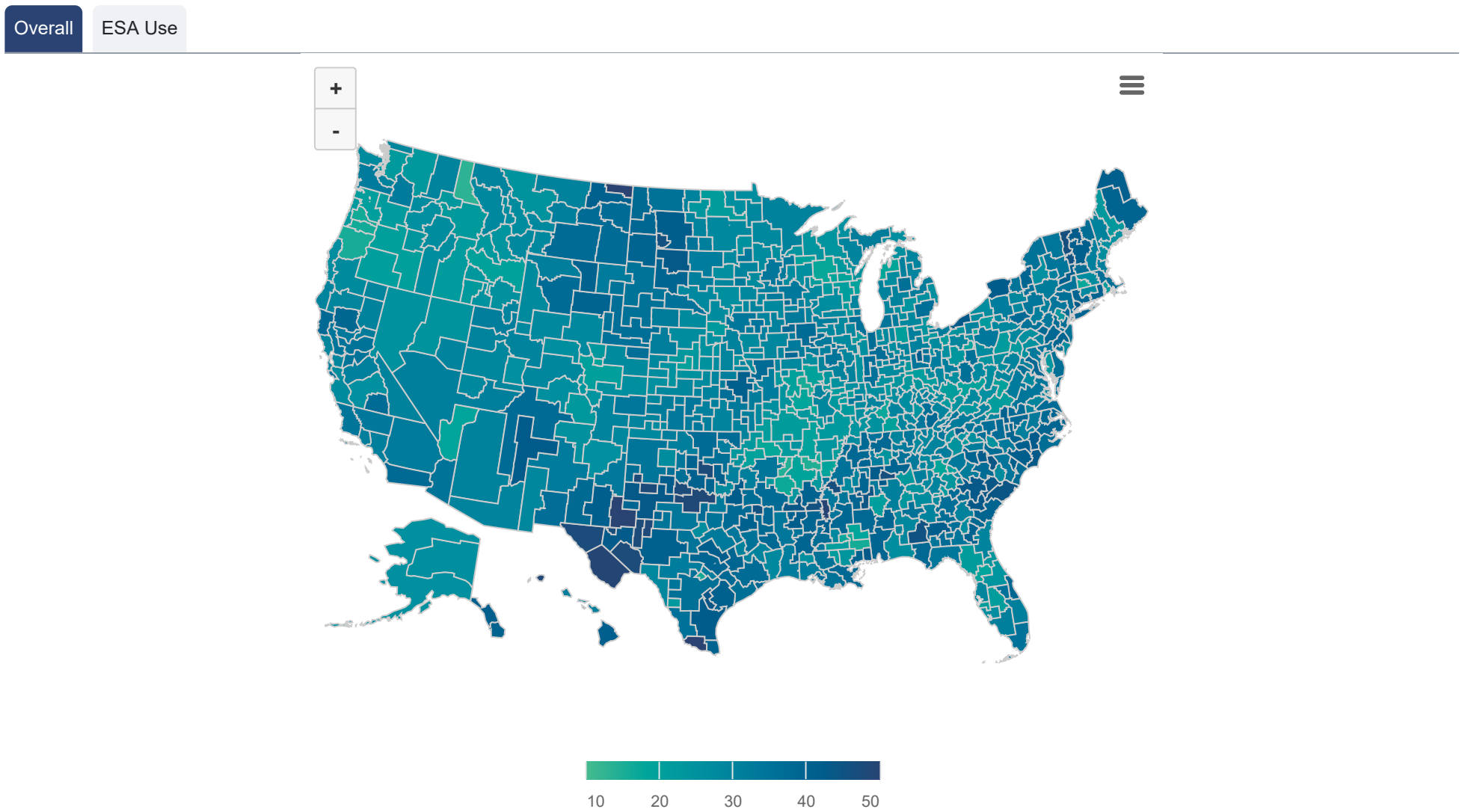
Figure 1.16 Prevalence (%) of estimated GFR >10 mL/min/1.73m² among incident ESRD patients by Health Service Area



Data Source: USRDS ESRD Database. U.S. ESRD patients with a Medical Evidence Report (form CMS 2728). eGFR calculated using the CKD-EPI equation for those aged ≥18 years and the Bedside Schwartz equation for those aged <18 years.

The percentage of incident ESRD patients in 2018-2019 with eGFR >10 mL/min/1.73 m² at onset of kidney replacement therapy is mapped by HSA in Figure 1.16. Many HSAs with high percentages of patients with eGFR >10 mL/min/1.73 m² were located north of the Ohio River, throughout the Upper Midwest, and in the middle of the country. HSAs with the lowest percentages of patients with estimated GFR >10 mL/min/1.73 m² were often in the southeast.

Figure 1.17 Prevalence (%) of hemoglobin <9 g/dL among incident ESRD patients overall and by ESA use, by Health Service Area,



Data Source: USRDS ESRD Database. U.S. ESRD patients with a Medical Evidence Report (form CMS 2728)

The percentage of incident ESRD patients in 2018-2019 with hemoglobin <9 g/dL is depicted in Figure 1.17. Many HSAs with the highest percentages of patients with hemoglobin <9 g/dL were located in the southern and southeastern U.S. Other areas with high percentages included western Massachusetts, eastern Virginia, the Detroit area, the corridor from Chicago to Milwaukee, southern Iowa and northern Missouri, and parts of the Pacific Northwest.

Table 1.3 Laboratory measurements among incident ESRD patients by patient characteristics

	eGFR (ml/min/1.73m2)	Serum Albumin (g/dL)	Dietary Care (%)	Hemoglobin (g/dL)	ESA Use (%)	Total Cholesterol (mg/dL)	LDL Cholesterol (mg/dL)	HbA1c %
Overall	9.6	3.3	12.2	9.3	15.8	155.7	90.0	6.6
Age								
0-17 Years	15.9	3.5	54.8	9.7	40.8	197.6	112.5	5.1
18-44 Years	8.8	3.3	11.6	9.2	12.6	172.1	103.6	6.8
45-64 Years	9.4	3.3	11.6	9.3	14.1	160.9	94.1	6.8
65-74 Years	9.8	3.3	12.6	9.4	16.8	148.9	84.5	6.6
75+ Years	10.1	3.3	11.7	9.4	18.2	142.0	79.4	6.4
Sex								
Female	9.3	3.3	12.4	9.2	17.2	167.1	95.8	6.7
Male	9.9	3.3	12.1	9.4	14.8	148.4	86.2	6.6
Race/Ethnicity								
White	10.5	3.4	13.4	9.5	17.1	151.8	86.1	6.6
Black	8.4	3.3	10.4	9.0	13.5	163.1	99.1	6.5
Hispanic	9.2	3.2	10.7	9.2	13.9	156.1	89.8	6.8
Asian	8.6	3.4	14.5	9.4	20.1	161.2	90.0	6.7
Native American	10.6	3.0	12.8	9.1	15.7	138.7	73.6	6.9
NH/PI	8.2	3.2	10.4	9.2	16.2	164.4	98.7	6.9
Primary Cause of ESRD	9.1	3.3	12.8	9.0	16.1	156.3	94.9	7.0
Diabetes	9.8	3.2	10.9	9.3	16.0	153.3	87.7	7.0
Hypertension	9.0	3.4	10.3	9.3	13.7	152.9	89.5	6.0
Glomerulonephritis	8.9	3.4	16.2	9.4	19.8	174.9	103.1	5.7
Cystic kidney	9.6	3.9	19.6	10.0	16.1	167.4	96.3	5.6
Other urologic	8.8	3.4	17.8	9.4	18.4	146.4	77.3	5.7
Other/Unknown	10.9	3.3	17.1	9.4	17.2	150.6	87.8	6.1

Data Source: USRDS ESRD Database. US and US territories ESRD patients with CMS form 2728, unknown sex and unknown or other race/ethnicity excluded.

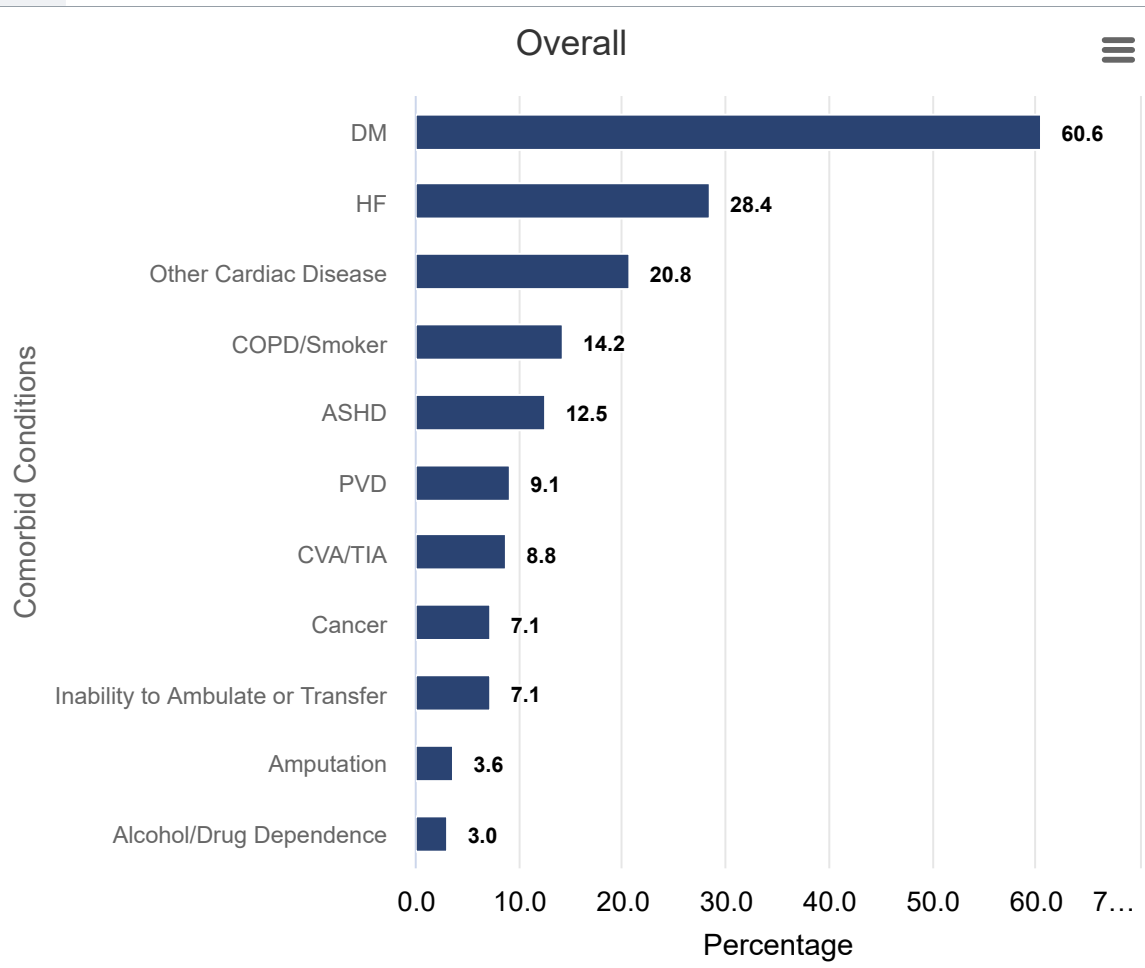
Table 1.3 displays data from the ESRD Medical Evidence Report among patients with incident ESRD in 2019. Overall, the mean estimated GFR at initiation of kidney replacement therapy was 9.6 mL/min/1.73m2. eGFR was higher among older than younger adults, among White and Native American than Black and Asian individuals, and (to a lesser extent) among men than women.

Mean serum albumin concentration was low (3.3 g/dL), with little variation among subgroups, except in patients with cystic kidney disease as the primary cause of ESRD, who had a higher mean serum albumin concentration (3.9 g/dL). Pre-ESRD dietician care was uncommon, with only about 1 in 8 individuals receiving such care; more than half of pediatric patients and nearly 1 in 5 patients with cystic kidney disease were seen by a dietician. White and Asian individuals were more likely to see a dietician than Black, Asian, or native Hawaiian/Pacific Islander individuals.

Mean hemoglobin level was 9.3 g/dL overall and was between 9.0 and 9.4 g/dL in every subgroup except for patients with cystic kidney disease as the cause of ESRD, who had higher hemoglobin (10.0 g/dL). Among children, 40.8% had received an ESA before ESRD onset; in adults, 12.6% to 18.2% received an ESA prior to ESRD. Asian (20.1%) and White (17.1%) individuals were more likely to receive an ESA than Black (13.5%) and Hispanic (13.9%) individuals.

Figure 1.18 Comorbid conditions of incident ESRD patients

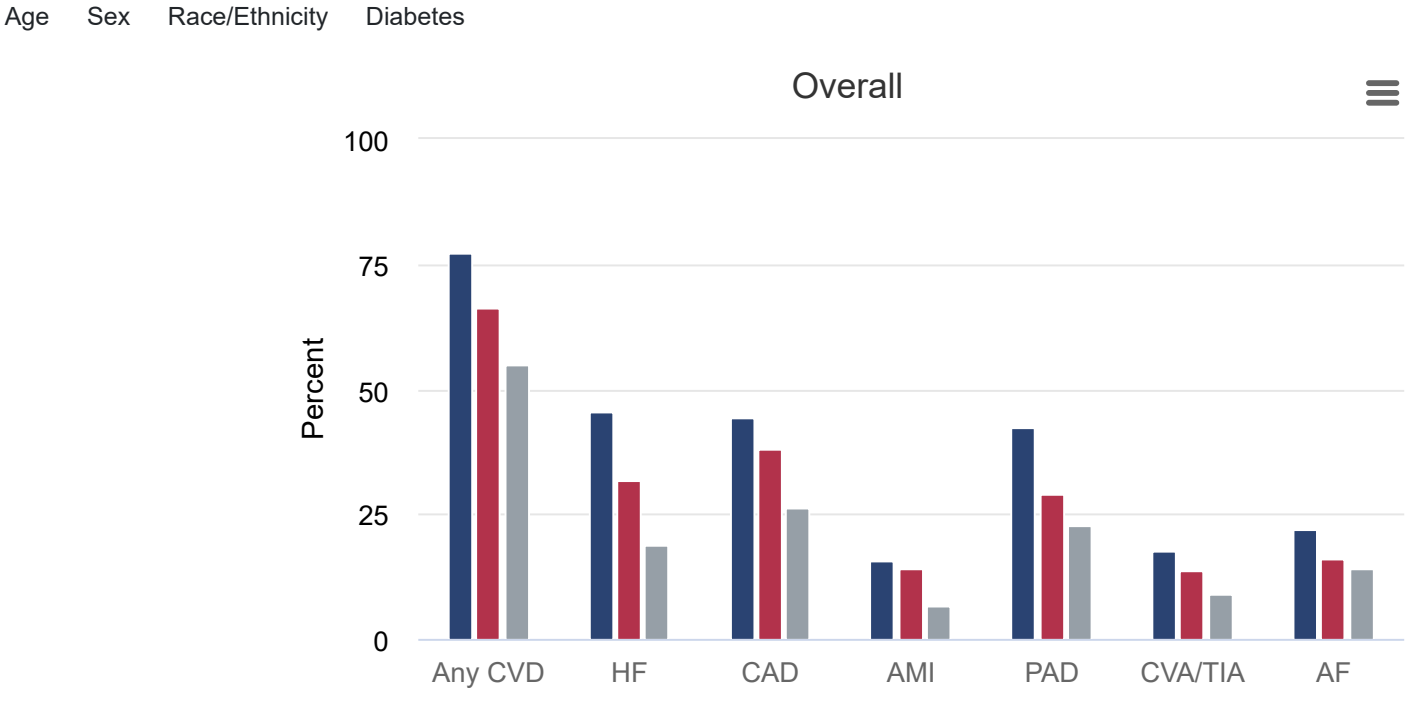
Overall | Age | Sex | Race/Ethnicity



Data Source: USRDS ESRD Database. U.S. and U.S. territory ESRD patients with a Medical Evidence Report (form CMS 2728) in 2019; Abbreviations: DM, diabetes mellitus; HF, heart failure; COPD, chronic obstructive pulmonary disease; ASHD, atherosclerotic heart disease; PVD, peripheral vascular disease; CVA/TIA, cerebrovascular accident/transient ischemic attack.

The presence of major comorbid conditions, as documented on the Medical Evidence Report (form CMS 2728) for incident ESRD patients, is shown in Figure 1.18, overall and by age, sex, and race/ethnicity. Overall, 60.6% had DM, 28.4% HF, and 20.8% other cardiac disease. DM was present in nearly two thirds of individuals aged 45-74 years but was less common in younger and older individuals. The major manifestations of cardiovascular disease – HF, atherosclerotic heart disease, PVD, CVA/TIA, and other cardiac disease – were more common among older individuals, as would be expected. Comorbidities varied little by sex. Fully 77.5% of Native American individuals had DM, compared with 57.8% of White individuals. HF was more common in White (31.1%) and Black (29.1%) individuals than in Asian (20.3%), Hispanic (22.4%), Native American (23.3%), or Native Hawaiian/Pacific Islander (24.2%) individuals.

Figure 1.19 Unadjusted prevalence of common cardiovascular diseases in adult patients with ESRD, by treatment modality, 2019



Data source: USRDS ESRD Database. Cohort: January 1, 2019 point prevalent U.S. and U.S. territories ESRD patients aged ≥18 years with Medicare fee-for-service (FFS) coverage. Abbreviations: DM, diabetes mellitus; CVD, cardiovascular disease; HF, heart failure; CAD, coronary artery disease; AMI, acute myocardial infarction; PAD, peripheral artery disease; CVA/TIA, cerebrovascular accident/transient ischemic attack; AF, atrial fibrillation.

The unadjusted prevalence of common cardiovascular diseases was high. In 2019, CVD of any type was present in 77.3% of patients receiving HD, 66.4% of patients receiving PD, and 54.8% of patients with a kidney transplant. As expected, older individuals were more likely to have CVD than younger ones, regardless of kidney replacement therapy modality. The patterns by sex and race/ethnicity were heterogeneous.

Summary

Data presented in this chapter provide reasons for cautious optimism and also for concern. As the U.S. population continues to grow, age, and become more racially and ethnically diverse, there are more total cases of incident ESRD and a corresponding increase in the unadjusted incidence of ESRD. However, adjusted ESRD incidence increased by “only” about one quarter of one percent between 2018 and 2019. Indeed, 2019 was the third consecutive year in which adjusted ESRD incidence was below 390 cases pmp – a level not previously observed in at least two decades. However, despite overall progress, there remains substantial variation in the adjusted incidence of ESRD around the country. Some very large areas of the country have persistently high incidence, including Texas, with an adjusted incidence of 437 pmp, and Southern California, with an incidence of 418 pmp; many other areas have adjusted incidence exceeding 400 pmp. Alarmingly, some HSAs even demonstrate adjusted incidence of 600, 700, or even 800 pmp. Focused efforts in these areas will be key to accomplishing one of the primary objectives of the Executive Order on Advancing American Kidney Health, namely reducing the incidence of ESRD by 25% by 2030.

The growth in ESRD prevalence is a result, primarily, of patients with ESRD living longer. The near-uniform linear increase in the prevalent count (and corresponding increase in the adjusted prevalence) of ESRD is the result of consistent annual growth in prevalence of between 1-2% since 2009. That patients with ESRD are living longer is a welcome development, but the growth of the ESRD population nevertheless represents a burden on the U.S. healthcare system that can be abated only by decreasing ESRD incidence, liberating more patients from dialysis through kidney transplantation, and increasing the use of home-based dialysis modalities over in-center HD.

The high burden of ESRD among Black individuals is striking. For nearly two decades, there had been progress in closing this disparity, but it actually increased between 2018 and 2019. Over the past year, the adjusted incidence decreased by about 2% in White individuals and increased about 2.5% in Black individuals. Indeed, there was an increase in all non-White groups over this period, most strikingly (>4%) in Native American individuals. The disparity in adjusted ESRD incidence between White and non-White individuals is another important target for reducing the national incidence of ESRD during the next decade. A related disparity is in the use of kidney transplantation. White individuals were substantially more likely than individuals of other racial and ethnic groups to receive a preemptive kidney transplant (incident ESRD) and to be living with a functioning kidney transplant (prevalent ESRD).

Although in-center HD remains the most common form of kidney replacement therapy by a wide margin, its use in the prevalent ESRD population has slowly declined, from approximately 65% two decades ago to approximately 61% in 2019. Although the prevalent population receiving HD grew by <2% between 2018 and 2019, the prevalent count receiving PD increased by approximately 8.5% and receiving home HD by approximately 20%. Relatively faster growth of the home dialysis patient population is likely to continue in future years in light of the

Executive Order (U.S. Department of Health and Human Services, 2019) and the recently finalized ESRD Treatment Choices payment model (Centers for Medicare & Medicaid Services, 2021), although the degree to which this growth can be sustained must be carefully monitored. A sustained shift to home-based dialysis would have profound consequences for the dialysis delivery system in the U.S., as there will be a need not only for more accessible home dialysis machines and related equipment but, more profoundly, for nurses trained in PD and home HD, nephrologists who are comfortable prescribing and managing these therapeutic modalities, and an overhaul in the "systems-based approach" to maintenance dialysis that has focused heavily on construction of brick-and-mortar in-center HD units over the past several decades (Wetmore & Collins, 2015).

Pre-ESRD nephrology care remains an area of concern. In every subgroup of incident ESRD patients defined by age, sex, race and ethnicity, less than half of individuals had seen a nephrologist for more than a year prior to requiring kidney replacement therapy – an astonishing figure given that CKD is a chronic disease that usually evolves over years or decades. Here, too, there are marked disparities by race. This is a notable shortcoming of the U.S. healthcare system because lack of pre-ESRD nephrology care is likely to result in poorer transitions to ESRD, including a higher risk of initiating dialysis in the hospital, a higher risk of initiating HD with a catheter, and lower likelihood of selecting a home dialysis modality. The new Kidney Care Choices payment models aim to build a bridge between advanced CKD and ESRD and may be effective in improving preparation for ESRD.

Nearly 4 in 10 individuals had an eGFR ≥10 mL/min/1.73 m^2 at onset of registered ESRD in 2019. A major clinical trial demonstrated that dialysis initiation at higher levels of eGFR did not reduce mortality or improve health-related quality of life (Cooper et al., 2010), and the year of this study's publication appears to have marked the high water mark in terms of percentage of patients starting at eGFRs above 10 ml/min/1.73m^2. However, the increase in the percentage of patients starting ESRD treatment with eGFR <10 ml/min/1.73m^2 that followed the publication of this study was nowhere near as pronounced as the decline that preceded it. As a result, a far higher percentage of patients started ESRD treatment a higher eGFR in 2019 than in 2009, despite good evidence that the shift towards higher eGFR was not beneficial. The USRDS will continue to track this metric to see whether the new ESRD payment models result in a lowering of eGFR at ESRD onset as intended. In addition, a greater understanding of the "bedside" decision-making process that prompts dialysis initiation, such as the role symptoms play in dialysis initiation and which treatments may help delay it, may be required to more fully understand why the mean eGFR has been relatively stable in recent years. The degree of variability in this very fundamental process of deciding when to initiate dialysis and the resulting large differences in the practice of starting patients early (Figure 1.16) suggests that this is an area in which there is substantial room for improvement. Delaying dialysis initiation has the potential to save money and improve patient care, yet there has been little progress in the last decade.

Treatment of anemia is an interesting aspect of pre-ESRD care. The mean hemoglobin among incident ESRD patients in 2019 was 9.3 g/dL, and the prevalence of hemoglobin <9 g /dL at onset of ESRD was over 40% in hundreds of HSAs around the U.S. Moreover, less than 1 in 6 incident ESRD patients had received ESAs prior to initiating kidney replacement therapy despite the large percentage of patients with low hemoglobin. Whether approaches to anemia treatment among patients not requiring kidney replacement therapy change may depend partly on whether hypoxia-inducible factor (HIF) stabilizers are shown to be beneficial in clinical practice.

The USRDS will continue to examine and present trends in ESRD incidence and prevalence; characteristics and treatments of patients with ESRD; and racial and ethnic disparities in ESRD in the 2022 ADR. However, 2019 may represent the end of a period of relative stability. It will be challenging to understand the combined impacts of the COVID-19 pandemic and upcoming changes in payment models in patients with advanced CKD and ESRD.

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