

**2014 USRDS ANNUAL DATA REPORT**  
**Volume 2: End-Stage Renal Disease**



# ESRD in the United States: An Overview of USRDS Annual Data Report Volume 2

## Introduction

As in previous years, Volume 2 of the ADR continues to serve as a source of detailed descriptive epidemiology of end-stage renal disease (ESRD) in the United States (U.S.). In the U.S., registration in the national ESRD database legally requires the completion of the ESRD Medical Evidence Form (CMS 2728, ME). This documentation of new ESRD patients must be submitted to the Centers for Medicare & Medicaid Services (CMS) within 45 days of onset of renal replacement therapy. A copy of the current-use version of this form (2005) is included in the Appendix. An updated version of the CMS 2728 was also released in July 2014, in preparation for the transition from ICD-9 to ICD-10 that will occur on October 1, 2015.

Data collection for many national projects administered by the CMS has been transitioning from paper-based data entry to a fully web-based system. These projects include data to create core metrics and measures, such as the assessment and reporting of provider performance through Dialysis Facility Reports (DFR) and Dialysis Facility Compare (DFC), as well as the Quality Incentive Program (QIP), which ties provider achievement of selected quality targets to Medicare reimbursement. This web-based system is known as the Consolidated Renal Operations in a Web-Enabled Network (CROWNWeb). For Volume 2 of the USRDS Annual Data Report (ADR), the coordinating center has previously relied on data from Medicare claims for its analyses. This year, for the first time, some chapters in Volume 2 include data from CROWNWeb, particularly for analyses pertaining to dialysis adequacy, vascular access (VA) among prevalent hemodialysis (HD) patients, selected anemia measures, and Chapter 8 on ESRD Providers.

There were 114,813 new cases of ESRD reported in 2012, representing a 3.7 percent decrease from the previous year (see Table i.1). Despite this decrease in ESRD incidence, at the end of 2012 there were 636,905

dialysis and transplant patients receiving treatment for ESRD—a 1.3 percent increase from 2011.

The number of new dialysis patients fell by 3.8 percent in 2012, to reach 106,331 individuals. During the same period, approaching 5,200 patients who experienced a graft failure returned to dialysis from transplant, a number similar to the 5,500 reported in 2011. The number of patients restarting dialysis treatment following temporary recovery of kidney function or treatment non-compliance decreased by 7.3 percent—3,608 individuals as compared to 3,894 in 2011. Overall, the CMS Annual Facility Survey showed 115,126 patients starting or restarting dialysis in 2012, a total reduction of 4 percent from 2011 levels of 119,970.

In 2012, 114,813 new dialysis and transplant patients initiated ESRD therapy, for an adjusted incidence rate of 358.6 per million population (see Figure i.1). At the end of 2012, there were 636,905 patients receiving treatment, for an adjusted prevalence of 1,942.9 per million population. Over 450,000 of these patients were being treated with dialysis, while 186,303 had a functioning kidney transplant; 88,638 ESRD patients died during the year. A total of 17,330 transplants were performed during 2012, including 5,617 from living donors.

In 2012, 28,867 patients were added to the transplant waiting lists (kidney and kidney/pancreas, see Table i.2). 81,981 were on the kidney and kidney/pancreas waiting lists at the end of 2011; as shown in Table 1.2, the median time on the wait list is longer for adult patients than for pediatric patients.

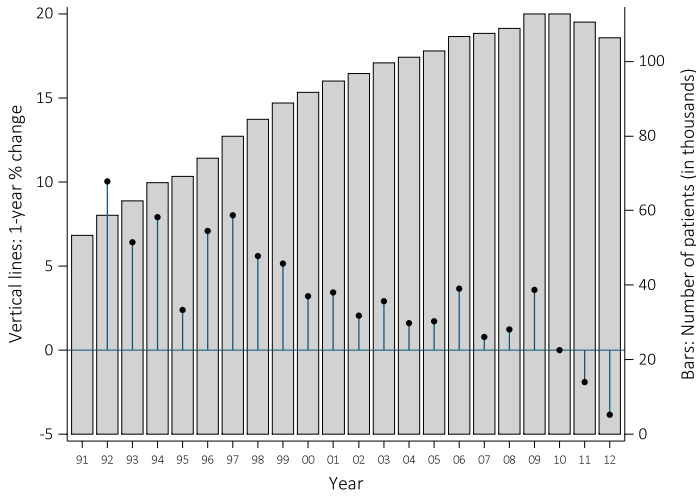
vol 2 Table i.1 Summary statistics on reported ESRD therapy in the United States, by age, race, ethnicity, sex, & primary diagnosis, 2012

	Incidence <sup>a</sup>			December 31 point prevalence							Deceased donor	Living donor	ESRD deaths <sup>d</sup>
	Count	%	Adj. rate <sup>b</sup>	Count	%	Adj. rate <sup>b</sup>	Dialysis <sup>c</sup>	%	Tx <sup>c</sup>	%			
<b>0-19 <sup>e</sup></b>	1,163	1.0	13.1	7,545	1.2	83.1	2,060	0.5	5,485	2.9	549	350	84
<b>20-44</b>	13,162	11.5	122.2	101,994	16.0	938.0	59,045	13.1	42,949	23.1	2,918	1,925	3,929
<b>45-64</b>	45,069	39.3	570.2	283,021	44.4	3,550.1	188,571	41.8	94,450	50.7	5,851	2,549	26,555
<b>65-74</b>	27,933	24.3	1,270.1	140,238	22.0	6,301.8	106,101	23.5	34,137	18.3	1,928	696	24,563
<b>75+</b>	27,486	23.9	1,618.4	104,107	16.3	6,261.1	94,825	21.0	9,282	5.0	247	76	33,507
<b>Unknown age</b>	.	.	.	.	.	.	.	.	.	.	42	21	.
<b>White</b>	76,089	66.3	279.2	383,534	60.2	1,431.8	252,053	55.9	131,481	70.6	6,892	4,450	59,868
<b>Black/African American</b>	31,398	27.3	908.0	200,797	31.5	5,670.5	164,211	36.4	36,586	19.6	3,547	718	23,868
<b>Native American</b>	1,273	1.1	411.5	8,154	1.3	2,599.5	6,310	1.4	1,844	1.0	135	41	1,012
<b>Asian</b>	5,840	5.1	378.9	35,878	5.6	2,271.8	25,230	5.6	10,648	5.7	809	352	3,400
<b>Other</b>	50	0.0	.	5,860	0.9	.	2,515	0.6	3,345	1.8	75	*	490
<b>Unknown</b>	163	0.1	.	2,682	0.4	.	283	0.1	2,399	1.3	77	48	.
<b>Hispanic</b>	17,024	14.8	501.3	106,308	16.7	2,931.9	79,352	17.6	26,956	14.5	1,956	804	11,433
<b>Non-Hispanic</b>	97,789	85.2	340.5	530,597	83.3	1,857.8	371,250	82.4	159,347	85.5	9,579	4,813	77,205
<b>Male</b>	65,842	57.3	446.0	363,497	57.1	2,396.7	252,526	56.0	110,971	59.6	6,973	3,483	49,939
<b>Female</b>	48,971	42.7	278.0	273,312	42.9	1,558.4	198,006	43.9	75,306	40.4	4,520	2,113	38,696
<b>Unknown gender</b>	.	.	.	96	0.0	.	70	0.0	26	0.0	42	21	*
<b>Diabetes</b>	50,534	44.0	154.3	239,837	37.7	731.0	197,079	43.7	42,758	23.0	3,355	1,081	40,795
<b>Hypertension</b>	32,610	28.4	101.1	159,049	25.0	489.4	129,092	28.6	29,957	16.1	2,505	833	24,975
<b>Glomerulonephritis</b>	9,115	7.9	28.3	106,012	16.6	325.8	52,841	11.7	53,171	28.5	2,549	1,679	6,828
<b>Cystic kidney disease</b>	2,530	2.2	7.9	29,881	4.7	92.4	11,526	2.6	18,355	9.9	832	620	1,548
<b>Urologic disease</b>	538	0.5	1.6	7,447	1.2	22.9	3,576	0.8	3,871	2.1	133	91	589
<b>Other known cause</b>	12,281	10.7	38.2	59,714	9.4	184.7	37,458	8.3	22,256	11.9	1,356	783	9,935
<b>Unknown cause</b>	3,506	3.1	10.8	25,977	4.1	78.2	15,883	3.5	10,094	5.4	423	216	3,101
<b>Missing cause</b>	3,699	3.2	10.6	8,988	1.4	18.1	3,147	0.7	5,841	3.1	382	314	867
<b>All</b>	114,813	100.0	353.2	636,905	100.0	1,942.9	450,602 <sup>f</sup>	100.0	186,303	100.0	11,535	5,617	88,638
<b>Unadjusted rate <sup>g</sup></b>			<b>358.6</b>			<b>1,968.2</b>					<b>Total</b>	<b>17,330</b>	<b>transplants<sup>h</sup></b>

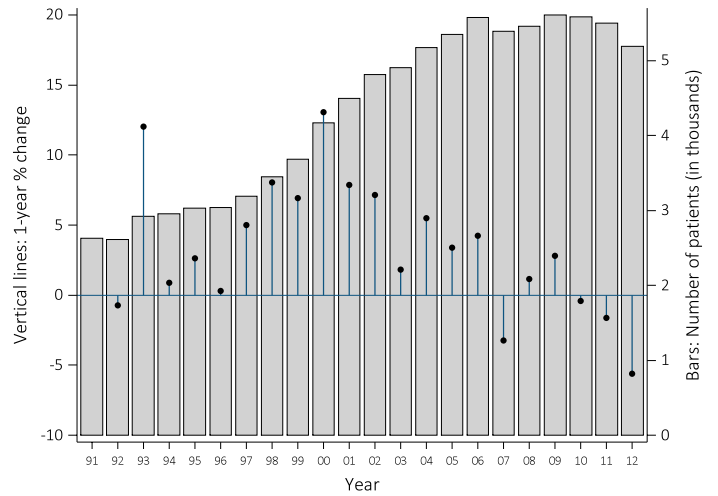
Data Source: Reference tables: A, B, D, E & H. a Incident counts: include all known ESRD patients, regardless of any incomplete data on patient characteristics and of U.S. residency status; b Includes only residents of the 50 states and Washington D.C. Rates are adjusted for age, race, and/or sex using the estimated 2011 U.S. resident population as the standard population. All rates are per million population. Rates by age are adjusted for race and sex. Rates by sex are adjusted for race and age. Rates by race are adjusted for age and sex. Rates by disease group and total adjusted rates are adjusted for age, sex, and race. Adjusted rates do not include patients with other or unknown race. c Patients are classified as receiving dialysis or having a functioning transplant. Those whose treatment modality on December 31 is unknown are assumed to be receiving dialysis. Includes all Medicare and non-Medicare ESRD patients, and patients in the U.S. territories and foreign countries. d Deaths are not counted for patients whose age is unknown. e Age is computed at the start of therapy for incidence, on December 31 for point prevalence, at the time of transplant for transplants, and on the date of death for death. f Includes patients whose modality is unknown. g Unadjusted total rates include all ESRD patients in the 50 states and Washington D.C. h Total transplants as known to the USRDS \* Values for cells with ten or fewer patients are suppressed. . Zero values in this cell. Abbreviations: Adj., adjusted; ESRD, end-stage renal disease; Tx, transplant.

vol 2 Figure i.1 Counts of new & returning dialysis patients, 1991–2012

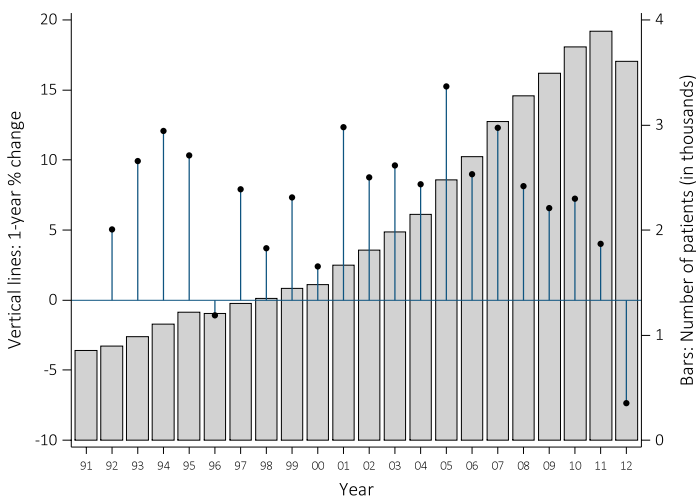
(a) New patients



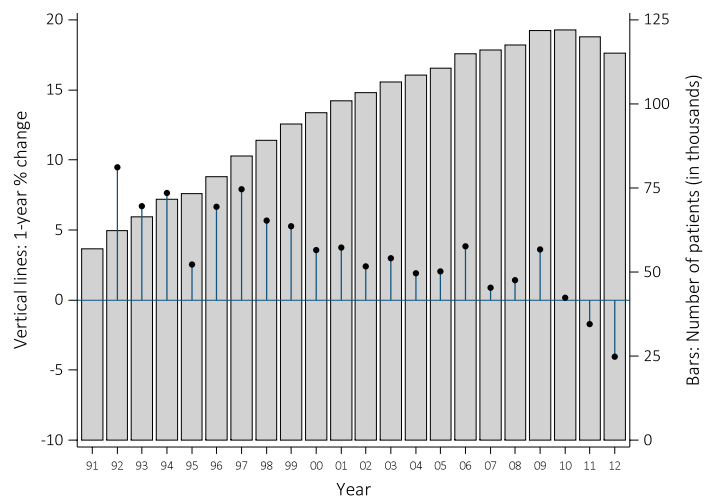
(c) Patients returning from transplant



(b) Patients restarting dialysis



(d) Total patients starting /restarting



Data Source: CMS Form 2744, Annual Facility Survey. Patients restarting dialysis (Panel b) are those who had temporarily recovered kidney function, had discontinued dialysis or had been lost to follow-up but restarted routine dialysis during the survey period.

vol 2 Table i.2 ESRD-certified patients on the waiting list for kidney and kidney/pancreas transplants

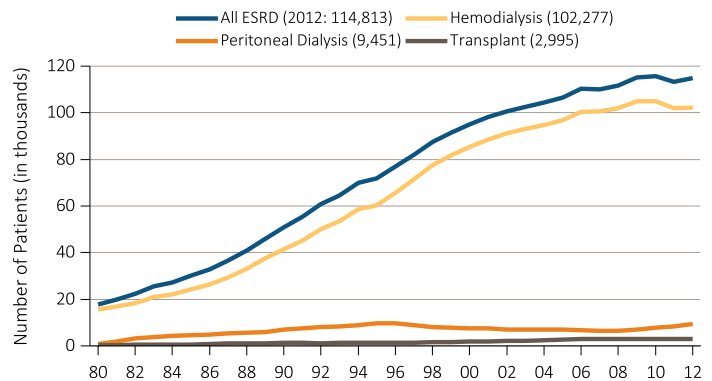
	New listings in 2012	N (as of 12/31/2012)	Median time on list (years) <sup>a</sup>
<b>0-17</b>	633	564	0.30
<b>18-44</b>	8,195	20,547	3.19
<b>45-64</b>	15,336	45,159	3.55
<b>65-74</b>	4,271	14,088	3.76
<b>75+</b>	432	1,623	4.98
<b>Unknown</b>	.	.	.
<b>Male</b>	17,750	49,230	3.21
<b>Female</b>	11,117	32,751	3.53
<b>White</b>	17,537	44,248	2.61
<b>African American</b>	8,895	29,987	4.14
<b>Native American</b>	364	996	4.49
<b>Asian</b>	1,843	6,006	5.21
<b>Other</b>	228	744	4.59
<b>Unknown</b>	.	.	.
<b>Hispanic</b>	5,413	16,080	4.49
<b>Non-Hispanic</b>	23,454	65,901	3.15
<b>Diabetes</b>	10,323	28,240	4.47
<b>Hypertension</b>	6,385	19,764	3.56
<b>Glomerulonephritis</b>	6,061	18,331	2.46
<b>Cystic kidney disease</b>	1,515	4,582	1.92
<b>Urologic disease</b>	273	850	2.47
<b>Other known cause</b>	2,964	7,026	1.33
<b>Unknown cause</b>	877	2,729	2.36
<b>Missing cause</b>	469	459	.
<b>A</b>	9,317	22,964	2.23
<b>B</b>	4,224	13,375	4.20
<b>AB</b>	1,127	2,267	1.36
<b>O</b>	14,199	43,375	4.18
<b>PRA &lt;10%</b>	26,529	67,518	3.04
<b>10% or greater</b>	2,338	14,394	4.33
<b>Unknown</b>	.	69	.
<b>Total</b>	<b>28,867</b>	<b>81,981</b>	<b>3.31</b>

Data source: Reference Table E. a patients listed for a kidney-alone transplant during 2007. \* cells with ten or fewer patients are suppressed. .zero patients in this cell. Abbreviations: A, blood group A; AB, blood group AB, B, Blood group B; ESRD, end-stage renal disease; O, blood group O; PRA, panel reactive antibody.

## Chapter 1: Incidence, Prevalence, Patient Characteristics, and Modalities

Chapter 1 analyses further examine current status and changes for the ESRD cohort, with a longitudinal view of trends over time. As evidenced by the data presented above, while prevalence of ESRD continues to increase, early trends indicate that the ESRD incidence rate may have begun to decrease after having plateaued for many years. This trend is clearer in the adjusted analyses found in Chapter 1 of this volume. The number of incident (newly reported) ESRD cases in 2012 was 114,813 (see Figure i.2). The incidence rate of ESRD per million per year had virtually plateaued, but has declined each year since 2009 to an adjusted incidence rate of 353 per million per year in 2012. This rate was the lowest since 1997.

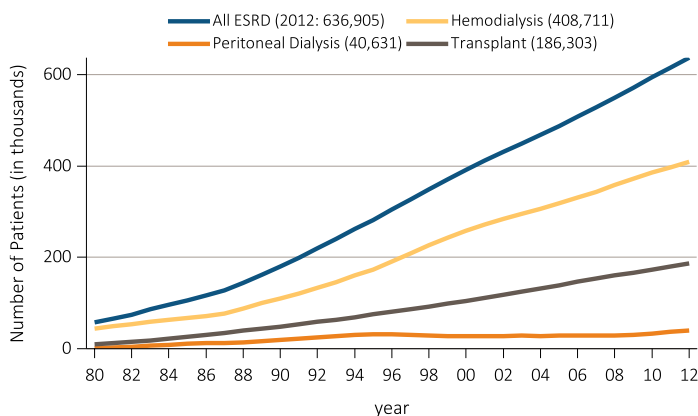
vol 2 Figure i.2 Trends in the number of incident cases of ESRD, in thousands, by modality, in the U.S. population, 1980-2012



Data Source: Reference table D1. Abbreviations: ESRD, end-stage renal disease. This graphic is also presented as Figure 1.1.

It is encouraging to note that the rate of growth of the ESRD prevalent population is slowing; the percentage increase in 2011 and 2012 was the lowest recorded over the last three decades. The size of the prevalent dialysis population (hemodialysis and peritoneal dialysis) increased 3.8 percent in 2012, reaching 449,342, and is now 57.4 percent larger than in 2000 (Figure i.3). The size of the transplant population rose 3.6 percent in 2012 to 186,303 patients, and is now 77.7 percent larger than in 2000.

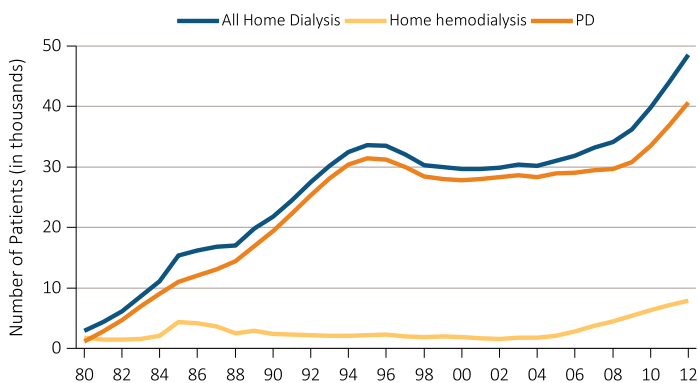
**vol 2 Figure i.3 Trends in the number of prevalent cases of ESRD, in thousands, by modality, in the U.S. population, 1980-2012**



Data Source: Reference table D.1. Abbreviations: ESRD, end-stage renal disease. This graphic is also presented as Figure 1.10.

In 2012, over 90 percent of new patients (98,954) began ESRD therapy with hemodialysis (HD), 9,175 with peritoneal dialysis (PD), and 2,803 received a preemptive kidney transplant (these data exclude patients with missing demographic information). Use of PD and pre-emptive kidney transplant were relatively more common in younger age groups. Use of home dialysis therapies among incident ESRD patients has increased notably in recent years (Figure i.4).

**vol 2 Figure i.4 Trend in the number of prevalent ESRD patients using home dialysis, in thousands, by type of therapy, in the U.S. population, 1980-2012**



Data Source: Reference table: D.1. December 31 prevalent ESRD patients; peritoneal dialysis consists of CAPD & CCPD only. Abbreviations: CAPD, continuous ambulatory peritoneal dialysis; CCPD, continuous cycler peritoneal dialysis; ESRD, end-stage renal disease. This graphic is also presented as Figure 1.18.

## Chapter 2: Healthy People 2020

Chapter 2 provides an analysis of nine of the 14 Healthy People 2020 (HP2020) objectives (15 of 20 indicators) for the improvement of chronic kidney disease (CKD). Positive trends were observed for nearly all the CKD indicators that were examined. For

10 out of 15 indicators, the HP2020 target was met or exceeded, based on the most recently available data.

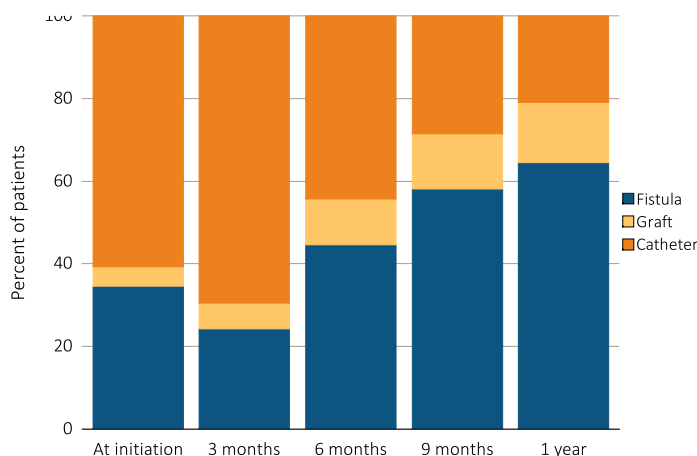
The overall incidence of ESRD remains above the HP2020 target, but has continued to decline steadily since 2009. Rates of pre-ESRD care by a nephrologist continue to improve, with about one-third of patients receiving specialized care at least 12 months before initiation of renal replacement therapy. Notably, nearly all mortality indicators are now meeting HP2020 targets, and we continue to observe favorable trends in overall and cardiovascular mortality among all patients on dialysis, as well as those with a functioning kidney transplant.

## Chapter 3: Clinical Indicators and Preventive Care

Given the high morbidity and mortality of the ESRD population receiving dialysis, quality improvement has long been a priority.

Figure i.5 shows cross-sectional data from both the CMS Medical Evidence Form 2728 (at initiation) and CROWNWeb data (for follow-up data at 3, 6, 9 months and 1 year). At 90 days, most HD patients were still using a catheter, highlighting the importance of ongoing efforts to improve pre-dialysis access planning. At 1 year, 79 percent of patients were using either an arteriovenous fistula or an arteriovenous graft, without the presence of a catheter.

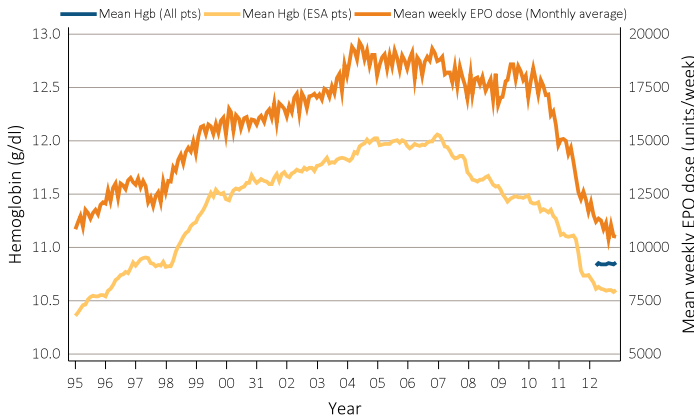
**vol 2 Figure i.5 VA use during the first year of HD by time since initiation of ESRD treatment, among patients new to HD in 2012, from the ESRD Medical Evidence 2728 Form and CROWNWeb data**



Data Source: Special analyses, USRDS ESRD Database and CROWNWeb. ESRD patients initiating HD in 2012. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; VA, vascular access. This graphic is also presented as Figure 3.15.

Mean hemoglobin (Hgb) levels have declined substantially since they peaked near 12.0 g/dL in 2007 in erythropoiesis stimulating agent-treated HD patients (see Figure i.6). Mean weekly erythropoietin (EPO) doses (averaged over a month) have declined substantially (42 percent since 2007) in HD patients. Changes in mean Hgb levels over time have occurred in parallel with concomitant changes in mean EPO dose levels.

**vol 2 Figure i.6 Mean monthly Hgb level and mean weekly EPO dose (monthly average, expressed in units/week) in adult HD patients on dialysis ≥90 days, from Medicare claims: time trend from 1995-2012**



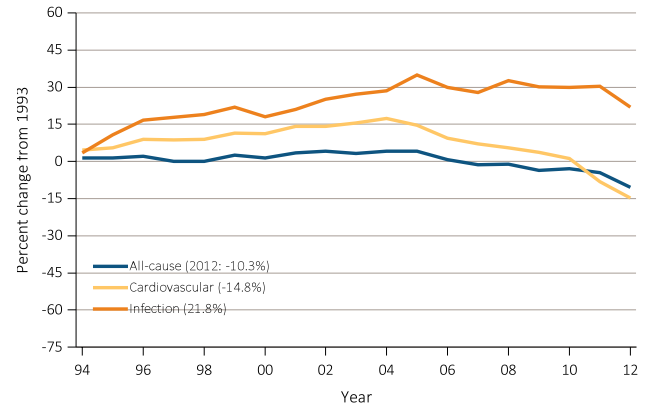
Data Source: Data Source: Special analyses, USRDS ESRD Database. Mean monthly Hgb level among ESA-treated HD patients within a given month (1995 through 2012) or all HD patients irrespective of ESA use (April to December 2012 only) if, within the given month, the patient had an Hgb claim, was on dialysis ≥90 days, and was ≥18 years old at the start of the month. Mean monthly EPO (epoetin alfa) dose among HD patients within a given month who had an EPO claim, were on dialysis ≥90 days, and were ≥18 years old at the start of the month. EPO dose is expressed as mean EPO units per week averaged over all EPO claims within a given month. This graphic is adapted from Figure 3.2.

## Chapter 4: Hospitalization

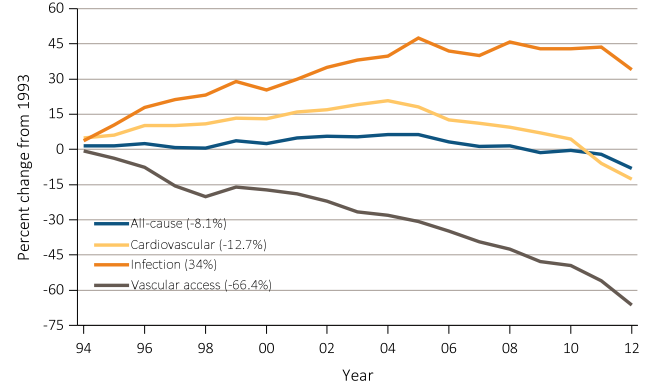
Hospital admissions among ESRD patients represent a significant societal and financial burden, and have a major negative impact on patients' well-being and quality of life. Among HD patients, the overall hospitalization rate in 2012 was 1.73 admissions per patient year—a reduction from 1.84 in 2011, and 1.87 in 2010 (see Figure i.7).

**vol 2 Figure i.7 Trends in adjusted all-cause & cause-specific hospitalization rates, by modality**

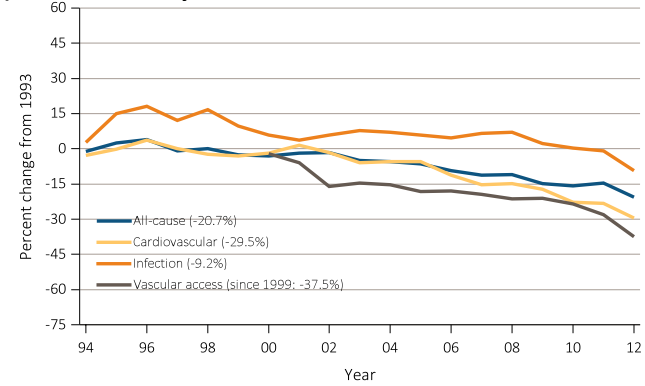
**(a) All ESRD**



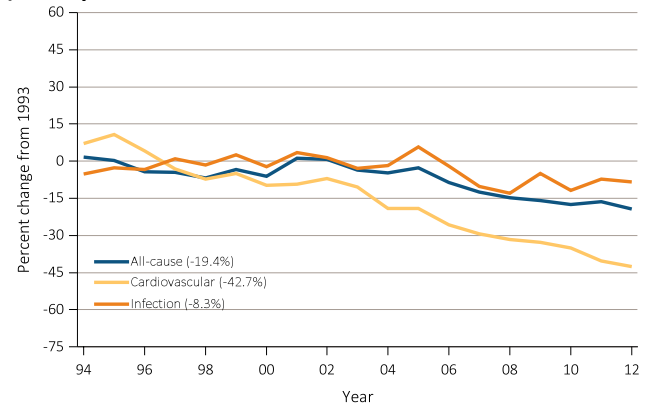
**(b) Hemodialysis**



**(c) Peritoneal dialysis**



**(d) Transplant**

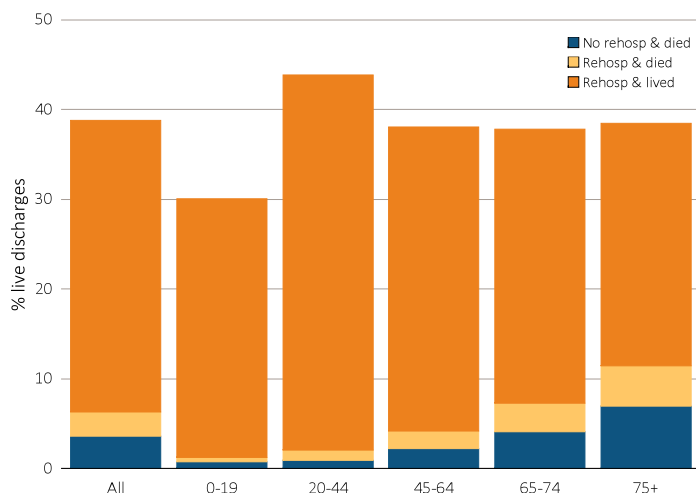


Data Source: Reference tables: G.1, G.3, G.4, G.5, and special analyses, USRDS ESRD Database. Period prevalent ESRD patients; adjusted for age, sex, race, & primary diagnosis; ref: ESRD patients, 2010. Percent changes from 1993 for the year 2012 are shown in parentheses. Abbreviations: ESRD, end-stage renal disease. This graphic is also presented as Figure 4.1.



Rehospitalization is an important indicator of both morbidity and quality of life. It is also often costly, particularly among the ESRD patients being treated in dialysis facilities. Among hemodialysis patients prevalent in 2012, 35.2 percent of discharges from an all-cause hospitalization were followed by a rehospitalization within 30 days (see Figure i.8).

**vol 2 Figure i.8** Rehospitalization or death within 30 days from live hospital discharge, by age, 2012

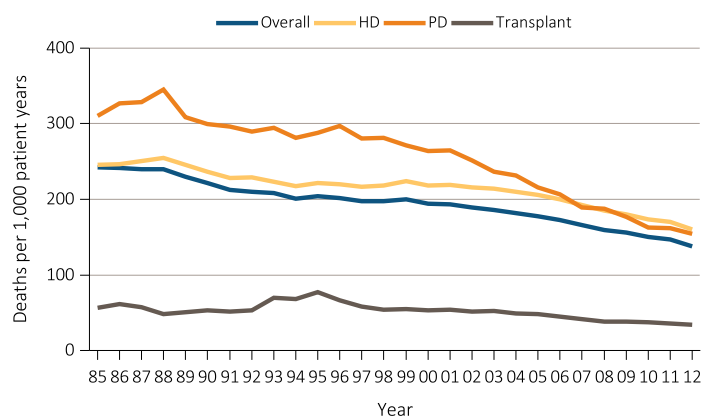


Data Source: Special analyses, USRDS ESRD Database. Period prevalent hemodialysis patients, all ages, 2012; unadjusted. Includes live hospital discharges from January 1 to December 1, 2012. Cause-specific hospitalizations are defined by principal ICD-9-CM codes. See Vol. 2, ESRD Analytical Methods for principal ICD-9-CM diagnosis codes included in each cause of hospitalization category. Abbreviations: ESRD, end-stage renal disease; rehosp, rehospitalization. This graphic is also presented as Figure 4.3.

## Chapter 5: Mortality

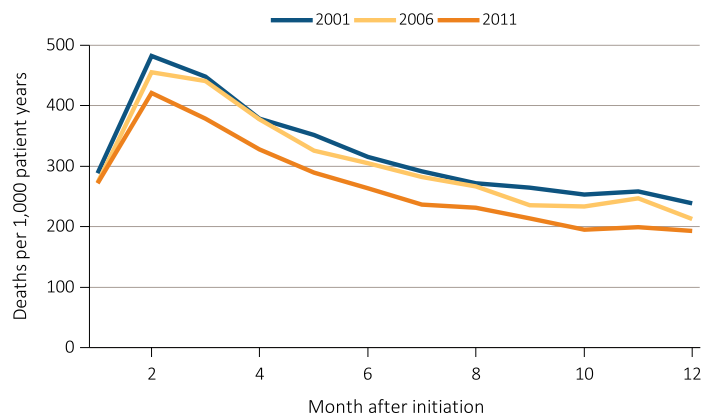
Overall mortality rates among ESRD patients continue to decline. Over the last two decades, the adjusted death rates fell by nine percent from 1993 to 2002, and by 26 percent from 2003 to 2012 (Figure i.9). Since 1993, the net reduction in mortality has been 28 percent for HD patients, 47 percent for PD patients, and 51 percent for transplant patients. In the first year of HD, all-cause mortality, cardiovascular disease mortality, and mortality due to other causes peak in month two, then decrease thereafter (Figure i.10).

**vol 2 Figure i.9** Adjusted all-cause mortality rates, overall and by modality



Data Source: Reference Tables H.2, H.8, H.9, and H.10, and special analyses, USRDS ESRD Database. Adjusted for age, sex, race, and primary diagnosis. Ref: 2011 patients. Abbreviations: HD, hemodialysis; PD, peritoneal dialysis. This graphic is also presented as Figure 5.1.

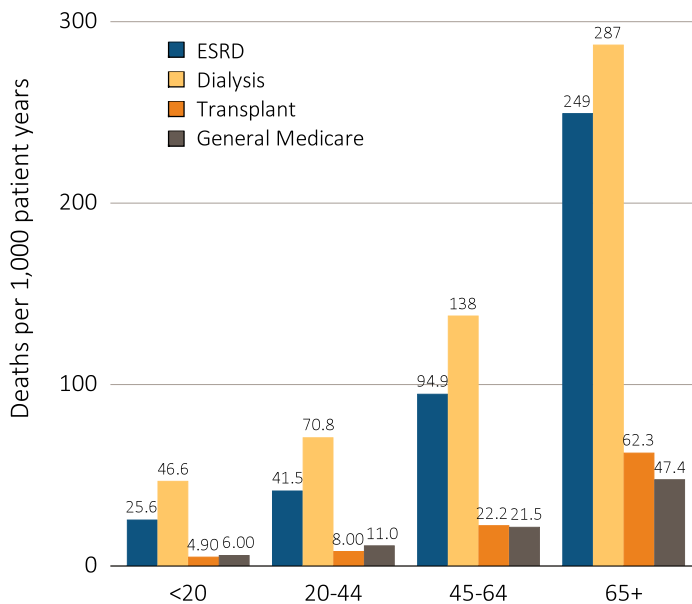
**vol 2 Figure i.10** Adjusted all-cause mortality in the first year of hemodialysis, by year of initiation of dialysis



Data Source: Special analyses, USRDS ESRD Database. Adjusted (age, race, sex, ethnicity, and primary diagnosis) all-cause & cause-specific mortality in the first year of hemodialysis. Ref: incident hemodialysis patients, 2011. This graphic is also adapted from Figure 5.3.

Adjusted rates of all-cause mortality are 6.1 to 7.8 times greater for dialysis patients than for individuals in the general age-matched Medicare population (Figure i.11). Mortality rates rise with age, reaching 287 per 1,000 patient years for dialysis patients aged 65 and older, as compared to 62.3 for transplant patients and 47.4 for the general Medicare population of the same age.

vol 2 Figure i.11 Adjusted all-cause mortality in the ESRD & general populations, by age, 2012



Data Source: Special analyses, USRDS ESRD Database and Medicare 5 Percent Sample. Adjusted for sex and race. Medicare data limited to patients with at least one month of Medicare eligibility in 2012. Ref: Medicare patients, 2012. Abbreviation: ESRD, end-stage renal disease. This graphic is also presented as Figure 5.4.

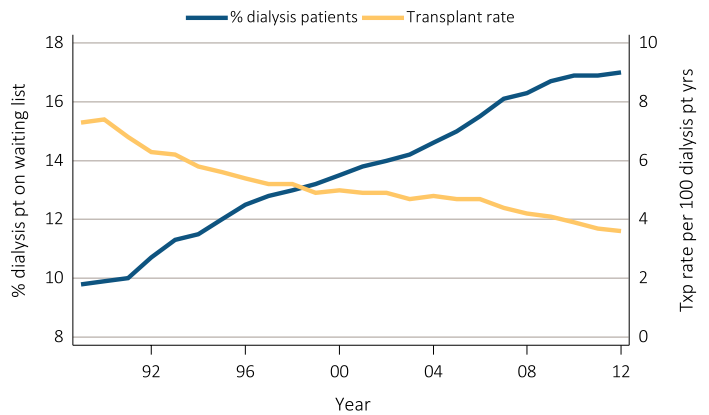
## Chapter 6: Transplantation

The unadjusted transplant rate per 100 dialysis patient years is falling, while the percent of prevalent dialysis patients wait-listed for a kidney has been rising (Figure i.12a). Probable contributing causes include a higher prevalent dialysis population, longer survival of ESRD patients on dialysis, initiation of older and perhaps more ill dialysis patients who are not suitable candidates for transplantation, and the growing mismatch between donor supply and demand which in turn leads to longer kidney transplant waiting times.

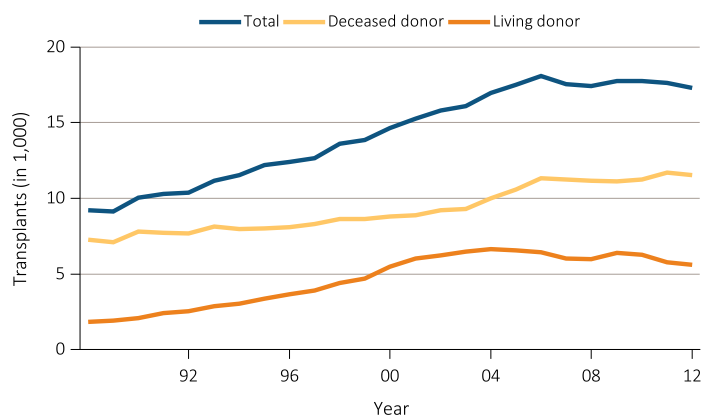
The total number of kidney transplants has leveled off over the past decade (Figure i.12b). During this period, a small overall increase in deceased donation has balanced a small decrease in living donation. The latter is driven in part by changes in pediatric allocation policy that direct deceased donor kidneys from those under the age of 35 years to children.

vol 2 Figure i.12 Trends in transplantation: unadjusted rates, waiting list counts, waiting time, counts of transplants per year.

(a) Percent of dialysis patients wait-listed and unadjusted and transplant rates



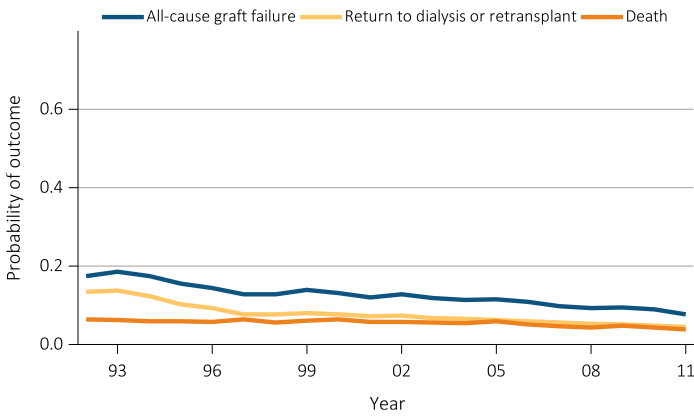
(b) Counts of total transplants



Data Source: Reference Tables E4, E9; E2, E3; E8, E8(2), E8(3); D9. Percent of dialysis patients on the kidney waiting list is for all dialysis patients. Unadjusted transplant rates are for all dialysis patients. Waiting list counts include all candidates listed for a kidney transplant on December 31 of each year. Waiting time is calculated for all recipients enrolled on the waiting list in a given year. Functioning transplant is the annual status on December 31 of each year of all patients who received a kidney transplant, regardless of transplant date. This graphic is adapted from Figure 6.1.

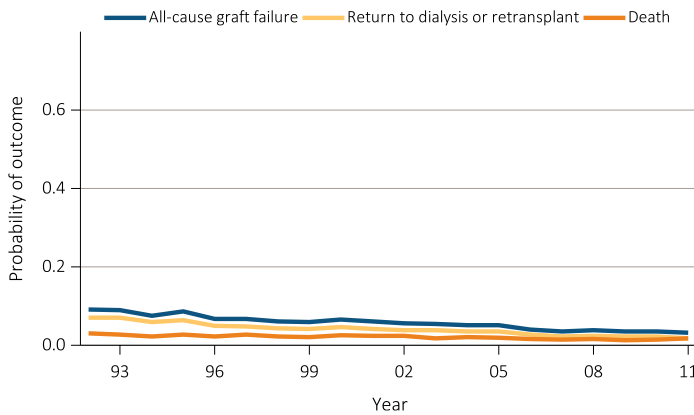
Among recipients of a deceased donor kidney transplant in 2011, the probability of all-cause graft failure (including death with a functioning graft) in the first year following transplant was 0.08, or 92 percent transplant success (Figure i.13), compared to 0.03 (i.e. 97 percent) in those receiving a transplant from a living donor (Figure i.14). The probability of death among the recipients who received a deceased donor kidney transplant in the first year post-transplant was 0.04 (i.e. 96 percent alive; Figure i.13), compared to 0.01 (i.e., 99 percent alive; Figure i.14) in those receiving a living donor transplant.

**vol 2 Figure i.13 Outcomes: deceased donor transplants at one year**



Data Source: Reference Tables F2, F14, I26; F5, F17, I29; F6, F18, I30. Outcomes among recipients of a first-time deceased donor kidney transplant; unadjusted. This graphic is adapted from Figure 6.8.

**vol 2 Figure i.14 Outcomes: living donor transplants at one year**



Data Source: Reference Tables F8, F20, I32; F11, F23, I35; F12, F24, I36. Outcomes among recipients of a first-time live donor kidney transplant; unadjusted. This graphic is adapted from Figure 6.9.

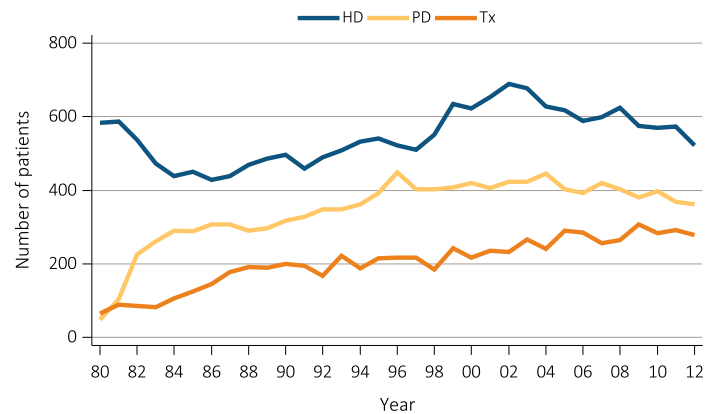
## Chapter 7: Pediatric ESRD

The number of incident pediatric patients with ESRD requiring renal replacement therapy peaked at 1,298 in 2003, and has plateaued at 1,161 in 2012. The prevalent population of pediatric patients with ESRD has also plateaued, with a 1.3 percent decline from 2011 to 2012, totaling 7,522 as of December 31, 2012.

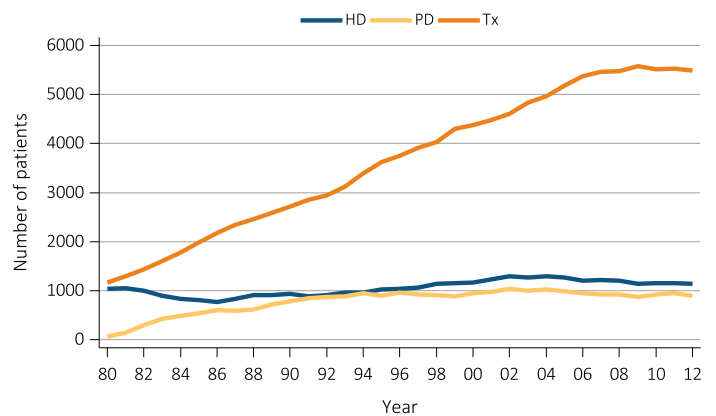
Hemodialysis remains the most common initial modality for renal replacement therapy in pediatric patients, at 45 percent in 2012 (Figure i.15). Kidney transplant patients form the majority of children with prevalent ESRD.

**vol 2 Figure i.15 Incident & December 31 point prevalent ESRD patients (aged 0–19 years)**

**(a) Incidence of ESRD in children (aged 0-19 years)**



**(b) Prevalence of ESRD in children (aged 0-19 years)**

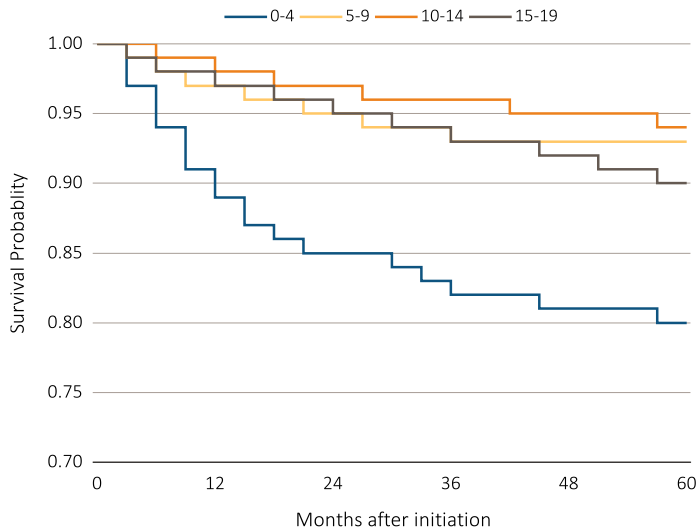


Data Source: Reference tables D3-D5, D7-D9, and special analyses, USRDS ESRD Database. Peritoneal dialysis consists of continuous ambulatory peritoneal dialysis and continuous cycling peritoneal dialysis. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant. This graphic is also presented as Figure 7.1.

For patients starting ESRD therapy in 2003-2007, the probability of five-year survival was 89 percent. Children aged 0-4 years have the lowest probability of survival at 80 percent, when compared with 94 percent in the 0-14 age group and 90 percent of patients aged 15-19 years (Figure i.16).

**vol 2 Figure i.16 Pediatric ESRD patient survival by age and modality (aged 0-19 years)**

**(a) Adjusted 5 year survival in pediatric patients from day 1 by age, 2003-2007**



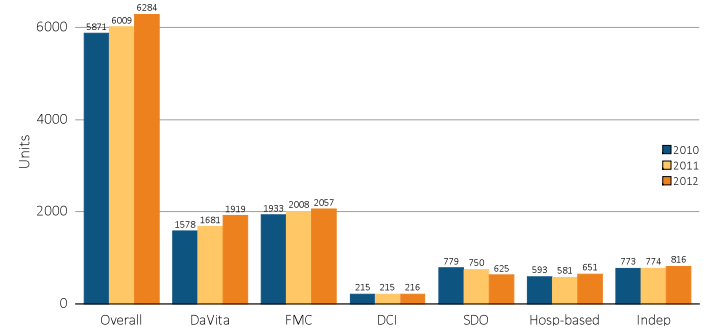
Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2012. Adjusted for age, sex, race, Hispanic ethnicity, and primary diagnosis. Ref: incident ESRD patients age 0-19, 2010-2011. Abbreviations: HD, hemodialysis; PD, peritoneal dialysis, Tx, transplant. This graphic is also presented as Figure 7.11.

## Chapter 8: Providers

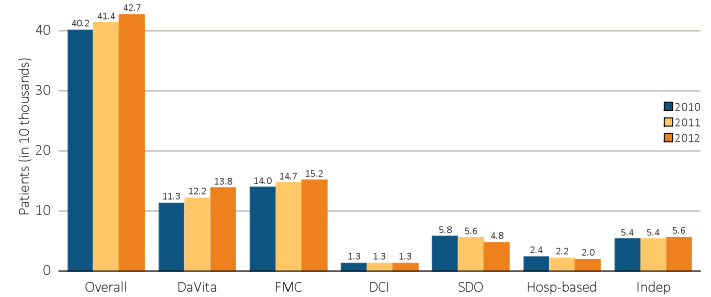
At the end of 2012, there were 6,284 dialysis units in the United States (see Figure i.17). Together, the three large dialysis organizations (LDOs; DaVita, Fresenius [FMC], and Dialysis Clinic, Inc. [DCI]) treated 303,529 patients (71 percent) in 4,192 dialysis units (68 percent). Small dialysis organizations (SDOs) treated 10 percent of patients, whereas independent and hospital-based providers treated 13 and five percent of patients, respectively. Nationwide, 413 dialysis units were added during the three-year period from 2010 to 2012, with most belonging to the LDOs. In the SDOs, the numbers of patients and units continued to decline over the same period.

**vol 2 Figure i.17 Dialysis units & patient counts, by unit affiliation, 2010-2012**

**(a) Dialysis units**



**(b) Patient counts**



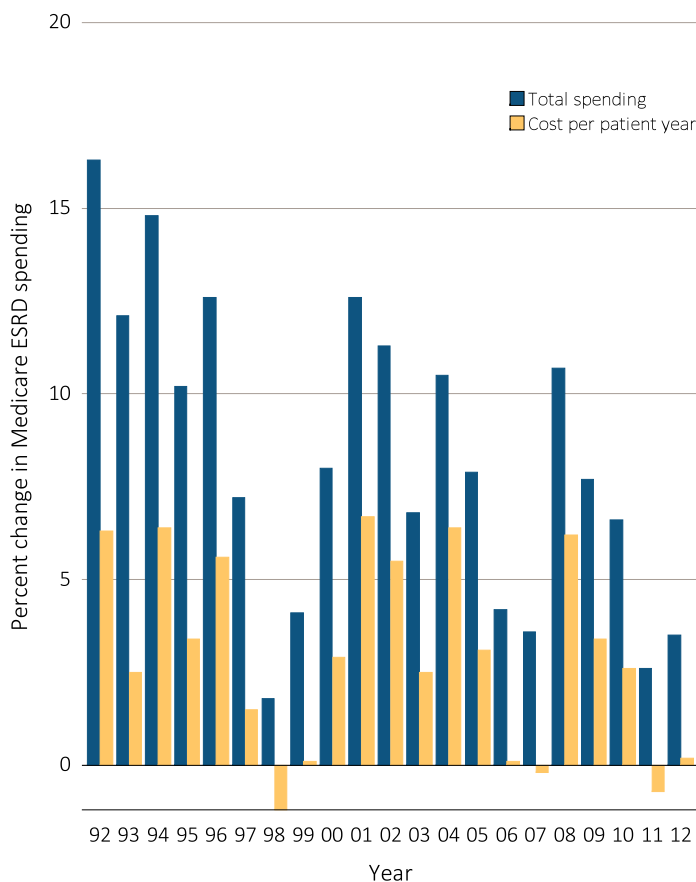
Data source: Special analyses, USRDS ESRD Database. Abbreviations: DCI, Dialysis Clinic, Inc.; FMC, Fresenius; Hosp-based, hospital-based dialysis centers; Indep, independent dialysis providers; SDO, small dialysis organizations. This graphic is also presented as Figure 8.1.

## Chapter 9: Costs of ESRD

Annual percent change in Medicare ESRD spending for all ESRD patients for whom Medicare is either the primary or secondary payer is reported in Figure i.18. Because Part D spending is excluded from these measures, total Medicare spending is not captured for years 2006-2012. However, the exclusion of Part D implies that the spending changes reported in Figure i.18 reflect the costs of a consistent set of services.

Total Medicare paid claims in 2012 were 3.5 percent higher than in 2011 (\$28.6 billion versus \$27.7 billion). An increased number of patients accounted for almost all of the cost growth, as spending per patient, per year was nearly flat (0.2 percent growth) for the second consecutive year.

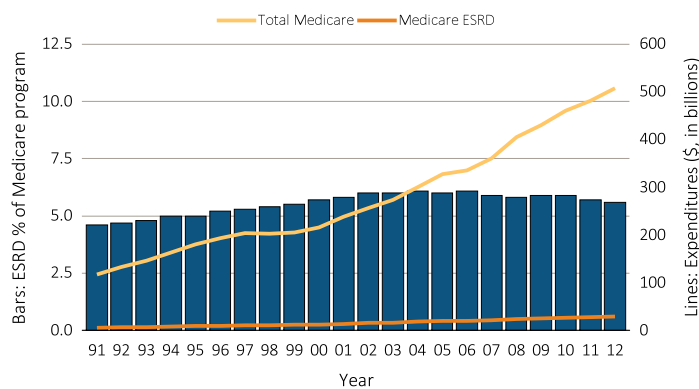
vol 2 Figure i.18 Annual percent change in Medicare ESRD spending



Data Source: USRDS ESRD Database. Total Medicare ESRD costs from claims data; includes all Medicare as primary payer claims as well as amounts paid by Medicare as secondary payer. Abbreviations: ESRD, end-stage renal disease. This graphic is also presented as Figure 9.4.

As illustrated in Figure i.19, total Medicare spending (excluding Part D) rose 5.2 percent in 2012, to \$507 billion; spending for ESRD patients increased 3.2 percent, to \$28.6 billion, accounting for 5.6 percent of the Medicare budget costs (inflated by two percent), including estimated costs for Health Maintenance Organization and organ acquisition. This continues the downward trend in the fraction of Medicare spending attributable to ESRD patients since that share peaked at 6.1 percent in 2006.

vol 2 Figure i.19 Costs of the Medicare & ESRD programs (excluding Part D)



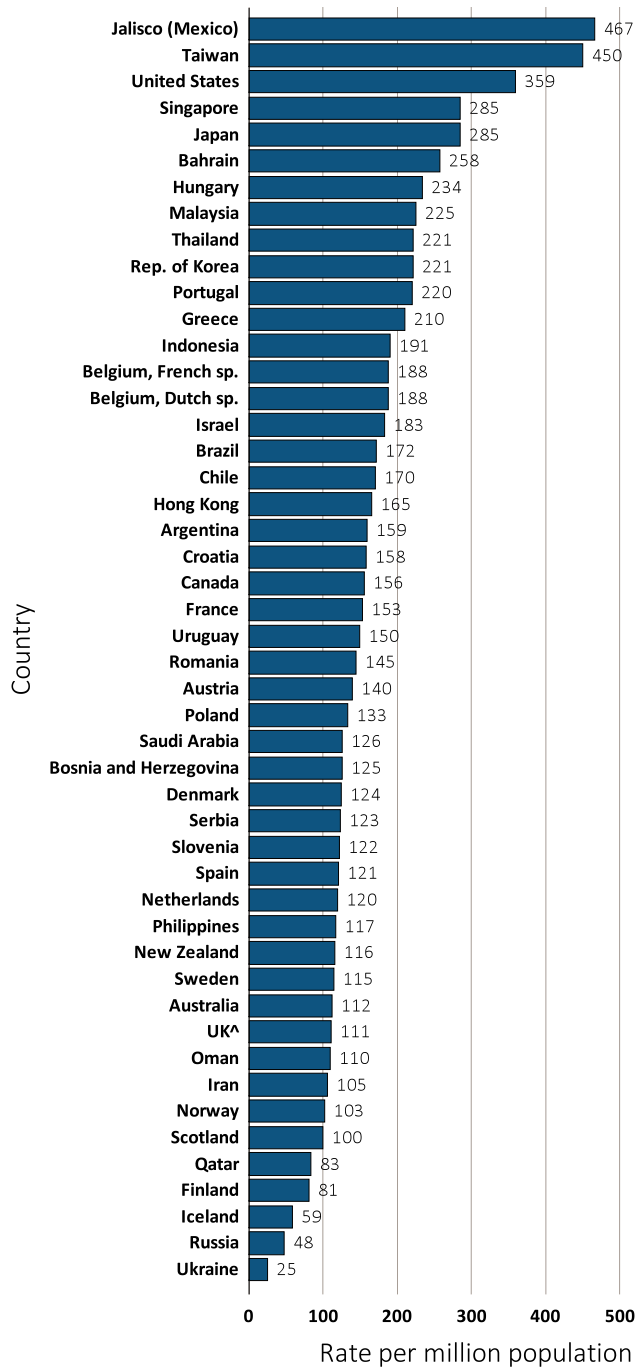
Data Source: USRDS ESRD Database. Total Medicare expenditures obtained from <http://CMS.gov>. Abbreviations: ESRD, end-stage renal disease. This graphic is also presented as Figure 9.2.

## Chapter 10: International Comparisons

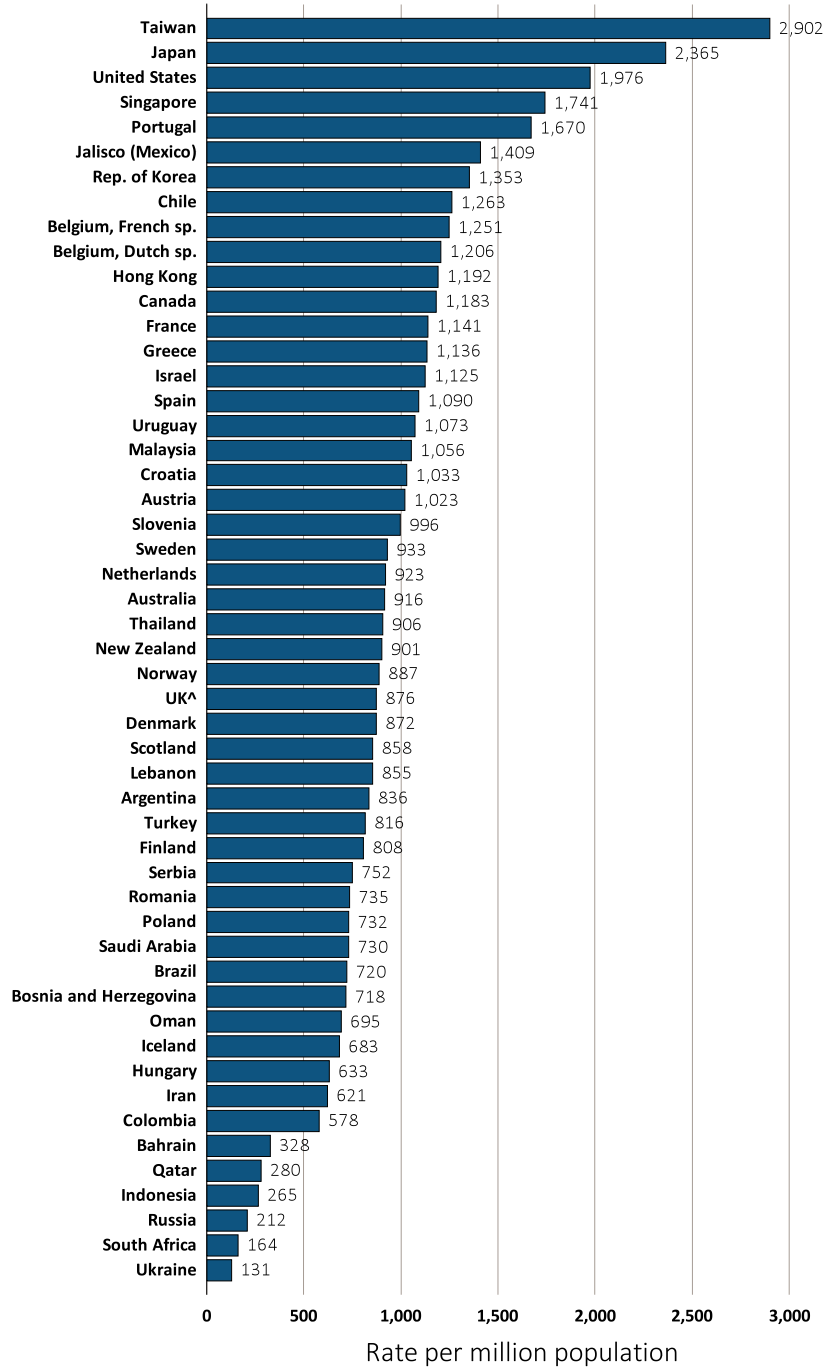
In Chapter 10, we summarize data from the international community, and present a map of ESRD incidence worldwide. We are grateful to the 54 countries and registries sharing this information, allowing us to see the U.S. ESRD community through a wider lens.

In 2012, country ESRD incidence rates varied more than 15-fold, ranging from 25 to 467 new ESRD patients per million population across countries (Figure i.20). In most countries, ESRD incidence rates are highest among elderly patients 75 years or older. The highest rate of ESRD incidence in younger individuals (ages 20-44 years old) was seen in the U.S., at over twice that reported in the great majority of countries with data in 2012.

vol 2 Figure i.20 Incidence rate of ESRD, per million population, by country, in 2012



vol 2 Figure i.21 Prevalence of ESRD, per million population, by country, in 2012



Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. ^UK: England, Wales, Northern Ireland (Scotland data reported separately). Japan and Taiwan are dialysis only. Data for Belgium do not include patients younger than 20. Data for Indonesia represent the West Java region. Data for France include 22 regions. Data for Spain include 18 of 19 regions. Abbreviations: ESRD, end-stage renal disease; sp., speaking. This graphic is also presented as Figure 10.1.

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted and reflect prevalence at the end of 2012; rates for Colombia and Lebanon reflect prevalence at the end of June 2012. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Japan and Taiwan include dialysis patients only. Data for Belgium do not include patients younger than 20. Data for Indonesia represent the West Java region. Data for Spain include 18 of 19 regions. Data for France include 22 regions. Data for Turkey in 2012 was collected with the collaboration of the Ministry of Health, which collects patient-based data; however, in previous years center-based data were reported. This graphic is also presented as Figure 10.5.

Prevalence of ESRD varied more than 20-fold across countries in 2012, from 131 per million population in the Ukraine to 2,902 per million population in Taiwan (Figure i.21). In countries reporting data from 2006 to 2011 or 2012, ESRD prevalence increased across all countries during this time period, ranging from a six percent to 135 percent overall rise.

## Chapter 11: USRDS Special Study Center on Palliative and End-of-Life Care

The limited survival of many patients with ESRD and their very high levels of disability, frailty, and functional impairment provide a strong rationale for efforts to integrate a more palliative and patient-centered approach to their care.

The overarching goal of the USRDS Special Study Center (SSC) on Palliative and End-of-Life Care is to provide the nephrology community with innovative, rigorous, and nationally representative information about a domain of ESRD care for which little information is currently available to guide policy and practice. The SSC will conduct prospective surveys of patients with ESRD, using previously validated instruments, to obtain information and further our understanding of a range of domains related to palliative and end-of-life care.

The SSC will also collect information from family members of patients with ESRD about their level of involvement in the patient's care, the impact of the patient's illness on their own health, and their understanding of the patient's goals and preferences. Ultimately, prospective information collected from patients and family members will be linked to each patient's patterns of health care utilization at the end of their life.

In parallel with these prospective data collection efforts, the SSC will conduct secondary analyses of existing Medicare and USRDS sources to gain a broad understanding of patterns of health care utilization and costs during the final months and years of life for patients with ESRD.

## Chapter 12: USRDS Special Study Center on Transition of Care in CKD

In patients with very-late-stage, non-dialysis dependent (NDD) CKD (eGFR <25 ml/min/1.73 m<sup>2</sup>), the optimal transition of care to renal replacement therapy (RRT) is currently unknown. The overarching goal of the newly funded Transition of Care in Chronic Kidney Disease SSC is to reduce knowledge gaps that have persisted in the area of transitions from advanced CKD to ESRD, specifically to investigate: (1) the best timing for the transition, (2) the optimal modality, and (3) the impact of comorbid conditions and events, including blood pressure and glycemic control, acute kidney injury (AKI) episodes, and management of CKD-specific conditions prior to ESRD. This study proposes to leverage two large longitudinal databases of CKD patients—the national Veterans Affairs database and the regional (Southern California) Kaiser Permanente database, each containing health care data of thousands of CKD patients who transition to ESRD each year. For this year's ADR, the SSC has sought to examine recent cohorts of incident ESRD patients from these databases. In subsequent years (2013-2016), these organizations will examine data from thousands of advanced CKD patients who transition to ESRD.





# Chapter 1: Incidence, Prevalence, Patient Characteristics, and Treatment Modalities

## Introduction

The focus of this chapter is the incidence and prevalence of ESRD in the U.S. population. Incidence refers to the occurrence or detection of new cases of ESRD during a given period; it is expressed in this chapter as a count (number of incident cases) and as a rate (approximated by the number of new cases in one year divided by the mid-year census for the population at risk in that year); rates are then expressed per million population per year. For example, if 3,000 incident ESRD cases occurred in 2012 in a population of 10,000,000 adults, the incidence rate would be 0.000300 per year or 300 per million per year. Incidence is used in etiologic studies to identify risk factors for ESRD and in primary-prevention studies to evaluate the impact of interventions for reducing ESRD risk.

Prevalence refers to the presence of existing ESRD cases at a point in time (point prevalence) or during a specific period (period prevalence; not used in this chapter); it is expressed in this chapter as a count (number of prevalent cases) and as a proportion (number of prevalent cases), divided by the size of the population from which those cases were identified; prevalence at the end of each year is then expressed per million population. Prevalence is used to quantify the need for health care services and to allocate health care resources.

Although prevalence is easier to estimate than incidence, prevalence findings are more difficult to interpret because the prevalence of a condition depends on both the incidence rate of that condition and how long cases live with the condition before dying (or recovering). For example, if something favorable is done to improve survival among ESRD cases without changing the incidence rate, the prevalence of ESRD will increase. On the other hand, if something favorable is done to reduce the ESRD incidence rate without changing the survival of ESRD cases, the prevalence of ESRD will decrease.

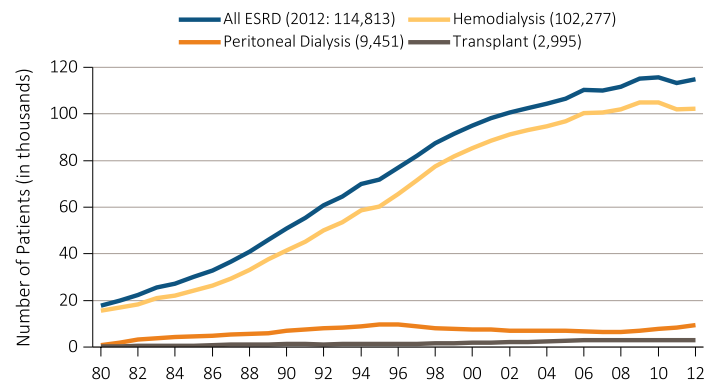
This chapter examines trends in ESRD incidence and prevalence, patient characteristics, and treatment modalities from as early as 1980 through 2012. While the prevalence of ESRD continues to rise, the trend over the past decade indicates that ESRD incidence may have plateaued after increasing for many years. If these incidence and prevalence trends are substantiated in coming years, this would be good news indeed as it implies likely improvements in prevention of ESRD as well as longer survival among patients who have reached ESRD. Special studies are required to identify specific determinants of these changes.

## Incident ESRD: Trends in Counts and Rates

### Overall

The number of incident (newly reported) ESRD cases in 2012 was 114,813 (Figure 1.1). After a year-by-year rise in this number over three decades from 1980 through 2010, it now appears to have plateaued or declined slightly, with the number of incident ESRD cases lower in both 2011 and 2012 than in 2010.

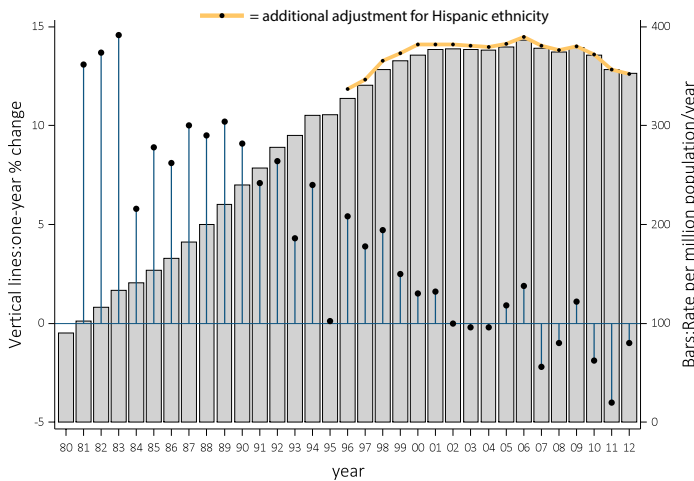
**vol 2 Figure 1.1 Trends in the number of incident cases of ESRD, in thousands, by modality, in the U.S. population, 1980-2012**



Data Source: Reference table D1. Abbreviation: ESRD, end-stage renal disease.

The incidence rate of ESRD per million/year virtually plateaued beginning in 2000, and has declined each year since 2009 to an adjusted incidence rate of 353 per million/year in 2012 (Figure 1.2). This rate was the lowest since 1997. These findings provide further indication that the sustained rise in ESRD incidence through the 1980s and 1990s, both counts and rates, has not continued. Future analyses are needed to assess the causes of these trends.

**vol 2 Figure 1.2 Trends in the adjusted\* incidence rate of ESRD, per million/year (bars; scale on right), and annual percent change in the adjusted\* incidence rate of ESRD (lines; scale on left) in the U.S. population, 1980-2012**

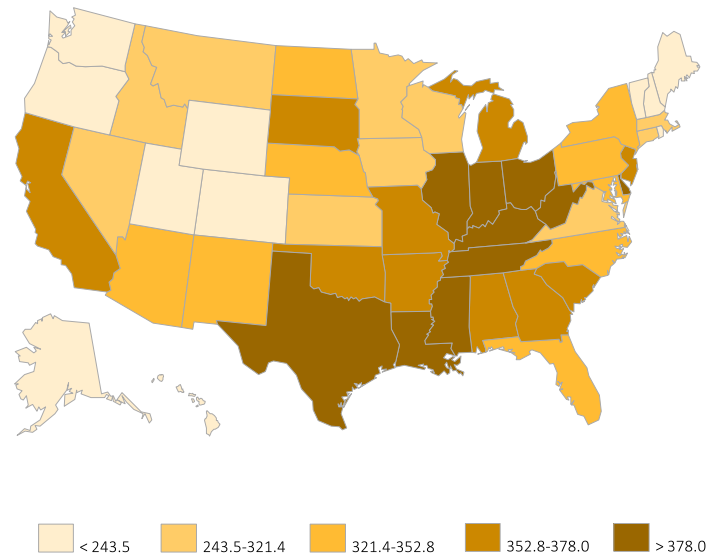


Data Source: Reference tables A.2(2) and A.2(3). \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

### Incidence of ESRD: By Geographic Region

In 2012, the adjusted incidence rate of ESRD varied by over 50% from the lowest to the highest quintile of states (Figure 1.3). Incidence counts and rates for each state are provided in reference tables A.8 and A.9. The rates were generally highest in the Ohio and Mississippi River valleys and Texas, and lowest in New England, the Northwest, and certain Rocky Mountain states.

**vol 2 Figure 1.3 Map of the adjusted\* incidence rate of ESRD, per million/year, by state, in the U.S. population, 2012**



Data Source: Reference table A.9, and special analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

Variation in ESRD incidence rates among the 18 ESRD Networks remains substantial (Table 1.1). Adjusting for differences in age, sex, and race, the lowest rate was 256 per million/year in Network 1 (ME, NH, RI), while the rate in Network 14 (TX) was 66% higher at 426 per million/year.

Among incident ESRD patients, mean age varied by nearly 5 years from 60.3 years in Network 14 to 65.0 years in Network 4. The distribution of race continues to vary widely across Networks. Blacks/African Americans constitute fewer than 10% of all incident patients in Networks 15 and 16, but nearly 50% in Networks 5 and 8 and 54 percent in Network 6. Hispanics constitute fewer than 5% of patients in eight networks, but approximately 40% in Networks 3, 14, and 18.

### Incidence of ESRD: By Age

The number of incident ESRD cases per year among children and among adults ages 20-44 has been generally stable for the past two decades (Figure 1.4.a.). By contrast, for age 45 and over, the number of incident ESRD cases per year had been rising for many years, with especially dramatic increases for age 65 and over. However, these trends appear to have plateaued over the past two to three years; additional follow-up is needed to confirm these findings.

vol 2 Table 1.1 Adjusted\* incidence rate of ESRD, per million/year, and percentage distribution of diabetes, race and ethnicity among incident ESRD patients, by ESRD network, 2012

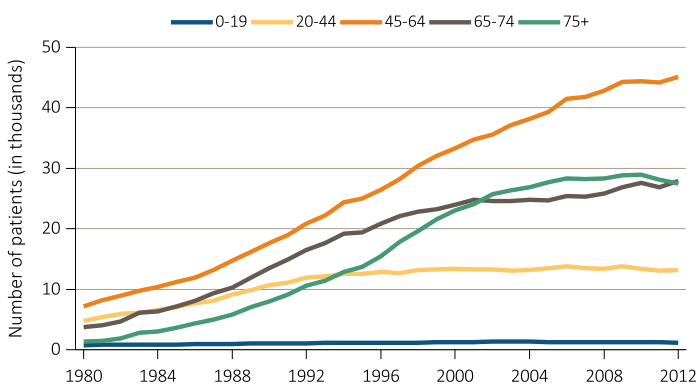
Network	States in Network	Total patients	% of total	Rate per million/year	Mean age	% Diabetic	Race				Ethnicity
							% White	% Af Am	% N Am	% Asian	% Hisp
1	CT, MA, ME, NH, RI VT	3,654	3.2	256.4	64.1	39.2	82.4	14.5	0.2	2.8	9.6
16	AK, ID, MT, OR, WA	3,380	2.9	269.3	61.7	43.2	82.4	6.1	3.4	8.0	7.8
15	AZ, CO, NV, NM, UT, WY	5,337	4.6	301.5	61.1	47.6	78.1	8.3	8.8	4.5	24.3
7	FL	7,444	6.5	319.5	64.2	39.6	67.8	30.0	0.2	2.0	15.4
2	NY	6,964	6.1	325.7	64.1	43.2	63.0	30.5	0.3	6.1	14.3
6	NC, SC, GA	9,918	8.6	328.0	60.6	40.4	44.0	53.7	0.7	1.5	2.3
5	MD, DC, VA, WV	6,596	5.7	334.7	62.5	39.3	50.6	45.9	0.1	3.2	2.7
12	IA, KS, MO, NE	4,229	3.7	336.9	63.3	40.4	76.6	21.0	0.8	1.5	4.5
11	MI, MN, ND, SD, WI	7,151	6.2	337.5	63.2	39.9	71.8	22.7	2.8	2.5	3.7
4	DE, PA	5,130	4.5	341.0	65.0	41.5	74.7	23.7	0.1	1.5	3.8
17	N. CA, HI, GUAM, AS	5,792	5.0	358.5	62.4	49.0	56.3	11.6	0.6	31.3	20.2
8	AL, MS, TN	6,310	5.5	364.4	61.2	43.0	51.0	47.6	0.4	0.9	1.4
3	NJ, PR	5,092	4.4	366.7	63.9	49.5	71.5	24.7	0.0	3.6	38.7
13	AR, LA, OK	4,651	4.1	372.4	61.3	44.1	56.1	38.8	3.9	1.1	3.3
10	IL	5,210	4.5	395.5	63.6	38.4	64.7	30.9	0.3	3.9	12.3
9	IN, KY, OH	9,152	8.0	404.0	63.3	44.5	76.6	22.2	0.1	1.1	2.4
18	S. CA	8,816	7.7	420.4	62.8	48.8	72.9	12.3	0.5	13.9	41.3
14	TX	9,800	8.5	426.4	60.3	54.7	73.6	23.5	0.2	2.6	40.9
All		114,813	100.0	353.2	62.5	44.0	66.3	27.4	1.1	5.1	14.8

Data Source: Reference table: A.10, A.11, and Special Analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Listed from lowest to highest rate per million/year. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; Hisp, Hispanic; N Am, Native American.

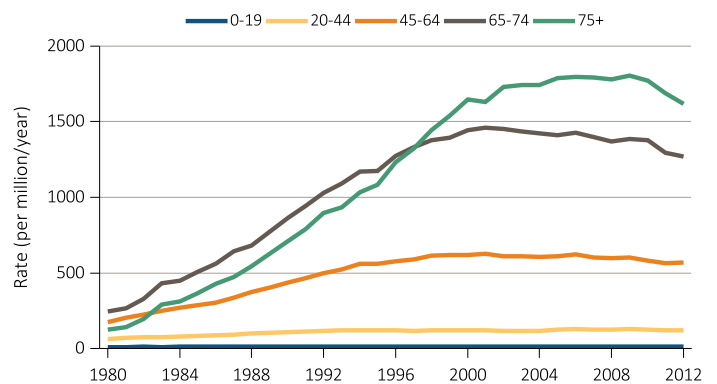
Across age groups, ESRD incidence rates have been generally stable or fallen for a decade or more (Figure 1.4.b). Dramatic declines have been seen recently in the oldest age groups: among ages 65-74 the ESRD incidence rate is the lowest since 1995; and among age 75 and over, the rate is the lowest since 1999.

vol 2 Figure 1.4 Trends in (a) ESRD incident cases, in thousands, and (b) adjusted\* ESRD incidence rate, per million/year, by age group, in the U.S. population, 1980-2012

(a) Incident cases



(b) Incidence rates



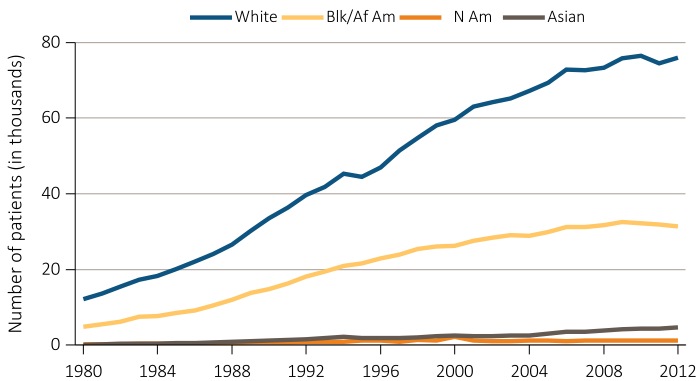
Data Source: Reference tables A.1, A.2(2). \*Adjusted for sex and race. The standard population is the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

### Incidence of ESRD: By Race and Ethnicity

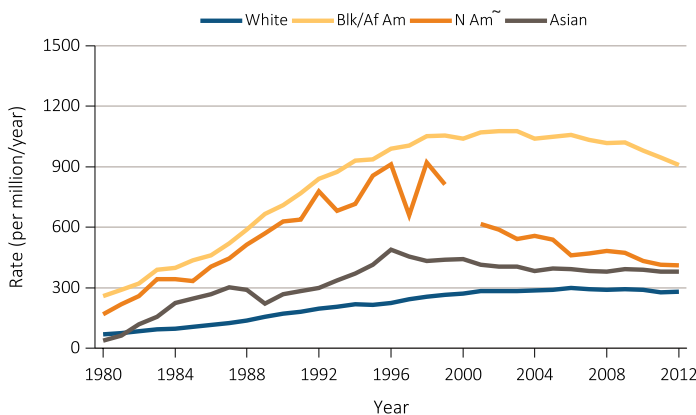
The number of incident ESRD cases per year had been rising since 1980 across racial groups, but has plateaued over the past two to five years among Whites, Blacks/African Americans, and Native Americans (Figure 1.5.a). Among Asians, the number of incident ESRD cases appears to still be rising.

**vol 2 Figure 1.5 Trends in (a) ESRD incident cases, in thousands, and (b) adjusted\* ESRD incidence rate, per million/year, by race, in the U.S. population, 1980-2012**

**(a) Incident cases**



**(b) Incidence rates**



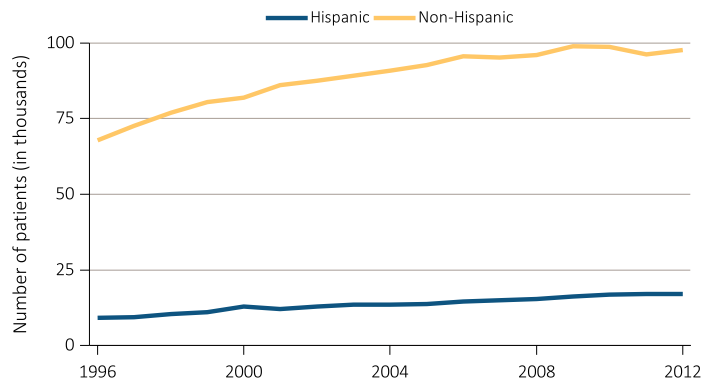
Data Source: Reference tables A.1, A.2(2). \*Adjusted for age and sex; the standard population was the U.S. population in 2011. Panel b: ~Estimate shown is imprecise due to small sample size and may be unstable over time. The line for Native Americans has a discontinuity because of unreliable data for that year. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; N Am, Native American.

The ESRD incidence rates for Blacks/African Americans and Native Americans increased dramatically from 1980 to about 2000 (Figure 1.5.b). Then the rates in both groups leveled off and have declined in the most recent years. In contrast, the rate for Whites increased less dramatically until about 2000, and has been stable through 2012. While Black/African American and Native American racial groups have had much larger declines in ESRD incidence rates than White and Asian groups in recent years, the absolute rates are still much higher. Specifically, the adjusted incidence rates for Blacks/African Americans and Native Americans were 3.3 and 1.5 times greater, respectively, than for Whites in 2012.

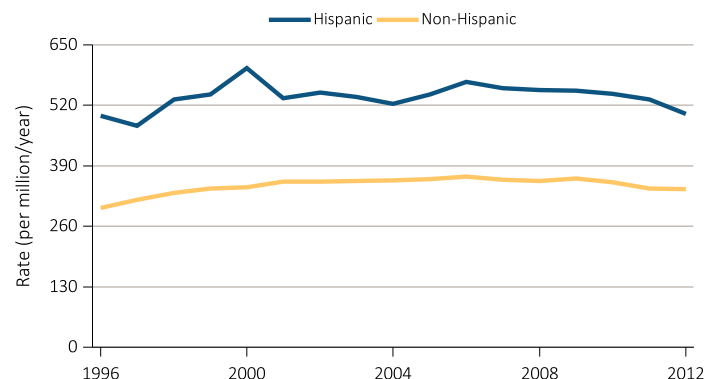
Among both Hispanic and non-Hispanic populations, the number of incident ESRD cases per year had been rising since data were first available in 1997, but it has been stable for the past two to four years (Figure 1.6.a). For both groups, ESRD incidence rates were stable since around 2000 and have declined over the last several years (Figure 1.6.b). However, the ESRD incidence rate remains nearly 50% higher among Hispanics than in the non-Hispanic population.

**vol 2 Figure 1.6 Trends in (a) ESRD incident cases, in thousands, and (b) adjusted\* ESRD incidence rate, per million/year, by Hispanic ethnicity, in the U.S. population, 1996-2012**

**(a) Incident cases**



**(b) Incidence rates**



Data Source: Reference tables A.1, A.2(3). \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

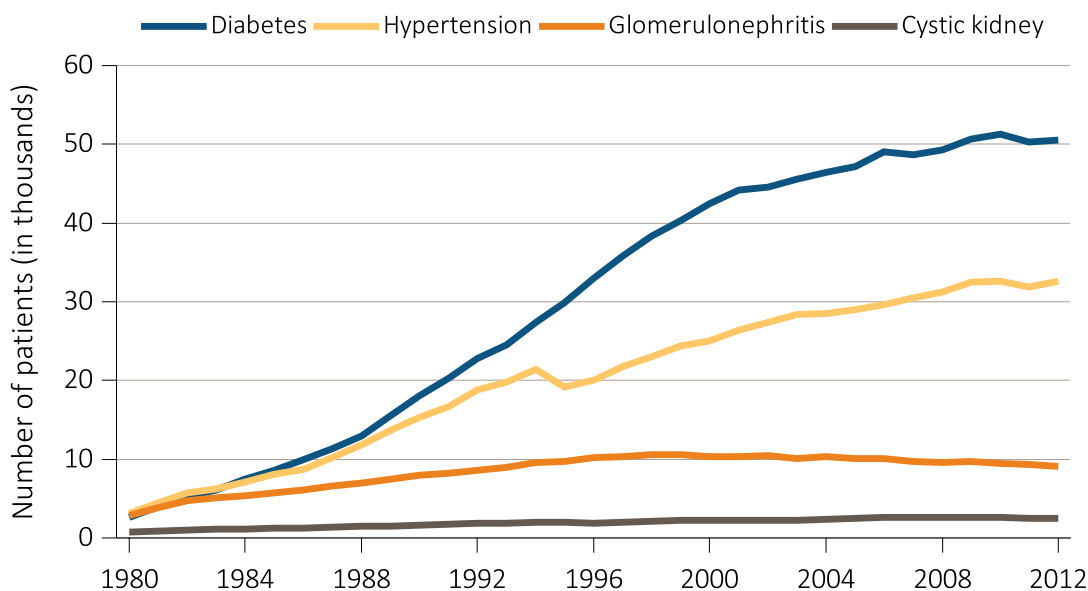
### Incidence of ESRD: By Primary Diagnosis

The number of incident ESRD cases per year with diabetes or hypertension listed as the primary cause had been rising rapidly since 1980, but each have now declined over the most recent two years, from 2010 to 2012 (Figure 1.7.a). The number with glomerulonephritis as the primary cause of ESRD has declined since the 1990s, while the number with cystic kidney disease as the primary cause has been generally stable over this period.

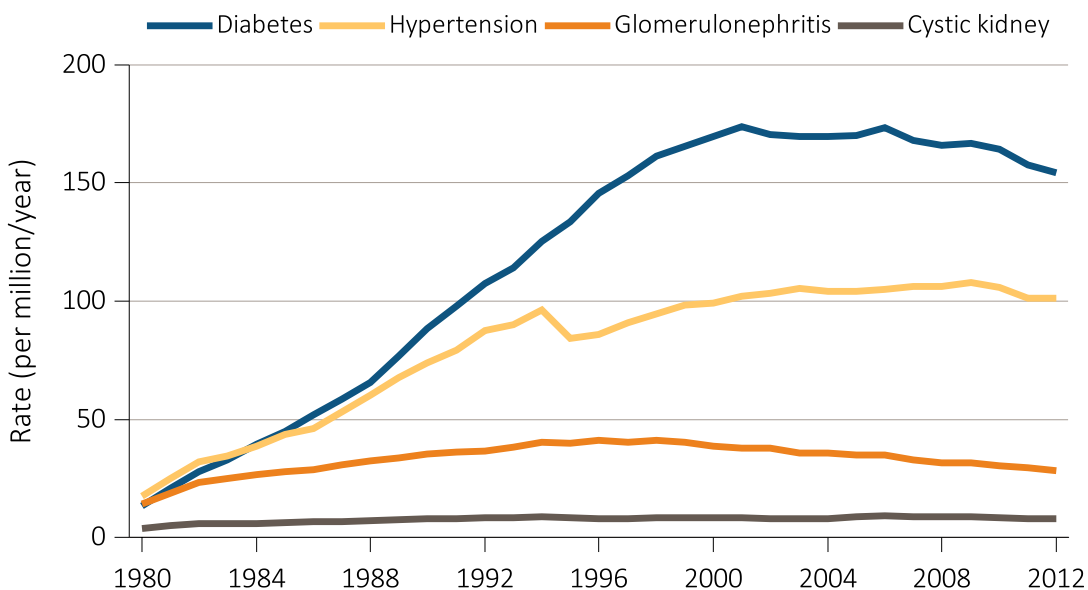
The rate of new ESRD cases with diabetes listed as the primary cause has declined since 2006, with the lowest rate in 2012 since 1997 (Figure 1.7.b). The rate with ESRD due to hypertension peaked in 2009, and in 2011 and 2012 was the lowest since 2000. The rate due to glomerulonephritis has fallen since the 1990s, while the rate due to cystic disease has remained stable.

vol 2 Figure 1.7 Trends in (a) ESRD incident cases, in thousands, and (b) adjusted\* ESRD incidence rate, per million/year, by primary cause of ESRD, in the U.S. population, 1980-2012

#### (a) Incident cases



#### (b) Incidence rates



Data Source: Reference tables A.1, A.2(2). \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

## ESRD incidence rates by primary cause of ESRD

### Diabetes as primary cause of ESRD

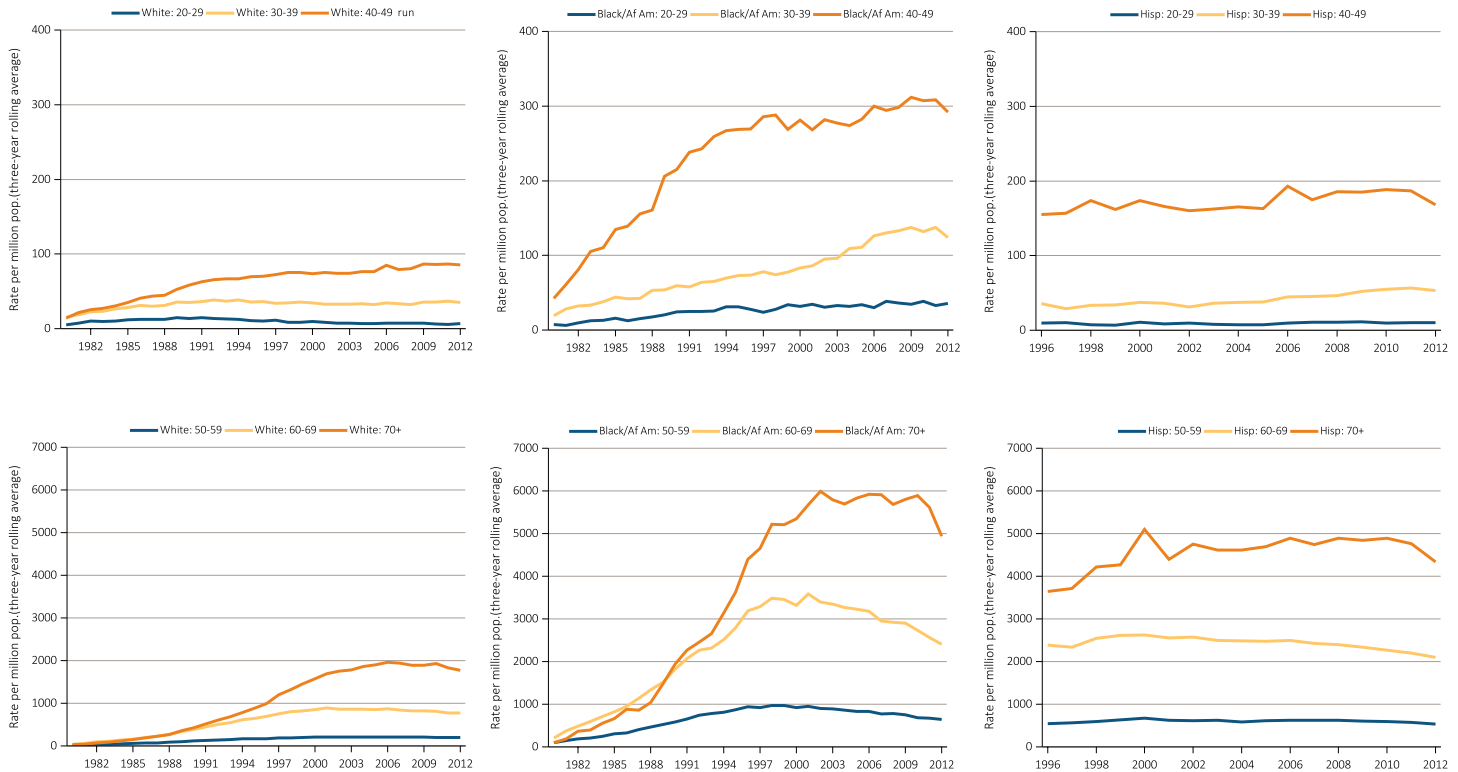
The incidence rate of ESRD due to diabetes is higher with increasing age in all racial groups, as expected (Figure 1.8). These rates have been generally stable or risen slightly in recent years among younger individuals, but they have declined in older individuals in most racial groups.

Incidence rates of ESRD due to diabetes were several-fold higher in Blacks/African Americans, compared to Whites, within each age group category. These racial differences in the incidence rate of ESRD due to diabetes are generally similar to those seen for overall ESRD incidence.

Among Hispanics, the incidence rates of ESRD due to diabetes are comparable to Whites for age groups <40, but much higher than for Whites for age groups 40+. Incidence rates among Hispanics are lower than the rates in Blacks/African Americans.

Racial/ethnic variations in trends in incidence rates of ESRD due to diabetes are also apparent. For example, among Whites ages 30–39, the sex-adjusted incidence rate increased by 1.7 percent from 2000 to 2012. For Blacks/African Americans age 30–39, the rate increased by 33.0 percent over the same period. This rate is now three-and-half fold higher among Blacks/African Americans than among Whites.

**vol 2 Figure 1.8 Trends in the sex-adjusted incidence rate\* of ESRD due to diabetes as the primary cause, per million/year, by age, race, and ethnicity, in the U.S. population, 1980-2012**



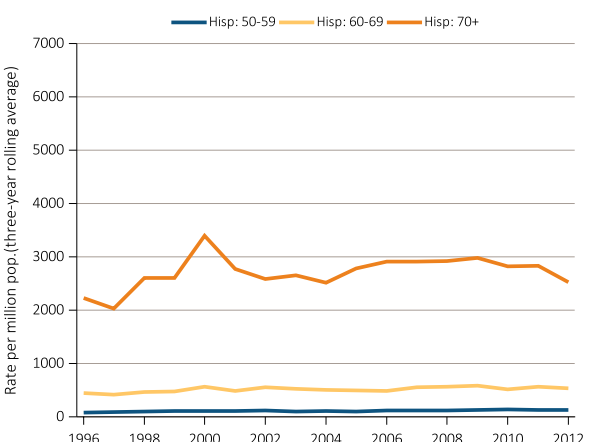
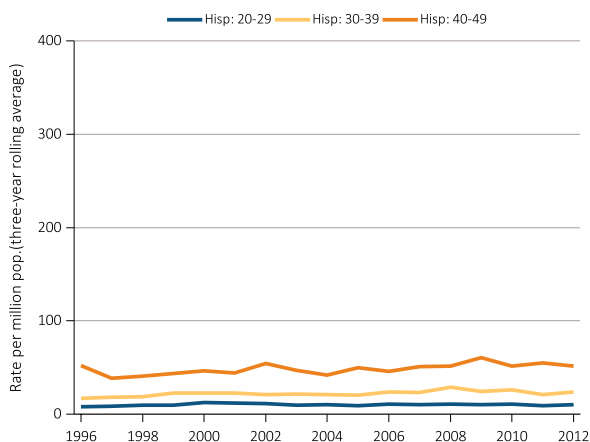
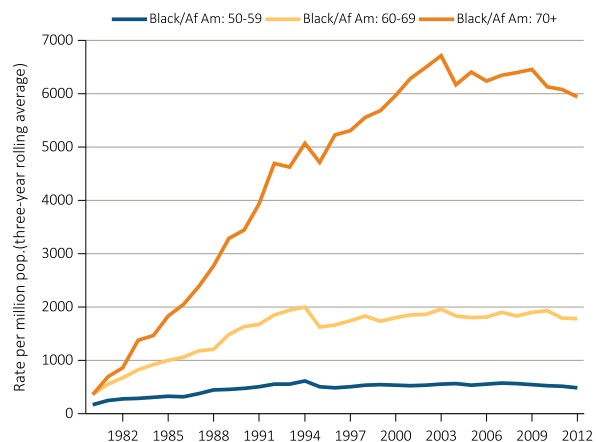
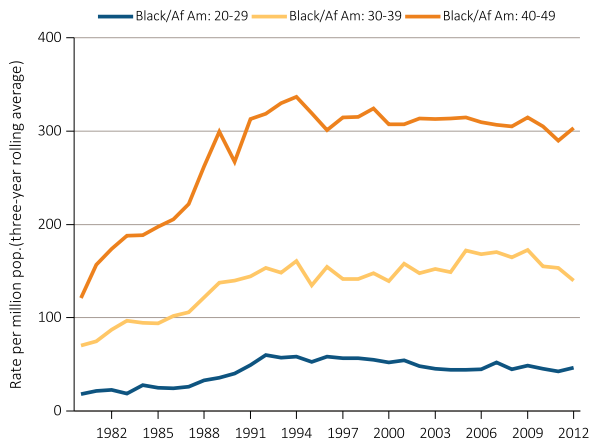
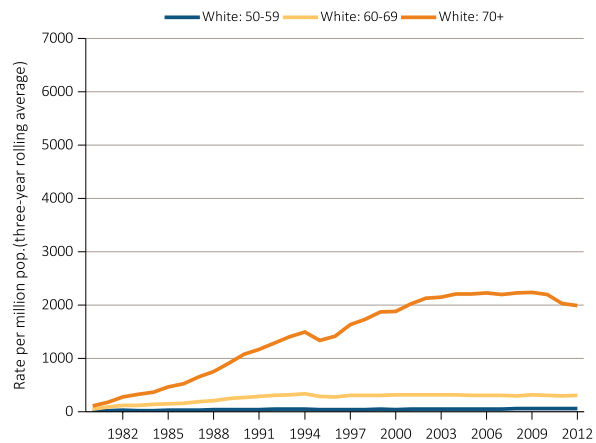
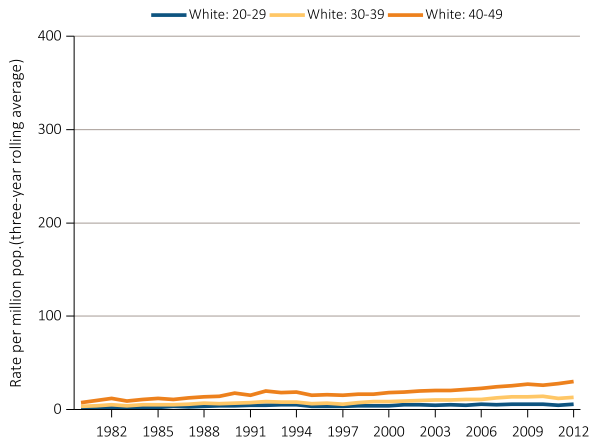
Data Source: Special analyses, USRDS ESRD Database. \*Rates are based on three-year rolling averages, and they are adjusted for sex. The standard population is the U.S. population in 2011. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; Hisp, Hispanic.

### Hypertension as primary cause of ESRD

Within each age category, the incidence rates of ESRD due to hypertension (i.e., hypertension identified as primary cause of ESRD) are dramatically higher among Blacks/African Americans than among all other racial/ethnic groups. Incidence rates have

generally been stable or fallen among Blacks/African Americans across age groups since 2000, but they are still over ten-fold higher than for Whites in younger age categories, and two-and-half-fold higher than for Whites at age 70 and over.

**vol 2 Figure 1.9 Trends in the sex-adjusted incidence rate\* of ESRD due to hypertension as the primary cause, per million/year, by age and race/ethnicity, in the U.S. population, 1980-2012**



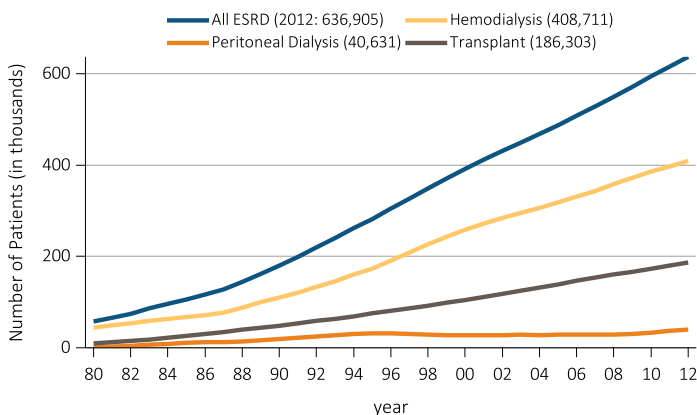
Data Source: Special analyses, USRDS ESRD Database. \*Rates are based on three-year rolling averages, and they are adjusted for sex. The standard population is the U.S. population in 2011. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; Hisp, Hispanic.

## Prevalent ESRD: Trends in Counts and Rates

### Overall

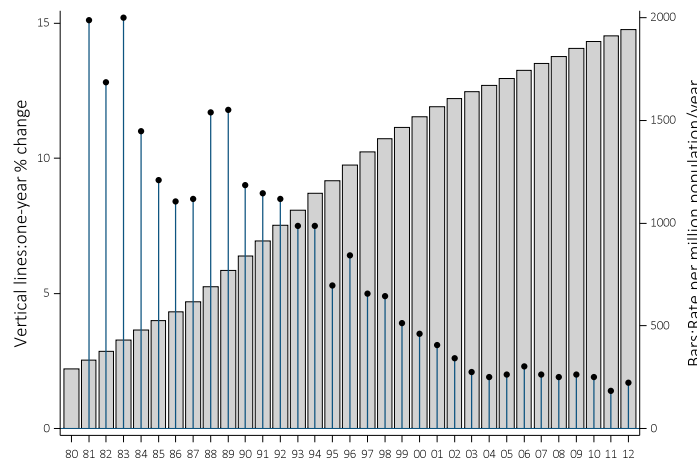
On December 31, 2012 there were 636,905 prevalent cases of ESRD in the U.S., an increase of 3.7% since 2011 (Figure 1.10). The ESRD prevalence per million reached 1,943, an increase of 1.4% from 2011 (Figure 1.11). The percentage growth in 2011 and 2012 were the lowest over the last three decades. The size of the prevalent dialysis population (hemodialysis and peritoneal dialysis) increased 3.8 percent in 2012, reaching 449,342, and is now 57.4 percent larger than in 2000. The size of the transplant population rose 3.6 percent in 2012 to 186,303 patients, and is now 77.7 percent larger than in 2000.

**vol 2 Figure 1.10 Trends in the number of prevalent cases of ESRD, in thousands, by modality, in the U.S. population, 1980-2012**



Data Source: Reference table D.1. Abbreviation: ESRD, end-stage renal disease.

**vol 2 Figure 1.11 Trends in the adjusted\* ESRD prevalence per million (bars; scale on left), and annual percent change in adjusted\* prevalence of ESRD (lines; scale on right), in the U.S. population, 1980-2012**

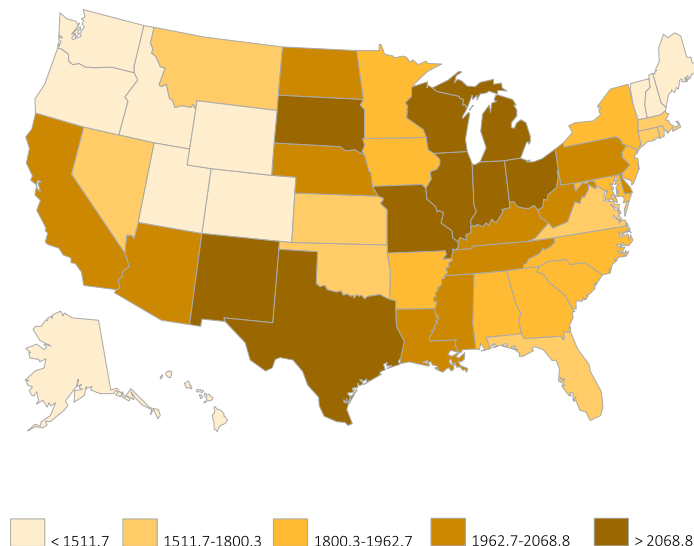


Data Source: Reference table: B.2(2), and B.2(3). \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

### Prevalence of ESRD: By Geographic Region

In 2012, the adjusted prevalence of ESRD varied by over 33% from the lowest to highest quintile of states (Figure 1.12). Prevalence by state is provided in reference tables B.8 and B.9. ESRD prevalence in 2012 was highest in much of the Midwest as well as Texas and New Mexico, and it was lowest in New England, the Northwest, and some Rocky Mountain states. These patterns were roughly similar to patterns of ESRD incidence (in Figure 1.3).

**vol 2 Figure 1.12 Map of the adjusted\* prevalence of ESRD per million, by state, in the U.S. population, 2012**



Data Source: Reference table B.9, and special analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

There was a two-fold variation in dialysis prevalence per million among the 18 ESRD Networks, from a low of 772 per million in Network 16 to a high of 1,559 in Network 8. (Table 1.2).

Among prevalent dialysis patients, mean age varied by nearly 5 years, from 60.1 years in Network 13 to 64.9 years in Network 1. The distribution of patients by race continues to vary widely across Networks. Blacks/African Americans, for example, constitute just 9.5 percent of the prevalent dialysis population in Network 16 but 68.7 percent of patients in Network 6. This variability probably reflects, to some extent but not entirely, the racial/ethnic distributions of the network populations.



**vol 2 Table 1.2 Adjusted\* prevalence of dialysis, per million, and percentage distribution of diabetes, race, and ethnicity among prevalent dialysis patients, by ESRD network, 2012**

Network	States in Network	Total patients	% of total	Rate per million/year	Mean age	% Diabetic	Race				Ethnicity
							% White	% Af Am	% N Am	% Asian	% Hisp
16	AK, ID, MT, OR, WA	11,187	2.7	772	61.9	44.7	75.9	9.5	4.0	10.3	11.0
1	CT, MA, ME, NH, RI VT	12,422	3.0	831	64.9	40.2	74.2	21.4	0.3	3.4	11.7
15	AZ, CO, NV, NM, UT, WY	19,135	4.7	929	61.7	52.6	70.2	11.2	13.2	5.0	31.6
12	IA, KS, MO, NE	13,531	3.3	961	62.9	41.5	66.1	30.9	1.1	1.7	5.8
11	MI, MN, ND, SD, WI	24,138	5.9	1,048	63.1	41.7	61.0	32.7	3.2	2.9	4.7
9	IN, KY, OH	27,997	6.9	1,224	62.5	44.3	63.5	35.2	0.1	1.0	2.8
4	DE, PA	17,264	4.2	1,237	63.5	41.4	61.0	36.6	0.1	1.9	5.2
7	FL	24,661	6.0	1,241	62.9	40.7	54.1	43.0	0.3	2.1	17.9
17	N. CA, HI, GUAM, AS	21,696	5.3	1,295	62.8	51.1	49.0	15.4	0.8	33.7	23.6
2	NY	26,616	6.5	1,320	63.5	41.2	49.9	41.4	0.4	6.8	16.6
10	IL	17,616	4.3	1,342	62.7	39.6	53.4	42.3	0.2	3.8	14.8
3	NJ, PR	17,436	4.3	1,350	63.5	47.3	59.5	33.4	0.1	3.9	37.7
13	AR, LA, OK	16,041	3.9	1,387	60.1	43.5	40.1	54.0	4.4	1.3	3.7
5	MD, DC, VA, WV	23,770	5.8	1,401	61.9	39.4	35.6	60.4	0.3	3.1	4.0
18	S. CA	34,850	8.5	1,429	62.6	49.9	70.0	15.6	0.4	13.5	48.6
14	TX	38,712	9.5	1,444	60.3	54.0	66.5	30.2	0.3	2.3	45.8
6	NC, SC, GA	38,706	9.5	1,544	60.3	40.6	28.9	68.7	0.7	1.3	2.9
8	AL, MS, TN	22,665	5.6	1,559	60.2	41.5	35.5	63.2	0.5	0.6	1.2
All		408,711	100.0	1,251	62.1	44.6	54.9	37.6	1.4	5.4	17.9

Data Source: Special analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Listed from lowest to highest prevalence per million. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; Hisp, Hispanic; N Am, Native American.

**vol 2 Table 1.3 Adjusted\* prevalence of kidney transplant patients, per million, and percentage distribution of diabetes, race, and ethnicity among prevalent transplant patients, by ESRD network, 2012**

Network	States in Network	Total patients	% of total	Rate per million/year	Mean age	% Diabetic	Race				Ethnicity
							% White	% Af Am	% N Am	% Asian	% Hisp
13	AR, LA, OK	5,554	3.0	482.1	52.2	24.0	64.0	30.9	2.6	2.0	3.5
7	FL	9,649	5.2	482.3	54.9	22.3	71.1	23.0	0.5	3.4	19.5
14	TX	13,089	7.0	482.3	51.4	25.3	75.3	17.7	0.4	4.0	37.5
16	AK, ID, MT, OR, WA	7,205	3.9	498.3	53.3	22.9	83.4	5.2	1.8	8.6	7.5
6	NC, SC, GA	12,554	6.7	501.8	52.5	22.8	55.0	40.8	0.8	2.3	3.4
15	AZ, CO, NV, NM, UT, WY	10,436	5.6	506.2	52.9	28.3	83.0	5.8	5.4	4.4	23.4
18	S. CA	12,985	7.0	525.6	51.7	19.8	73.9	9.9	0.4	13.3	41.5
8	AL, MS, TN	7,804	4.2	540.2	51.9	21.4	60.6	37.6	0.2	1.3	1.5
9	IN, KY, OH	12,937	6.9	565.7	53.0	24.8	79.7	17.6	0.1	1.6	2.4
1	CT, MA, ME, NH, RI VT	8,538	4.6	568.1	53.9	20.2	82.5	11.4	0.3	3.8	8.6
2	NY	12,153	6.5	587.4	53.4	21.3	64.8	23.2	0.5	6.9	18.2
17	N. CA, HI, GUAM, AS	9,764	5.2	589.8	53.3	22.1	61.8	8.9	0.7	24.6	24.4
12	IA, KS, MO, NE	8,328	4.5	593.7	53.3	23.8	82.0	13.9	1.4	2.2	5.2
4	DE, PA	8,808	4.7	626.0	54.6	23.0	74.8	20.5	0.2	2.6	4.2
3	NJ, PR	7,255	3.9	629.7	53.6	23.3	64.0	20.3	0.2	5.7	29.1
5	MD, DC, VA, WV	11,046	5.9	647.2	53.6	22.0	55.1	38.0	0.3	4.8	4.6
10	IL	9,191	4.9	687.7	52.8	23.3	69.4	22.6	0.4	4.9	14.7
11	MI, MN, ND, SD, WI	16,256	8.7	707.7	53.9	26.3	79.9	14.0	1.9	3.5	3.5
All		186,303	100.0	562.4	53.0	23.0	70.6	19.6	1.0	5.7	14.5

Data Source: Special analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Listed from lowest to highest prevalence per million. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; Hisp, Hispanic; N Am, Native American.

The adjusted prevalence of kidney transplant patients varied by nearly 50% among the ESRD Networks, from 482 per million in Network 13 to 708 in Network 11. Differences in the racial/ethnic distribution between transplant and dialysis patients by ESRD Network raise the possibility of disparities in access to kidney transplants or transplant care. For example, Blacks/African Americans account for 69 percent of prevalent dialysis patients, but only 41 percent of prevalent transplant patients, in Network 6.

**Prevalent ESRD: By Age**

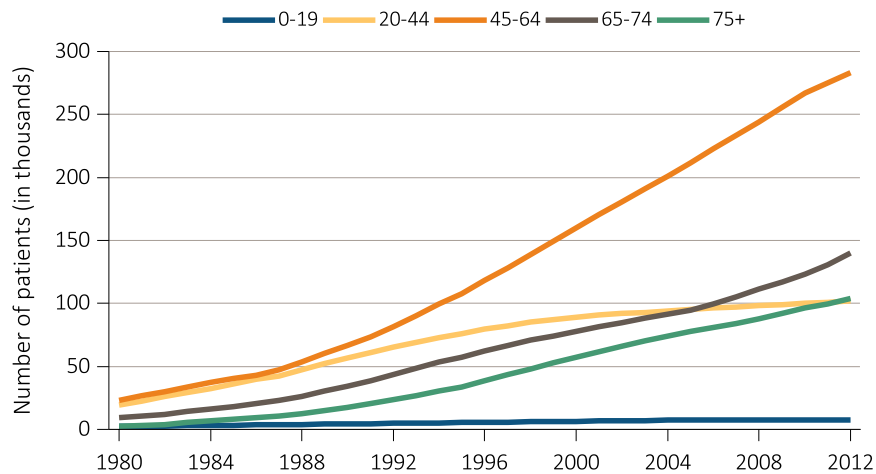
The number of prevalent ESRD patients continues to increase in all age groups, with a steeper increase among patients aged 45 and over than among younger patients. With the recent leveling off of the number of

incident ESRD patients, the continuing rise in ESRD prevalence is presumably due to longer survival among ESRD patients in recent years.

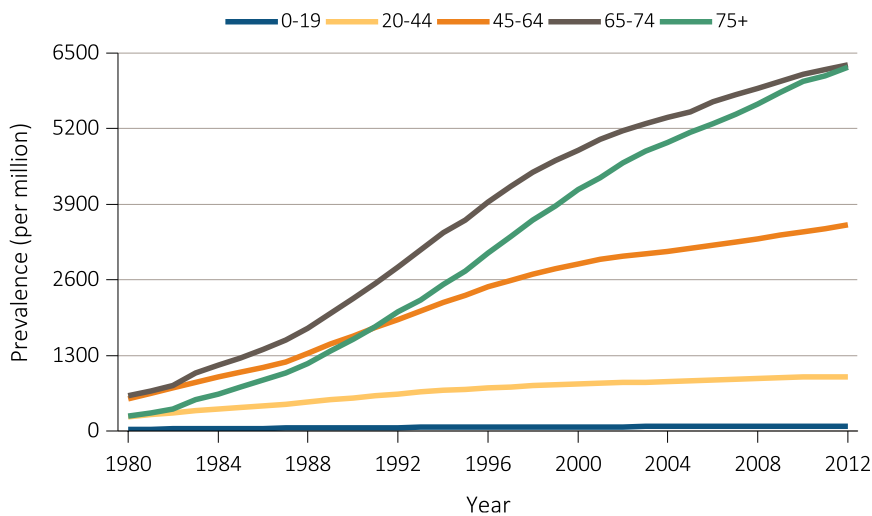
In 2012, the adjusted prevalence of ESRD per million was 83 for age 0-19, 938 for age 20-44, 3,550 for age 45-64, 6,302 for age 65-74, and 6,261 for age 75+ (Figure 1.13.b). The prevalence per million continues to increase in all age groups, with the relative magnitude of increase greater in older age groups. Relative increases since 2000 are 14% at age 0-19, 16% at age 20-44, 23% at age 45-64, 30% at age 65-74, and 50% at age 75+.

**vol 2 Figure 1.13 Trends in (a) prevalent ESRD cases and (b) the adjusted\* prevalence of ESRD, per million, by age group, in the U.S. population, 1980-2012**

**(a) Prevalent cases**



**(b) Prevalence per million**



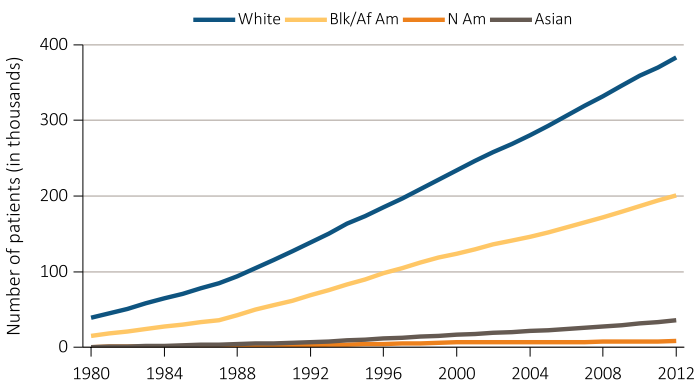
Data Source: Reference tables B.1, B.1(2). \*Point prevalence on December 31 of each year; Adjusted for sex and race; The standard population was the U.S. population in 2011 ESRD patients. Abbreviation: ESRD, end-stage renal disease.

### Prevalent ESRD: By Race and Ethnicity

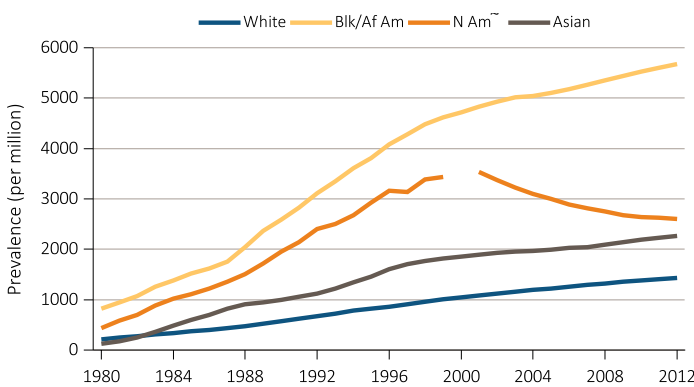
The prevalence of ESRD continues to rise among all three of the four racial groups shown (Figure 1.14.a). However, among Native Americans, the prevalence rate has declined since 2000, reflecting substantial decreases in new cases during those years. In 2012, the prevalence per million was 5,671 among black/African Americans, 2,600 among Native Americans, 2,272 among Asians, and 1,432 among Whites (Figure 1.14.b). The prevalence per million remains much higher in blacks/African Americans than in other racial groups, at nearly 2-fold higher than Native Americans, 2.5-fold higher than Asians, and 4-fold higher than Whites.

**vol 2 Figure 1.14 Trends in (a) prevalent ESRD cases and (b) the adjusted\* prevalence of ESRD, per million, by race, in the U.S. population, 1980-2012**

#### (a) Prevalent cases



#### (b) Prevalence per million

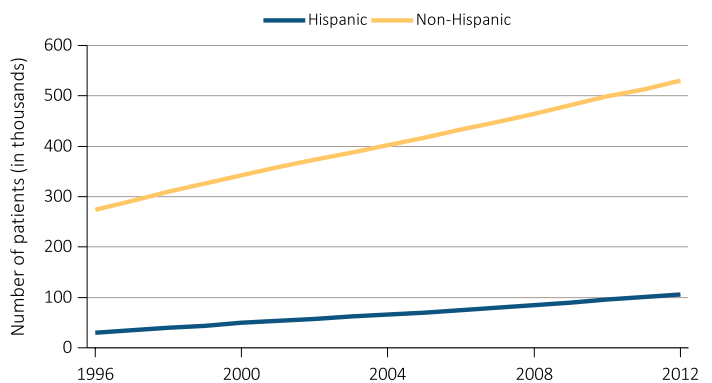


Data Source: Reference tables B.1, B.1(2). \*Point prevalence on December 31 of each year; Adjusted for age and sex; The standard population was the U.S. population in 2011 ESRD patients. Panel b: Estimate shown is imprecise due to small sample size and may be unstable over time. The line for Native Americans has a discontinuity because of unreliable data for that year. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; N Am, Native American.

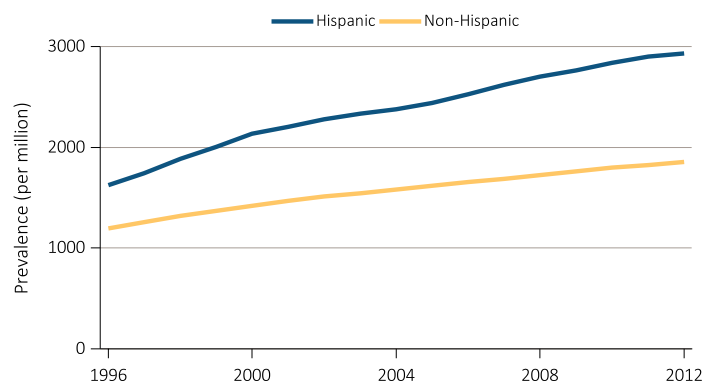
ESRD prevalence continues to rise by ethnicity category, and is more common among Hispanics than non-Hispanics (Figure 1.15). In 2012, the adjusted prevalence per million was 1,858 among non-Hispanics and nearly 60% higher, at 2,932, among Hispanics.

**vol 2 Figure 1.15 Trends in (a) prevalent ESRD cases and (b) the adjusted\* prevalence of ESRD, per million, by ethnicity, in the U.S. population, 1980-2012**

#### (a) Prevalent cases



#### (b) Prevalence per million



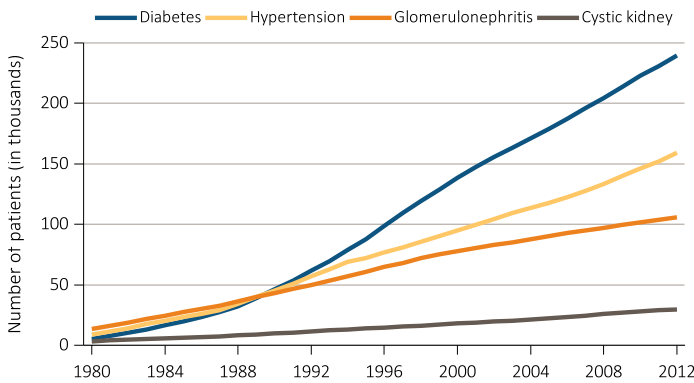
Data Source: Reference tables B.1, B.1(3). \*Point prevalence on December 31 of each year; Adjusted for age, sex, and race; The standard population was the U.S. population in 2011 ESRD patients. Abbreviation: ESRD, end-stage renal disease.

### Prevalent ESRD: By Primary Diagnosis

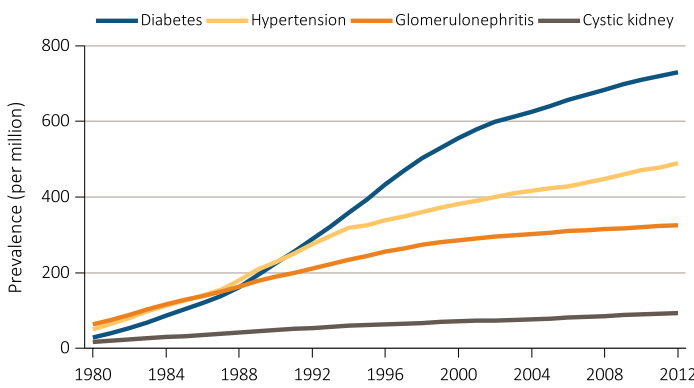
The number of prevalent ESRD cases with diabetes, hypertension, glomerulonephritis, or cystic kidney disease listed as the primary cause has risen since 1980 and continues to do so (Figure 1.16a), despite the recent stabilization of incidence rates. The prevalence per million also continues to rise for these causes of ESRD (Figure 1.16b). For diabetes, the rate of increase was slower over approximately the last decade than it had been previously.

vol 2 Figure 1.16 Trends in (a) prevalent ESRD cases and (b) adjusted\* prevalence of ESRD, per million, by primary cause of ESRD, in the U.S. population, 1980-2012

(a) Prevalent cases



(b) Prevalence per million



Data Source: Reference tables B.1, B.1(2). \*Point prevalence on December 31 of each year; Adjusted for age, sex, and race; The standard population was the U.S. population in 2011 ESRD patients. Abbreviation: ESRD, end-stage renal disease.

## Modality of renal replacement therapy: distributions and trends

### Incident Patients

In 2012, 98,954 new patients began ESRD therapy with hemodialysis, 9,175 with peritoneal dialysis, and 2,803 received a preemptive kidney transplant (these data exclude patients with missing demographic information). Use of PD and pre-emptive kidney transplant were relatively more common in younger age groups.

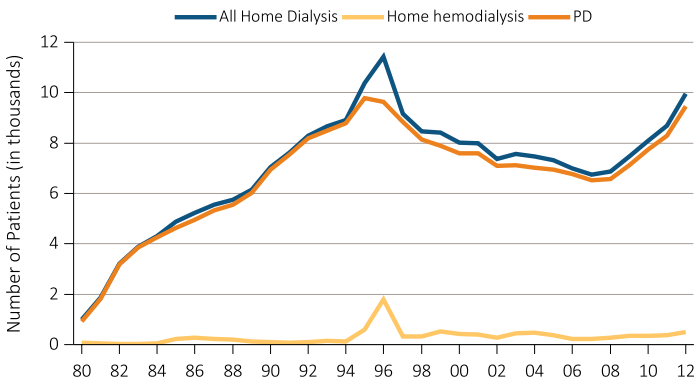
Use of home dialysis among incident ESRD patients has increased notably in recent years, and is 35% higher in 2012 than a decade ago in 2002. Of the 9,947 incident patients who received renal replacement therapy at home in 2012, 5.0 percent were treated with hemodialysis and 95.0% with PD.

vol 2 Table 1.4 Number and percentage of incident cases of hemodialysis (HD), peritoneal dialysis (PD), and transplantation (Tx) by age, sex, race, ethnicity, and primary ESRD diagnosis, in the U.S. population, 2012

	HD		PD		Tx	
	N	%	N	%	N	%
<b>Age</b>						
0-19	506	0.5	349	3.8	245	8.7
20-44	10,375	10.5	1,650	18.0	661	23.6
45-64	38,268	38.7	3,952	43.1	1,355	48.3
65-74	24,528	24.8	1,900	20.7	485	17.3
75+	25,277	25.5	1,324	14.4	57	2.0
<b>Sex</b>						
Male	56,847	57.4	5,197	56.6	1,612	57.5
Female	42,107	42.6	3,978	43.4	1,191	42.5
<b>Race</b>						
White	65,430	66.1	6,415	69.9	2,288	81.6
Black/African Am	28,659	29.0	2,137	23.3	292	10.4
Native American	1,139	1.2	87	0.9	29	1.0
Asian	3,726	3.8	536	5.8	194	6.9
<b>Ethnicity</b>						
Hispanic	13,702	13.8	1,251	13.6	420	15.0
Non-Hispanic	85,252	86.2	7,924	86.4	2,383	85.0
<b>Primary cause of ESRD</b>						
Diabetes	43,922	44.4	3,783	41.2	441	15.7
Hypertension	29,111	29.4	2,373	25.9	257	9.2
Glomerulonephritis	6,889	7.0	1,387	15.1	553	19.7
Cystic kidney	1,551	1.6	476	5.2	429	15.3
Other urologic	410	0.4	61	0.7	54	1.9
Other Cause	10,762	10.9	682	7.4	501	17.9
Unknown/missing	6,309	6.4	413	4.5	568	20.3
<b>All</b>	<b>98,954</b>	<b>100.0</b>	<b>9,175</b>	<b>100.0</b>	<b>2,803</b>	<b>100.0</b>

Data Source: Special analyses, USRDS ESRD Database. Abbreviation: African Am, African American; ESRD, end-stage renal disease.

**vol 2 Figure 1.17** Trend in the number of incident ESRD patients using home hemodialysis, in thousands, by type of therapy, in the U.S. population, 1980-2012



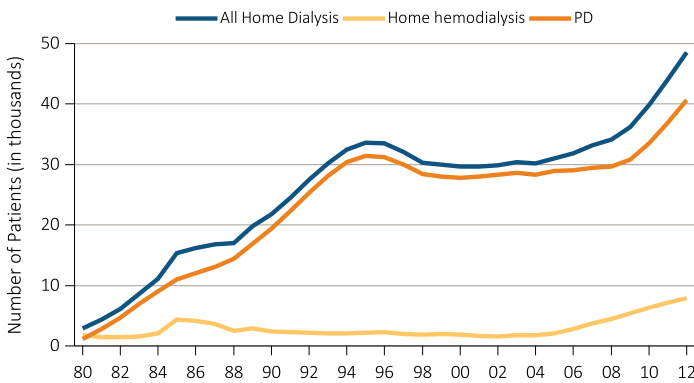
Data Source: Reference table: D.1.

**Prevalent Patients**

On December 31, 2012, nearly 402,514 ESRD patients were receiving hemodialysis therapy, 40,605 were being treated with peritoneal dialysis, and 175,978 had a functioning graft. Younger ESRD patients were more likely to be receiving renal replacement therapy by peritoneal dialysis or kidney transplant, as were White and Asian patients compared to Black/African American and Native American patients.

Forty-nine thousand prevalent dialysis patients received renal replacement therapy at home in 2012 (Figure 1.18). Of these patients, 16.3% were treated with hemodialysis and 83.7% with PD. Home hemodialysis has increased markedly during the past decade. Overall, it is 63% higher now than a decade ago in 2002. There were 5 times more patients using home hemodialysis in 2012 (N=7,923) than in 2002 (N=1,563). Despite this change, the vast majority (91.0%) of dialysis patients in the U.S., were treated by in-center hemodialysis in 2012 (Reference table: D.1).

**vol 2 Figure 1.18** Trend in the number of prevalent ESRD patients using home dialysis, in thousands, by type of therapy, in the U.S. population, 1980-2012



Data Source: Reference table: D.1. December 31 prevalent ESRD patients; peritoneal dialysis consists of CAPD and CCPD only. Abbreviations: CAPD, continuous ambulatory peritoneal dialysis; CCPD, continuous cycler peritoneal dialysis; ESRD, end-stage renal disease.

**vol 2 Table 1.5** Number and percentage of incident cases of hemodialysis (HD), peritoneal dialysis (PD), and transplantation (Tx) by age, sex, race, ethnicity, and primary ESRD diagnosis, in the U.S. population, 2012

	HD		PD		Tx	
	N	%	N	%	N	%
<b>Age</b>						
0-19	1,134	0.3	898	2.2	4,957	2.8
20-44	49,843	12.4	8,187	20.2	39,965	22.7
45-64	167,499	41.6	18,137	44.7	89,876	51.1
65-74	95,889	23.8	8,284	20.4	32,475	18.5
75+	88,149	21.9	5,099	12.6	8,705	4.9
<b>Sex</b>						
Male	226,205	56.2	21,968	54.1	104,654	59.5
Female	176,309	43.8	18,637	45.9	71,324	40.5
<b>Race</b>						
White	221,887	55.1	26,690	65.7	128,468	73.0
Black/African Am	153,264	38.1	10,534	25.9	35,628	20.2
Native American	5,839	1.5	476	1.2	1,755	1.0
Asian	21,524	5.3	2,905	7.2	10,127	5.8
<b>Ethnicity</b>						
Hispanic	68,710	17.1	5,915	14.6	35,467	20.2
Non-Hispanic	333,804	82.9	34,690	85.4	140,511	79.8
<b>Primary cause of ESRD</b>						
Diabetes	178,012	44.2	14,120	34.8	40,688	23.1
Hypertension	116,260	28.9	10,528	25.9	27,785	15.8
Glomerulonephritis	43,521	10.8	7,931	19.5	48,980	27.8
Cystic kidney	9,543	2.4	1,895	4.7	17,463	9.9
Other urologic	3,052	0.8	369	0.9	3,515	2.0
Other Cause	32,513	8.1	3,660	9.0	20,306	11.5
Unknown/missing	19,613	4.9	2,102	5.2	17,241	9.8
<b>All</b>	<b>402,514</b>	<b>100.0</b>	<b>40,605</b>	<b>100.0</b>	<b>175,978</b>	<b>100.0</b>

Data Source: Special analyses, USRDS ESRD Database. Abbreviation: African Am, African American; ESRD, end-stage renal disease.

**Payer Type: Trends**

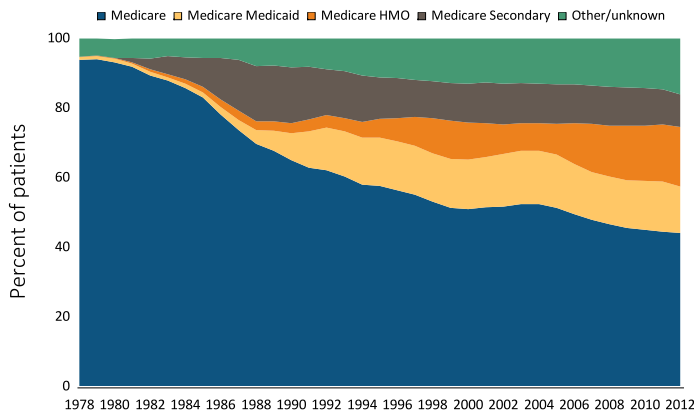
**Incident patients**

The historical decline in the percent of patients with Medicare-only coverage among new dialysis patients is continuing, especially in new hemodialysis patients. Medicare-only coverage remains lowest among pre-emptive transplant recipients. Among incident ESRD patients starting renal replacement therapy (RRT) by hemodialysis in 2012, 84.0% had Medicare coverage

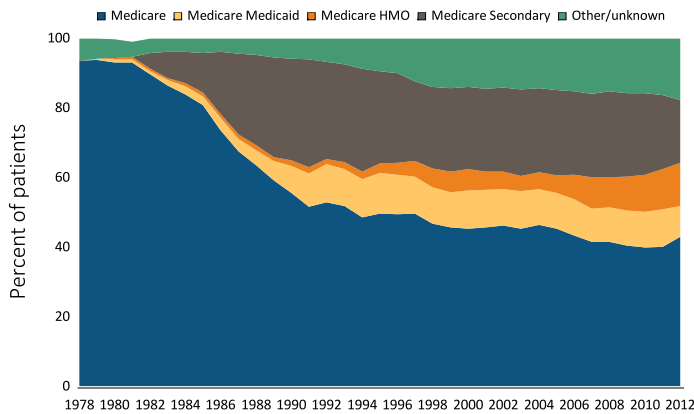
including 44.1% covered solely by Medicare, 13.3% with dual Medicare/Medicaid coverage, 17.2% with a Medicare HMO provider, and 9.4% with Medicare as secondary payer. The distribution of payer type was generally similar among incident ESRD patients starting RRT by peritoneal dialysis. Among patients receiving pre-emptive transplantation, Medicare as a secondary payer and 'other/unknown' were much more common.

**vol 2 Figure 1.19** Trend in the distribution of payer type, by modality, among incident ESRD patients, 1978-2012

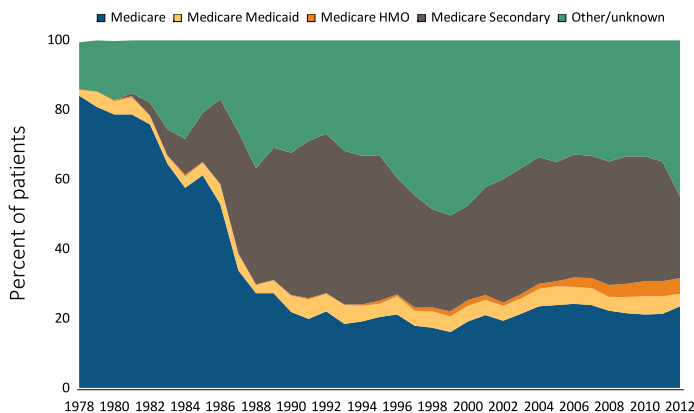
**(a) Hemodialysis**



**(b) Peritoneal dialysis**



**(c) Transplant**



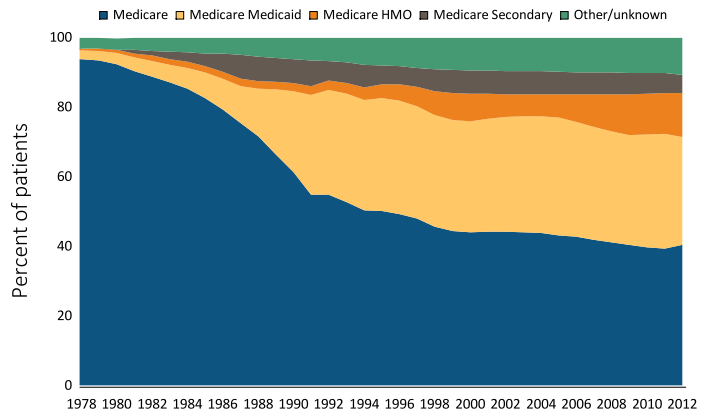
Data Source: Special analyses, USRDS ESRD Database. Peritoneal dialysis consists of CAPD and CCPD only. Abbreviations: CAPD, continuous ambulatory peritoneal dialysis; CCPD, continuous cycler peritoneal dialysis; ESRD, end-stage renal disease.

**Prevalent patients**

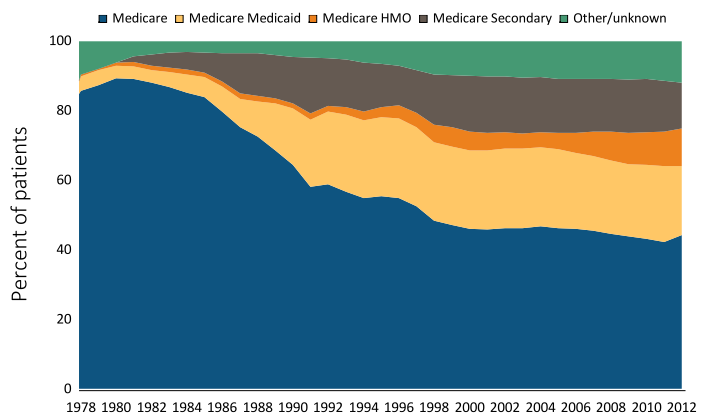
Among dialysis patients, the percent with Medicare-only coverage has declined for most years since 1980. This is due largely to the increase in combined Medicare and Medicaid coverage (Figure 1.20). In contrast to incident patients, a lower percentage of prevalent patients have Medicare as a secondary payer, and a higher percentage have combined Medicare

**vol 2 Figure 1.20** Trend in the distribution of payer type, by modality, among prevalent ESRD patients, 1978-2012

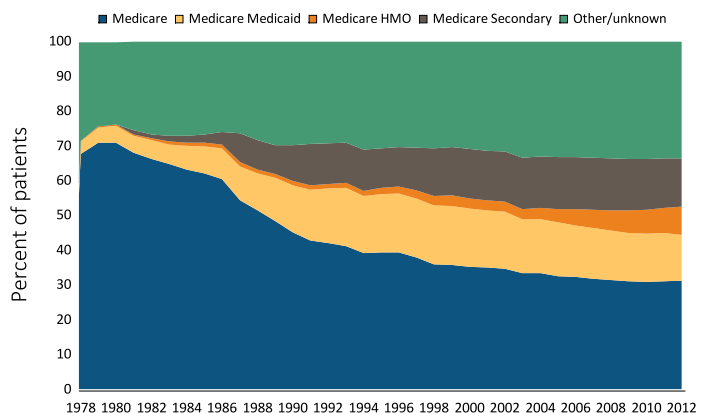
**(a) Hemodialysis**



**(b) Peritoneal dialysis**



**(c) Transplant**



Data Source: Special analyses, USRDS ESRD Database. Point prevalence on December 31 of each year; Peritoneal dialysis consists of CAPD and CCPD only. Abbreviations: CAPD, continuous ambulatory peritoneal dialysis; CCPD, continuous cycler peritoneal dialysis; ESRD, end-stage renal disease.

plus Medicaid coverage. Among both dialysis and transplant patients, there has been a gradual but sustained trend of a rising percentage with Medicare HMO coverage over the last two decades. This reflects the overall trend in the general Medicare population towards greater use of HMOs.

## Patient and Treatment Characteristics at ESRD Onset

### Overall distributions, and variation by pre-ESRD nephrology care

Forty-one percent of patients starting ESRD therapy in 2012 were reported on CMS Form 2728 to have differences are notable in the distributions of pre-ESRD nephrology care by demographic characteristics. Pediatric patients were more likely than adults to have had pre-ESRD nephrology care for >12 months, while adults age 20-44 were less likely to have had pre-ESRD care than other age groups. African Americans were somewhat less likely to have had pre-ESRD care than other race groups.

Patients with a primary diagnosis of GN or, especially, cystic kidney disease were more likely to have had pre-ESRD nephrology care than patients with a diagnosis of diabetes or HTN. No nephrology care was most common for patients with HTN as primary diagnosis; one can surmise that patients initially presenting at, or near, ESRD are often assigned this diagnosis in the absence of clear information about etiology.

Patients not receiving pre-ESRD nephrology care were, as expected, far less likely to use an ESA or receive dietary care before ESRD, had higher likelihood of ESRD onset (e.g., dialysis start) at eGFR <5 ml/min/1.73m<sup>2</sup>, and were far more likely to start dialysis with a catheter than patients with longer pre-ESRD nephrology care.

**vol 2 Table 1.6 Distribution of the reported duration of pre-ESRD nephrology care, by demographic and clinical characteristics, among incident ESRD patients in the U.S., 2012**

	None	0-12 mo.	>12 mo.*
<b>% of patients</b>	41.3	30.8	27.9
<b>Mean Age</b>	61.6	62.7	63.7
<b>Age</b>			
<b>0-19</b>	34.3	31.2	34.4
<b>20-24</b>	47.6	29.0	23.3
<b>45-64</b>	42.7	30.9	26.4
<b>65-74</b>	38.7	31.3	30.0
<b>75+</b>	38.9	30.7	30.3
<b>Sex</b>			
<b>Male</b>	39.1	31.8	29.1
<b>Female</b>	38.8	32.3	28.9
<b>Race</b>			
<b>White</b>	37.2	36.5	26.4
<b>Black</b>	42.1	32.2	25.7
<b>Native Amer.</b>	45.0	30.2	24.7
<b>Asian</b>	39.6	30.8	29.6
<b>Hispanic ethnicity</b>			
<b>Yes</b>	47.7	30.9	21.4
<b>No</b>	39.7	31.0	29.3
<b>Vascular Access</b>			
<b>Fistula</b>	10.5	36.0	53.5
<b>Catheter</b>	49.3	30.1	20.6
<b>Graft</b>	19.9	36.8	43.3
<b>ESA use</b>	3.8	42.5	53.7
<b>Dietary care</b>	0.7	45.7	53.5
<b>eGFR at RRT start*</b>			
<b>&lt;5</b>	53.0	24.8	22.2
<b>5-&lt;10</b>	37.8	31.7	30.5
<b>10-&lt;15</b>	34.6	34.1	31.3
<b>≥15</b>	42.8	32.0	25.1
<b>Primary diagnosis</b>			
<b>Diabetes</b>	35.3	34.6	30.1
<b>Hypertension</b>	41.9	31.2	26.8
<b>Glomerulonephritis</b>	31.8	31.4	36.8
<b>Cystic kidney</b>	17.3	27.3	55.3

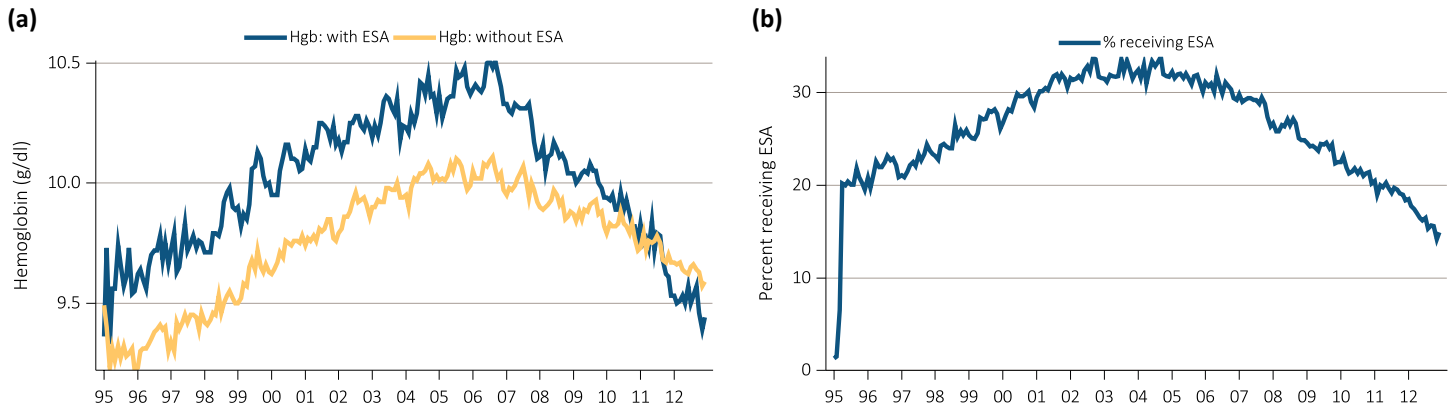
*Data Source: Reference tables C.8, C.10, and special analyses, USRDS ESRD Database. eGFR calculated using the CKD-EPI equation (CKD-EPI eGFR (ml/min/1.73 m<sup>2</sup>). Abbreviations: CKD-EPI; chronic kidney disease epidemiology calculation; DM, diabetes mellitus; eGFR, estimated glomerular filtration rate; ESA, erythropoiesis-stimulating agents; RRT, renal replacement therapy. \*All these numbers are percent within row, except mean age.*

**Anemia variables**

The percentage of incident ESRD patients who received pre-ESRD ESA treatment increased steadily (with seasonal variation) from 20 percent in 1995 to 32

percent in 2002, leveled off, then declined steadily from 2004 to 15 percent in 2012 (Figure 1.21b).

**vol 2 Figure 1.21 Trend in (a) Hgb levels and (b) the percentage of patients who received pre-ESRD erythropoiesis-stimulating agent (ESA) treatment, among incident ESRD patients, 1995-2012**



Data Source: Special analyses, USRDS ESRD Database. Abbreviations: ESA, erythropoiesis-stimulating agents; ESRD, end-stage renal disease.

**Other laboratory values**

The likelihood of starting dialysis with laboratory values outside traditional target values was high for certain measures. Average serum albumin was well below the

typical laboratory lower limit, and especially low in Native American patients. Total and LDL cholesterol were inversely associated with age. As expected, patients with cystic kidney disease had higher mean Hgb at ESRD onset than other patients.

**vol 2 Table 1.7 Mean laboratory values, by age, sex, race/ethnicity, and primary ESRD diagnosis, among incident ESRD patients, 2012**

	Serum albumin	Hgb (g/dL)	Total cholesterol (mg/dL)	LDL (mg/dL)	HDL (mg/dL)	Triglycer (mg/dL)	HbA1c	eGFR at RRT start
<b>Age</b>								
20-44	3.3	9.4	169.6	100.6	40.6	162.5	7.0	9.6
45-64	3.2	9.5	159.7	91.2	40.0	156.6	6.9	10.2
65-74	3.3	9.6	149.1	82.8	39.7	146.2	6.6	10.6
75+	3.2	9.7	140.4	76.1	40.6	127.8	6.4	10.6
<b>Sex</b>								
Male	3.3	9.7	147.5	83.7	37.8	144.8	6.7	10.7
Female	3.2	9.5	164.1	91.7	43.5	154.9	6.8	10.0
<b>Race/ethnicity</b>								
White	3.3	9.7	150.4	83.6	38.8	152.9	6.7	10.7
Black/Af Am	3.2	9.3	162.0	94.5	43.0	137.5	6.7	9.9
Native American	2.9	9.5	153.9	84.3	41.2	152.4	6.7	9.7
Asian	3.3	9.5	158.9	89.2	41.4	155.1	6.7	9.0
Hispanic	3.3	9.5	156.5	88.6	39.7	159.8	6.8	9.9
<b>Primary diagnosis</b>								
Diabetes	3.2	9.5	153.2	86.2	40.1	151.1	7.0	10.6
Hypertension	3.3	9.6	151.5	86.2	40.6	136.5	6.2	10.0
Glomerulonephritis	3.3	9.6	172.0	99.1	41.9	166.2	6.0	9.5
Cystic kidney	3.8	10.3	160.1	87.7	40.9	153.9	5.7	9.5
<b>All</b>	<b>3.3</b>	<b>9.6</b>	<b>154.2</b>	<b>87.0</b>	<b>40.1</b>	<b>148.9</b>	<b>6.7</b>	<b>10.4</b>

Data Source: Special analyses, USRDS ESRD Database. eGFR calculated using the CKD-EPI equation (CKD-EPI eGFR (ml/min/1.73 m2).

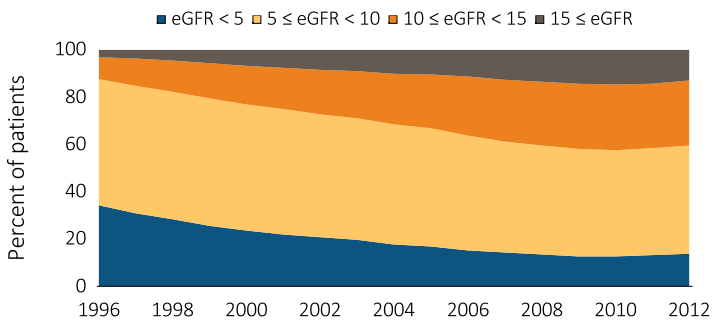
Abbreviations: Af Am, African American; CKD-EPI; chronic kidney disease epidemiology calculation; eGFR, estimated glomerular filtration rate; ESRD, end-stage renal disease; HbA1c, glycosylated hemoglobin; HDL, high-density lipoprotein; Hgb; hemoglobin; LDL, low-density lipoprotein; RRT, renal replacement therapy; Triglycer, triglycerides.



### eGFR at dialysis start

The percentage of incident ESRD patients who started renal replacement therapy at higher eGFR levels increased steadily from 1996 until 2010, but decreased slightly in 2011 and again in 2012. For example, the percent with eGFR  $\geq 10$  ml/min/1.73 m<sup>2</sup> rose from 12.5% in 1996 to 42.6% in 2010, but decreased to 40.5% in 2012. In parallel, the percentage of incident ESRD patients who started therapy at eGFR  $< 5$  ml/min/1.73 m<sup>2</sup> decreased from 34.4% in 1996 to 12.6% in 2010, then increased to 13.7% in 2012.

**vol 2 Figure 1.22 Trend in the distribution of eGFR (ml/min/1.73 m<sup>2</sup>) among incident ESRD patients, 1996-2012**



Data Source: Special analyses, USRDS ESRD Database. eGFR calculated using the CKD-EPI equation (CKD-EPI eGFR (ml/min/1.73 m<sup>2</sup>)).

Abbreviations: CKD-EPI; chronic kidney disease epidemiology calculation; eGFR, estimated glomerular filtration rate; ESRD, end-stage renal disease.



# Chapter 2: Healthy People 2020

## Introduction

For more than three decades, the Healthy People initiative has served as the nation's agenda for health promotion and disease prevention. Coordinated by the United States (U.S.) Department of Health and Human Services, the initiative provides a vision and strategy for improving the health of all Americans by setting priorities, identifying baseline data and 10-year targets for specific objectives, monitoring outcomes, and evaluating progress. Since its inaugural iteration in 1980, in each decade the program has released updated plans that reflect emerging health priorities, and have helped to align health promotion resources, strategies, and research. Healthy People 2020 (HP2020, 2010) launched on December 2, 2010. It represents the fourth-generation plan, and encompasses more than 1,000 objectives organized into 42 different topic areas. Built on the success of the three previous initiatives, HP2020 seeks to achieve the following overarching goals:

- Assist all Americans in attaining high-quality, longer lives free of preventable disease, disability, injury, and premature death;
- Achieve health equity, eliminate disparities, and improve the health of all groups;
- Create social and physical environments that promote good health for all; and
- Promote quality of life, healthy development, and healthy behaviors across all life stages (HP2020, 2010).

One of the key priorities of the HP2020 initiative is to “reduce new cases of chronic kidney disease (CKD) and its complications, disability, death, and economic costs.” The development of CKD and its progression to end-stage renal disease (ESRD) is a major source of reduced quality of life in the U.S., and is responsible for significant premature mortality.

The HP2020 CKD objectives are designed to reduce the long-term burden of kidney disease, increase lifespan, and improve quality of life among those with this condition, and to eliminate health care disparities among patients. To accomplish these goals, the HP2020 program developed 14 objectives (with 20 indicators) related to CKD, accompanied by targets designed to evaluate the program's success. Herein, we provide data for nine of these objectives, as well as information on urine albumin testing in non-CKD patients diagnosed with diabetes mellitus (DM). Because we use the Medicare 5 percent data sample to evaluate objectives related to CKD patients who are not on dialysis, results are limited to those aged 65 and older.

Overall, the data demonstrate both areas of improvement and continued need. Encouraging trends were noted for nearly all objectives, with 10 out of 15 CKD indicators meeting or exceeding their targets. For example, with respect to provision of appropriate care, indicators related to the proportion of patients with DM and CKD receiving recommended medical evaluation have surpassed their targets. Nearly all indicators related to reductions in mortality among ESRD patients have exceeded their targets. However, the data demonstrate that five indicators continue to fall short of their targets. Though the trend is moving in the direction of improvement, rates of kidney failure due to DM still exceed the overall target (151.9 cases per million population) by just over two cases per million. Indicators related to kidney transplant wait-listing and timely receipt remain below their respective targets, with the indicator for patients receiving a kidney transplant within three years of ESRD onset appearing to lose ground in recent years.

It is important to highlight that one of the four overarching goals of HP2020 is to eliminate health care disparities. While much of the data show promising trends, progress overall has not always translated into reduced disparities across subgroups.

For example, even though the overall target is close to being achieved for reducing the rate of new cases of ESRD (347.7 new cases per million population), non-Hispanic Blacks and Latinos experience substantially higher incidence rates than do non-Hispanic Whites. The overall target for increasing the proportion of CKD patients receiving care from a nephrologist at least 12 months before the start of renal replacement therapy (30.0 percent) has been exceeded. However, when examined by race and ethnicity, only non-Hispanic Whites, American Indians, and Asians have exceeded this target.

Below, the detailed findings and time trends for each of the nine objectives (with 17 indicators) are presented separately. Additional information on the HP2020 program objectives can be found at [www.healthypeople.gov](http://www.healthypeople.gov).

### Analytical Methods

See the ESRD Analytical Methods chapter for an explanation of analytical methods used to generate the figures and tables in this chapter.

## Recommended Care

In recent years, the link between acute kidney injury (AKI) and subsequent adverse renal outcomes has become increasingly recognized, further highlighting the importance of this objective. Follow-up of AKI patients provides the opportunity to identify

development of CKD, and to institute renoprotective measures early in the course of evolving disease. Over the past decade, there has been a significant increase in follow-up renal evaluation after an episode of AKI, but the levels remain low overall. In 2012, 13.2 percent of patients aged 65 and older who were hospitalized for AKI had a follow-up renal evaluation during the following 6 months (see Table 2.1). This is the second consecutive year that the HP2020 goal of 12.3 percent was achieved.

Of note, rates of renal evaluation vary significant by age group. While 17.6 percent of patients aged 65-74 receive follow-up evaluation, just 7.4 percent of those age 85 and older receive such care. In addition, men appear more likely to receive follow-up renal evaluation as compared with women.

In the diabetic population aged 65 and older, the percentage of patients receiving an annual urine albumin measurement has more than doubled in the past decade, increasing from 18.1 percent in 2002 to 42.4 percent in 2012, surpassing the HP2020 target of 36.6 percent (see Table 2.2).

The temporal trend of increasing testing is seen in all age groups, but the absolute rates decline with age. Nearly 50 percent of patients aged 65-74 had urine albumin testing compared with 28.0 percent of patients older than 85 years. Rates appear relatively stable when examined by race, with the exception of a markedly low rate of 23.9 percent for Native

**vol 2 Table 2.1 HP2020 CKD-3 Increase the proportion of hospital patients who incurred acute kidney injury who have follow-up renal evaluation in 6 months post-discharge: Target 12.3%**

	2001 (%)	2002 (%)	2003 (%)	2004 (%)	2005 (%)	2006 (%)	2007 (%)	2008 (%)	2009 (%)	2010 (%)	2011 (%)	2012 (%)
<b>All</b>	2.4	3.1	4.5	8.4	9.1	10.5	11.2	10.6	11.5	11.9	12.8	13.2
<b>American Indian or Alaskan Native only</b>	0.0	0.0	2.9	16.7	4.8	13.2	12.0	15.2	6.9	11.0	16.7	11.5
<b>Asian only</b>	3.8	2.0	4.5	8.1	12.6	19.0	15.2	11.4	16.7	15.4	16.5	16.8
<b>Black or Af Am only</b>	2.9	2.5	4.0	7.9	9.8	9.2	11.3	10.4	12.3	11.3	12.3	13.5
<b>White only</b>	2.3	3.2	4.5	8.3	8.8	10.5	11.1	10.4	11.2	11.9	12.7	13.0
<b>Hispanic or Latino</b>	1.4	6.6	7.1	12.8	12.2	10.1	12.4	15.5	13.5	13.6	17.1	15.0
<b>Male</b>	2.8	3.5	4.6	8.8	9.9	11.3	12.6	11.9	12.5	12.8	14.0	14.3
<b>Female</b>	2.0	2.8	4.3	8.0	8.3	9.7	10.0	9.4	10.6	11.1	11.8	12.2
<b>65-74</b>	3.6	4.2	6.2	11.7	12.9	14.7	16.1	14.8	16.0	16.5	17.7	17.6
<b>75-84</b>	2.0	3.2	4.2	8.5	8.6	10.4	11.1	10.8	11.3	12.4	13.3	13.4
<b>85+</b>	0.8	1.1	2.2	3.1	4.4	5.1	5.1	5.0	6.4	5.9	6.2	7.4

Data Source: Special analyses, Medicare 5 percent sample. Medicare patients age 65 & older with a hospitalized AKI event in given year. Abbreviations: Af Am, African American; AKI, acute kidney injury; CKD, chronic kidney disease.

**vol 2 Table 2.2 HP2020 D-12 Increase the proportion of persons with diagnosed diabetes who obtain an annual urine albumin measurement: Target 36.6%**

	2001 (%)	2002 (%)	2003 (%)	2004 (%)	2005 (%)	2006 (%)	2007 (%)	2008 (%)	2009 (%)	2010 (%)	2011 (%)	2012 (%)
<b>All</b>	15.3	18.1	21.2	25.5	28.5	31.0	33.3	35.3	36.9	38.6	40.5	42.4
<b>American Indian or Alaskan Native only</b>	11.4	12.0	13.0	15.5	18.9	20.2	20.9	21.1	24.1	22.9	24.6	23.9
<b>Asian only</b>	16.8	20.6	23.9	28.8	30.4	33.4	34.9	37.3	39.5	41.7	43.8	47.4
<b>Black or Af Am only</b>	13.1	15.6	18.5	23.5	26.4	29.0	31.5	33.3	35.3	36.9	39.0	40.6
<b>White only</b>	15.5	18.5	21.6	25.7	28.7	31.2	33.5	35.5	37.1	38.7	40.6	42.4
<b>Hispanic or Latino</b>	15.4	17.8	20.7	25.5	29.6	31.3	33.2	35.1	37.5	40.2	42.3	44.3
<b>Male</b>	15.9	18.8	21.9	26.5	29.4	31.9	34.5	36.4	37.9	39.5	41.6	43.3
<b>Female</b>	14.8	17.6	20.7	24.7	27.8	30.2	32.4	34.4	36.2	37.7	39.6	41.6
<b>65-74</b>	18.1	21.2	24.7	29.4	32.6	35.1	37.7	39.9	41.8	43.3	45.3	47.3
<b>75-84</b>	13.7	16.7	19.6	23.8	26.8	29.6	31.8	33.7	35.3	37.1	39.1	41.0
<b>85+</b>	7.2	9.0	10.9	13.9	16.1	18.1	20.5	22.2	23.5	25.0	26.7	28.0

Data Source: Special analyses, Medicare 5 percent sample. Medicare patients with diabetes mellitus, age 65 & older. Abbreviations: Af Am, African American; D, diabetes mellitus.

Americans. However, testing in Native Americans may be under-reported, as the Indian Health Service does not report claims through the Medicare system.

Serum creatinine and urine albumin are important laboratory markers for monitoring the presence and progression of CKD, and lipid tests are important for assessing cardiovascular risk in this population. Table 2.3 shows that in the Medicare population aged 65 and older, 31.2 percent of CKD patients underwent serum creatinine, lipid, and urine albumin testing in 2012, above the HP2020 goal of 28.3 percent, and a nearly

fourfold increase since 2002. Testing rates vary by race, ranging from 18.6 percent among Native Americans to 41.2 percent among Asians (again, testing by Indian Health Services is not reported to Medicare). Rates also decrease with age; testing occurred in 40.0, 31.2, and 17.0 percent of individuals in the 60-74, 75-84, and 85 years and older age groups, respectively.

**vol 2 Table 2.3 HP2020 CKD-4.1 Increase the proportion of persons with chronic kidney disease who receive medical evaluation with serum creatinine, lipids, and urine albumin: Target 28.3%**

	2001 (%)	2002 (%)	2003 (%)	2004 (%)	2005 (%)	2006 (%)	2007 (%)	2008 (%)	2009 (%)	2010 (%)	2011 (%)	2012 (%)
<b>All</b>	7.3	9.1	10.6	19.8	22.1	23.4	25.7	26.7	28.1	29.0	30.2	31.2
<b>American Indian or Alaskan Native only</b>	8.2	5.5	7.0	13.7	19.2	15.8	16.9	16.7	18.4	20.3	21.1	18.6
<b>Asian only</b>	8.4	14.4	14.1	27.5	27.9	32.5	35.3	34.1	37.6	36.9	39.5	41.2
<b>Black or Af Am only</b>	6.6	8.7	10.1	20.8	22.8	24.4	26.7	27.8	30.1	30.6	32.3	33.2
<b>White only</b>	7.1	8.8	10.4	19.3	21.6	22.9	25.1	26.3	27.4	28.3	29.4	30.4
<b>Hispanic or Latino</b>	13.1	17.3	17.7	26.8	30.5	31.1	33.0	32.0	36.0	36.7	38.9	41.3
<b>Male</b>	7.5	9.3	11.3	21.1	23.4	24.5	27.1	28.4	29.6	30.6	32.0	33.1
<b>Female</b>	7.0	8.9	10.0	18.6	20.9	22.3	24.3	25.2	26.7	27.6	28.6	29.5
<b>65-74</b>	10.3	12.6	14.2	26.1	29.2	31.4	33.9	35.1	36.7	37.7	38.9	40.0
<b>75-84</b>	6.2	8.0	9.8	18.5	20.8	22.6	24.9	26.2	27.7	28.9	30.3	31.2
<b>85+</b>	2.3	3.1	4.0	8.2	10.0	10.1	12.1	13.1	14.0	14.8	16.2	17.0

Data Source: Special analyses, Medicare 5 percent sample. Medicare patients age 65 & older with CKD. Abbreviations: Af Am, African American; CKD, chronic kidney disease.

Patients with either Type 1 or Type 2 DM and CKD require comprehensive laboratory monitoring to assess for development of complications. The glycosylated hemoglobin (HgbA1c) test is used to assess blood glucose control over prolonged periods of time in patients with DM, while diabetic retinopathy can be detected through regular eye examinations. In the

diabetic CKD population aged 65 and older, 27.7 percent of patients received serum creatinine, urine albumin, HgbA1c, and lipid testing, as well as an eye examination in 2012. This was above the HP2020 goal of 25.3 percent, and continues a steady trend in improvement from 10.4 percent in 2002 (see Table 2.4).

**vol 2 Table 2.4 HP2020 CKD-4.2 Increase the proportion of persons with Type 1 or Type 2 diabetes and chronic kidney disease who receive medical evaluation with serum creatinine, urine albumin, HgbA1c, lipids, and eye examinations: Target 25.3%**

	2001 (%)	2002 (%)	2003 (%)	2004 (%)	2005 (%)	2006 (%)	2007 (%)	2008 (%)	2009 (%)	2010 (%)	2011 (%)	2012 (%)
<b>All</b>	9.0	10.4	12.1	18.4	20.0	21.1	23.0	23.7	25.1	26.5	26.9	27.7
<b>American Indian or Alaskan Native only</b>	7.3	2.4	5.7	5.6	15.8	12.5	10.2	10.9	10.9	15.1	14.2	11.5
<b>Asian only</b>	8.3	12.4	12.8	24.9	21.8	26.1	26.7	25.3	27.0	29.6	30.8	32.5
<b>Black or Af Am only</b>	6.7	7.2	9.9	16.3	17.9	18.8	19.7	21.1	22.4	23.8	25.1	25.4
<b>White only</b>	9.4	11.0	12.5	18.6	20.3	21.4	23.4	24.2	25.6	27.0	27.1	28.0
<b>Hispanic or Latino</b>	10.4	11.8	11.8	20.4	20.3	19.8	22.2	21.7	24.6	24.0	26.5	25.3
<b>Male</b>	9.3	10.6	12.4	18.8	20.3	21.4	23.5	23.7	25.6	26.7	27.3	27.9
<b>Female</b>	8.7	10.3	11.8	18.0	19.7	20.9	22.5	23.6	24.7	26.2	26.6	27.5
<b>65-74</b>	10.9	12.3	14.3	22.0	23.4	24.6	26.6	27.2	28.5	30.0	30.1	30.8
<b>75-84</b>	8.1	9.9	11.6	16.9	18.9	20.7	22.6	23.3	25.2	26.7	27.4	28.4
<b>85+</b>	4.0	4.2	4.9	9.5	11.5	11.3	13.0	14.2	15.5	16.6	17.7	18.4

*Data Source: Special analyses, Medicare 5 percent sample. Medicare patients age 65 & older with CKD & diabetes mellitus. Abbreviations: Af Am, African American; CKD, chronic kidney disease; HgbA1c, glycosylated hemoglobin.*

## Incidence of End-Stage Renal Disease

The rate of new cases of ESRD has been slowly declining since 2006, and at 359.2 new cases per million population, is now nine percent lower than in 2006. Unfortunately, this rate still exceeds the target rate of 347.7 new cases per million population. As seen in Table 2.5, there also continues to be substantial variation in the rate of new ESRD cases by race, with the lowest rates observed among Whites (290.7 new cases per million) and Asians (343.8 new cases per million). Much higher rates are seen among Blacks/African Americans (955.4 new cases per million) and Native Hawaiians/Pacific Islanders (NH/PI; 2,527.7 new cases per million). The extraordinarily high rates among NH/PI may be due in part to differential race reporting between the Census Bureau and the ESRD Medical Evidence Report forms (CMS 2728; ME) reporting. In the Census, one-half of NH/PI persons self-identify as of multiple race. In the ME, it is only seven percent. The rate of incident ESRD among Hispanics (521.1 per million) is nearly 50 percent greater than among non-Hispanics (349.1 per million).

The overall rates have decreased in both sexes, with a rate of 452.4 cases per million population among men and a rate of 283.7 new cases per million among women. However, the gap has increased from 2001, when males had a rate 42 percent higher than females, to 2012, where males have a 59 percent higher rate.

vol 2 Table 2.5 HP2020 CKD-8 Reduce the rate of new cases of end-stage renal disease: Target 347.7 new cases per million population

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
All	384.0	384.6	384.6	384.1	387.5	394.4	386.3	382.3	385.7	378.7	362.3	359.2
American Indian or Alaskan Native only	704.3	671.6	618.2	636.0	613.0	523.2	536.0	548.8	539.8	498.4	473.3	469.9
Asian only	319.9	312.9	304.6	282.0	337.8	355.2	357.1	357.3	365.3	358.5	350.3	343.8
Native Hawaiian or other Pacific Islander only~	3368.2	3505.6	3464.8	3650.9	2872.8	2781.5	2370.6	2125.0	2376.3	2565.5	2321.6	2527.7
Black or Af Am only	1120.1	1126.6	1126.1	1088.9	1099.7	1109.3	1085.5	1069.7	1070.8	1034.0	995.1	955.4
White only	291.4	292.3	292.5	296.8	301.0	309.5	303.6	301.4	305.9	303.3	289.9	290.7
Two or more races	.	.	.	.	.	122.6	113.1	112.0	89.2	71.2	47.3	16.1
Hispanic or Latino	622.4	632.1	631.0	607.2	594.0	594.9	580.6	576.4	573.7	568.9	554.5	521.1
Not Hispanic or Latino	368.0	368.3	369.1	370.4	373.3	378.6	371.6	368.3	372.5	365.7	350.0	349.1
Black or Af Am only, not Hispanic or Latino	1136.5	1144.0	1143.8	1103.5	1116.0	1126.0	1105.1	1088.9	1088.4	1053.3	1012.9	975.4
White only, not Hispanic or Latino	267.3	266.3	266.3	271.8	274.1	279.1	273.3	270.1	273.5	269.6	255.9	259.1
Male	459.8	465.8	465.2	473.0	479.6	489.2	481.5	479.0	484.4	477.0	456.9	452.4
Female	323.6	320.3	321.0	313.3	314.5	318.6	310.8	305.5	307.2	300.0	285.9	283.7
<18	12.0	12.3	12.4	12.7	12.6	11.5	12.3	12.1	12.0	11.6	11.8	11.7
0-4	9.6	8.3	9.7	11.1	10.2	9.1	11.1	10.2	10.9	11.3	11.5	11.6
5-11	7.8	9.3	7.9	8.0	8.0	6.5	7.0	7.6	7.2	7.2	6.9	7.5
12-17	18.9	19.1	20.0	19.5	20.0	19.2	19.5	18.9	18.4	17.0	17.8	16.7
18-44	113.5	112.7	111.7	112.9	117.5	121.2	119.4	118.7	122.4	118.9	115.6	115.2
18-24	44.5	42.3	42.6	39.6	42.2	43.3	42.5	41.3	40.4	39.4	39.6	36.3
25-44	137.6	137.3	135.9	138.5	143.9	148.5	146.3	145.8	151.1	146.7	142.1	142.9
45-64	617.6	607.3	608.8	602.3	603.5	613.7	598.4	594.0	594.4	577.8	558.0	562.2
45-54	391.4	389.4	391.9	390.3	388.0	404.1	391.1	386.9	389.6	375.2	372.8	373.3
55-64	843.9	825.2	825.7	814.3	819.1	823.3	805.6	801.0	799.1	780.3	743.1	751.1
65+	1585.2	1629.4	1619.0	1616.4	1634.9	1657.7	1624.5	1602.1	1614.7	1609.2	1526.4	1476.7
65-74	1441.5	1429.3	1410.2	1400.9	1389.7	1416.2	1381.1	1354.9	1364.1	1359.6	1275.7	1252.3
75-84	1761.0	1857.9	1848.3	1850.1	1896.8	1917.0	1878.9	1856.7	1871.3	1871.0	1792.6	1716.0
85+	1264.6	1346.6	1414.5	1433.5	1469.3	1479.2	1514.3	1527.6	1555.0	1486.7	1372.6	1327.1

Data Source: Special analyses, USRDS ESRD Database and CDC Bridged Race Intercensal Estimates Dataset Incident ESRD patients. Adj: overall, age/sex/race; rates by age adjusted for sex/race; rates by sex adjusted for age/race; rates by race/ethnicity adjusted for age/sex. Reference: 2011 patients. "" Zero values in this cell. ~Estimate shown is imprecise due to small sample size and may be unstable over time. Abbreviations: Adj, adjusted; Af Am, African American; CKD, chronic kidney disease; ESRD, end-stage renal disease.

## Kidney Failure Due to Diabetes

While DM remains the leading cause of ESRD in the United States, Table 2.6 illustrates that the rate of kidney failure due to DM has decreased by 12 percent in the last decade, reaching 154.0 per million population in 2012 compared with 172.3 per million in 2002. Wide variation exists in these rates by race, with

Whites having the lowest rate, at 127.2 per million, compared with 402.4 among African Americans. Males also had a higher rate of diabetic kidney failure than females, at 186.5 compared with 126.4 per million population. The overall rates remain just short of the HP2020 goal of 151.9 per million, although this target is being met by some subgroups, including Whites, females, and patients aged 44 years and younger.

vol 2 Table 2.6 HP2020 CKD-9.1 Reduce kidney failure due to diabetes: Target 151.9 per million population

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
<b>All</b>	175.1	172.3	171.4	171.3	171.6	174.6	168.7	166.2	167.0	164.4	157.0	154.0
<b>American Indian or Alaskan Native only</b>	519.8	492.2	464.8	475.0	427.5	363.0	376.9	391.2	388.0	353.2	327.5	318.3
<b>Asian only</b>	150.8	142.0	138.3	128.2	159.5	176.4	171.4	178.9	179.7	172.8	173.5	165.1
<b>Native Hawaiian or other Pacific Islander only~</b>	2158.0	1960.9	1966.1	2220.1	1664.7	1700.4	1467.6	1283.7	1476.3	1609.1	1411.8	1462.8
<b>Black or Af Am only</b>	519.7	513.8	504.0	490.7	492.1	495.6	473.5	468.7	466.7	452.4	431.2	402.4
<b>White only</b>	132.0	130.6	130.8	132.7	133.9	137.8	134.3	132.2	133.5	132.9	127.5	127.2
<b>Two or more races</b>	.	.	.	.	.	59.4	58.7	49.0	42.3	29.3	18.4	4.6
<b>Hispanic or Latino</b>	397.4	398.8	400.6	386.1	371.7	368.9	360.5	361.2	353.5	351.0	340.1	315.5
<b>Not Hispanic or Latino</b>	162.3	159.4	158.7	159.6	159.7	162.0	156.5	154.2	155.6	153.1	146.1	144.7
<b>Black or Af Am only, not Hispanic or Latino</b>	527.5	521.3	511.3	497.1	499.3	503.3	481.4	476.7	475.2	460.4	438.7	411.6
<b>White only, not Hispanic or Latino</b>	113.5	111.1	110.7	113.0	113.2	115.1	111.4	108.1	109.2	108.0	102.2	103.6
<b>Male</b>	191.5	192.2	191.9	197.5	199.3	203.5	199.1	197.8	200.2	198.0	190.1	186.5
<b>Female</b>	161.2	155.5	154.3	149.5	148.4	150.2	143.4	140.0	139.3	136.2	129.2	126.4
<b>&lt;18</b>	0.1	0.1	0.1	0.1	0.1	0.1	*	0.1	0.1	0.1	0.1	0.1
0-4	*	*	*	*	*	0.2	.	*	0.3	0.3	*	0.2
5-11	.	0.1	.	.	*	.	.	*	.	.	.	*
12-17	*	*	*	*	0.2	*	*	*	*	*	*	*
<b>18-44</b>	33.8	32.8	33.6	34.4	35.2	38.5	37.8	37.5	39.9	39.6	39.7	37.8
18-24	3.7	2.9	3.0	2.1	3.1	3.2	2.7	2.4	2.6	2.5	2.3	2.4
25-44	44.3	43.3	44.3	45.7	46.5	50.9	50.2	49.8	53.0	52.6	52.8	50.1
<b>45-64</b>	344.2	333.8	329.3	324.1	323.5	323.3	309.9	307.9	306.6	295.0	280.6	281.1
45-54	191.7	188.8	187.3	185.6	182.9	189.2	179.2	178.1	179.8	175.6	173.0	173.9
55-64	496.8	478.8	471.4	462.5	464.2	457.5	440.6	437.6	433.3	414.5	388.3	388.3
<b>65+</b>	679.1	688.9	682.4	690.1	694.8	705.8	690.0	672.8	673.1	678.9	645.4	611.1
65-74	749.6	734.6	727.7	721.3	712.1	724.4	697.2	676.9	674.6	668.1	630.1	607.5
75-84	649.1	682.2	673.4	693.2	714.1	722.0	715.1	698.4	700.0	719.2	689.4	641.1
85+	274.9	298.4	318.4	345.9	329.3	358.0	366.4	376.7	389.8	383.8	358.5	345.6

Data Source: Special analyses, USRDS ESRD Database and CDC Bridged Race Intercensal Estimates Dataset Incident ESRD patients. Incident ESRD patients. Adj: age/sex/race; Reference: 2011. "." Zero values in this cell. \*Values for cells with 10 or fewer patients are suppressed. ~Estimate shown is imprecise due to small sample size and may be unstable over time. Abbreviations: Adj, adjusted; Af Am, African American; CDC, Centers for Disease Control and Prevention; CKD, chronic kidney disease; ESRD, end-stage renal disease.

In 2012, the adjusted rate of kidney failure due to DM among diabetic patients was 2,245 per million population, continuing a favorable trend since 2007, when the rate was 2,618 per million, and below the HP2020 target of 2,356 for the third consecutive year (see Table 2.7). Rates remain highest in Black/African American diabetics, at 3,670 per million, although

this represents an 18 percent drop from 2007. Male diabetics also remain at higher risk for kidney failure compared with females; again, both sexes have experienced significant declines overall, by 14 and 15 percent respectively since 2007.



**vol 2 Table 2.7 HP2020 CKD-9.2 Reduce kidney failure due to diabetes among persons with diabetes: Target 2,356 per million population**

	2007	2008	2009	2010	2011	2012
<b>All</b>	2,618	2,487	2,405	2,350	2,276	2,245
<b>American Indian or Alaskan Native only</b>	2,585	2,968	2,992	2,667	2,306	2,278
<b>Asian only</b>	2,091	2,213	2,247	2,154	2,124	2,137
<b>Native Hawaiian or other Pacific Islander only</b>	.	.	.	.	.	.
<b>Black or Af Am only</b>	4,492	4,347	4,262	3,996	3,841	3,670
<b>White only</b>	2,278	2,141	2,054	2,033	1,976	1,967
<b>Two or more races</b>	447	346	273	196	158	36
<b>Hispanic or Latino</b>	3,313	3,170	2,955	2,903	2,895	2,772
<b>Not Hispanic or Latino</b>	2,517	2,389	2,322	2,264	2,181	2,159
<b>Black or Af Am only, not Hispanic or Latino</b>	4,698	4,536	4,489	4,204	4,075	3,871
<b>White only, not Hispanic or Latino</b>	2,050	1,903	1,829	1,806	1,734	1,751
<b>Male</b>	2,931	2,745	2,627	2,547	2,523	2,516
<b>Female</b>	2,327	2,236	2,180	2,144	2,026	1,975
<b>&lt;18</b>	*	34	34	51	35	59
0-4	.	.	.	.	.	.
5-11	*	.	.	.	.	*
12-17	*	*	*	*	*	*
<b>18-44</b>	1,613	1,532	1,507	1,462	1,561	1,497
18-24	341	272	289	293	338	291
25-44	1,748	1,678	1,642	1,579	1,668	1,632
<b>45-64</b>	2,380	2,257	2,199	2,139	2,072	2,096
45-54	2,010	1,844	1,855	1,869	1,879	1,874
55-64	2,645	2,573	2,441	2,313	2,182	2,233
<b>65+</b>	3,102	2,941	2,807	2,728	2,579	2,489
65-74	3,188	2,993	2,900	2,776	2,624	2,544
75-84	3,351	3,159	2,941	2,884	2,804	2,702
85+	1,950	2,069	1,985	2,085	1,774	1,688

Data Source: Special analyses, USRDS ESRD Database and CDC Bridged Race Intercensal Estimates Dataset Incident ESRD patients. Incident ESRD patients. Adj: age/sex/race; Ref: 2011. NHIS 2006–2012 used to estimate diabetes mellitus prevalence; “.” Zero values in this cell. \*Values for cells with 10 or fewer patients are suppressed. Abbreviations: Adj, adjusted; Af Am, African American; CDC, Centers for Disease Control and Prevention; CKD, chronic kidney disease; ESRD, end-stage renal disease; NHIS, National Health Interview Survey; Ref, reference.

## Nephrologist Care

In 2012, 33.1 percent of patients beginning ESRD therapy on hemodialysis (HD) had received care from a nephrologist at least 12 months prior to initiation, exceeding the HP2020 goal of 30.0 percent, and reflecting an increase from the level of 25.7 percent seen in 2005 (Table 2.8).

By race, rates of pre-ESRD nephrologist care were highest among Whites (34.7 percent) and Asians (32.1 percent). Rates were lower among Blacks/African Americans (29.7 percent) and American Indians/Alaskan Natives (30.1 percent). While rates overall have increased, the gap from lowest to highest has increased slightly from 5.1 percent in 2005 to 7.3 percent in 2012. Rates by ethnicity are lowest among Hispanics/Latinos, at 25.9 percent.

Rates of pre-ESRD nephrologist care were nearly identical by sex, at 33.2 percent among males and 33.1 percent among females. However, broader variation was seen by age, with rates ranging from 27.8 percent among those aged 18-44 to 40.7 percent among those under age 18.

## Vascular Access

In 2012, 36.8 percent of incident hemodialysis patients had a maturing arteriovenous fistula or were using one as their primary vascular access, the second consecutive year above the HP2020 target of 35.0 percent, and an improvement from 31.2 percent in 2005 (see Table 2.9). This varied by race, from 36.0 percent among Blacks/African Americans to 40.7 percent among American Indians, and was more common among men than women.

Programs such as HP2020 and the Fistula First Initiative continue to work to increase the use of fistulas and promote early placement prior to initiation of ESRD therapy.

vol 2 Table 2.8 HP2020 CKD-10 Increase the proportion of chronic kidney disease patients receiving care from a nephrologist at least 12 months before the start of renal replacement therapy: Target 30.0%

	2005 (%)	2006 (%)	2007 (%)	2008 (%)	2009 (%)	2010 (%)	2011 (%)	2012 (%)
<b>All</b>	25.7	26.4	27.3	28.6	28.6	29.6	31.0	33.1
<b>American Indian or Alaskan Native only</b>	25.4	27.0	26.0	27.9	27.2	24.2	28.3	30.1
<b>Asian only</b>	25.8	24.0	26.7	27.7	29.3	29.9	31.6	32.1
<b>Native Hawaiian or other Pacific Islander only</b>	23.2	25.4	24.0	22.0	23.8	25.3	27.1	27.4
<b>Black or Af Am only</b>	22.2	23.1	24.1	24.7	25.0	25.5	27.2	29.7
<b>White only</b>	27.3	28.0	28.8	30.4	30.2	31.3	32.7	34.7
<b>Two or more races</b>	21.4	21.6	22.1	27.5	26.0	25.9	25.0	25.0
<b>Hispanic or Latino</b>	20.0	21.3	21.4	22.3	22.6	23.7	25.1	25.9
<b>Not Hispanic or Latino</b>	26.6	27.2	28.2	29.6	29.5	30.5	32.1	34.4
<b>Black or Af Am only, not Hispanic/Latino</b>	22.2	23.2	24.1	24.7	25.0	25.6	27.3	29.8
<b>White only, not Hispanic or Latino</b>	28.8	29.4	30.5	32.3	32.0	33.2	34.7	37.0
<b>Male</b>	26.1	26.5	27.3	28.4	28.3	29.6	30.8	33.2
<b>Female</b>	25.3	26.3	27.3	28.8	28.9	29.5	31.4	33.1
<b>&lt;18</b>	39.7	36.1	35.1	40.1	39.1	37.7	44.7	40.7
0-4	25.0	19.8	26.0	26.9	22.8	23.3	25.2	26.6
5-11	50.5	48.9	40.7	53.1	47.7	49.0	58.3	51.7
12-17	41.4	37.0	36.7	40.4	42.2	39.3	47.7	42.5
<b>18-44</b>	23.3	23.0	23.7	24.4	23.9	24.3	25.8	27.8
18-24	24.7	23.2	25.0	24.0	24.8	25.4	27.6	26.5
25-44	23.2	22.9	23.5	24.5	23.8	24.2	25.6	27.9
<b>45-64</b>	25.7	26.1	26.7	27.3	27.4	27.9	29.5	31.2
45-54	24.1	25.0	25.5	25.3	25.8	26.2	28.4	29.5
55-64	26.8	26.9	27.4	28.6	28.5	29.0	30.1	32.2
<b>65+</b>	26.1	27.5	28.6	30.5	30.5	32.0	33.4	35.9
65-74	27.0	28.4	28.9	30.6	30.7	32.0	33.4	35.6
75-84	25.9	27.3	28.9	31.2	30.9	32.7	33.9	36.7
85+	22.9	24.2	26.6	27.6	28.4	29.7	31.6	34.2

Data Source: Special analyses, Medicare 5 percent sample. Incident hemodialysis patients with a valid ESRD Medical Evidence CMS 2728 form; nephrologist care determined from Medical Evidence form. Abbreviations: Af Am, African American; CMS, Centers for Medicare and Medicaid Services; CKD, chronic kidney disease; ESRD, end-stage renal disease.

vol 2 Table 2.9 HP2020 CKD-11.3 Increase the proportion of adult hemodialysis patients who use arteriovenous fistulas or have a maturing fistula as the primary mode of vascular access at the start of renal replacement therapy: Target 35.0%

	2005 (%)	2006 (%)	2007 (%)	2008 (%)	2009 (%)	2010 (%)	2011 (%)	2012 (%)
<b>All</b>	31.2	32.1	31.8	31.3	32.4	33.9	35.2	36.8
<b>American Indian or Alaskan Native only</b>	36.5	39.1	38.0	41.6	41.3	40.9	40.6	40.7
<b>Asian only</b>	36.3	37.7	35.5	35.9	35.8	37.6	37.3	38.1
<b>Native Hawaiian or other Pacific Islander only</b>	40.6	34.9	35.6	32.7	32.3	32.8	36.0	37.7
<b>Black or Af Am only</b>	28.5	29.4	29.9	29.3	30.8	32.2	34.1	36.0
<b>White only</b>	32.0	32.9	32.3	31.9	32.8	34.4	35.5	37.1
<b>Two or more races</b>	23.0	36.2	29.3	24.8	33.2	31.3	33.0	38.1
<b>Hispanic or Latino</b>	31.5	32.4	30.0	29.8	31.1	32.8	33.6	34.5
<b>Not Hispanic or Latino</b>	31.1	32.0	32.0	31.6	32.6	34.1	35.5	37.3
<b>Black or Af Am only, not Hispanic/Latino</b>	28.4	29.3	29.9	29.2	30.7	32.0	34.0	36.0
<b>White only, not Hispanic or Latino</b>	32.1	33.0	32.9	32.4	33.3	34.9	36.2	37.9
<b>Male</b>	35.1	35.3	35.0	34.0	35.0	36.4	38.0	39.3
<b>Female</b>	26.4	28.0	27.6	27.8	29.0	30.6	31.5	33.5
<b>&lt;18</b>	29.6	29.7	28.3	27.6	29.3	31.1	32.0	32.7
0-4	25.9	22.7	20.9	21.0	23.0	23.7	24.9	26.1
5-11	30.0	30.4	29.1	28.3	29.9	31.8	32.7	33.4
12-17	33.3	33.5	32.7	32.6	33.4	34.4	36.0	38.0
<b>18-44</b>	32.5	33.2	32.5	32.2	33.0	34.1	36.0	37.3
18-24	33.9	33.7	32.9	32.9	33.6	34.7	36.0	38.4
25-44	30.0	31.6	31.8	31.1	32.4	34.1	35.3	36.8
<b>45-64</b>	31.8	33.6	34.2	33.0	34.4	36.0	37.1	39.0
45-54	29.4	30.8	30.7	30.9	32.0	33.9	35.1	36.3
55-64	23.7	25.2	25.4	24.3	25.5	26.7	28.4	29.2
<b>65+</b>	26.1	27.5	28.6	30.5	30.5	32.0	33.4	35.9
65-74	27.0	28.4	28.9	30.6	30.7	32.0	33.4	35.6
75-84	25.9	27.3	28.9	31.2	30.9	32.7	33.9	36.7
85+	22.9	24.2	26.6	27.6	28.4	29.7	31.6	34.2

Data Source: Special analyses, Medicare 5 percent sample. Incident hemodialysis patients age 18 & older. Abbreviations: Af Am, African American; CKD, chronic kidney disease.

## Transplantation

Among 2011 ESRD patients younger than 70, 17.7 percent were wait-listed or received a deceased donor kidney transplant within one year of initiation, a level below the HP2020 target of 18.7 percent.

As shown in Table 2.10, the target is currently being met by Asians (33.3 percent), Whites (18.7 percent), those younger than age 18 (54.9 percent), those aged 18-44 (28.9 percent), and those aged 45-55 (18.8 percent). Groups furthest from the target include those aged 65-69, African Americans, and Native Americans. Gaps between groups with the highest and lowest percentages have remained fairly stable, showing only minor decreases over time.

Among patients younger than age 70 starting ESRD therapy in 2009, 14.7 percent received a kidney transplant within three years of initiation, well below the HP2020 target of 20.1 percent, and approximately one percentage point lower than the previous year (see Table 2.11). This continues the slow but consistent decrease observed since 1998, when 20.1 percent of patients received a transplant within three years of initiating ESRD therapy.

Rates are highest among Whites (18.2 percent) and lowest among Blacks/African Americans (7.7 percent) and American Indians/Alaskan Natives (7.2 percent). Males (15.0 percent) are slightly more likely to receive a transplant as compared with females (13.4 percent). The percentage of patients receiving transplants decreases with age, from 78.2 in pediatric patients to 7.9 among those ages 65-69.

**vol 2 Table 2.10 HP2020 CKD-12 Increase the proportion of dialysis patients wait-listed and/or receiving a deceased donor kidney transplant within 1 year of end-stage renal disease start (among patients under 70 years of age): Target 18.7% of dialysis patients**

	2000 (%)	2001 (%)	2002 (%)	2003 (%)	2004 (%)	2005 (%)	2006 (%)	2007 (%)	2008 (%)	2009 (%)	2010 (%)	2011 (%)
<b>All</b>	15.4	14.6	14.6	14.7	15.4	15.9	17.0	17.1	16.8	17.3	17.0	17.7
<b>American Indian or Alaskan Native only</b>	12.8	9.7	10.1	9.6	10.2	11.3	10.4	11.3	10.7	11.5	11.5	11.3
<b>Asian only</b>	27.0	29.1	28.0	28.3	32.1	28.2	31.3	30.8	31.3	32.3	32.1	33.1
<b>Native Hawaiian or other Pacific Islander only</b>	17.4	17.5	18.8	19.5	18.1	16.0	15.2	14.9	14.1	15.2	15.2	14.8
<b>Black or Af Am only</b>	11.2	10.5	10.7	10.6	11.6	12.1	13.1	13.3	13.3	13.9	13.9	14.5
<b>White only</b>	17.1	16.3	16.1	16.4	16.8	17.6	18.5	18.6	18.2	18.3	17.9	18.7
<b>Two or more races</b>	*	*	*	*	*	14.1	19.4	14.1	23.7	23.8	23.0	17.4
<b>Hispanic or Latino</b>	13.0	12.7	13.3	14.1	14.6	15.8	17.6	17.7	17.4	18.2	17.6	18.6
<b>Not Hispanic or Latino</b>	15.5	14.7	14.5	14.5	15.4	15.8	16.7	16.8	16.6	16.9	16.8	17.4
<b>Black or Af Am only, not Hispanic or Latino</b>	11.2	10.5	10.7	10.6	11.6	12.0	13.0	13.2	13.2	13.9	13.9	14.5
<b>White only, not Hispanic or Latino</b>	18.1	17.1	16.8	16.8	17.2	18.1	18.8	18.9	18.4	18.3	18.0	18.5
<b>Male</b>	16.5	15.3	15.7	15.6	16.5	16.9	18.0	17.8	17.5	18.1	17.8	18.4
<b>Female</b>	13.4	13.4	12.7	13.1	13.7	14.3	15.3	15.8	15.7	15.8	15.8	16.5
<b>&lt;18</b>	42.9	40.7	43.0	50.1	46.3	53.3	57.5	56.2	58.2	57.9	56.5	54.9
0-4	26.2	32.1	32.9	41.2	32.5	34.3	42.7	38.2	40.2	43.9	39.6	37.5
5-11	44.8	49.5	45.6	50.3	51.9	65.0	65.3	66.7	69.8	65.9	64.9	62.5
12-17	47.5	41.2	43.2	52.9	48.2	55.9	63.5	60.7	64.6	63.0	62.3	61.2
<b>18-44</b>	29.5	27.6	27.7	26.1	27.8	26.9	28.9	27.8	27.6	27.9	27.1	28.9
18-24	31.3	29.3	30.9	29.9	33.8	28.4	32.7	33.0	30.7	33.2	33.1	33.9
25-44	26.2	24.9	23.9	23.4	24.6	24.8	25.8	25.2	25.0	25.4	24.7	26.7
<b>45-64</b>	18.0	17.0	16.3	16.5	17.0	17.5	18.3	18.6	17.7	18.4	18.3	19.1
45-54	18.5	17.4	17.1	16.7	16.8	17.0	18.3	18.6	17.3	18.4	18.0	18.8
55-64	11.3	10.5	10.7	11.4	12.2	13.1	13.9	14.1	14.4	14.2	14.4	15.0
<b>65+</b>	7.4	7.3	7.9	8.4	9.2	10.0	11.1	11.4	11.9	12.3	12.3	12.6
65-69	7.4	7.3	7.9	8.4	9.2	10.0	11.1	11.4	11.9	12.3	12.3	12.6

Data Source: Special analyses, Medicare 5 percent sample. Incident ESRD patients younger than 70. \* Values for cells with 10 or fewer patients are suppressed. Abbreviations: Af Am, African American; CKD, chronic kidney disease; ESRD, end-stage renal disease.

vol 2 Table 2.11 HP2020 CKD-13.1 Increase the proportion of patients receiving a kidney transplant within 3 years of end-stage renal disease: Target 20.1%

	1998 (%)	1999 (%)	2000 (%)	2001 (%)	2002 (%)	2003 (%)	2004 (%)	2005 (%)	2006 (%)	2007 (%)	2008 (%)	2009 (%)
<b>All</b>	20.1	19.5	19.3	18.4	18.4	18.2	18.3	17.8	17.2	16.6	15.7	14.7
<b>American Indian or Alaskan Native only</b>	13.7	9.5	15.5	8.7	11.5	8.8	9.2	8.9	9.9	10.1	6.8	7.2
<b>Asian only</b>	19.2	18.7	18.7	19.1	21.0	21.8	20.3	18.5	19.0	17.6	18.1	16.8
<b>Native Hawaiian or other Pacific Islander only</b>	13.6	13.4	8.3	12.8	12.4	11.8	12.7	9.6	9.8	10.5	10.7	8.4
<b>Black or Af Am only</b>	9.8	9.5	9.8	8.8	9.6	9.2	10.0	9.6	9.0	9.0	8.7	7.7
<b>White only</b>	26.2	25.3	24.6	23.9	23.2	23.0	22.7	22.1	21.4	20.7	19.3	18.2
<b>Two or more races</b>	*	*	*	*	*	*	*	16.3	16.4	14.4	18.3	17.4
<b>Hispanic or Latino</b>	16.8	14.9	15.4	14.6	14.5	14.9	14.7	14.6	14.5	13.8	12.6	11.8
<b>Not Hispanic or Latino</b>	20.1	19.6	19.2	18.5	18.6	18.1	18.4	17.8	17.2	16.8	15.9	14.8
<b>Black or Af Am only, not Hispanic or Latino</b>	9.8	9.4	9.7	8.8	9.5	9.2	9.9	9.6	8.9	9.0	8.6	7.7
<b>White only, not Hispanic or Latino</b>	28.1	27.8	26.9	26.3	25.8	25.3	25.1	24.4	23.8	23.1	21.8	20.5
<b>Male</b>	21.6	20.5	20.1	19.3	19.6	19.2	19.2	18.7	18.1	17.2	16.0	15.0
<b>Female</b>	17.2	16.9	16.8	16.2	15.8	15.6	16.0	15.4	14.9	15.1	14.5	13.4
<b>&lt;18</b>	75.1	75.9	73.2	72.9	72.7	77.5	76.2	76.9	78.7	78.9	77.1	78.2
0-4	78.7	81.8	78.1	77.0	76.6	79.2	77.2	74.6	76.6	76.7	68.5	74.7
5-11	81.4	80.4	75.1	81.9	78.8	82.5	83.9	82.2	82.7	88.5	86.3	83.9
12-17	70.7	72.1	71.0	67.0	68.5	74.8	72.7	75.7	78.1	76.3	76.7	77.5
<b>18-44</b>	33.8	32.6	31.6	30.3	29.8	29.0	29.5	27.7	26.9	25.5	24.1	22.8
18-24	44.4	42.7	44.0	42.6	39.9	42.5	42.6	40.0	37.9	35.9	34.3	35.0
25-44	32.6	31.5	30.2	28.9	28.6	27.4	28.0	26.4	25.6	24.4	23.0	21.5
<b>45-64</b>	16.3	15.7	16.1	15.3	15.1	15.1	15.2	15.0	14.6	14.1	13.3	12.4
45-54	21.1	20.2	20.4	19.6	18.4	18.5	18.5	17.6	17.2	17.0	15.7	14.9
55-64	12.6	12.1	12.6	11.9	12.5	12.5	12.7	13.2	12.7	12.1	11.7	10.7
<b>65+</b>	5.3	6.0	6.3	6.5	7.4	7.7	8.1	7.9	8.3	8.3	8.3	7.9
65-69	5.3	6.0	6.3	6.5	7.4	7.7	8.1	7.9	8.3	8.3	8.3	7.9

Data Source: Special analyses, Medicare 5 percent sample. Incident ESRD patients younger than 70. \*Values for cells with 10 or fewer patients are suppressed. Abbreviations: Af Am, African American; CKD, chronic kidney disease; ESRD, end-stage renal disease.

The percentage of patients receiving a preemptive transplant at the start of ESRD has risen by approximately 0.5 percent over the past decade, from 3.2 percent in 2001 to 3.7 percent in 2012. As seen in Table 2.12, preemptive transplants are most common in pediatric patients, reaching 30.3 percent among those aged 5-11. Rates are similar by sex at approximately three percent. Substantial variation is observed by race, however, ranging from 0.9 percent among Blacks/African Americans to 4.2 percent among Whites.

vol 2 Table 2.12 HP2020 CKD-13.2 Increase the proportion of patients who receive a preemptive transplant at the start of end-stage renal disease

	2001 (%)	2002 (%)	2003 (%)	2004 (%)	2005 (%)	2006 (%)	2007 (%)	2008 (%)	2009 (%)	2010 (%)	2011 (%)	2012 (%)
<b>All</b>	3.2	3.3	3.3	3.6	3.8	4.0	4.0	3.9	3.8	3.8	3.9	3.7
<b>American Indian or Alaskan Native only</b>	*	*	1.5	*	*	1.4	*	*	1.7	*	1.6	1.1
<b>Asian only</b>	2.0	2.8	2.6	2.4	2.6	2.9	3.1	3.4	2.9	3.4	3.8	3.0
<b>Native Hawaiian or other Pacific Islander only</b>	*	*	*	*	*	*	1.9	2.6	2.0	*	*	*
<b>Black or Af Am only</b>	0.5	0.7	0.7	0.7	0.9	0.9	1.1	1.1	1.0	1.1	1.2	0.9
<b>White only</b>	3.9	4.1	4.0	4.5	4.8	5.0	5.2	4.9	4.6	4.6	4.7	4.2
<b>Two or more races</b>	*	*	*	*	1.3	*	*	*	*	*	*	*
<b>Hispanic or Latino</b>	1.1	1.3	1.3	1.5	1.5	2.0	2.0	2.0	2.0	2.0	2.2	2.1
<b>Not Hispanic or Latino</b>	2.8	3.0	2.9	3.3	3.5	3.7	3.9	3.8	3.5	3.6	3.7	3.2
<b>Black or Af Am only, not Hispanic/Latino</b>	0.5	0.7	0.7	0.7	0.9	0.9	1.1	1.1	1.0	1.1	1.2	0.9
<b>White only, not Hispanic or Latino</b>	4.6	4.8	4.7	5.3	5.6	6.0	6.2	5.9	5.4	5.5	5.6	5.0
<b>Male</b>	2.7	2.8	2.8	3.0	3.2	3.6	3.7	3.4	3.3	3.3	3.4	2.9
<b>Female</b>	2.5	2.7	2.6	3.0	3.2	3.3	3.5	3.6	3.3	3.4	3.5	3.2
<b>&lt;18</b>	19.5	18.7	21.1	19.3	23.5	25.2	22.0	22.3	26.3	23.9	26.2	25.2
0-4	17.6	12.7	18.8	17.4	17.6	17.6	19.4	11.9	19.2	16.1	19.4	17.6
5-11	21.3	26.8	28.3	21.8	29.0	33.5	31.1	32.3	36.1	32.6	30.2	30.3
12-17	19.2	16.4	18.7	19.0	23.4	24.7	19.5	22.3	25.0	23.5	27.7	26.6
<b>18-44</b>	5.7	5.8	5.4	6.0	5.7	6.3	6.0	6.0	5.8	5.6	6.0	5.6
18-24	8.5	8.6	8.9	8.9	8.8	10.3	8.4	9.1	9.3	9.5	9.2	9.6
25-44	5.4	5.5	5.0	5.7	5.4	5.8	5.8	5.7	5.5	5.2	5.6	5.2
<b>45-64</b>	2.5	2.6	2.8	3.1	3.3	3.5	3.6	3.4	3.2	3.4	3.3	3.1
45-54	3.5	3.6	3.7	3.9	4.2	4.3	4.6	4.2	3.9	4.3	4.0	3.8
55-64	1.8	1.9	2.1	2.4	2.6	2.8	3.0	2.9	2.7	2.8	2.9	2.7
<b>65+</b>	0.7	0.9	1.2	1.3	1.6	1.9	1.8	2.0	1.9	2.1	2.3	2.2
65-69	0.7	0.9	1.2	1.3	1.6	1.9	1.8	2.0	1.9	2.1	2.3	2.2

Data Source: Special analyses, Medicare 5 percent sample. Incident ESRD patients younger than 70. \*Values for cells with 10 or fewer patients are suppressed. Abbreviations: Af Am, African American; CKD, chronic kidney disease; ESRD, end-stage renal disease.

## Mortality

Since 2001, the overall death rate among prevalent patients on dialysis has fallen nearly 25 percent, from 240.7 deaths per 1,000 patient years to 181.4 in 2012, exceeding the HP2020 target of 193.2 for the second year in a row (Table 2.13). Rates were highest among Whites, at 217.3 deaths per 1,000 patient years, and lowest among those with two or more races, at 125.3 deaths per 1,000. Rates were identical by sex, at 181.4

deaths per 1,000 patient years. Significant reductions in rates since 2001 were observed across all age groups, with approximately 34 percent fewer deaths observed in 2012 (32.3 deaths per 1,000 patient years) compared with those in 2001 (48.9 deaths) for patients younger than 18 years. Overall rates were highest among patients aged 65 and older (281.4 deaths per 1,000 patient years).

vol 2 Table 2.13 HP2020 CKD-14.1 Reduce the total death rate for persons on dialysis: Target 193.2 deaths per 1,000 patient years

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
<b>All</b>	240.7	239.1	237.4	232.1	228.5	224	214.7	207.4	201.6	194.3	190.2	181.4
<b>American Indian or Alaskan Native only</b>	208.1	199.2	192.2	183.6	180	170.8	164.1	167.9	172	150.8	147.4	143.5
<b>Asian only</b>	174.1	164.3	172.9	168.2	172.3	160.4	156.4	142.2	143.5	134.6	138	132
<b>Native Hawaiian or other Pacific Islander only</b>	162.5	180	171.2	165.3	151.3	161.7	162.8	149.1	157.2	153.1	138.7	132.2
<b>Black or Af Am only</b>	189.8	186.7	187.2	186.2	181.7	176.2	169.4	163.1	157.9	150.2	145.2	138.8
<b>White only</b>	286.5	286.2	282.8	274.1	270.8	266.2	254.2	245.8	238.5	231.9	228	217.3
<b>Two or more races</b>	*	*	*	*	159	166.5	150.5	157.1	154.2	140.7	138	125.3
<b>Hispanic or Latino</b>	178.3	177.9	175.9	170.6	167	160.3	149.7	144.1	145.7	137.3	136.5	134.9
<b>Not Hispanic or Latino</b>	245.2	246	245.9	241.7	238.5	234.9	226.4	219.1	212.3	205.4	201	191
<b>Black or Af Am only, not Hispanic/Latino</b>	190.2	187	187.6	186.4	182.1	176.7	170.1	163.7	158.3	150.6	145.5	138.5
<b>White only, not Hispanic or Latino</b>	311.7	312.3	310.2	302.6	299.8	297.6	287.1	280	271.3	266.4	263	251
<b>Male</b>	235.2	233	233.4	228.9	225.3	221.1	212.3	206	201.6	193.6	189.4	181.4
<b>Female</b>	246.8	245.9	242	235.8	232.3	227.3	217.7	209.1	201.7	195.2	191.2	181.4
<b>&lt;18</b>	48.9	48.1	64.9	49.4	41	44.2	42.4	45.6	42.8	49.4	30.5	32.3
0-4	132.1	84.2	93.7	78	70.9	73.5	64.6	84.1	88.8	73.2	36.7	61.6
5-11	37.7	31.3	63.3	53.8	31	40.9	47.2	39.7	37.7	51	*	*
12-17	33.3	46.4	59.6	41.6	37.4	38.2	35.6	36.9	31.4	42.1	29.6	23.4
<b>18-44</b>	103.7	104.7	105.1	101.1	99.7	96.8	93.5	86.2	84.6	79.9	77.7	74.2
18-24	57.9	61	56.1	58.8	56.2	53.5	51.9	51.1	45.9	44.7	46.4	44.5
25-44	108.4	109.2	110.3	105.5	104.2	101.3	97.8	89.9	88.6	83.6	80.9	77.2
<b>45-64</b>	192.6	189.4	190.5	186.1	179.7	177.8	168.3	163.5	159.9	154	150.7	144.6
45-54	161	159.3	157.3	154.4	150.1	149.7	141.4	137	134.8	128.3	124.1	118.9
55-64	218.1	213.8	217.6	212.1	204	200.6	190	184.8	179.7	174.1	171.2	164.1
<b>65+</b>	362.2	360.5	354	348	347.5	339.9	329.4	320.4	310.9	300.8	295.4	281.4
65-74	308.1	305.6	298.8	294.2	291	279.8	268.1	263.9	256.4	244.9	241	229.8
75-84	426.6	420.4	411.9	401.6	402.9	398.7	387.5	373.9	358.5	351.1	344.4	328.8
85+	607.9	614	595.6	578.4	574.1	562.2	557.8	521.8	516.7	500.9	494.3	468.6

Data Source: Special analyses, Medicare 5 percent sample. Period prevalent dialysis patients. \*Values for cells with 10 or fewer patients are suppressed. Abbreviations: Af Am, African American; CKD, chronic kidney disease.

The rate of mortality among dialysis patients in the first three months after initiation has fallen nearly 24 percent from its peak in 2003 of 386.9 deaths per 1,000 patient years at risk to 311.8 in 2012, and for the first time achieves the HP2020 target of 329.0 (see Table 2.14). Rates were substantially higher among Whites, at 372.8 deaths per 1,000, compared with Native Hawaiians and Pacific Islanders (122.4 deaths per 1,000) and Asians (187.1 deaths per 1,000). Females were slightly higher than males, at 317.0 deaths per

1,000 patient years compared with 307.8 deaths per 1,000. Rates were highest among those aged more than 85 years (837.2 deaths per 1,000 patient years).

**vol 2 Table 2.14 HP2020 CKD-14.2 Reduce the death rate in dialysis patients within the first 3 months of initiation of renal replacement therapy: Target 329.0 deaths per 1,000 patient years at risk**

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
<b>All</b>	381.0	380.7	386.9	381.3	377.8	370.1	365.6	362.1	352.2	353.3	335.8	311.8
<b>American Indian or Alaskan Native only</b>	172.4	146.8	193.8	209.2	214.2	158.0	175.7	237.3	154.1	151.6	151.2	218.2
<b>Asian only</b>	232.9	226.0	236.2	231.9	251.7	207.8	247.0	203.3	213.4	216.5	177.8	187.1
<b>Native Hawaiian or other Pacific Islander only</b>	212.1	181.3	185.4	187.7	169.3	219.3	173.8	149.2	197.2	163.3	184.5	122.4
<b>Black or Af Am only</b>	274.9	266.4	278.3	274.9	274.8	267.2	254.2	253.6	246.8	243.0	230.6	206.7
<b>White only</b>	448.4	454.3	457.7	447.4	440.0	432.6	431.1	428.1	417.1	419.8	401.2	372.8
<b>Two or more races</b>	*	*	*	*	310.0	302.4	285.3	302.1	197.9	262.8	257.0	*
<b>Hispanic or Latino</b>	247.9	229.0	243.5	227.1	241.1	216.5	219.0	212.3	206.8	207.9	204.2	194.6
<b>Not Hispanic or Latino</b>	398.4	401.9	407.4	403.2	397.1	392.9	387.9	385.7	375.5	377.7	358.8	331.5
<b>Black or Af Am only, not Hispanic/Latino</b>	275.9	266.2	279.0	276.0	274.7	267.5	255.9	254.3	247.3	243.7	232.1	205.1
<b>White only, not Hispanic or Latino</b>	484.8	498.8	499.8	491.8	482.8	483.5	481.1	482.5	470.9	476.5	456.8	421.7
<b>Male</b>	383.1	376.3	386.1	382.4	372.5	367.1	367.4	363.7	357.0	350.5	335.8	307.8
<b>Female</b>	378.7	385.9	387.8	380.0	384.2	373.8	363.2	360.2	346.1	357.0	335.7	317.0
<b>&lt;18</b>	*	*	*	71.1	*	*	*	*	*	*	*	*
0-4	*	*	*	*	*	*	*	*	*	*	*	*
5-11	*	*	*	*	*	*	*	*	*	*	*	*
12-17	*	*	*	*	*	*	*	*	*	*	*	*
<b>18-44</b>	101.6	101.6	103.7	106.5	105.7	102.6	97.5	100.3	102.9	94.2	93.7	70.6
18-24	74.0	60.0	62.5	74.7	59.9	91.7	66.9	56.9	50.2	66.3	72.7	*
25-44	104.4	105.9	108.1	109.7	110.4	103.7	100.6	104.8	108.0	97.0	95.9	74.7
<b>45-64</b>	215.0	210.2	217.5	212.1	213.6	205.0	199.3	206.6	202.9	202.1	193.6	179.8
45-54	158.9	165.3	168.6	166.9	174.8	154.8	156.0	171.7	160.6	157.5	149.2	134.8
55-64	256.9	243.4	252.9	244.3	240.5	240.1	228.6	229.5	230.3	229.7	221.4	206.8
<b>65+</b>	580.5	580.5	590.2	583.0	577.7	571.5	569.3	555.5	537.9	539.2	512.9	480.5
65-74	431.0	427.9	421.0	422.2	418.3	401.4	404.8	405.2	390.9	391.6	367.3	349.8
75-84	673.3	674.3	676.9	668.9	655.4	656.0	652.7	615.7	611.3	610.8	593.2	545.9
85+	1046.0	982.9	1073.5	1009.6	990.6	1007.9	961.6	964.4	889.2	912.1	850.4	837.2

Data Source: Special analyses, Medicare 5 percent sample. Incident dialysis patients; unadjusted. \*Values for cells with 10 or fewer patients are suppressed. Abbreviations: Af Am, African American; CKD, chronic kidney disease.

For the third year in a row, the HP2020 goal of 83.2 cardiovascular deaths per 1,000 patient years at risk was met in 2012, with a rate of 75.5. Over the past decade, since 2001, the rate has fallen approximately 38 percent overall. As shown in Table 2.15, rates were highest—and above the target—among Whites, at 88.1 deaths per 1,000 patient years and lowest among those with two or more races, at 52.8 deaths per 1,000. Rates were slightly lower among females (72.6

deaths per 1,000) compared with males (77.8 deaths per 1,000), though both were below the target. Large reductions in rates by age were observed since 2001, with approximately 40 percent fewer deaths observed in 2012 (110.5 deaths per 1,000 patient years) compared with those in 2001 (184.4 deaths per 1,000) for patients older than 65 years.



**vol 2 Table 2.15 HP2020 CKD-14.3 Reduce the cardiovascular death rate for persons on dialysis: Target 83.2 deaths per 1,000 patient years at risk**

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
<b>All</b>	122.1	119.2	116.3	110.8	104.5	98.3	92.4	87.7	84.7	81.6	78.3	75.5
<b>American Indian or Alaskan Native only</b>	105.7	95.3	90.3	83.9	77.2	72	70.2	61.7	69.2	61.4	58.2	56.3
<b>Asian only</b>	97.3	91.1	96.2	86	89.6	73.2	71.4	67.7	69.1	63.4	63.8	59.9
<b>Native Hawaiian or other Pacific Islander only</b>	102.4	111.3	102.7	89.3	77	87.9	80	73.6	82	82.3	67.9	66.1
<b>Black or Af Am only</b>	92.7	91.3	89.3	87.6	83.4	79.4	74.5	71.3	68.4	64.5	61.2	60.4
<b>White only</b>	146.9	142.9	139.2	131.2	123	114.7	107.7	101.6	97.8	95.4	92.1	88.1
<b>Two or more races</b>	*	*	*	*	72.6	76.2	70.1	73.8	67.4	69.4	65.4	52.8
<b>Hispanic or Latino</b>	95.1	93	87.9	84.4	80.3	74.3	68	66.1	67.3	63.9	61.9	61.2
<b>Not Hispanic or Latino</b>	123.8	121.9	120.1	114.8	108.3	102.4	96.7	91.6	88	85	81.6	78.5
<b>Black or Af Am only, not Hispanic/Latino</b>	92.9	91.3	89.5	87.5	83.4	79.6	74.7	71.5	68.5	64.7	61.3	60.2
<b>White only, not Hispanic or Latino</b>	159.2	155.2	152.5	144.1	134.8	126.7	120.2	113.5	108.4	106.8	103.5	99.1
<b>Male</b>	121.7	118.6	116.8	112.1	105.2	99.8	93.6	89.8	87	83.5	80.1	77.8
<b>Female</b>	122.6	120	115.7	109.3	103.6	96.5	90.9	85	81.8	79.2	76	72.6
<b>&lt;18</b>	20.9	14.4	18.7	18.5	17	18.4	14.1	15.2	17.7	17.2	10	13.1
0-4	48.4	*	*	*	*	*	*	*	38	*	*	*
5-11	*	*	*	*	*	*	*	*	*	*	*	*
12-17	16.6	14.2	20.8	16.5	15.8	18.2	14.3	12.9	13.1	20.2	12.2	10.4
<b>18-44</b>	47.8	48.6	48.6	45.9	45.1	43	41.6	38.1	38.1	36.2	34.4	33.5
18-24	22.2	26.5	26.1	25.3	25.9	22.7	21.8	19.8	21.4	20.3	19.9	19.2
25-44	50.5	50.9	50.9	48	47.1	45.1	43.6	40	39.8	37.8	35.9	35
<b>45-64</b>	99.5	96.4	94.3	90.7	84.9	82.1	75.3	73.2	71.7	69	66.4	64.4
45-54	82.6	81.2	76.1	74.8	70.8	69.9	64.2	62.3	61.9	58.1	55.9	54
55-64	113.1	108.8	109.2	103.8	96.5	91.9	84.3	81.9	79.4	77.4	74.5	72.4
<b>65+</b>	184.4	179.6	173.9	165.2	156.1	144.4	137.8	129.8	123.9	119.8	115.1	110.5
65-74	158.9	154.7	147.9	143.5	132.7	122.3	116.5	111.4	106.4	100.5	98.5	93.7
75-84	214.8	205.7	200.3	185.3	179.6	164.8	157.8	146.9	137.1	137.4	128.2	125.6
85+	300.3	303.6	292.7	267.5	245.5	234.1	218.5	197.8	201.1	188.4	184.6	174

Data Source: Special analyses, Medicare 5 percent sample. Period prevalent dialysis patients; unadjusted. \*Values for cells with 10 or fewer patients are suppressed. Abbreviations: Af Am, African American; CKD, chronic kidney disease.

In 2012, the death rate for patients with a functioning transplant fell to 27.2 deaths per 1,000 patient years at risk, just above the HP2020 goal of 27.1 (Table 2.16). Rates were highest among American Indian/Alaskan Natives, at 30.2 per 1,000, and lowest among Asians, at 18.5. Rates were slightly higher among males (28.8 deaths per 1,000 patient years), who were above the target, compared with females, at 24.8 deaths per 1,000, who were below. Functioning transplant rates

were the highest among those aged 65 and older, at 65.5 deaths per 1,000 patient years compared with those aged 18-44, at 6.8.

vol 2 Table 2.16 HP2020 CKD-14.4 Reduce the total death rate for persons with a functioning kidney transplant:  
Target 27.1 deaths per 1,000 patient years at risk

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
<b>All</b>	33.3	31.7	32.4	30.6	31.5	30.8	30.1	28.8	29.8	29.5	29.9	27.2
<b>American Indian or Alaskan Native only</b>	37.7	34.8	31.8	36.0	37.5	46.0	33.5	31.8	50.3	45.0	42.1	30.2
<b>Asian only</b>	19.3	22.2	17.5	20.5	21.5	19.8	23.2	18.1	16.8	16.7	20.4	18.5
<b>Native Hawaiian or other Pacific Islander only</b>	30.8	32.3	24.5	23.5	37.7	19.0	17.2	18.4	26.7	18.9	17.0	19.8
<b>Black or Af Am only</b>	37.9	35.8	36.2	33.2	33.2	32.7	29.8	30.0	29.6	29.0	30.0	28.4
<b>White only</b>	33.0	31.4	32.7	30.8	31.6	31.2	31.1	29.4	30.7	30.6	30.7	27.7
<b>Two or more races</b>	*	*	*	*	24.5	21.7	15.6	21.9	22.6	22.6	23.8	23.3
<b>Hispanic or Latino</b>	21.1	20.0	18.7	17.3	21.1	22.4	19.9	19.7	21.4	20.9	21.6	18.4
<b>Not Hispanic or Latino</b>	34.6	33.1	34.1	32.3	32.9	32.0	31.6	30.1	31.1	30.9	31.2	28.6
<b>Black or Af Am only, not Hispanic/Latino</b>	38.1	36.3	36.1	33.4	33.7	32.9	30.1	30.5	29.7	29.3	30.2	28.8
<b>White only, not Hispanic or Latino</b>	34.6	32.9	34.8	32.9	33.3	32.6	33.0	31.2	32.7	32.6	32.7	29.7
<b>Male</b>	35.4	33.5	33.7	32.9	33.9	32.7	31.9	30.4	31.1	31.6	31.9	28.8
<b>Female</b>	30.1	29.2	30.4	27.4	28.0	28.1	27.6	26.4	27.9	26.6	27.0	24.8
<b>&lt;18</b>	5.4	7.7	6.6	3.7	7.3	4.0	*	*	3.4	6.4	3.1	*
0-4	*	*	*	*	*	*	*	*	*	*	*	*
5-11	*	*	*	*	*	*	*	*	*	*	*	*
12-17	5.8	7.3	6.5	*	8.4	*	*	*	*	6.4	*	*
<b>18-44</b>	14.8	13.8	12.2	11.9	11.4	11.2	10.5	9.4	9.7	8.7	7.9	6.8
18-24	8.5	3.8	5.1	7.2	7.2	7.8	5.7	6.3	6.4	6.1	4.2	4.7
25-44	15.4	14.8	13.0	12.3	11.9	11.5	11.0	9.7	10.1	9.0	8.4	7.1
<b>45-64</b>	38.4	34.9	35.7	31.8	32.9	31.0	29.1	27.4	26.9	25.8	26.6	22.1
45-54	29.1	27.5	26.3	23.4	25.2	24.0	21.5	20.6	20.7	17.9	17.7	14.2
55-64	51.7	45.0	47.6	42.0	41.8	38.7	37.1	34.3	33.0	33.1	34.7	29.1
<b>65+</b>	90.5	87.3	88.2	84.3	81.1	78.6	77.1	70.9	73.1	71.9	69.5	65.5
65-74	84.3	81.3	79.7	77.0	74.2	70.0	68.3	61.3	63.6	62.8	59.3	55.5
75-84	138.0	130.9	148.5	131.0	119.6	125.2	119.6	116.2	115.7	108.1	109.3	101.4
85+	*	*	*	*	168.6	117.8	196.3	118.9	136.0	172.2	140.3	160.2

Data Source: Special analyses, Medicare 5 percent sample. Period prevalent transplant patients; unadjusted. \*Values for cells with 10 or fewer patients are suppressed. Abbreviations: Af Am, African American; CKD, chronic kidney disease.

The rate of cardiovascular mortality among transplant patients has fallen by 35 percent since 2001, and continues to meet the HP2020 target of 4.4 deaths per 1,000 patients, declining to 3.3 deaths per 1,000 2012 (see Table 2.17). Rates were highest among Blacks/African Americans, though still below the target at 3.9. Rates were lowest among Asians, at 2.2 deaths per 1,000 patients; and similar among Hispanics/Latinos

at 2.4. Rates were the same for males and females, at 3.3 deaths per 1,000 patients, which is below the target.

vol 2 Table 2.17 HP2020 CKD-14.5 Reduce the cardiovascular death rate in persons with a functioning transplant:  
Target 4.4 deaths per 1,000 patient years at risk

	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
<b>All</b>	5.1	4.8	4.9	5.3	5.4	5.1	4.9	4.1	4.0	4.1	3.5	3.3
<b>American Indian or Alaskan Native only</b>	*	10.7	*	*	*	8.8	*	*	*	*	*	*
<b>Asian only</b>	*	3.8	*	*	2.3	3.6	3.0	*	*	*	2.0	2.2
<b>Native Hawaiian or other Pacific Islander only</b>	*	*	*	*	*	*	*	*	*	*	*	*
<b>Black or Af Am only</b>	6.6	5.6	5.8	6.0	6.0	5.9	5.3	5.0	4.9	4.8	4.2	3.9
<b>White only</b>	5.0	4.6	4.9	5.4	5.4	5.0	5.0	4.0	4.0	4.2	3.4	3.2
<b>Two or more races</b>	*	*	*	*	*	*	*	*	4.4	*	*	*
<b>Hispanic or Latino</b>	3.2	4.0	3.4	3.0	3.9	4.1	3.2	3.4	3.4	2.8	3.1	2.2
<b>Not Hispanic or Latino</b>	5.4	4.9	5.1	5.5	5.6	5.2	5.1	4.1	4.1	4.3	3.5	3.4
<b>Black or Af Am only, not Hispanic/Latino</b>	6.7	5.7	5.7	6.1	6.1	6.0	5.4	5.1	5.0	4.8	4.2	4.0
<b>White only, not Hispanic or Latino</b>	5.3	4.6	5.2	5.7	5.6	5.1	5.3	4.1	4.1	4.5	3.4	3.4
<b>Male</b>	5.6	5.2	5.2	5.9	5.8	5.3	5.6	4.5	4.0	4.6	3.8	3.3
<b>Female</b>	4.5	4.3	4.4	4.4	4.7	4.7	3.9	3.4	4.0	3.4	2.9	3.3
<b>&lt;18</b>	*	*	*	*	*	*	*	*	*	*	*	*
0-4	*	*	*	*	*	*	*	*	*	*	*	*
5-11	*	*	*	*	*	*	*	*	*	*	*	*
12-17	*	*	*	*	*	*	*	*	*	*	*	*
<b>18-44</b>	2.3	2.3	2.2	2.2	2.1	1.9	1.9	1.6	1.3	1.3	1.0	1.0
18-24	*	*	*	*	*	*	*	*	*	*	*	*
25-44	2.4	2.4	2.3	2.4	2.2	1.9	2.0	1.7	1.4	1.4	1.0	1.1
<b>45-64</b>	6.2	5.4	5.5	5.8	5.8	5.5	4.9	4.1	3.7	3.9	3.3	2.8
45-54	5.7	4.0	4.3	4.8	4.5	4.1	4.2	3.2	3.1	2.8	2.2	1.9
55-64	7.0	7.2	7.0	7.0	7.2	7.0	5.8	5.1	4.4	4.9	4.4	3.7
<b>65+</b>	12.2	12.2	12.0	12.9	13.2	11.3	11.4	8.7	9.7	9.2	7.4	7.2
65-74	12.2	10.9	10.6	12.1	12.8	10.0	10.0	8.0	8.3	8.6	6.8	6.2
75-84	12.0	21.6	22.4	18.1	15.5	18.7	18.2	12.5	16.4	11.2	9.3	11.3
85+	*	*	*	*	*	*	*	*	*	*	*	*

Data Source: Special analyses, Medicare 5 percent sample. Period prevalent transplant patients; unadjusted. \*Values for cells with 10 or fewer patients are suppressed. Abbreviations: Af Am, African American; CKD, chronic kidney disease.

## References

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# Chapter 3: Clinical Indicators and Preventive Care

## Introduction

Given the high morbidity and mortality of the end-stage renal disease (ESRD) population on dialysis, quality improvement has long been a priority. Notable efforts in this regard are published practice guidelines from the Kidney Disease Outcomes Quality Initiative (KDOQI) and projects administered by the Centers for Medicare & Medicaid Services (CMS). The latter include assessment and reporting of provider performance through Dialysis Facility Reports (DFR) and Dialysis Facility Compare (DFC) ([www.dialysisdata.org](http://www.dialysisdata.org)), as well as the Quality Incentive Program (QIP), which ties provider achievement of selected quality targets to Medicare reimbursement. Data collection for these projects has been undergoing a transition from paper-based data entry to a fully web-based data entry system, the Consolidated Renal Operations in a Web-Enabled Network (CROWNWeb). This system also newly allows for monthly electronic submission of selected laboratory and clinical data from facilities for patients under their care. The system was implemented nationally in May 2012, although there have been ongoing challenges with completeness and reliability of data collection. For this chapter, the Annual Data Report (ADR) has traditionally relied on data from Medicare claims for its analyses. This year, for the first time, data from CROWNWeb are also utilized for analyses pertaining to dialysis adequacy, vascular access (VA) among prevalent hemodialysis (HD) patients, and selected anemia measures.

In Figure 3.1, we present CROWNWeb data from December 2013 on clinical indicators relating to dialysis adequacy, achieved hemoglobin (Hgb) level, and prevalent VA. Achievement of KDOQI dialysis adequacy targets for HD is nearly universal, with 97 percent of such patients obtaining a single pool Kt/V  $\geq 1.2$ . Achievement of the KDOQI adequacy target for peritoneal dialysis (PD) of a weekly Kt/V  $\geq 1.7$  is somewhat lower at 87 percent.

Views on anemia treatment with erythropoiesis-stimulating agents (ESAs) have evolved in recent years, as safety concerns about targeting Hgb levels above 11 g/dL have emerged from clinical trials. This has resulted in generally lower Hgb levels among dialysis patients. Using CROWNWeb data, Figure 3.1b presents a more representative view of Hgb levels for the dialysis population than was previously possible, as it includes data from both Medicare and non-Medicare insured patients. Among HD patients (both ESA-treated and non-treated), the majority (66 percent) have Hgb levels in the range of 10-12 g/dL, with only 13 percent achieving Hgb  $\geq 12$  g/dL. The pattern is similar with PD patients, though a somewhat higher percentage (23 percent) have Hgb  $\geq 12$  g/dL. For the remainder of this chapter, Medicare claims (updated through 2012) are utilized for the anemia analyses in order to provide information on time trends. The downward trend in mean Hgb levels among dialysis patients started in 2007 and continued into 2012, but appears to have plateaued since April 2012. Following the Hgb trend, erythropoietin (EPO) doses have also continued to fall, with levels in December 2012 nearly half of what they were in 2007, at 10,491 units/week and 9,145 units/week among HD and PD patients, respectively.

Comprehensive patient care has long been a focus of the ADR. Among diabetic patients with ESRD, there has been a slight decrease in the percentage of patients receiving recommended hemoglobin A<sub>1c</sub> (HbA<sub>1c</sub>) testing and lipid testing following a sustained improvement over the past decade. The overall rate of comprehensive diabetes monitoring (defined as at least one HbA<sub>1c</sub> test, one lipid test, and one dilated eye exam) in the past year has remained fairly constant at approximately 30 percent. This trend appears to be due to the low and static rate of diabetic eye exams (approximately 40 percent). The failure to achieve higher rates of dilated eye exams represents a major missed opportunity for prevention, as many diabetic patients with ESRD have advanced diabetic

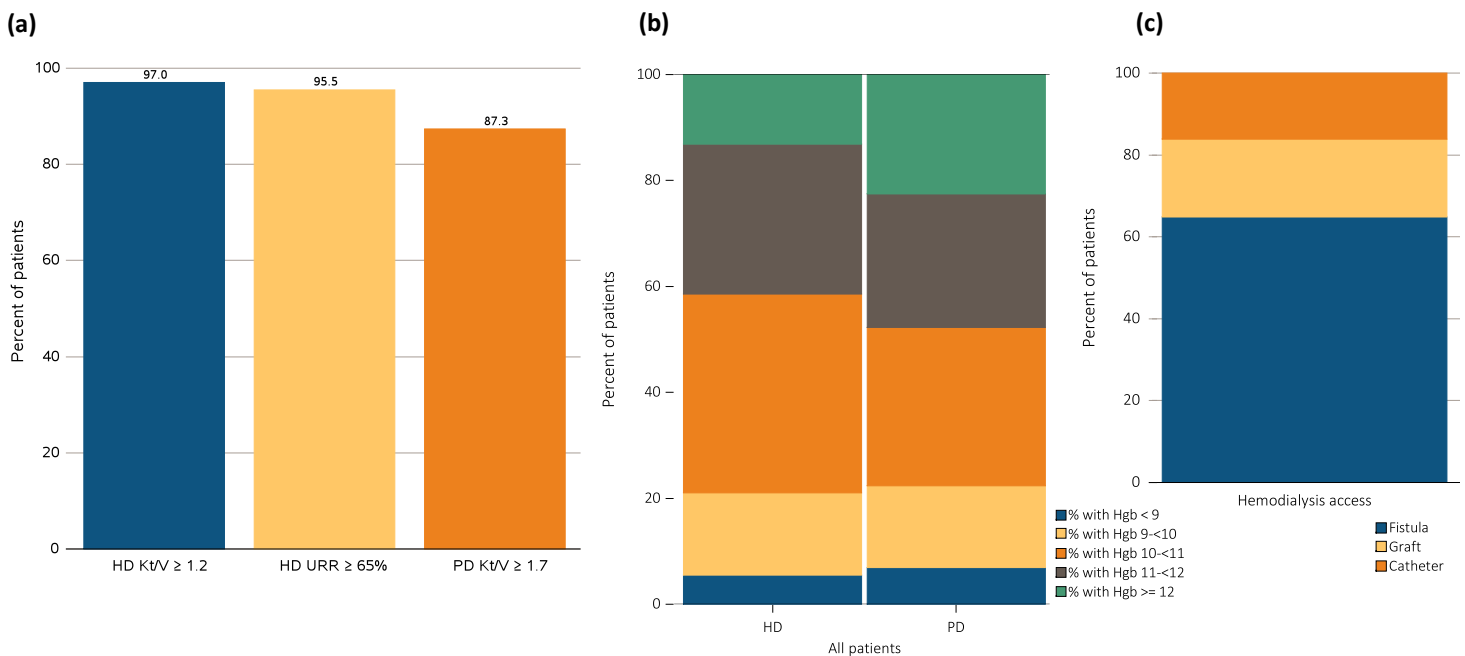
retinopathy and might benefit from diagnosis and timely treatment of their eye disease.

Influenza vaccination rates have risen over the last decade, though there appears to be a plateau over the last two seasons reported. The most recent data reveal a vaccination rate of 67 percent, still below the Healthy People 2020 (HP2020) target of 90 percent.

VA continues to receive substantial attention due to the adverse prognostic implications of catheter use for both incident and prevalent HD patients. Historically, arteriovenous fistula (AVF) and catheter use have fallen short of the goals set by CMS and other workgroup coalitions, such as the Fistula First Breakthrough Initiative (FFBI). Overall, there has been improvement in AVF use, and the focus has shifted to not only increasing AVF use, but decreasing catheter use with

efforts such as the Fistula First Catheter Last (FF/CL) Workgroup. Now, as national data are available with CROWNWeb, monthly individual and facility-level data can be used to analyze the progress dialysis facilities are making towards meeting the clinical goals set forth by CMS and the FFBI of 66 percent AVF use in prevalent dialysis patients. In Figure 3.1c, CROWNWeb data show that, among prevalent HD patients (those on ESRD treatment for 90 days or more) in December 2013, 65 percent were using an AVF, and only 16 percent were using a catheter for dialysis access. However, data from the ESRD Medical Evidence Form (CMS 2728) shows that, in 2012, 61 percent of patients with incident ESRD started HD with a catheter alone (without a maturing arteriovenous graft [AVG] or AVF), highlighting an ongoing need for improvement in pre-dialysis access planning.

**vol 2 Figure 3.1 Clinical indicators: Percentage of prevalent patients meeting clinical care guidelines on dialysis adequacy, percentage distribution of achieved mean Hgb among prevalent HD and PD patients, and percentage distribution of VA among prevalent HD patients, from CROWNWeb data**



Data Source: CROWNWeb clinical extracts for December 2013. Panel a: Dialysis patients initiating treatment for ESRD at least 1 year before December 1, 2013, and who were alive through December 31, 2013. Panel b: Dialysis patients initiating treatment for ESRD at least 90 days prior to December 1, 2013, who were ≥18 years old as of December 1, 2013, and who were alive through December 31, 2013. Panel c: HD patients initiating treatment for ESRD at least 90 days prior to December 1, 2013, who were ≥18 years old as December 1, 2013, and who were alive through December 31, 2013. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; Hgb, hemoglobin; Kt/V, see Glossary; PD, peritoneal dialysis; URR, urea reduction ratio; VA, vascular access.

### Anemia Treatment by Modality

In this section, long-term trends in Hgb levels, EPO dose, intravenous (IV) iron use, and red blood cell (RBC) transfusion rates are described through the year 2012 by dialysis modality. Prior to 2012, to meet CMS billing requirements, Hgb values were only reported by dialysis providers when filing a claim for

patients receiving an ESA during the given month. Consequently, Hgb values based on CMS claims data prior to 2012 were restricted to ESA-treated patients. Beginning in 2012, CMS required reporting of Hgb values for all patients, regardless of whether they received an ESA. This has allowed, for the first time, a comparison of Hgb values for ESA-treated patients, and for all patients regardless of ESA treatment.

### Hgb Levels, ESA Use, and IV Iron Use in HD Patients

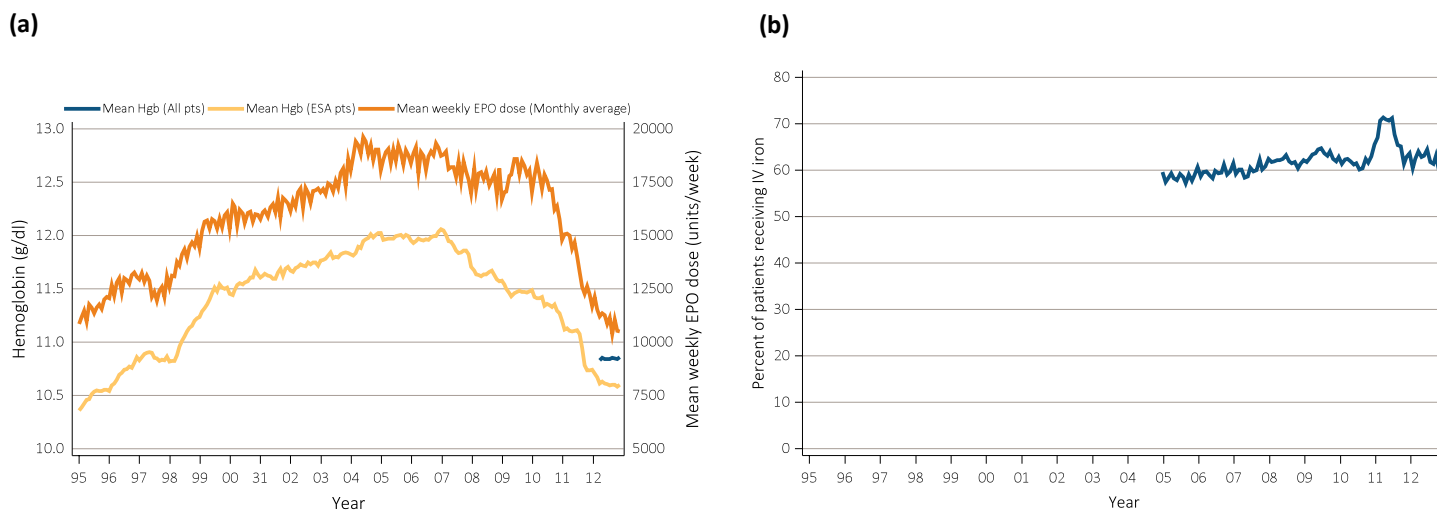
Mean Hgb levels have declined substantially since they peaked near 12.0 g/dL in 2007 in ESA-treated HD patients (Figure 3.2A). In 2011, the mean Hgb level for ESA-treated HD patients declined by 0.5 g/dL from 11.2 g/dL to 10.7 g/dL. Hgb levels continued to decline in 2012, with mean Hgb levels of 10.6 g/dL and 10.9 g/dL seen for ESA-treated versus all HD patients, respectively, by December 2012. However, mean Hgb levels appeared to have stabilized by April 2012, with little change seen thereafter throughout the remaining months of 2012 in ESA-treated HD patients and among all HD patients.

Mean weekly EPO doses (averaged over a month) have declined 42 percent since 2007 in HD patients (Figure 3.2A). Mean weekly EPO doses declined 22 percent from December 2010 to December 2011. In 2012, mean weekly EPO doses continued to decline by an additional 14 percent from 12,244 units per week in December 2011, to 10,490 units per week in December 2012. Changes in mean Hgb levels over time have occurred in parallel with concomitant changes in mean EPO dose levels.

Trends in IV iron use are shown from 2005 to 2012 for HD patients (Figure 3.2B). IV iron use increased sharply from 61 percent in August 2010 to peak at 73 percent by April 2011. However, since August 2011, IV iron use has declined steadily to 62 percent by the last half of 2012.

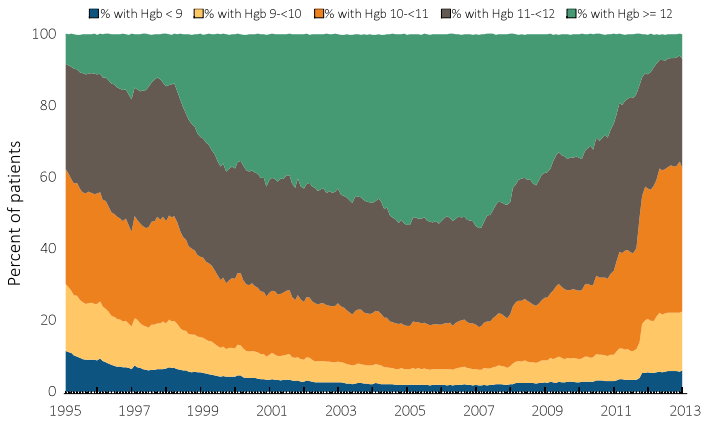
A large shift has been seen in the percentage of ESA-treated HD patients in the highest versus lowest Hgb concentration categories (Figure 3.3) from December 2007 to December 2012. The percentage with Hgb <10 g/dL has increased from 7 percent in 2007 to 22 percent in 2012, and the percentage with Hgb  $\geq$ 12 g/dL has declined from 47 percent in 2007 to 7 percent in 2012. Among all HD patients in 2012, 5.4 percent had Hgb <9 g/dL, 14.2 percent had Hgb of 9.0 to <10 g/dL, 65.4 percent had Hgb between 10-12 g/dL, and 15 percent had Hgb  $\geq$ 12 g/dL (data not shown).

vol 2 Figure 3.2 (a) Mean monthly Hgb level and mean weekly EPO dose (monthly average, expressed in units/week) in adult HD patients on dialysis  $\geq$ 90 days, from Medicare claims: time trend from 1995-2012; (b) Monthly IV iron use in adult HD patients on dialysis  $\geq$ 90 days, from Medicare claims: time trend from 2005-2012



Data Source: Special analyses, USRDS ESRD Database. Panel a: Mean monthly Hgb level among ESA-treated HD patients within a given month (1995 through 2012) or all HD patients irrespective of ESA use (April to December 2012 only) if, within the given month, the patient had an Hgb claim, was on dialysis  $\geq$ 90 days, and was  $\geq$ 18 years old at the start of the month. Mean monthly EPO (epoetin alfa) dose among HD patients within a given month who had an EPO claim, were on dialysis  $\geq$ 90 days, and were  $\geq$ 18 years old at the start of the month. EPO dose is expressed as mean EPO units per week averaged over all EPO claims within a given month. Panel b: Monthly IV iron use among HD patients on dialysis  $\geq$ 90 days and  $\geq$ 18 years old at the start of the given month. Abbreviations: EPO, erythropoietin; ESA, erythropoiesis-stimulating agents; HD, hemodialysis; Hgb, hemoglobin; IV, intravenous.

**vol 2 Figure 3.3 Distribution of monthly Hgb (g/dL) levels in ESA-treated adult HD patients on dialysis ≥90 days, from Medicare claims: time trend from 1995-2012**



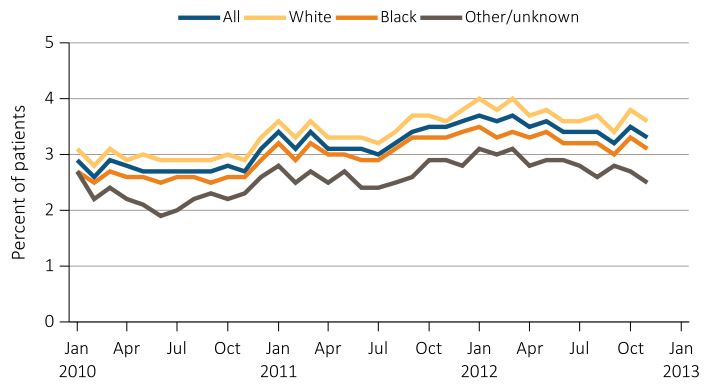
Data Source: Special analyses, USRDS ESRD Database. Patient distribution among HD patients within a given month who had claims for Hgb level and ESA use, were on dialysis ≥90 days, and were ≥18 years old at the start of the month. Abbreviations: ESA, erythropoiesis-stimulating agents; HD, hemodialysis; Hgb, hemoglobin.

**RBC Transfusions in HD Patients**

Throughout most of 2010, approximately 2.7 percent of HD patients had claims for one or more RBC transfusions within a month (Figure 3.4). This transfusion rate began increasing in December 2010, peaking at 3.7 percent between January and March 2012. It has since declined to 3.3 percent by November 2012. Caution should be used in interpreting mean values and trends for transfusions based on the last several months of 2012, as these may be underestimates of the true transfusion rates due to incomplete adjudication of transfusion claims for these months since transfusions may also be associated with hospitalizations.

The percentage of HD patients with an RBC transfusion within a month showed some variation by race. From January to November 2012, on average 3.7 percent of White HD patients had ≥1 RBC transfusion in a month compared with 3.3 percent of Black HD patients and 2.9 percent of HD patients of Other/Unknown race.

**vol 2 Figure 3.4 Percentage of adult HD patients with ≥1 claim for an RBC transfusion in a month, from Medicare claims data, by race: monthly time trend from 2010-2012**



Data Source: Special analyses, USRDS ESRD Database. The percentage of HD patients ≥18 years old at the start of the month with ≥1 RBC transfusion claim in a given month among HD patients having a claim for at least one dialysis session during the month. Abbreviations: HD, hemodialysis; RBC, red blood cell.

**Hgb Levels, ESA Use, and IV Iron Use in PD Patients**

Mean Hgb levels have declined substantially in ESA-treated PD patients since peaking near 11.8 g/dL in January 2007 (Figure 3.5A). In 2011, the mean Hgb level for ESA-treated PD patients declined 0.6 g/dL from 11.1 g/dL to 10.5 g/dL. This was a larger decline, and the mean Hgb level achieved was lower than that seen for ESA-treated HD patients during 2011. Hgb levels continued to decline in 2012, with mean Hgb levels of 10.4 g/dL and 11.0 g/dL seen for ESA-treated versus all PD patients, respectively, by December 2012. However, mean Hgb levels appear to have stabilized by April 2012, with little change seen thereafter throughout the remaining months of 2012 in ESA-treated PD patients and among all PD patients.

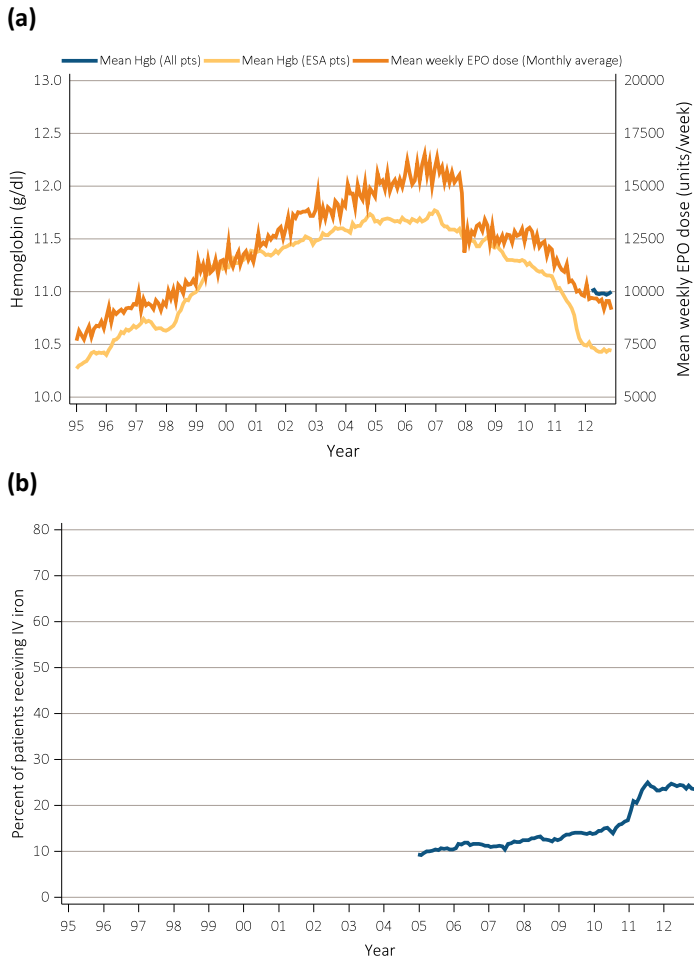
Mean weekly EPO dose (averaged over a month) among PD patients declined 18 percent from December 2010 to December 2011 (Figure 3.5A). In 2012, mean weekly EPO doses declined by an additional 7 percent, from 9,857 units per week in December 2011 to 9,145 units per week in December 2012. The rapid, large decline in mean weekly EPO dose seen at the start of 2008 (Figure 3.5A) is under further investigation since this change also coincides with a change in the reporting codes for EPO-related claims submission at that time.

IV iron use is shown in PD patients from 2005 to 2012 (Figure 3.5B). IV iron use rose steadily from 12 percent in 2005 to 18 percent in November 2010, but then increased sharply to 29 percent by July 2011,



concomitant with implementation of Prospective Payment System (PPS) bundling, which began in January 2011. However, since August 2011, IV iron use has shown a gradual decline to 24 percent IV iron use by December 2012.

**vol 2 Figure 3.5 (a) Mean monthly Hgb level and mean weekly EPO dose (monthly average, expressed in units/week) in adult PD patients on dialysis ≥90 days, from Medicare claims: time trend from 1995-2012; (b) Monthly IV iron use in adult PD patients on dialysis ≥90 days, from Medicare claims: time trend from 2005-2012**

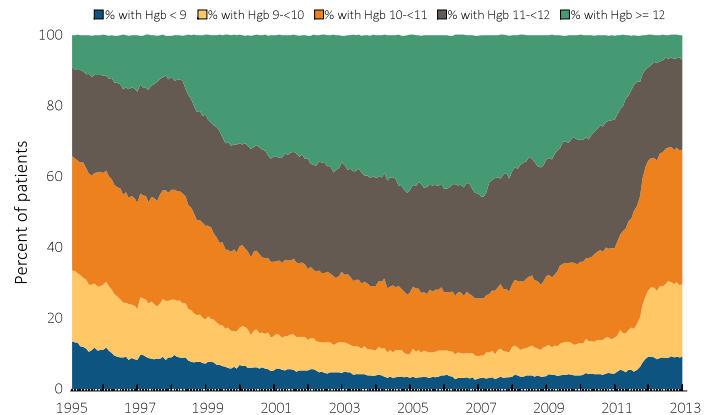


*Data Source: Special analyses, USRDS ESRD Database. Panel a: Mean monthly Hgb level among ESA-treated PD patients within a given month (1995 through 2012) or all PD patients regardless of ESA use (April to December 2012 only) if, within the given month, the patient had an Hgb claim, was on dialysis ≥90 days, and was ≥18 years old at the start of the month. Mean monthly EPO (epoetin alfa) dose was among PD patients within a given month who had an EPO claim, were on dialysis ≥90 days, and were ≥18 years old at the start of the month. EPO dose is expressed as mean EPO units per week averaged over all EPO claims within a given month. Panel b: Monthly IV iron use is among PD patients on dialysis ≥90 days and ≥18 years old at the start of the given month. Abbreviations: EPO, erythropoietin; ESA, erythropoiesis-stimulating agents; Hgb, hemoglobin; IV, intravenous; PD, peritoneal dialysis.*

From December 2007 to December 2012, a large shift occurred in the percentage of ESA-treated PD patients in the highest versus lowest Hgb concentration

categories (Figure 3.6). The percentage with Hgb <10 g/dL has increased from 12 percent in 2007 to 30 percent in 2012, and the percentage with Hgb ≥12 g/dL declined from 39 percent in 2007 to 7 percent in 2012. In all PD patients in 2012, 7 percent had an Hgb <9 g/dL, 16 percent with an Hgb of 9 to <10 g/dL, 54 percent with an Hgb between 10-12 g/dl, and 23 percent with an Hgb ≥12 g/dL (data not shown).

**vol 2 Figure 3.6 Distribution of monthly Hgb (g/dL) levels in ESA-treated adult (≥18 years old) PD patients on dialysis ≥90 days, from Medicare claims: time trend from 1995-2012**

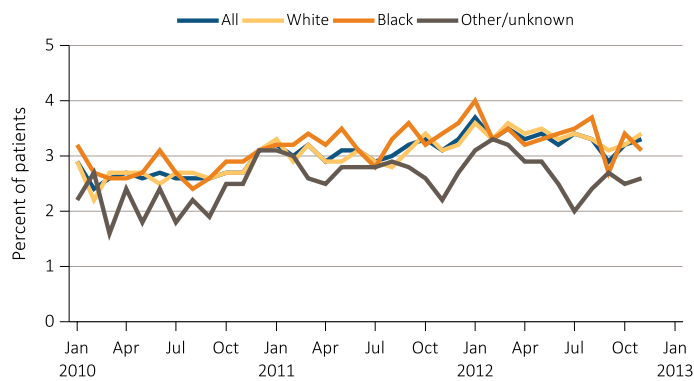


*Data Source: Special analyses, USRDS ESRD Database. Distribution of Hgb levels among PD patients within a given month who had claims for Hgb level and ESA use, were on dialysis ≥90 days, and were ≥18 years old at the start of the month. Abbreviations: ESA, erythropoiesis-stimulating agents; Hgb, hemoglobin; PD, peritoneal dialysis.*

### RBC Transfusions in PD Patients

The frequency of PD patients receiving one or more RBC transfusions in a month has increased from an average of 2.7 percent of patients in 2010 to 3.3 percent in 2012 (Figure 3.7). In 2012, an average of 3.4 percent of PD patients in a month received RBC transfusions both among Black and White PD patients compared with 2.7 percent among patients of Other/Unknown race.

**vol 2 Figure 3.7 Percentage of adult PD patients ≥18 years old with ≥1 claim for RBC transfusion in a month, from Medicare claims data, by race: monthly time trend from 2010-2012**



Data Source: Special analyses, USRDS ESRD Database. The percentage of PD patients with ≥1 RBC transfusion claim in a given month was among PD patients having a claim for at least one dialysis session during the month, and who were ≥18 years old at the start of the month. Abbreviations: PD, peritoneal dialysis; RBC, red blood cell.

**Patients New to Dialysis (Incident Patients)**

Hgb levels were evaluated among incident dialysis patients 18 years or older based upon claims data in 2012 (data not shown). Incident HD patients in 2012 displayed a mean Hgb of 9.9 g/dL (standard deviation=1.3 g/dL) near the time of starting HD. This analysis was based upon the first reported Hgb value within 30 days after initiating chronic HD therapy (N=38,623 patients; median number of days from date of first-ever chronic dialysis treatment to first Hgb measurement was 6 days; interquartile range: 0 to 11 days). Among these patients, 23 percent had Hgb <9 g/dL, 32 percent had Hgb of 9 to <10 g/dL, 40 percent had Hgb of 10 to <12 g/dL, and 6 percent had Hgb ≥12 g/dL. Thus, over 50 percent of new ESRD patients when initiating HD have an Hgb <10 g/dL, indicating the widespread anemia among advanced chronic kidney disease (CKD) patients in 2012.

Comparable analyses among incident PD patients showed a mean Hgb of 10.3 g/dL (standard deviation =1.5 g/dL; N =3,245 patients; median number of days from date of first-ever chronic dialysis treatment to first Hgb measurement was 0 days; interquartile range: 0 to 5 days). Among these PD patients, 17 percent had Hgb <9 g/dL, 26 percent had Hgb of 9 to <10 g/dL, 45 percent had Hgb of 10 to <12 g/dL, and 12 percent had Hgb ≥12 g/dL. Thus, nearly 43 percent of new ESRD patients initiating PD had an Hgb <10 g/dL in 2012.

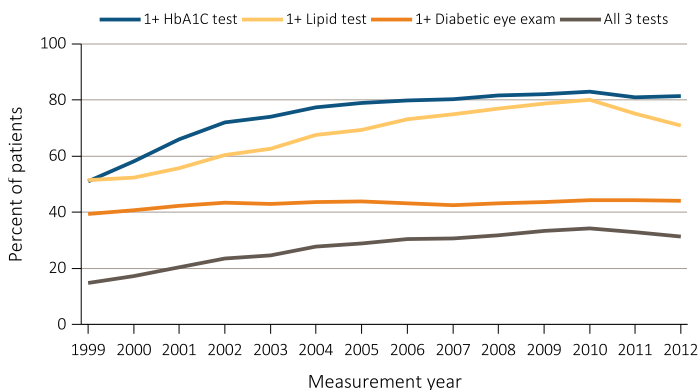
**Preventive Care**

**Diabetes Mellitus**

Recommendations for glycemic and lipid monitoring and treatment in diabetic patients with ESRD are controversial. The role of regular dilated eye exams and timely treatment in preventing visual loss is, however, well established.

Over the past two years, following steady increases from 2000 to 2010, there has been a slight decrease in the percentage of patients receiving at least one HbA1c test per year and a more substantial decrease in the percentage of patients receiving at least one lipid test per year (Figure 3.8). National Committee for Quality Assurance Comprehensive Diabetes Care data show a leveling off, but do not demonstrate similar decreases in LDL cholesterol screening rates in the commercial, Medicaid, or Medicare populations with diabetes (National Committee for Quality Assurance, 2013). The reason for the apparent decrease in lipid screening rates in the Medicare ESRD population with diabetes is unclear, but may possibly be related to the publication of two reports demonstrating a lack of effect of statin therapy on fatal and nonfatal cardiovascular outcomes in patients undergoing HD (Wanner et al., 2005; Fellstrom et al., 2009) The rate of reported annual dilated eye exams has remained low but constant over the past decade (~40 percent), as has the rate of performance of all three tests (~30 percent). There remains a substantial opportunity for quality improvement.

**vol 2 Figure 3.8 Diabetes-related care among patients with diabetes mellitus 18-75 years old with ESRD, from Medicare claims: time trend from 1999-2012**

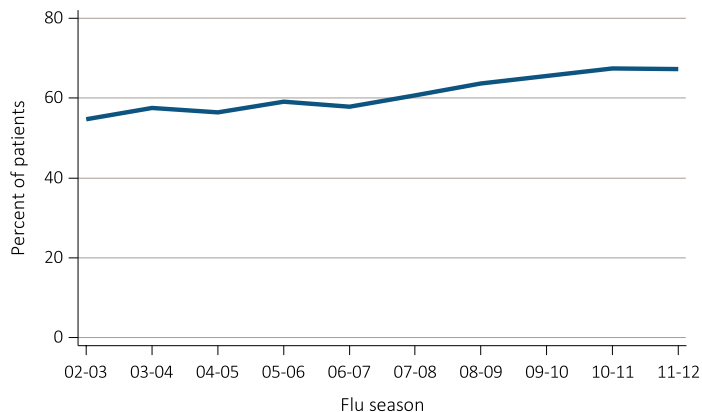


Data Source: Special analyses, USRDS ESRD Database. Point prevalent Medicare ESRD patients ages 18 to 75 with a diagnosis claim for diabetes mellitus in the previous year; diabetes-related care in the measurement year. Abbreviations: ESRD, end-stage renal disease.

**Vaccination**

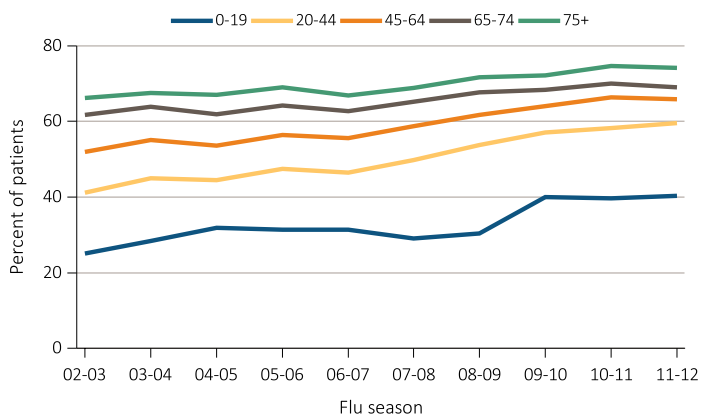
Yearly influenza vaccination is recommended for all ESRD patients. Seasonal influenza vaccination is defined here more broadly than the typical October through March influenza season, and covers the period of August 1 through April 30 to account for early or later vaccinations. Influenza vaccination rates based on Medicare claims have slowly improved over the past decade, from 55 percent in the 2002-2003 season to 67 percent in the 2011-2012 season, though there appears to be a plateau over the last two seasons (Figure 3.9). Vaccination rates are highest in older age groups, with only 40 percent of patients aged 0-19 vaccinated in the 2011-2012 season (Figure 3.10). Rates of vaccination are similar in the most recent years across race/ethnicity, though slightly lower among Blacks at 65 percent in the 2011-2012 season (Figure 3.11). By modality, HD patients were vaccinated at the highest rate (72 percent in the most current data), compared with 68 percent in PD patients and 51 percent in kidney transplant patients (Figure 3.12). The higher rate in HD patients may relate to the greater frequency of medical contact, providing more opportunities for vaccination. Rates may also be lower in transplant patients in part because vaccination is often delayed for several months after a new transplant due to concerns about an ineffective immune response. The rates of vaccination reported here may be underestimates, as they are derived from claims, which may not completely capture all vaccination events. Future analyses for the ADR will utilize CROWNWeb data, which should provide more complete information on vaccination, including status for other recommended vaccinations such as for pneumococcus and hepatitis B.

**vol 2 Figure 3.9 Percentage of ESRD patients with a claim for seasonal influenza vaccination (August 1-April 30 of subsequent year) based on Medicare data, overall: time trend from 2002-2012**



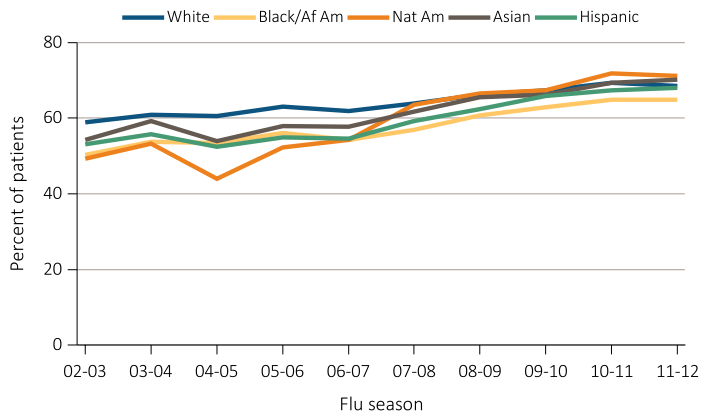
Data Source: Special analyses, USRDS ESRD Database. ESRD patients initiating treatment for ESRD at least 90 days before seasonal period: August 1-April 30 for influenza. Abbreviations: ESRD, end-stage renal disease.

**vol 2 Figure 3.10 Percentage of ESRD patients with a claim for seasonal influenza vaccination (August 1-April 30 of subsequent year) based on Medicare data, by age: time trend from 2002-2012**



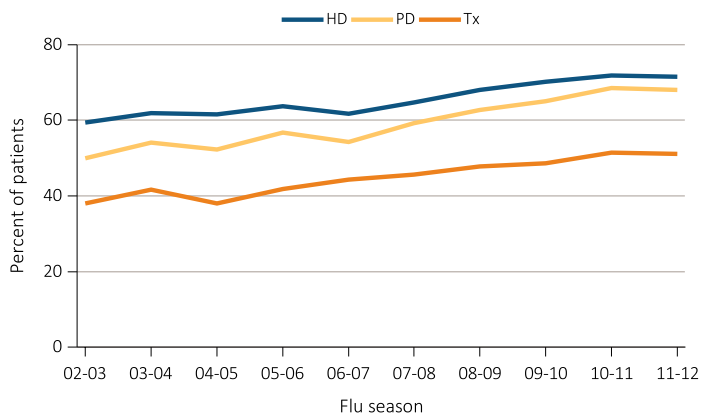
Data Source: Special analyses, USRDS ESRD Database. ESRD patients initiating treatment for ESRD at least 90 days before seasonal period: August 1-April 30 for influenza. Abbreviations: ESRD, end-stage renal disease.

**vol 2 Figure 3.11 Percentage of ESRD patients with a claim for seasonal influenza vaccination (August 1-April 30 of subsequent year) based on Medicare data, by race/ethnicity: time trend from 2002-2012**



Data Source: Special analyses, USRDS ESRD Database. ESRD patients initiating treatment for ESRD at least 90 days before seasonal period: August 1-April 30 for influenza. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; Nat Am, Native American.

**vol 2 Figure 3.12 Percentage of ESRD patients with a claim for seasonal influenza vaccination (August 1-April 30 of subsequent year) based on Medicare data, by modality: time trend from 2002-2012**

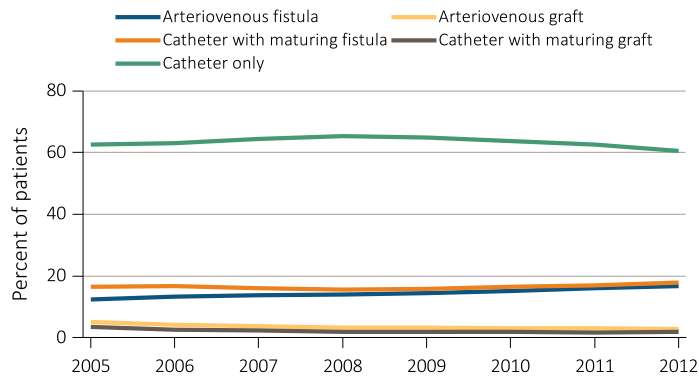


Data Source: Special analyses, USRDS ESRD Database. ESRD patients initiating treatment for ESRD at least 90 days before seasonal period: August 1-April 30 for influenza. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

**Vascular Access**

Figure 3.13 shows that, in 2012, at their first outpatient HD session, 61 percent of patients with incident ESRD had a catheter alone as their VA. If patients who also had a maturing AVF or AVG are included in this group, a total of 81 percent of patients were using a catheter at HD initiation, which has changed little since 2005. Over the last 7 years, there has been an increase in AVF use at initiation of HD, from 12 percent in 2005 to 17 percent in 2012.

**vol 2 Figure 3.13 VA use among HD patients at initiation of ESRD treatment, from the ESRD Medical Evidence Form (CMS 2728): time trend from 2005-2012**



Data Source: Special analyses, USRDS ESRD Database. ESRD patients initiating HD in 2005-2012. Abbreviations: AV, arteriovenous; ESRD, end-stage renal disease; HD, hemodialysis; VA, vascular access.

Table 3.1 shows dialysis access use at initiation of HD stratified by patient characteristics. The 0-19 age group has the highest percentage of catheters alone at initiation of HD (83 percent). This is expected, as many of these patients will receive a renal transplant relatively quickly. The 65-74 age group has the highest percentage of patients who are either using an AVF or have a maturing AVF in place at initiation of HD (37 percent). Patients of Hispanic ethnicity have the lowest rates of AVF (33 percent) at initiation and the highest catheter alone use (64 percent).

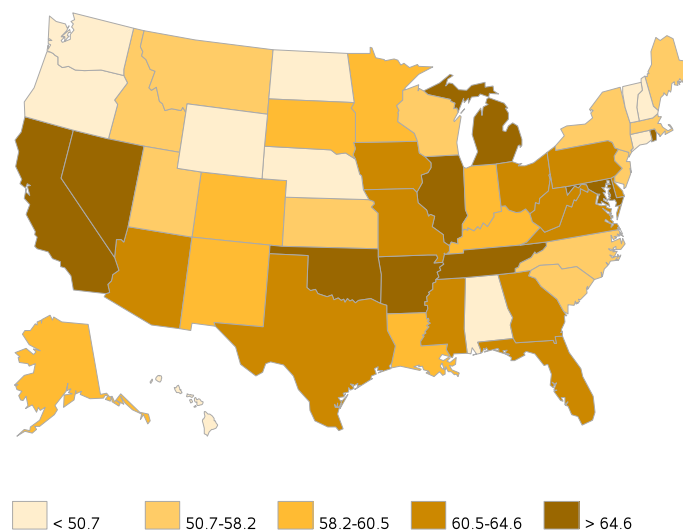
vol 2 Table 3.1 VA at HD initiation in year 2012, by patient characteristics from the ESRD Medical Evidence Form (CMS 2728)

	AV fistula used or maturing AVF in place	AV graft used or maturing AVG in place	Catheter alone
<b>All</b>	34.6	4.8	60.6
<b>Age</b>			
0-19	14.3	2.3	83.4
20-44	31.0	3.5	65.5
45-64	36.2	4.4	59.4
65-74	36.7	5.3	58.0
75+	31.9	5.5	62.6
<b>Sex</b>			
Male	36.9	3.8	59.3
Female	31.5	6.2	62.3
<b>Race/Ethnicity</b>			
White	35.0	4.0	61.0
Black/African American	34.3	6.9	58.8
Native American	39.3	3.8	56.9
Asian	35.9	5.2	58.9
Hispanic	32.7	3.8	63.6
<b>Primary Cause of ESRD</b>			
Diabetes	38.4	5.2	56.4
Hypertension	34.0	5.1	60.9
Glomerulonephritis	33.8	4.2	62.0
Cystic kidney	57.2	5.0	37.8
Other urologic	34.3	4.6	61.1
Other cause	20.1	3.2	76.7
Unknown/missing	24.0	4.0	72.0
<b>Comorbidities</b>			
Diabetes	36.3	5.0	58.7
Congestive heart failure	32.7	4.7	62.5
Atherosclerotic heart disease	37.0	5.1	57.9
Cerebrovascular disease	34.0	6.3	59.7
Peripheral vascular disease	35.5	4.7	59.8
Hypertension	35.7	4.9	59.4
Other cardiac disease	32.0	4.7	63.3

Data Source: Special analyses, USRDS ESRD Database. Abbreviations: AV, arteriovenous; AVF, arteriovenous fistula; AVG, arteriovenous graft; ESRD, end-stage renal disease; HD, hemodialysis; VA, vascular access.

Figure 3.14 illustrates the substantial geographic variation in catheter alone use at HD initiation. By location, patients residing in the South, Southeast, and the Midwest were the most likely to initiate dialysis with a catheter alone. Patients least likely to initiate dialysis with a catheter alone tended to reside in the Pacific Northwest and New England. Overall, catheter alone use at initiation of HD ranges from a low of 42 percent in New Hampshire to a high of 71 percent in Arkansas.

vol 2 Figure 3.14 Geographic variation in percentage of catheter alone use at HD initiation, in year 2012, from the ESRD Medical Evidence Form (CMS 2728)



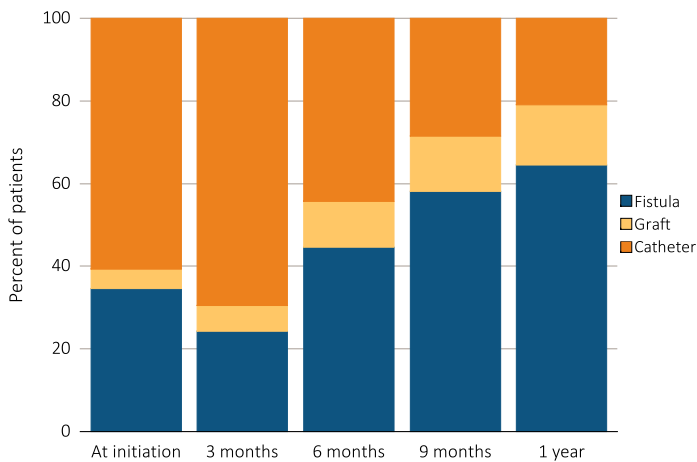
Data Source: Special analyses, USRDS ESRD Database. ESRD patients initiating HD in 2012. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis.

Figure 3.15 shows cross-sectional data from both the ESRD Medical Evidence Form (CMS 2728) (at initiation) and CROWNWeb data (for follow-up data at 3, 6, 9 months and 1 year). For the data at initiation of HD, the AVF and AVG categories include patients who also had a maturing access, even if they were still using a catheter for access at time of initiation. For the data on prevalent use of vascular access at 3 months and beyond, the AVF and AVG categories represent patients actually using those accesses for dialysis. At 90 days, most HD patients were still using a catheter, highlighting the importance of ongoing efforts to improve pre-dialysis access planning. The percentage of patients using an AVF exclusively at 1 year was 65 percent, increasing from 35 percent at initiation of HD either using an AVF or having a maturing AVF in place. The proportion of patients either using an AVG for access or having a maturing AVG in place was 5 percent at initiation, but increased to 15 percent using an AVG for access at 1 year. Thus, at 1 year, 79 percent

of patients were using either an AVF or AVG, without the presence of a catheter.

In an additional longitudinal analysis, the change in VA over time was examined for a cohort of patients initiating HD. Among those patients who began HD with a catheter, 36 percent were still using a catheter at 1 year, whereas 51 percent had transitioned to an AVF for dialysis access. Among patients who began HD with an AVF, 83 percent were still using an AVF at 1 year.

**vol 2 Figure 3.15 VA use during the first year of HD by time since initiation of ESRD treatment, among patients new to HD in 2012, from the ESRD Medical Evidence Form (CMS 2728) and CROWNWeb data**



Data Source: Special analyses, USRDS ESRD Database and CROWNWeb. ESRD patients initiating HD in 2012. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; VA, vascular access.

## References

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# Chapter 4: Hospitalization

## Introduction

Hospital admissions among end-stage renal disease (ESRD) patients represent a significant societal and financial burden, and have a major negative impact on patients' well-being and quality of life. Hence, monitoring trends in hospitalization is a key to ensuring that quality of care is maintained. Care providers can respond with appropriate strategies to prevent inappropriate admissions and reduce the incidence of rehospitalization, especially for frailer patient groups.

## Hospitalization Trends and Comparisons

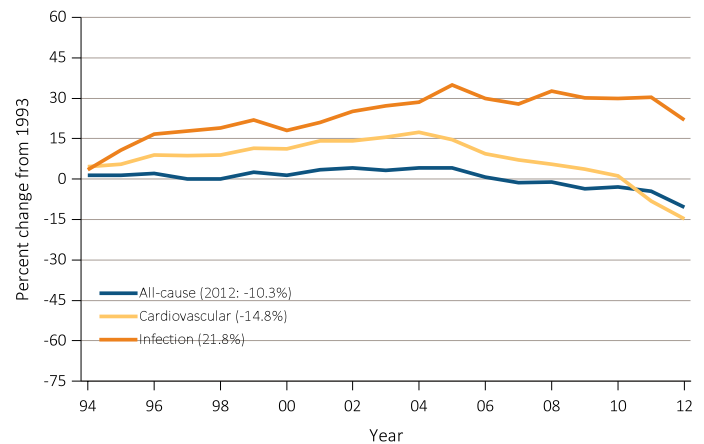
Among hemodialysis (HD) patients, the overall hospitalization rate in 2012 was 1.73 admissions per patient year—down from 1.84 in 2011, and 1.87 in 2010 (see Figure 4.1). Total hospital days per year fell to 11.0, from 11.8 in 2011. In the peritoneal dialysis (PD) population the hospitalization rate fell to 1.61, from 1.73 in 2011. Hospitalization rates in 2011 and 2012 continued to decline, as compared to prior years. Average length of stay also declined, continuing a downward trend observed since 2004.

In recent years, the Annual Data Report has increasingly focused on cause-specific hospitalization as an important morbidity surveillance issue. Between 1993 and 2012, hospitalizations due to infection rose by 21.8 percent. Among HD patients, hospitalization due to infection has increased by 34 percent since 1993, while hospital admissions resulting from other causes have decreased over the same time period (e.g., a 66.4 percent decrease in hospitalizations for vascular access procedures).

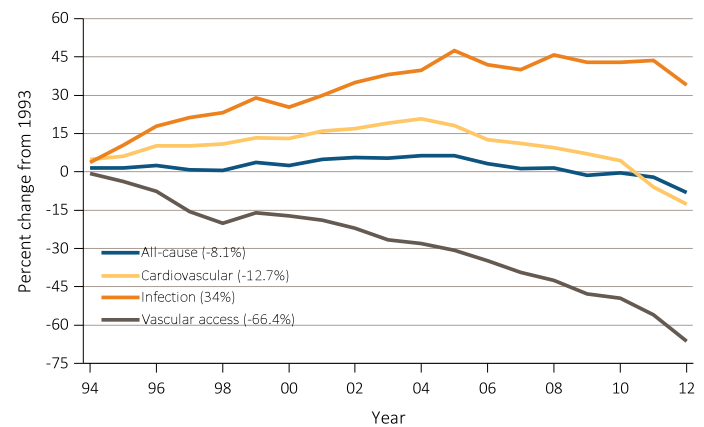
In the PD population, the overall rate of hospitalization for infection has changed little over time. Admissions for peritonitis, in contrast, have reduced, with rates now similar to those for vascular access infections in the hemodialysis population. These have shown an encouraging decline of 37.5 percent since 1999.

vol 2 Figure 4.1 Trends in adjusted all-cause & cause-specific hospitalization rates, by modality

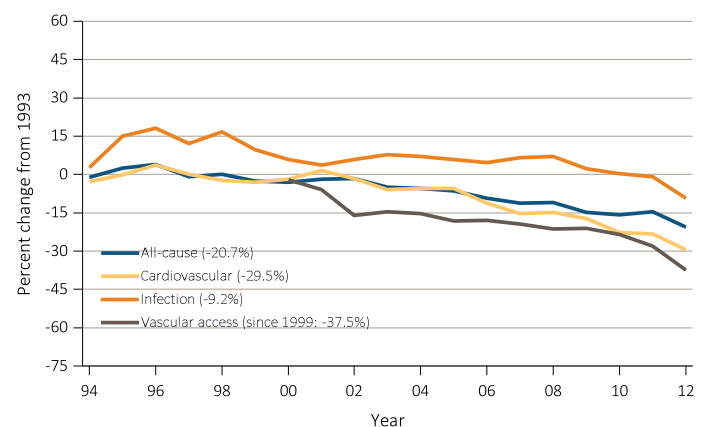
### (a) All ESRD



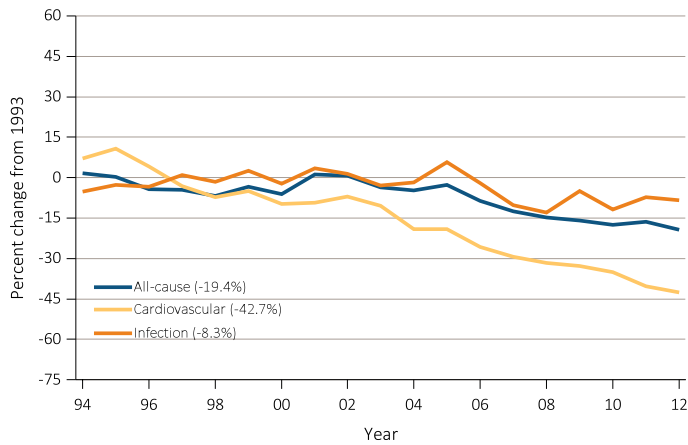
### (b) Hemodialysis



### (c) Peritoneal dialysis



**(d) Transplant**



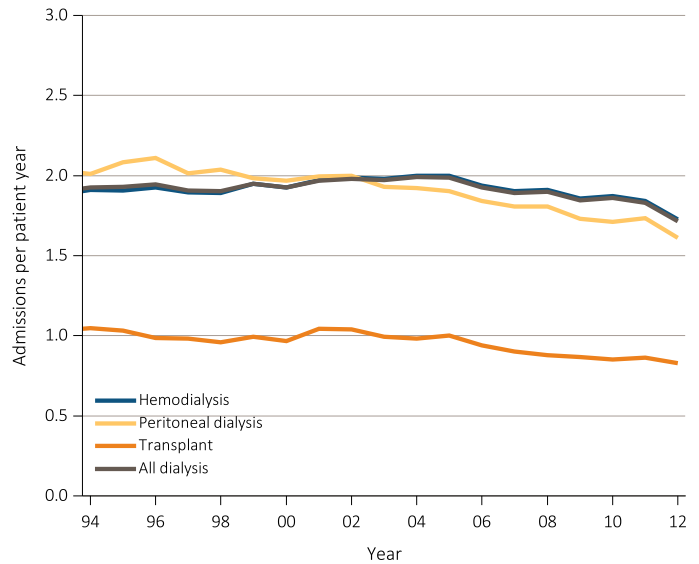
Data Source: Reference tables: G.1, G.3, G.4, G.5, and special analyses, USRDS ESRD Database. Period prevalent ESRD patients; adjusted for age, sex, race, & primary diagnosis; ref: ESRD patients, 2010. Percent changes from 1993 for the year 2012 are shown in parentheses. Abbreviations: ESRD, end-stage renal disease.

As shown in Figure 4.2, 2012 admissions for hemodialysis patients decreased to 1.73 per patient year, as compared to 1.88 in 1993. During that same period, rates for peritoneal dialysis and transplant patients have improved to a greater degree, falling by 20.7 and 19.4 percent, respectively. Hospital days per patient year have decreased to approximately 11.0 for both HD and PD patients and to 5.4 for those with a kidney transplant.

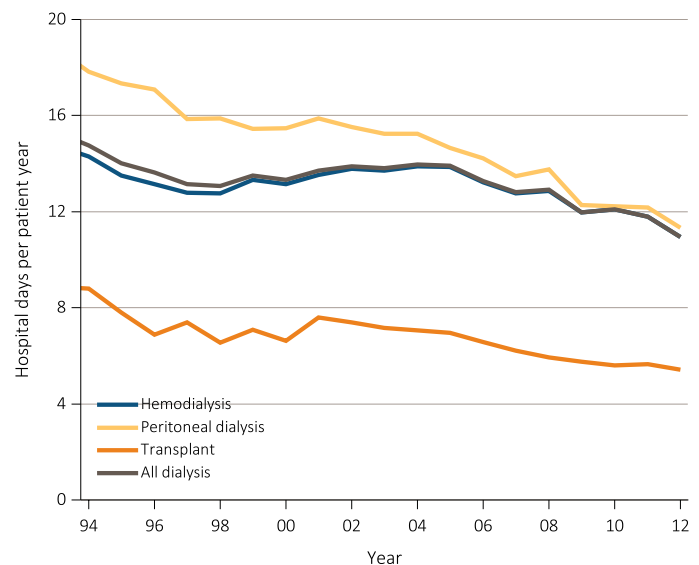
When adjusted for demographic and diagnostic characteristics, all-cause hospitalization rates among hemodialysis patients exhibited little change from 2001-2002 to 2005-2006, but decreased by 10 percent in the following six years. Rates related to cardiovascular admissions and those for vascular access infection fell 22.4 and 43.0 percent, respectively, during the same time period; rates for infection overall, however, increased by 4.5 percent. Patient groups shown to have a higher risk of hospitalization (both overall and for most cause-specific diagnoses) include those aged 20-44 or 75 and older, females, Whites, Blacks/African Americans, and patients who have diabetes as their primary cause of renal failure.

**vol 2 Figure 4.2 Trends in adjusted hospitalization rates and hospital days, by modality**

**(a) Admissions**



**(b) Hospital days**



Data Source: Reference tables: G.1, G.3, G.4, G.5, G.6, G.8, G.9, G.10, and special analyses, USRDS ESRD Database. Period prevalent ESRD patients; adjusted for age, sex, race, & primary diagnosis; ref: ESRD patients, 2010. Abbreviations: ESRD, end-stage renal disease.



vol 2 Table 4.1 Adult hemodialysis patients: Unadjusted &amp; adjusted all-cause &amp; cause-specific hospitalization rates (per patient year)

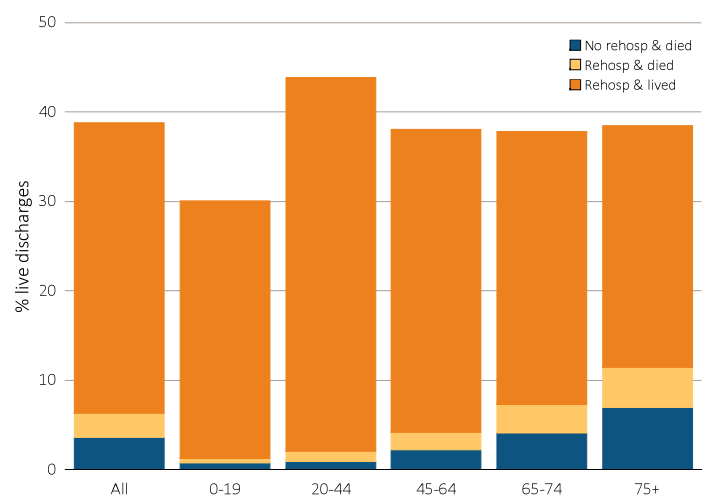
	All		Cardiovascular		Infection (any)		Vascular access infection	
	Unadjusted	Adjusted	Unadjusted	Adjusted	Unadjusted	Adjusted	Unadjusted	Adjusted
<b>2001-2002</b>	1.99	2.00	0.59	0.59	0.43	0.43	0.12	0.12
<b>2003-2004</b>	2.00	2.01	0.61	0.61	0.45	0.45	0.13	0.13
<b>2005-2006</b>	1.98	1.99	0.58	0.58	0.47	0.47	0.13	0.13
<b>2007-2008</b>	1.92	1.92	0.56	0.56	0.47	0.47	0.12	0.12
<b>2009-2010</b>	1.88	1.88	0.53	0.53	0.47	0.47	0.11	0.11
<b>2011-2012</b>	1.79	1.79	0.46	0.46	0.45	0.45	0.07	0.07
<b>2011-2012</b>								
<b>20-44</b>	1.80	1.98	0.36	0.39	0.43	0.47	0.10	0.10
<b>45-64</b>	1.74	1.74	0.43	0.43	0.43	0.43	0.07	0.07
<b>65-74</b>	1.83	1.79	0.50	0.49	0.46	0.45	0.06	0.06
<b>75+</b>	1.85	1.85	0.52	0.51	0.50	0.49	0.06	0.06
<b>Male</b>	1.66	1.66	0.43	0.44	0.42	0.42	0.06	0.06
<b>Female</b>	1.96	1.96	0.49	0.49	0.49	0.49	0.08	0.08
<b>White</b>	1.83	1.83	0.47	0.46	0.49	0.48	0.07	0.07
<b>Black/African American</b>	1.79	1.82	0.47	0.47	0.41	0.43	0.08	0.08
<b>Other race</b>	1.45	1.42	0.36	0.36	0.39	0.38	0.06	0.06
<b>Hispanic</b>	1.68	1.68	0.42	0.42	0.44	0.44	0.07	0.07
<b>Diabetes</b>	1.98	2.01	0.50	0.50	0.50	0.50	0.07	0.07
<b>Hypertension</b>	1.67	1.67	0.47	0.47	0.40	0.40	0.07	0.07
<b>Glomerulonephritis</b>	1.54	1.55	0.36	0.39	0.39	0.39	0.07	0.06
<b>Other</b>	1.67	1.70	0.37	0.38	0.46	0.46	0.07	0.07

Data Source: Reference tables: G.3, G.13, and special analyses, USRDS ESRD Database. Period prevalent hemodialysis patients aged 20 & older; adjusted for age, sex, race, & primary diagnosis; rates by one factor adjusted for the remaining three; ref: hemodialysis patients, 2010. See Vol. 2, ESRD Analytical Methods for principal ICD-9-CM diagnosis codes included in each cause of hospitalization category. Abbreviations: ESRD, end-stage renal disease.

## Rehospitalization

Rehospitalization is an important indicator of both morbidity and quality of life. It is also often costly, particularly among the ESRD patients being treated in dialysis facilities. Among hemodialysis patients prevalent in 2012, 35.2 percent of discharges from an all-cause hospitalization were followed by a rehospitalization within 30 days (see Figure 4.3). Reprehospitalization rates commonly decrease as mortality increases in the older age groups, illustrating these competing risks, as death precludes the opportunity for readmission. Rates of death without rehospitalization, for example, are highest in patients age 75 and older, at 6.9 percent, while these patients have the lowest rehospitalization rates, at 31.6 percent.

vol 2 Figure 4.3 Rehospitalization or death within 30 days from live hospital discharge, by age, 2012

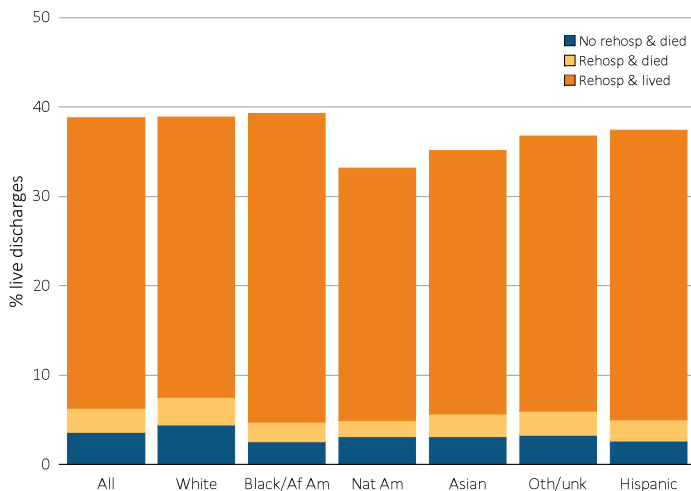


Data Source: Special analyses, USRDS ESRD Database. Period prevalent hemodialysis patients, all ages, 2012; unadjusted. Includes live hospital discharges from January 1 to December 1, 2012. Cause-specific hospitalizations are defined by principal ICD-9-CM codes. See Vol. 2, ESRD Analytical Methods for principal ICD-9-CM diagnosis codes included in each cause of hospitalization category. Abbreviations: ESRD, end-stage renal disease; rehospi, rehospitalization.

The highest rates of rehospitalization occur for adults age 20–44—42.9 percent of their discharges are followed by a readmission within 30 days. For the combined endpoint of rehospitalization and/or death, the highest rates are again seen among patients age 20–44, at 43.8 percent. The rehospitalization rate exceeds the rate of the combined endpoint even in patients age 75 and older, at 38.5 percent. These data suggest that the observed, elevated rehospitalization rates among younger versus older groups may not be entirely attributable to the competing risk of mortality.

As illustrated in Figure 4.4, when considering patient race, the highest rates of rehospitalization or rehospitalization/death are seen among Blacks /African Americans, at 36.7 and 39.3 percent, respectively. The lowest rates occur among Native Americans, at 30.1 and 33.2 percent. However, the highest rate of post-discharge death is found among White hemodialysis patients.

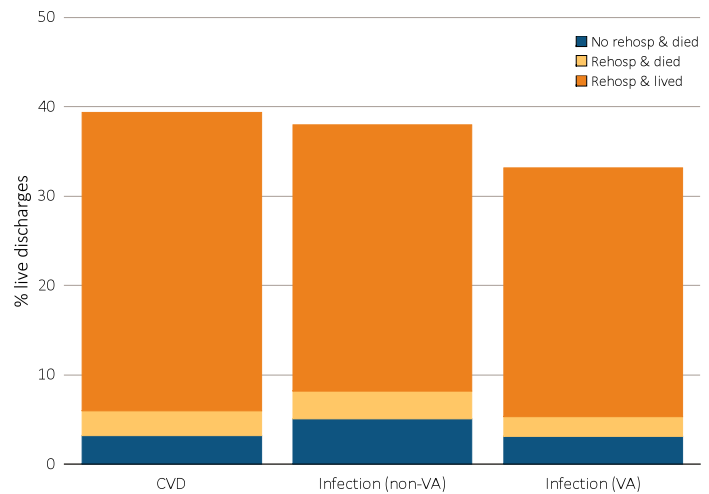
**vol 2 Figure 4.4** Rehospitalization or death within 30 days from live hospital discharge, by race & ethnicity, 2012



Data Source: Special analyses, USRDS ESRD Database. Period prevalent hemodialysis patients, all ages, 2012; unadjusted. Includes live hospital discharges from January 1 to December 1, 2012. Cause-specific hospitalizations are defined by principal ICD-9-CM codes. See Vol. 2, ESRD Analytical Methods for principal ICD-9-CM diagnosis codes included in each cause of hospitalization category. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; Nat Am, Native American; Oth/unk, other or unidentified race; rehosp, rehospitalization.

For hemodialysis patients, specific cause of hospital admission also contributes to the outcome. The overall all-cause rehospitalization rate in 2012 was 35.2 percent (Figure 4.3). For cardiovascular, infection, and vascular access infection hospitalizations the rates were 36.2, 32.9, and 30.1 percent, respectively (see Figure 4.5).

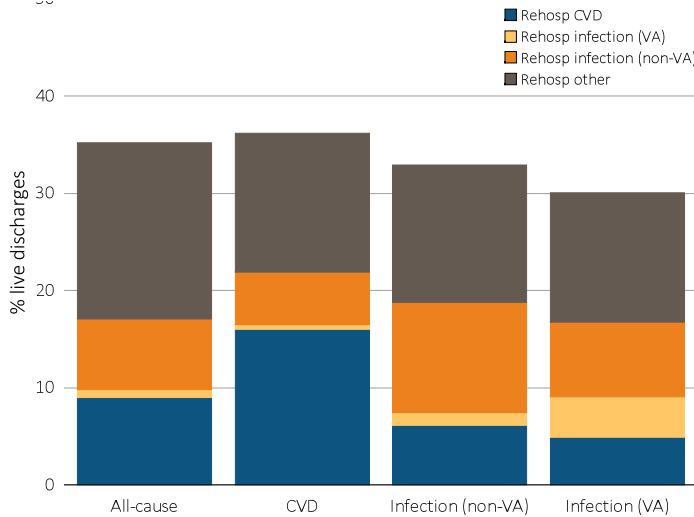
**vol 2 Figure 4.5** Rehospitalization or death within 30 days from live hospital discharge, by cause of index hospitalization, 2012



Data Source: Special analyses, USRDS ESRD Database. Period prevalent hemodialysis patients, all ages, 2012, unadjusted. Includes live hospital discharges from January 1 to December 1, 2012. Cause-specific hospitalizations are defined by principal ICD-9-CM codes. See Vol. 2, ESRD Analytical Methods for principal ICD-9-CM diagnosis codes included in each cause of hospitalization category. Abbreviations: CVD, cardiovascular disease; ESRD, end-stage renal disease; rehosp, rehospitalization; VA, vascular access.

Figure 4.6 illustrates that rehospitalization in the 30 days following a live hospital discharge frequently results from a similar diagnostic cause, possibly indicating an incomplete resolution of the initial complaint. During 2012, following a discharge from a cardiovascular index hospitalization, 16.0 percent of patients experienced a rehospitalization for a similar condition. Specific rehospitalization for overall infection and vascular access infection followed 11.4 and 4.2 percent of discharges, respectively, from index hospitalizations of the same categories. This compares to the lower rates of 7.2 percent (overall infection) and 0.8 percent (vascular access infection) following discharges from all-cause index hospitalizations. Much of these differences can be attributed to the difference between chronic (i.e. CVD) and acute (i.e. infection) conditions. Chronic conditions do not resolve whereas acute conditions are expected to get better.

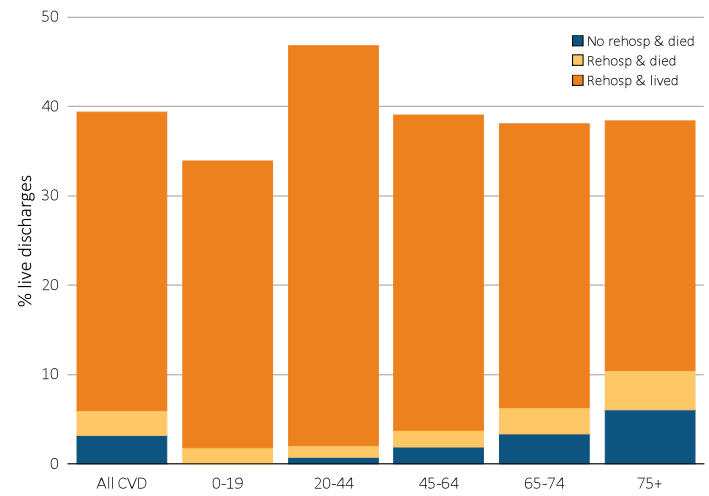
**vol 2 Figure 4.6 Cause-specific rehospitalization within 30 days from live hospital discharge, by cause of index hospitalization, 2012**



Data Source: Special analyses, USRDS ESRD Database. Period prevalent hemodialysis patients, all ages, 2012, unadjusted. Includes live hospital discharges from January 1 to December 1, 2012. Cause-specific hospitalizations are defined by principal ICD-9-CM codes. See Vol. 2, ESRD Analytical Methods for principal ICD-9-CM diagnosis codes included in each cause of hospitalization category. Abbreviations: CVD, cardiovascular disease; ESRD, end-stage renal disease; rehosp, rehospitalization; VA, vascular access.

Rehospitalization rates following discharge from a cardiovascular index hospitalization are highest among younger adults. In those aged 20–44, for example, 46.1 percent of discharges are followed by a rehospitalization within 30 days (Figure 4.7). These rates mirror those for all-cause index hospitalizations (Figure 4.3), but their values are somewhat greater. As with the all-cause rates, rehospitalization following a cardiovascular index hospitalization was more common for all patients than were the rates of the combined endpoint of rehospitalization and/or mortality, among even the oldest patients, at 38.4 percent.

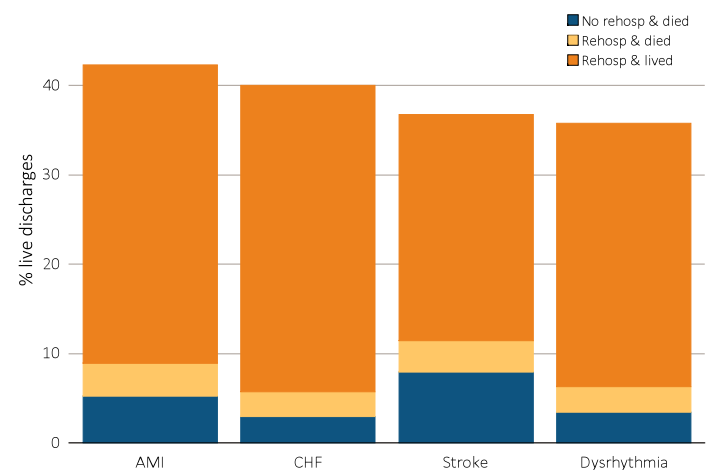
**vol 2 Figure 4.7 Rehospitalization or death within 30 days from live hospital discharge for cardiovascular index hospitalization, by age, 2012**



Data Source: Special analyses, USRDS ESRD Database. Period prevalent hemodialysis patients, all ages, 2012, unadjusted. Includes live hospital discharges from January 1 to December 1, 2012. Cause-specific hospitalizations are defined by principal ICD-9-CM codes. See Vol. 2, ESRD Analytical Methods for principal ICD-9-CM diagnosis codes included in each cause of hospitalization category. Abbreviations: CVD, cardiovascular disease; ESRD, end-stage renal disease; rehosp, rehospitalization.

For cardiovascular index hospitalizations (Figure 4.8), rehospitalization occurs most frequently following discharge from treatment of acute myocardial infarction (AMI) and congestive heart failure (CHF), at 42.3 and 40.0 percent, respectively. The lowest rates occur following discharge after dysrhythmia, at 35.8 percent. Stroke patients have the highest post-discharge mortality rate.

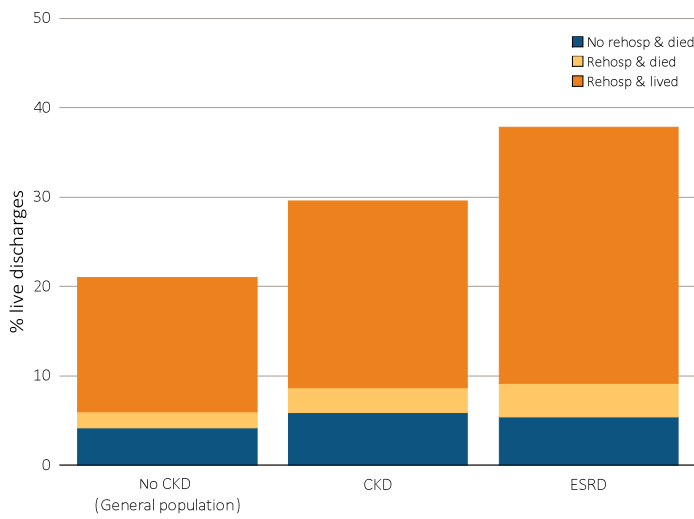
**vol 2 Figure 4.8 Rehospitalization or death within 30 days from live hospital discharge, by cause-specific cardiovascular index hospitalization, 2012**



Data Source: Special analyses, USRDS ESRD Database. Period prevalent hemodialysis patients, all ages, 2012, unadjusted. Includes live hospital discharges from January 1 to December 1, 2012. Cause-specific hospitalizations are defined by principal ICD-9-CM codes. See Vol. 2, ESRD Analytical Methods for principal ICD-9-CM diagnosis codes included in each cause of hospitalization category. Abbreviations: AMI, acute myocardial infarction; CHF, congestive heart failure; ESRD, end-stage renal disease; rehosp, rehospitalization.

Figure 4.9 illustrates the relatively negative 30-day post-discharge outcomes for patients diagnosed with kidney disease, as compared to the general population. Among older Medicare beneficiaries, those with chronic kidney disease (CKD) or ESRD experienced rehospitalization at rates of 23.7 and 32.4 percent, respectively, as compared to only 16.8 percent for patients without kidney conditions. This holds true for the outcomes of death and/or rehospitalization—29.6 (CKD) and 37.8 percent (ESRD), versus only 21.0 percent for patients without CKD.

**vol 2 Figure 4.9** Rehospitalization or death within 30 days from live hospital discharge in patients age 66 & older, by kidney function, 2012



Data Source: Special analyses, USRDS ESRD Database. January 1, 2012 point prevalent Medicare patients age 66 & older on December 31, 2011; for the CKD & no CKD cohorts during 2011, CKD is defined & patients are continuously enrolled in Medicare Parts A & B with no HMO coverage & without ESRD. Abbreviations: CKD, chronic kidney disease; ESRD, end-stage renal disease; rehospitalization.

# Chapter 5: Mortality

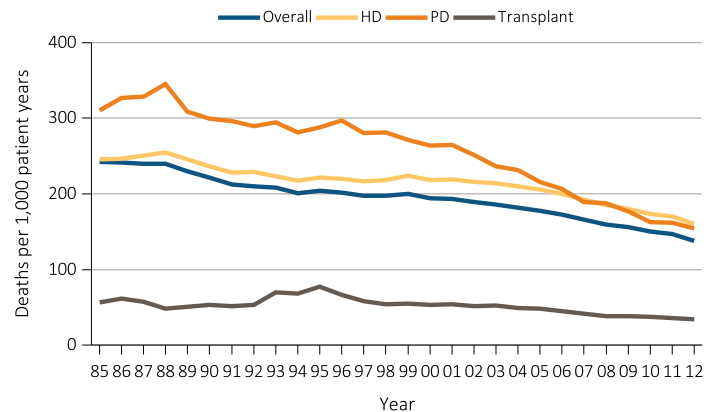
## Introduction

Data sources for mortality analyses in this chapter include both end-stage renal disease (ESRD) data and general population data. ESRD data are from the USRDS ESRD database. General population data are based on the Medicare 5 percent standard analytical files and US Census mortality data. Universal reporting to CMS of ESRD patient deaths is required as a condition of coverage for dialysis units and transplant centers.

## Mortality among ESRD Patients: Overall and by Modality

Overall mortality rates among ESRD patients continue to decline. Over the last two decades, the adjusted death rates fell by 9 percent from 1993 to 2002, and by 26 percent from 2003 to 2012 (Figure 5.1). The mortality rate for hemodialysis patients fell by 3 percent from 1993 to 2002 and by 25 percent from 2003 to 2012. Among peritoneal dialysis patients, mortality fell by 15 percent from 1993 to 2002 and by 35 percent from 2003 to 2012. Among transplant patients, mortality fell by 27 percent from 1993 to 2002 and by 35 percent from 2003 to 2012. Since 1993 the net reduction in mortality has been 28 percent for hemodialysis patients, 47 percent for peritoneal patients, and 51 percent for transplant patients.

vol 2 Figure 5.1 Adjusted all-cause mortality rates, overall and by modality



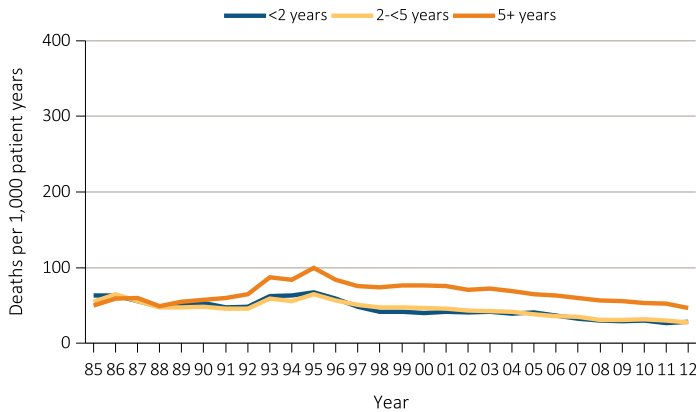
Data Source: Reference Tables H.2, H.8, H.9, and H.10, and special analyses, USRDS ESRD Database. Adjusted for age, sex, race, and primary diagnosis. Ref: 2011 patients. Abbreviations: HD, hemodialysis; PD, peritoneal dialysis.

## Mortality by Duration of ESRD

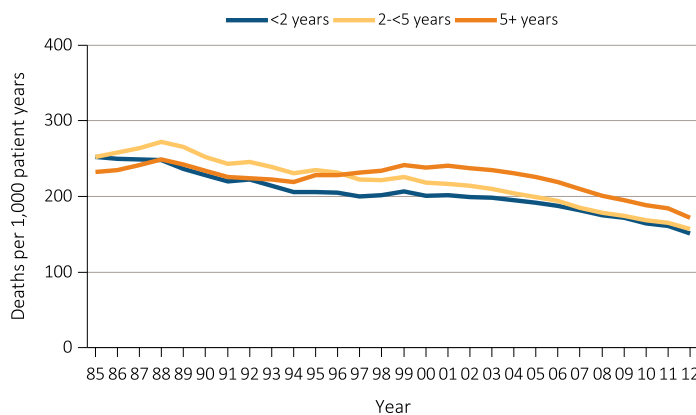
Mortality rates have declined over time across ESRD vintages (i.e., duration of ESRD) (Figure 5.2). Among peritoneal dialysis patients, mortality at vintages of less than 2 years is lower than at later vintages. Across all three modalities, mortality is slightly higher at vintages of 5 years and greater than at earlier vintages. Note that grouping patients by vintage of 0 to 2 years obscures the excess mortality seen early in the first year among hemodialysis patients (Figure 5.3).

vol 2 Figure 5.2 Adjusted all-cause mortality rates, by ESRD vintage

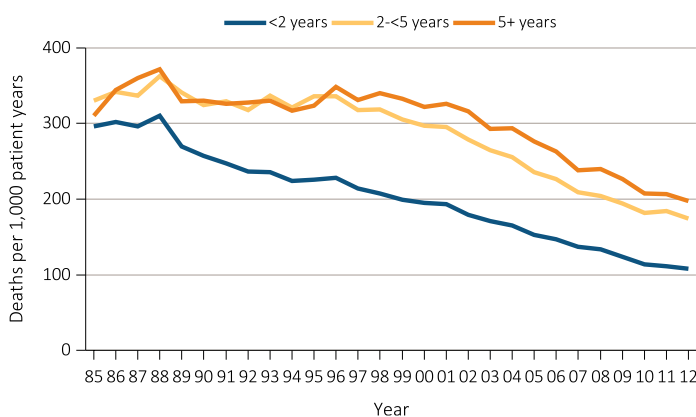
(a) Transplant



(b) Hemodialysis



(c) Peritoneal dialysis



Data Source: Reference Tables H.4, H.8, H.9, and H.10, and special analyses, USRDS ESRD Database. Adjusted for age, sex, race, and primary diagnosis. Ref: 2011 patients. Abbreviation: ESRD, end-stage renal disease.

## Mortality in First Year of Hemodialysis: All-Cause and Cause-Specific

In the first year of hemodialysis, all-cause mortality, cardiovascular disease mortality, and mortality due to other causes peak in month two, then decrease thereafter (Figure 5.3). For example, among 2011 incident hemodialysis patients:

- All-cause mortality reached 421 deaths per 1,000 patient years in month two, then decreased to 193 by month 12.
- Cardiovascular mortality peaked at 163 deaths per 1,000 patient years, then decreased to 79 in month 12.
- Mortality due to infection peaks in months 2 and 3, at 35 and 38 per 1,000 patient years respectively, and falls to 17 in month 12.

The very early patterns (steep rise in mortality rates from month 0 to 2) may reflect data reporting issues; some patients who die soon after starting dialysis may not be properly documented and included in the CMS database (Foley et al., 2014).

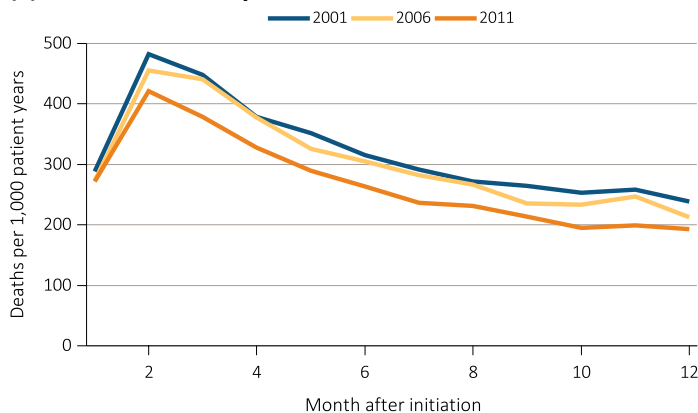
Month-by-month mortality rates in the first year of hemodialysis have shown improvements over time, overall and for deaths due to cardiovascular disease and infection. Compared to 2001 incident hemodialysis patients, rates of death during the first year of treatment for 2011 decreased by 19 percent for all-cause mortality, by 30 percent for cardiovascular death, and by 56 percent for death due to infection. In contrast, mortality due to other causes increased by 12 percent since 2001, a finding which requires further investigation.

## Survival Probabilities for ESRD Patients

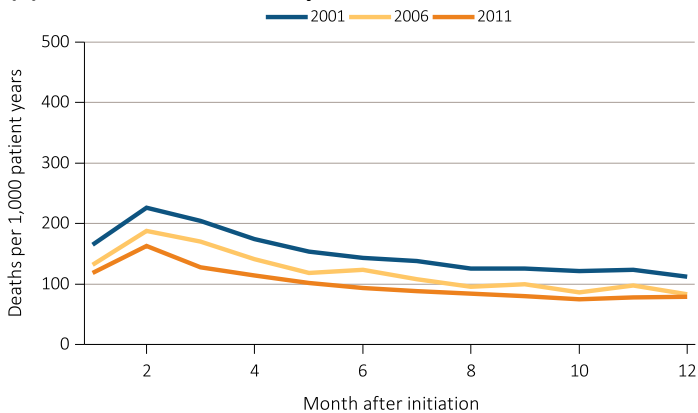
Despite improvements in survival on dialysis over the years, only 54 percent of hemodialysis patients, and 65 percent of peritoneal dialysis patients, are alive three years after ESRD onset (adjusted survival among patients starting dialysis in 2007 table 5.1.a.), which illustrates the extreme vulnerability of these patients relative to the general population. For dialysis patients, adjusted survival probability increased gradually between 1999 and 2007. For example, five-year survival improved during this period by 6 percent (to 40 percent) and 13 percent (to 49 percent) among hemodialysis and peritoneal dialysis patients, respectively.

vol 2 Figure 5.3 Adjusted mortality in the first year of hemodialysis, by year of initiation of dialysis

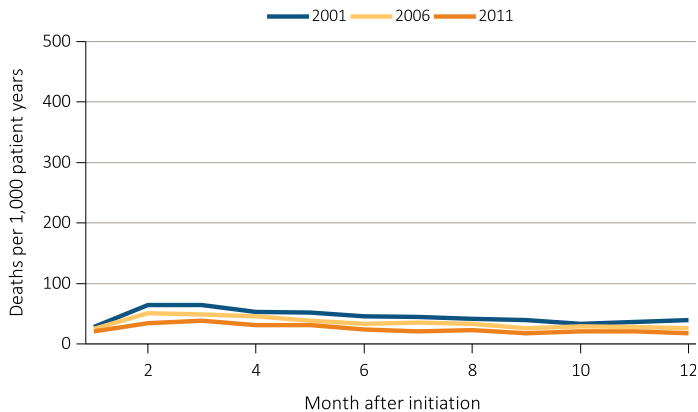
(a) All-cause mortality



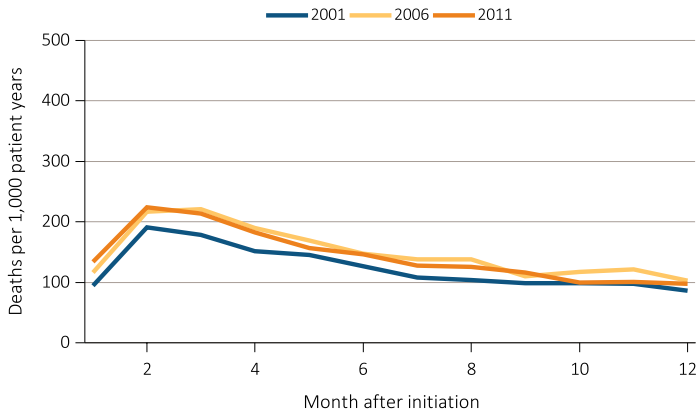
(b) Cardiovascular mortality



(c) Infection mortality



(d) Other mortality



Data Source: Special analyses, USRDS ESRD Database. Adjusted (age, race, sex, ethnicity, and primary diagnosis) all-cause and cause-specific mortality in the first year of hemodialysis. Ref: incident hemodialysis patients, 2011.

vol 2 Table 5.1 Adjusted survival probabilities among ESRD patients, by months after initiation of treatment

5.1.a By modality and year of initiation of treatment

	3 months	12 months	24 months	36 months	60 months
<b>Dialysis</b>					
1999	91.2	74.9	61.0	50.0	34.5
2001	91.2	75.1	61.8	51.2	36.0
2003	91.2	75.1	62.2	51.8	37.1
2005	91.4	75.7	63.0	53.4	39.0
2007	91.7	76.4	64.4	54.9	40.4
<b>Hemodialysis</b>					
1999	90.9	74.5	60.7	49.8	34.2
2001	90.9	74.6	61.2	50.7	35.6
2003	90.9	74.5	61.6	51.3	36.5
2005	91.1	75.1	62.4	52.7	38.4
2007	91.4	75.8	63.7	54.2	39.8
<b>Peritoneal dialysis</b>					
1999	94.3	79.6	63.7	51.7	36.4
2001	95.5	82.0	67.2	55.5	39.3
2003	96.2	84.0	68.9	57.6	43.0
2005	96.4	85.8	72.5	61.9	45.9
2007	96.9	87.6	74.9	64.7	49.2
<b>Deceased-donor transplant</b>					
1999	94.3	88.6	83.9	78.3	66.5
2001	95.0	89.6	83.3	77.8	65.9
2003	95.8	90.1	84.7	79.6	69.2
2005	95.8	90.0	85.3	80.7	71.3
2007	96.8	92.5	88.4	84.1	73.7
<b>Living donor transplant</b>					
1999	97.3	94.2	90.7	85.5	76.3
2001	97.5	93.8	89.9	85.8	76.2
2003	98.3	95.8	92.2	88.2	79.9
2005	98.3	95.6	92.5	89.1	81.4
2007	99.2	97.6	95.5	93.0	87.0

Data Source: Reference Tables I.1-I.36, and special analyses, USRDS ESRD Database. Adjusted survival probabilities, from day one, without the 60 day rule, in the ESRD population. Ref: incident ESRD patients, 2011. Adjusted for age, sex, race, Hispanic ethnicity, and primary diagnosis. Abbreviation: ESRD, end-stage renal disease.

In the 2007 incident cohort, survival over the first five years of therapy is consistently highest in the transplant population and among younger patients, Blacks/African Americans (compared to Whites), and patients with a primary diagnosis of glomerulonephritis (compared to patients with diabetes or hypertension) (Table 5.1.b).

**vol 2 Table 5.1 Adjusted survival probabilities among ESRD patients, by months after initiation of treatment**

5.1.b By modality and age, sex, race, and primary cause of ESRD, for patients initiating ESRD treatment in 2007

	3 months	12 months	24 months	36 months	60 months
<b>2007 cohort</b>					
Dialysis	91.7	76.4	64.4	54.9	40.4
Hemodialysis	91.4	75.8	63.7	54.2	39.8
Peritoneal dialysis	96.9	87.6	74.9	64.7	49.2
Deceased-donor transplant	96.8	92.5	88.4	84.1	73.7
Living donor transplant	99.2	97.6	95.5	93.0	87.0
<b>Age</b>					
0-19	98.4	95.5	91.9	89.7	87.0
20-44	97.7	91.9	85.9	81.0	73.0
45-64	95.4	85.0	75.7	67.3	53.3
65-74	91.0	74.2	60.8	49.9	33.0
75+	84.6	60.4	43.4	31.5	15.8
<b>Sex</b>					
Male	91.7	76.9	64.9	55.4	41.3
Female	91.9	76.8	65.2	55.9	41.6
<b>Race</b>					
White	91.0	75.2	62.9	53.3	38.8
Black/African American	93.2	79.1	68.0	59.0	45.3
Native American	95.1	84.7	71.6	61.6	46.8
Asian	94.6	83.8	74.9	66.9	53.7
Other	91.1	72.1	55.4	44.2	26.1
<b>Primary cause of ESRD</b>					
Diabetes	92.7	77.6	64.4	53.7	37.2
Hypertension	92.0	77.9	66.4	57.4	43.6
Glomerulonephritis	94.3	83.4	73.9	66.3	53.8
Other	88.2	70.0	59.6	52.0	41.6

Data Source: Reference Tables I.1-I.36 and special analyses, USRDS ESRD Database. Adjusted survival probabilities, from day one, without the 60 day rule, in the ESRD population. Ref: incident ESRD patients, 2011. Adjusted for age, sex, race, Hispanic ethnicity, and primary diagnosis. Abbreviation: ESRD, end-stage renal disease.

**Expected Remaining Lifetime: Comparison of ESRD Patients to the General U.S. Population**

The contrast between the ESRD and general populations is striking with respect to expected remaining lifetime (Table 5.2). One of the most compelling differences in expected remaining lifetime between the general and ESRD populations is found among dialysis patients

in their 30s, 40s, and 50s, who are expected to live less than one-third as long as their counterparts without ESRD. Transplant patients fare considerably better, with expected remaining lifetimes estimated at 83-87 percent of those of the general population.

**vol 2 Table 5.2 Expected remaining lifetime (years) of the general U.S. population, prevalent dialysis patients and transplant patients, by sex and age**

Ages	ESRD patients, 2012						General U.S. population, 2010		
	Dialysis			Transplant			All	M	F
0-14	22.3	23.2	21.3	61.0	60.1	62.5	72.9	70.5	75.3
15-19	19.9	20.6	19.0	48.7	47.9	50.0	59.5	57.1	61.7
20-24	17.0	17.7	16.1	44.7	44.0	45.9	54.7	52.4	56.9
25-29	14.9	15.5	14.1	40.7	40.0	41.8	50.0	47.8	52.0
30-34	13.4	13.8	12.7	36.8	36.1	37.9	45.2	43.1	47.2
35-39	12.0	12.3	11.5	32.8	32.1	33.9	40.5	38.5	42.4
40-44	10.5	10.6	10.2	28.9	28.2	30.0	35.9	33.9	37.7
45-49	8.9	9.0	8.7	25.1	24.4	26.2	31.4	29.6	33.2
50-54	7.6	7.6	7.6	21.6	20.9	22.7	27.2	25.4	28.8
55-59	6.5	6.4	6.5	18.3	17.7	19.3	23.1	21.5	24.5
60-64	5.5	5.4	5.6	15.4	14.8	16.4	19.1	17.7	20.3
65-69	4.6	4.5	4.8	12.9	12.4	13.8	15.5	14.2	16.5
70-74	3.9	3.8	4.1	10.8	10.4	11.5	12.1	11.0	12.9
75-79	3.3	3.2	3.5	9.1	8.7	9.7	9.1	8.2	9.7
80-84	2.7	2.6	2.9	a	a	a	6.5	5.8	6.9
85+	2.2	2.1	2.4	a	a	a	3.4	3.0	3.5
Overall	6.6	6.6	6.6	18.6	18.0	19.5	22.2	20.7	23.4

Data Source: Reference Table H.13; special analyses, USRDS ESRD Database; and Table 7 in National Vital Statistics Reports, Deaths: Final Data for 2010. Expected remaining lifetimes (years) of the general U.S. population and of prevalent dialysis and transplant patients. Prevalent ESRD population, 2012, used as weight to calculate overall combined-age remaining lifetimes. <sup>a</sup>cell values combine ages 75-85 and over. Abbreviation: ESRD, end-stage renal disease.

**Mortality Rates: Comparisons of ESRD Patients with the General Medicare Population**

Adjusted rates of all-cause mortality are 6.1 to 7.8 times greater for dialysis patients than for individuals in the general age-matched Medicare population (Figure 5.4). For renal transplant patients, rates are comparable to those of the general Medicare population less than 65 years old, but are 1.3 times higher among patients age 65 and older. (Note that patients on Medicare under the age of 65 are not representative of the general population.) Mortality rates rise with age, reaching 287 per 1,000 patient years for dialysis patients age 65 and older



compared to 62.3 for transplant patients and 47.4 for the general Medicare population of the same age.

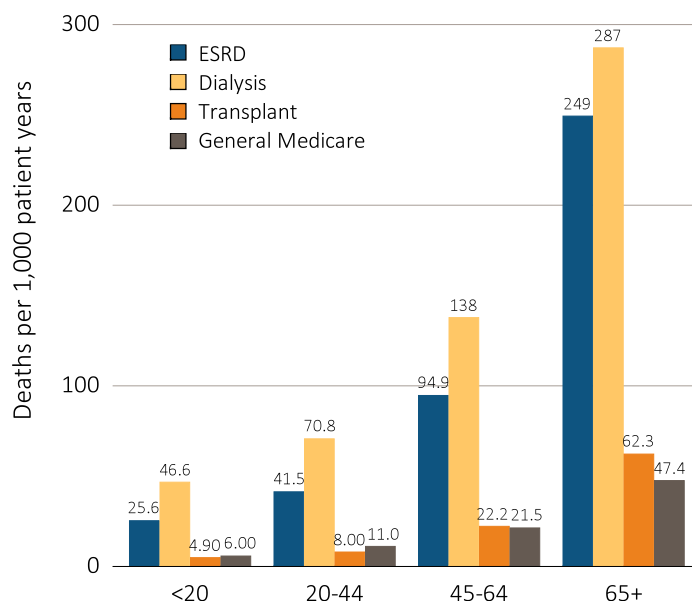
### Comparing ESRD with Comorbidity-Specific Medicare Patients, by Year

Since 1996, mortality adjusted for age, sex, and race fell 36 percent, from 350 to 223 in 2012 (Table 5.3). Among dialysis patients, adjusted mortality fell 31 percent, from 364 in 1996 to 252 in 2012. For transplant patients, adjusted mortality fell 38 percent, from 133 in 1996 to 83 in 2012.

Over the same time period, adjusted mortality fell 31 percent for cancer and 26 percent for diabetes, but somewhat less for cardiovascular conditions such as 14 percent for heart failure and 21 percent for CVA/TIA. No clear decline in mortality among AMI patients is evident.

vol 2 Figure 5.4 Adjusted all-cause mortality in the ESRD & general populations, by age, 2012

Data Source: Special analyses, USRDS ESRD Database and Medicare



5 Percent Sample. Adjusted for sex and race. Medicare data limited to patients with at least one month of Medicare eligibility in 2012. Ref: Medicare patients, 2012. Abbreviation: ESRD, end-stage renal disease.

vol 2 Table 5.3 Unadjusted & adjusted mortality rates in the ESRD & comorbidity-specific Medicare populations, age 65 & older (per 1,000 patient years), by calendar year

	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
<b>Unadjusted</b>																	
ESRD	337	329	335	338	324	320	315	307	300	296	286	276	264	257	247	241	223
Dialysis	354	347	354	359	344	342	338	332	327	326	317	308	298	291	281	277	258
Transplant	97	89	97	92	93	91	91	90	83	80	77	79	72	75	74	72	66
<b>General Medicare</b>																	
Cancer	150	146	142	139	138	132	128	125	121	122	119	117	115	113	111	109	109
Diabetes	93	93	94	94	90	87	85	82	77	79	76	74	74	71	71	71	72
CHF	205	209	208	206	208	202	197	196	189	192	191	190	196	183	189	188	191
CVA/TIA	156	156	158	154	153	151	145	143	134	137	135	133	133	125	129	127	128
AMI	149	149	155	155	157	156	152	153	149	149	148	145	155	146	153	153	163
<b>Adjusted</b>																	
ESRD	350	341	346	345	329	324	318	309	300	294	284	274	263	255	246	240	223
Dialysis	364	356	361	363	346	343	337	330	322	319	310	299	290	284	275	270	252
Transplant	133	112	112	106	116	107	108	112	106	99	100	101	94	93	94	89	83
<b>General Medicare</b>																	
Cancer	144	141	140	133	129	126	122	118	112	116	113	107	106	105	102	100	99
Diabetes	87	89	88	86	82	80	78	76	70	72	69	66	66	63	63	62	64
CHF	166	170	167	164	160	157	154	153	145	146	144	143	145	137	138	137	143
CVA/TIA	130	130	128	124	122	124	117	116	109	111	108	107	106	100	101	100	103
AMI	131	131	136	138	133	135	133	133	124	126	128	125	131	122	127	125	137

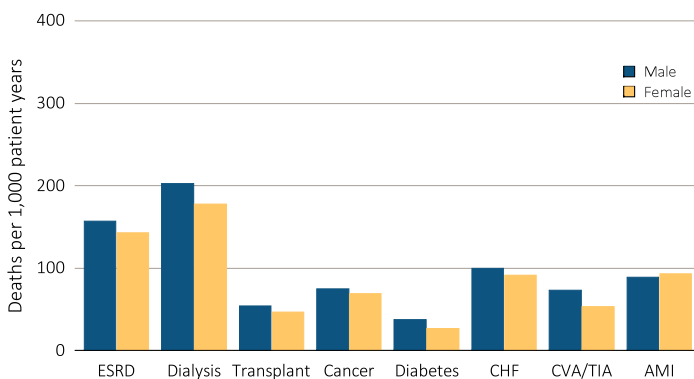
Data Source: Special analyses, USRDS ESRD Database and Medicare 5 percent sample. Unadjusted and adjusted (sex and race) mortality rates starting with January 1 point prevalent sample in the ESRD and general populations, age 65 and older (per 1,000 patient years at risk). Abbreviations: AMI, acute myocardial infarction; CHF, congestive heart failure; CVA/TIA, cerebrovascular accident/transient ischemic attack; ESRD, end-stage renal disease.

### Comparing ESRD with Comorbidity-Specific Medicare Patients by Age

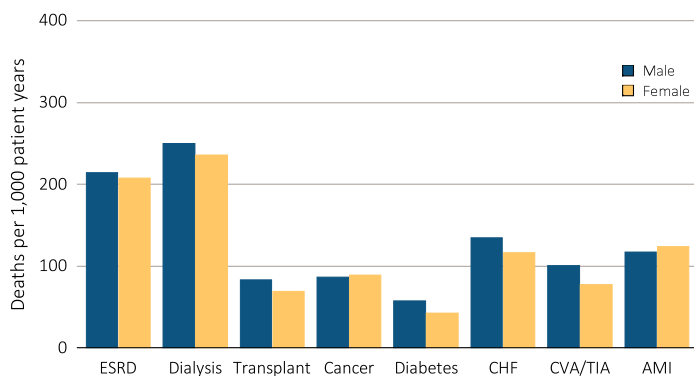
Among prevalent ESRD patients age 65 and older, adjusted mortality rates rise by age, not surprisingly (Figure 5.5). For dialysis patients, mortality rates are 2–3 times higher than for transplant patients and higher than for all general Medicare comorbidity-specific groups shown. In the transplant population, mortality rates within each age group are lower than for general Medicare patients with cancer or several of the other comorbidities shown.

**vol 2 Figure 5.5 Adjusted all-cause mortality in the ESRD, dialysis, transplant, and comorbidity-specific Medicare population, by sex, in 2012**

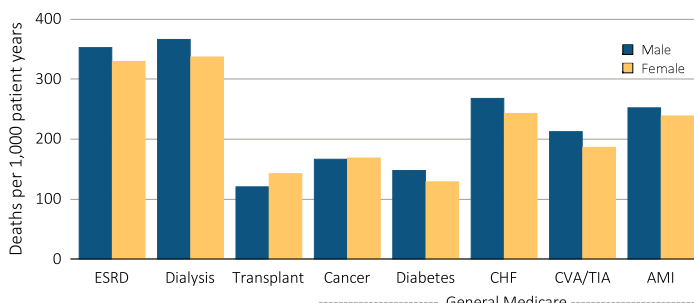
**(a) Ages 65-69**



**(b) Ages 70-79**



**(c) Age 80+**



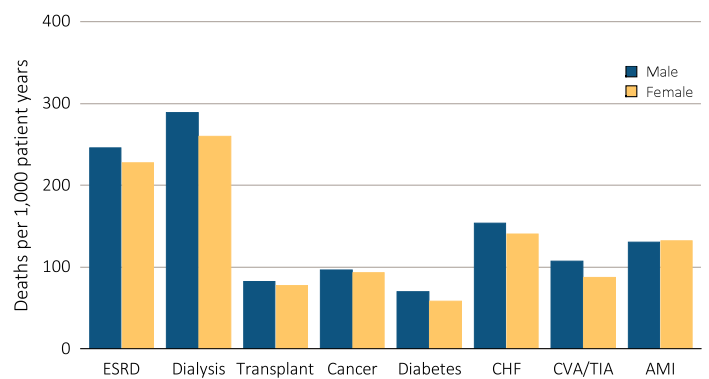
*Data Source: Special analyses, USRDS ESRD Database and Medicare 5 percent sample, 2012. All-cause mortality in the ESRD and Medicare populations with specific comorbid conditions identified in the preceding year, by age and sex, point prevalent sample on January 1, 2012, adjusted for race. Ref: ESRD patients, 2012. Abbreviations: AMI, acute myocardial infarction; CHF, congestive heart failure; CVA/TIA, cerebrovascular accident/transient ischemic attack; ESRD, end-stage renal disease.*

### Comparing ESRD With Comorbidity-Specific Medicare Patients by Race

Adjusted mortality rates are generally higher in men than women (Figure 5.6). Among ESRD patients, men have 1 to 8 percent higher mortality rates than women, with the lowest ratio among Black/African Americans and the highest among White patients. Within each race group, death rates among dialysis patients are higher than for general Medicare patients with any of the other comorbidities shown.

**vol 2 Figure 5.6 Adjusted all-cause mortality in the ESRD, dialysis, transplant, and comorbidity-specific Medicare population, by sex, in 2012**

**(a) White**



**(b) Black/African American**

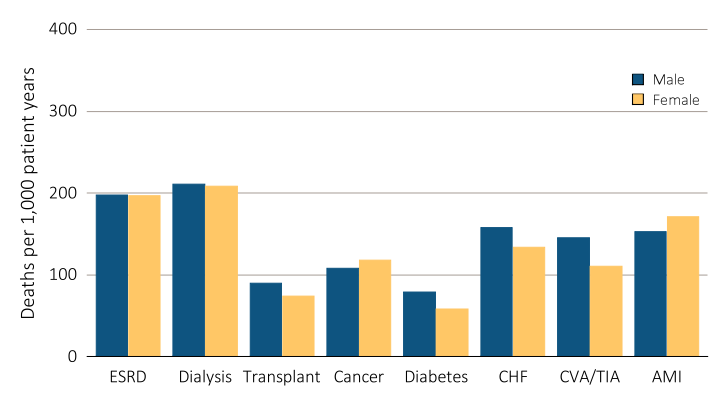
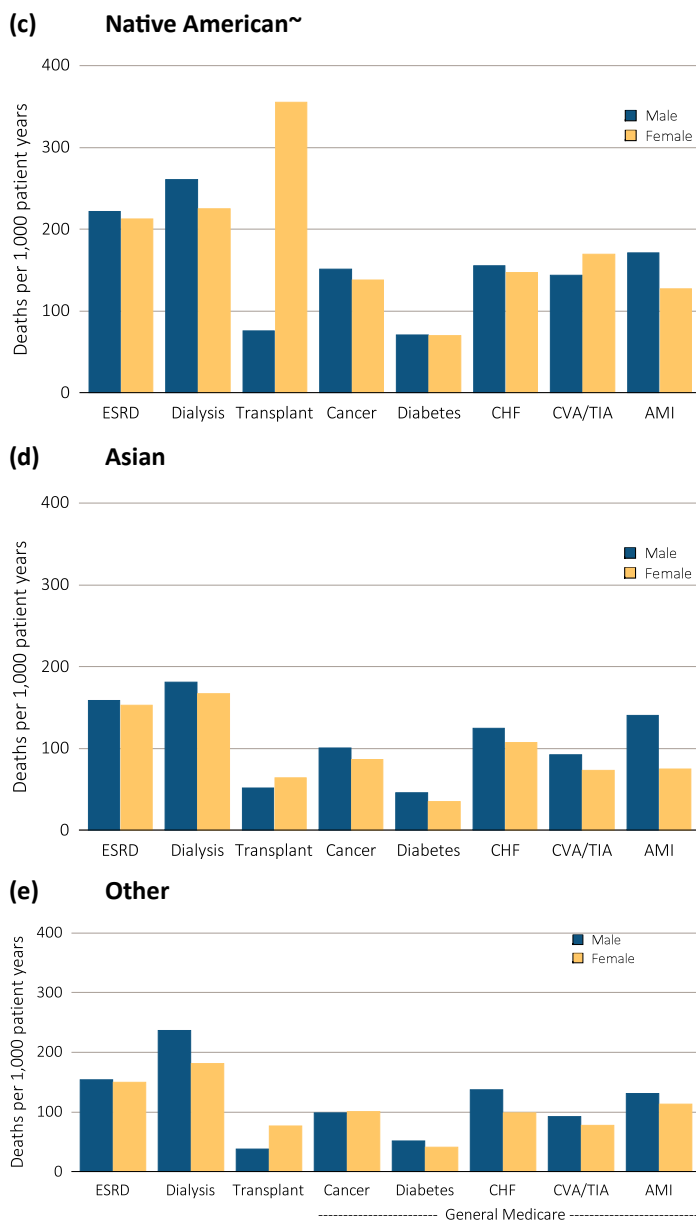


Figure 5.6 continued on next page.

**vol 2 Figure 5.6 Adjusted all-cause mortality in the ESRD, dialysis, transplant, and comorbidity-specific Medicare population, by sex, in 2012 (continued)**



*Data Source: Special analyses, USRDS ESRD Database and Medicare 5 percent sample, 2012. All-cause mortality in the ESRD and Medicare populations with specific comorbid conditions identified in the preceding year, by race and sex, point prevalent sample on January 1, 2012, adjusted for age group. ~ Estimates shown are imprecise due to small sample size and may be unstable over time. Abbreviations: AMI, acute myocardial infarction; CHF, congestive heart failure; CVA/TIA, cerebrovascular accident/transient ischemic attack; ESRD, end-stage renal disease.*

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Foley RN, Chen SC, Solid CA, Gilbertson DT, Collins AJ. Early mortality in patients starting dialysis appears to go unregistered. *Kidney Int* 2014;86(2):392-398.



# Chapter 6: Transplantation

## Introduction

During calendar year 2012, 17,305 kidney transplants, including kidney-alone and kidney plus at least one additional organ, were performed in the United States. Of these kidney transplants, 5,617 were identified as coming from living donors and 11,535 from deceased donors. Overall, there were 340 fewer kidney transplants in 2012 than in 2011. Although the number of kidney transplants has in general remained stable since 2005, ranging from a high of 18,072 in 2006, to a low of 17,305 in 2012, the cumulative number of recipients living with a functioning kidney transplant continues to grow, reaching 186,303 in 2012, a 3.6 percent increase over 2011.

The kidney transplant waiting list continues to increase, with a seven percent increase from 2011 to 2012, reaching 81,981 candidates on December 31, 2012, of which 83 percent were awaiting their first kidney transplant and 17 percent were listed for repeat kidney transplantation. On December 31, 2012, 35,288 (43 percent) candidates were wait-listed in Status 7 (inactive status) and 46,693 (57 percent) candidates were active. With fewer than 18,000 transplants performed in 2012, the active waiting list is 2.7 times larger than the supply of donor kidneys, representing a continuing challenge.

Sixteen percent of new candidates in 2011 were added to the waiting list or received a deceased or living donor transplant within one year of ESRD initiation. Among candidates newly wait-listed for either a first or repeat kidney-alone transplant in 2009, the median waiting time to transplant was 3.6 years.

The probability of first-year all-cause graft failure (return to dialysis, repeat transplantation, or death with a functioning transplant) for deceased donor kidney transplant recipients in 2011 was 7.7 percent, which improved from 9.1 percent in 2000. When graft failure is looked at as its separate components, the probability of either returning to

dialysis or undergoing repeat transplantation was 4.7 percent, while that of death was 3.7 percent. These probabilities were substantially lower in living donor transplant recipients, at 3.3 percent for all-cause graft failure, 1.8 percent for returning to dialysis or repeat transplantation, and 1.3 percent for death. For recipients of a deceased donor transplant in 2007, the probability of five-year all-cause graft failure fell to 29 percent compared to 30 percent in the prior year. Corresponding five-year graft failure rates remained the same as the previous year for living donor transplant recipients, at 17 percent.

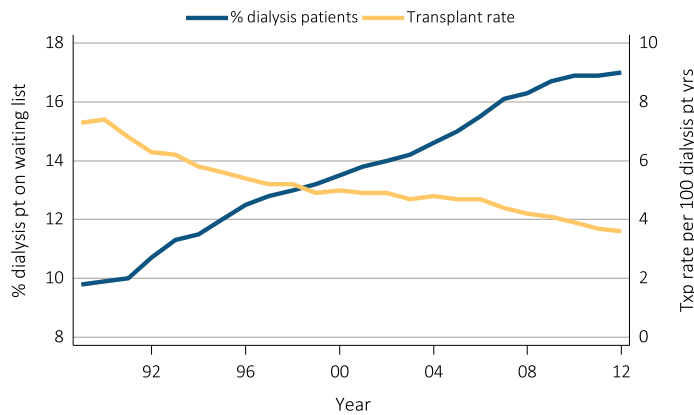
The percent of acute rejection during the first year was highest in 1996 among both deceased (51 percent) and living (52 percent) donor recipients. It declined over the next decade, and stabilized in 2006 at 12 and 10 percent for deceased and living donor recipients, respectively. Since 2004, the percent of reported biopsy-proven rejection during the first year post-transplant has been 7-9 percent for both deceased and living donor recipients.

The unadjusted transplant rate per 100 dialysis patient years is falling while the percent of prevalent dialysis patients wait-listed for a kidney has been rising (Figure 6.1.a). Probable contributing causes include a higher prevalent dialysis population; longer survival of ESRD patients on dialysis; initiation of older and perhaps more ill dialysis patients who are not suitable candidates for transplantation; and the growing mismatch between donor supply and demand, which in turn leads to longer kidney transplant waiting times. Waiting list counts and median waiting time to transplantation for both first and repeat kidney transplant candidates continue to grow (Figure 6.1.b). Many candidates waiting for repeat kidney transplantation were sensitized against a portion of the potential kidney donor pool as a consequence of their initial transplant. Thus, as expected, waiting times for those seeking a repeat kidney transplant are longer than those observed for candidates wait-listed

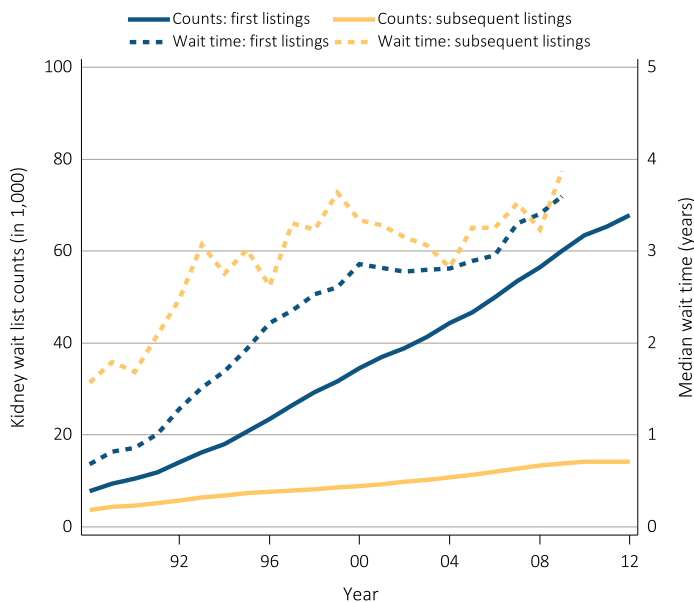
for a first kidney transplant. The total number of kidney transplants has leveled off over the past decade (Figure 6.1.c). During this period, a small overall increase in deceased donation has balanced a small decrease in living donation. The latter is driven in part by changes in pediatric allocation policy that direct deceased donor kidneys from donors under the age of 35 years to children. Introduction of this policy was associated with a decrease in living donation to children. As noted above, the total number of recipients with functioning living and deceased donor kidney transplants continues to grow (Figure 6.1.d).

**vol 2 Figure 6.1 Trends in transplantation: unadjusted rates, waiting list counts, waiting time, counts of transplants per year, & total functioning transplants**

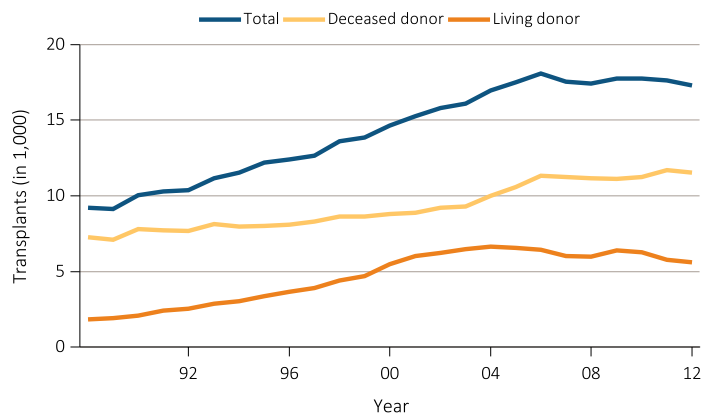
**(a) Percent of dialysis patients wait-listed and unadjusted transplant rates**



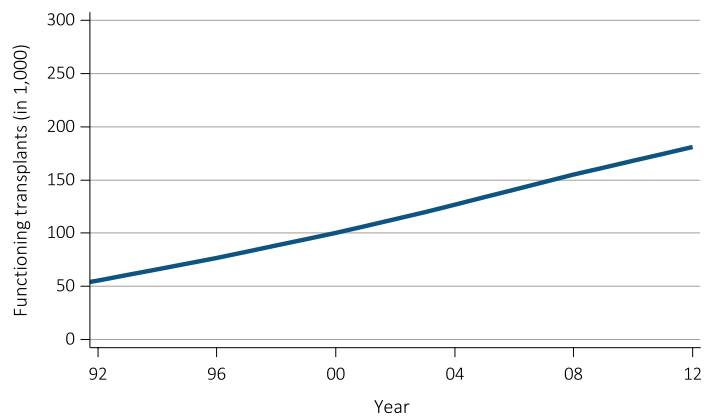
**(b) Kidney waiting list counts and waiting time**



**(c) Counts of transplants**



**(d) Counts of total functioning transplants**

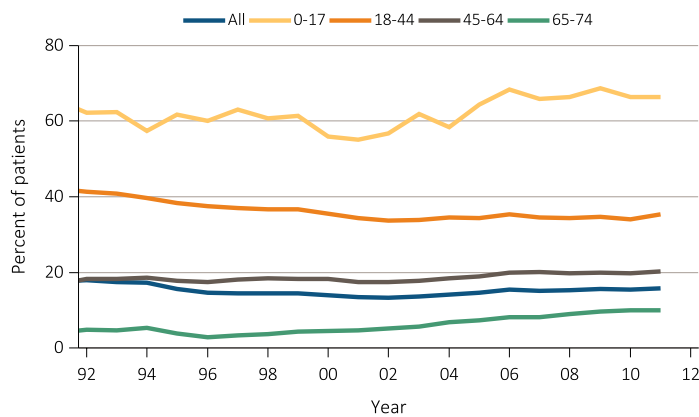


*Data Source: Reference Tables E4, E9; E2, E3; E8, E8(2), E8(3); D9. Percent of dialysis patients on the kidney waiting list is for all dialysis patients. Unadjusted transplant rates are for all dialysis patients. Waiting list counts include all candidates listed for a kidney transplant on December 31 of each year. Waiting time is calculated for all candidates enrolled on the waiting list in a given year. Functioning transplant is the annual status on December 31 of each year of all patients who received a kidney transplant, regardless of transplant date.*

## Waiting List

Kidney transplant rates are lower with increasing candidate age. As an indicator of access to transplantation, the percent of patients wait-listed or receiving a transplant in their first ESRD-year has declined for those between the ages of 18 and 44 and increased slightly in recent years for those age 44 and above (Figure 6.2).

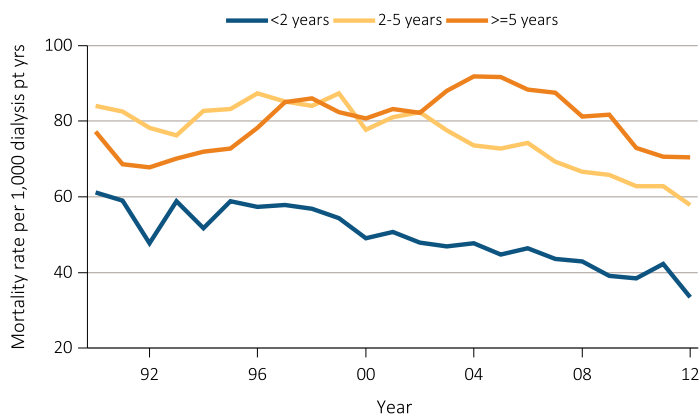
**vol 2 Figure 6.2 Percent of incident patients being wait-listed or receiving a kidney transplant within one year of ESRD initiation, by age**



Data Source: Reference Table E5(2). Waiting list or transplantation among incident ESRD patients by age (0-74 years).

The annual mortality rates of dialysis patients on the kidney transplant waiting list have declined in recent years (Figure 6.3).

**vol 2 Figure 6.3 Annual mortality rates while on the waiting list for dialysis patients from time of placement on the kidney transplant waiting list**



Data Source: Reference Table H6. Annual mortality rates of dialysis patients on the kidney transplant waiting list per 1,000 dialysis patient years at risk, by patient vintage.

## Transplant Events

### Counts of Deceased Donor Transplants

The overall number of deceased donor transplants has leveled off since 2007 (Figure 6.1.c). We review here trends by age, sex, race and primary diagnosis (cause of ESRD) (Figure 6.4). In addition to considering transplant counts, it is important to also examine transplant rates which are based on the number of dialysis patients for each category (Figure 6.5).

For the age groups 45-64 and 65-74, the number of deceased donor transplants has continued to increase

throughout the past two decades, although less steeply since 2006. The counts were highest for recipients in the 45-64 age group, reaching 5,851 in 2012 (Figure 6.4.a, Age). In contrast, during this same time period, the number of transplants has decreased steadily in the cohort aged 18-44 years to 2,997, while it remained fairly stable for children and for the small group of deceased donor kidney recipients older than 75 years.

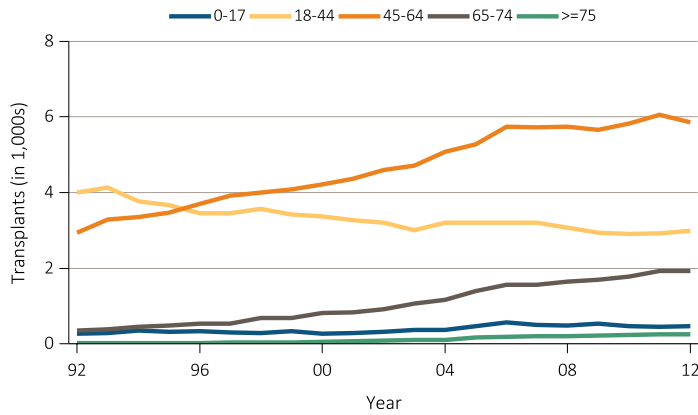
The trends for counts of deceased donor transplants by year are similar for males and females, rising over the past decade with some leveling off after 2006 (Figure 6.4.b, Sex). Males received substantially more transplants than females. This difference seems to be largely explained by the observation that males account for more than 58 percent (females less than 42 percent) of wait-listed candidates.

Among Whites and African Americans, the number of deceased donor transplants has grown substantially over the past decade, with smaller increases for Asians and Native Americans and small decreases for the other races (Figure 6.4.c, Race).

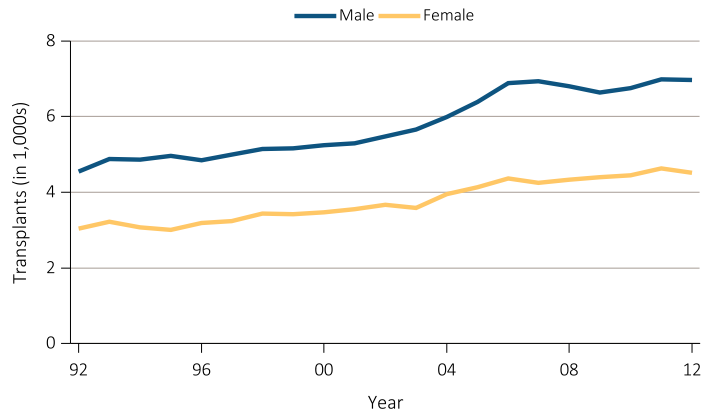
The largest growth in deceased donor transplant numbers has been among recipients with diabetes or hypertension, and these recipient diagnoses were the most common among the major causes of ESRD (Figure 6.4.d, Primary diagnosis).

vol 2 Figure 6.4 Deceased donor transplant counts and trends, by recipient age, sex, race, & primary diagnosis

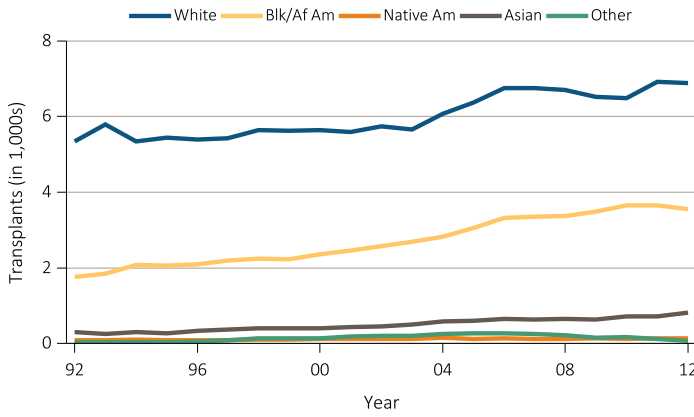
(a) Age



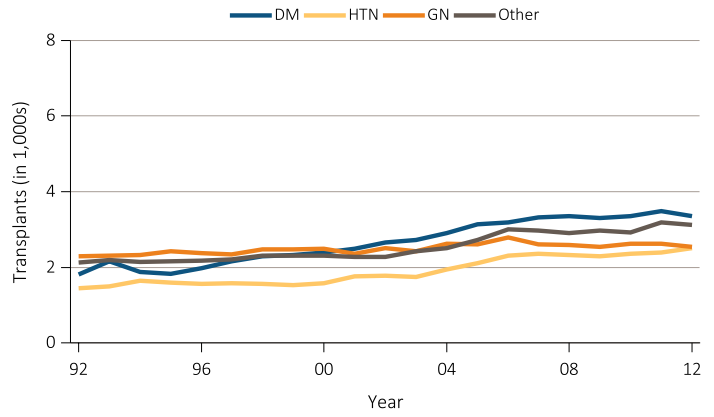
(b) Sex



(c) Race



(d) Primary diagnosis



Data Source: Reference Table E8(2). Deceased donor kidney transplant counts by recipient age, sex, race and primary diagnosis. Abbreviations: Blk/Af Am, Black/African American; DM, Diabetes Mellitus; GN, glomerulonephritis; HTN, hypertension; Native Am, Native American.

**Deceased Donor Transplant Rates**

Rates of deceased donor transplantation per 100 dialysis patient years are presented by demographic categories without statistical adjustment. As shown in Figure 6.5.a (Age), the patterns look very different than that seen for deceased donor transplant counts in Figure 6.4.a (Age) because the number of dialysis patients varies and increases markedly with age. Due to the small denominator for children on dialysis and pediatric allocation priority for kidneys from deceased donors under the age of 35 years, deceased donor transplant rates are highest in children (<18 years old) and their rates increased in 2005-2007, stabilizing thereafter. While there has been a reduction in deceased donor kidney transplantation rates for those aged 18-44 and 45-64 years, the rates for those aged 65-74 years and 75 and over have stabilized at low levels.

The rates of deceased donor kidney transplantation declined for both male and female dialysis patients (Figure 6.5.b, Sex). This is explained partly by the increasing number of dialysis patients. The difference

in transplantation rates between males and females has been narrowing in recent years.

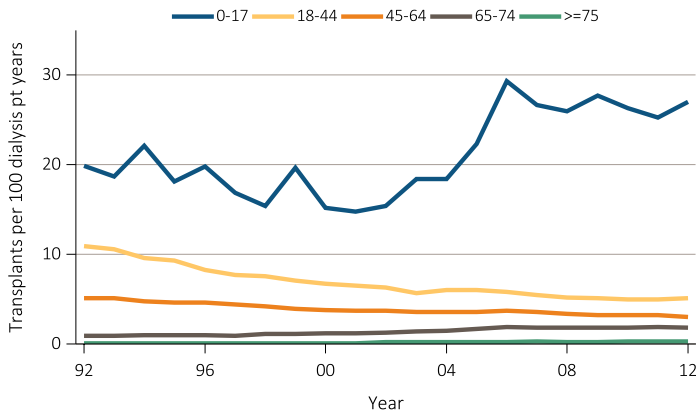
Since 1992, the deceased donor transplant rates for White dialysis patients have declined, and since 2003, the transplant rates for Asians have been higher than for Whites (Figure 6.5.c, Race). The rates of deceased donor transplants for African Americans and Native Americans have remained low although their deficit compared to Whites has persisted.

The rates of deceased donor transplants for all diagnosis groups have been declining since 2006 (Figure 6.5.d, Primary diagnosis). Transplant rates among dialysis patients with glomerular disease by far exceeded that for any other diagnoses, followed by the category of other causes. Deceased donor transplant rates for candidates with ESRD attributed to hypertension and diabetes are similar to each other, but lower than that observed for the other two categories. This rank order likely is partly explained by differences in the average age of patients with these primary diagnoses.

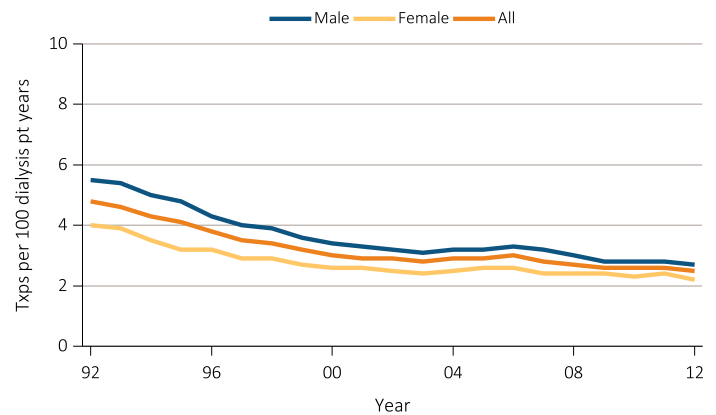


vol 2 Figure 6.5 Unadjusted transplant rates among deceased donors, by age, sex, race, & primary diagnosis

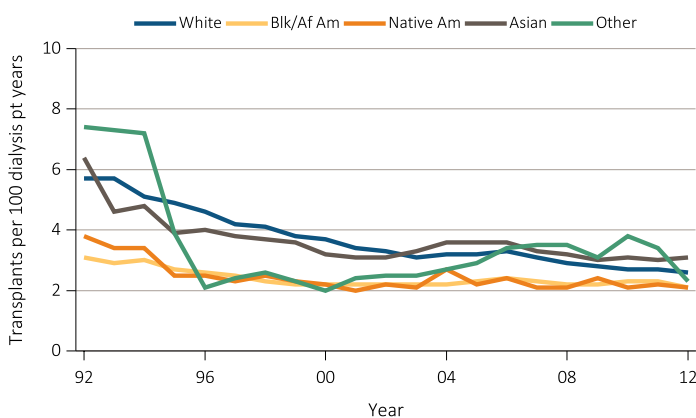
(a) Age



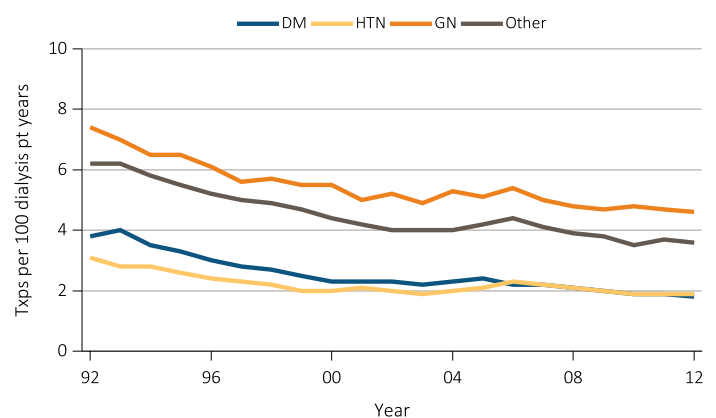
(b) Sex



(c) Race



(d) Primary diagnoses



Data Source: Reference Table E9(2). Unadjusted deceased donor kidney transplant rates by age, sex, race, primary diagnosis. Abbreviations: Blk/Af Am, Black/African American; DM, Diabetes Mellitus; GN, glomerulonephritis; HTN, hypertension; Native Am, Native American.

Counts of Living Donor Transplants

Live donor kidney transplants counts rose steadily for adult recipients between 1992 and 2004. Since 2004, the annual number of living donor transplants has declined. Counts for living donor transplants for those aged 18-44 years fell from 2,726 in 2004 to 1,991 in 2012, while the number of living donor transplants for the age group 45-64 years has shown a more recent decline, falling from 2,963 in 2010 to 2,549 in 2012 (Figure 6.6.a, Age). While transplant counts for those over 65 years old have shown an increase, more recently they have remained stable at close to 800 per year from 2010 to 2012.

The annual counts of live donor kidney transplantation show consistently higher numbers of male compared to female recipients (Figure 6.6.b, Sex). Since 2009,

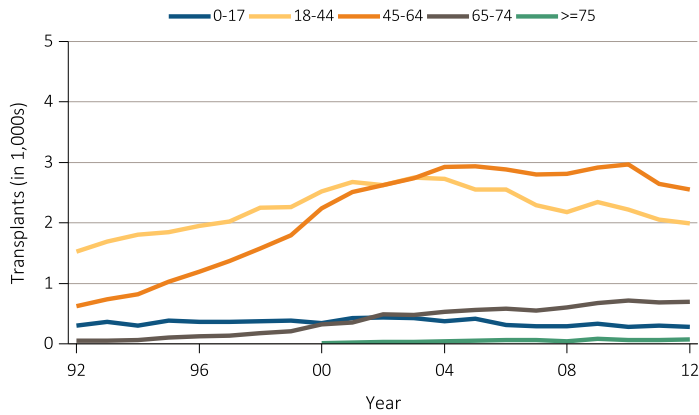
live donor kidney transplant counts have decreased for both males and females.

The overall live donor kidney transplant counts had been steadily increasing until 2004 for all races (Figure 6.6.c, Race). Since then, the number of live donor kidney transplants has decreased for Whites and African Americans while the counts for Asians have shown a small increase.

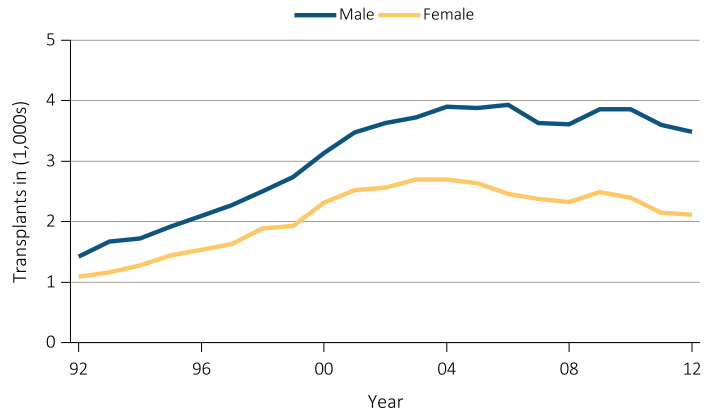
The ranking of living donor kidney transplantation counts by primary cause of ESRD (other, glomerulonephritis, diabetes, and hypertension) has remained the same over the past decade (Figure 6.6.d, Primary diagnosis). This is in contrast to the pattern seen in deceased donor recipients where the number with ESRD from diabetes mellitus has grown steadily in comparison to other diagnoses.

vol 2 Figure 6.6 Living donor transplant counts and trends by recipient age, sex, race, & primary diagnosis

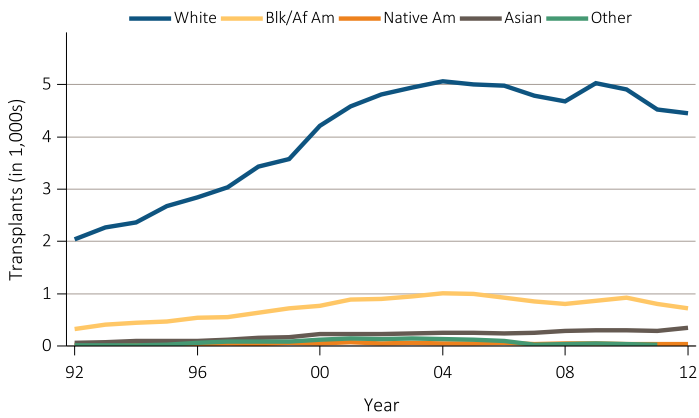
(a) Age



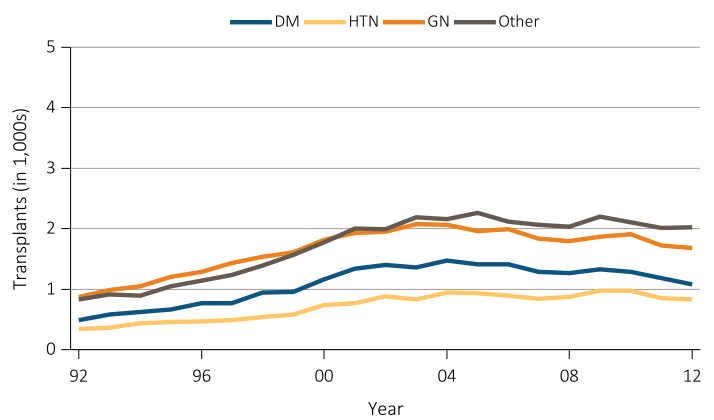
(b) Sex



(c) Race



(d) Primary diagnosis



Data Source: Reference Table E8(3). Live donor kidney transplant counts and trends by age, sex, race, and primary diagnosis. Abbreviations: Blk/Af Am, Black/African American; DM, Diabetes Mellitus; GN, glomerulonephritis; HTN, hypertension; Native Am, Native American.

**Living Donor Transplant Rates**

Similar to the observations for deceased donors, the patterns of living donor transplant counts (Figure 6.6) are markedly different from the unadjusted live donor transplantation rates shown in Figure 6.7, largely because the size of the dialysis patient denominator varies by patient group.

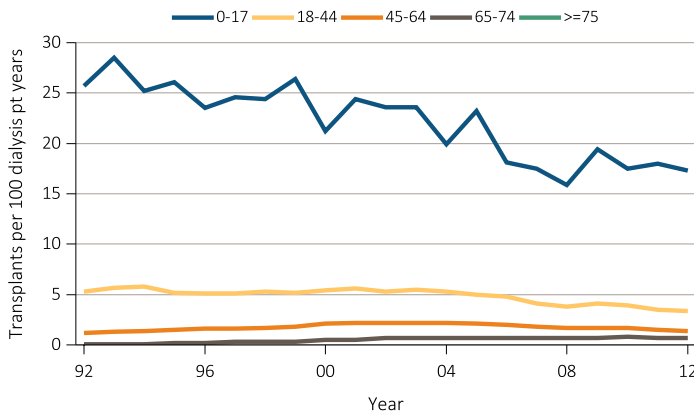
Kidney transplant rates from living donors per 100 dialysis patient years show that younger age groups have substantially higher annual transplant rates and also a steeper decline in these rates since about 1999 (Figure 6.7.a, Age). Among adults, the rates are declining slightly, but have remained highest for the 18-34 age group. Only the very low rates for ages 65-74 years have remained stable over the past decade.

The live donor transplant rates are higher for males than for females but the difference is relatively small (Figure 6.7.b, Sex). Live donor transplant rates for Whites are the highest among all racial groups while rates among Other are the lowest (Figure 6.7.c, Race). A decline since 2008 has been observed for all racial groups.

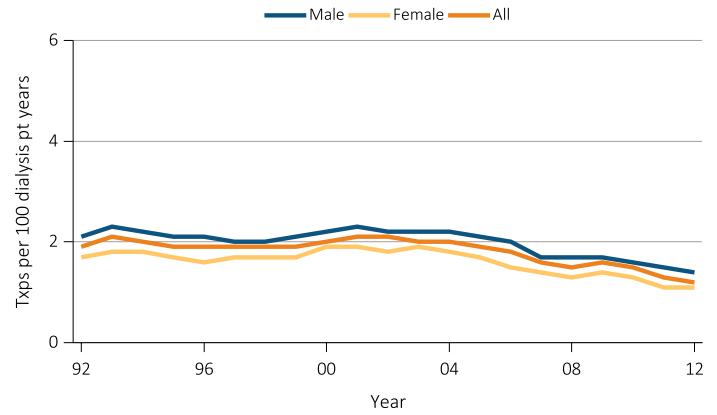
The rates of live donor transplantation for all diagnosis groups have been declining over the past decade (Figure 6.7.d, Primary diagnosis). The rate among patients with glomerular disease by far exceeds that for any other diagnoses, followed by other causes including cystic disease, and is lowest for hypertension and diabetes.

vol 2 Figure 6.7 Unadjusted transplant rates among living donors, by age, sex, race, & primary diagnosis

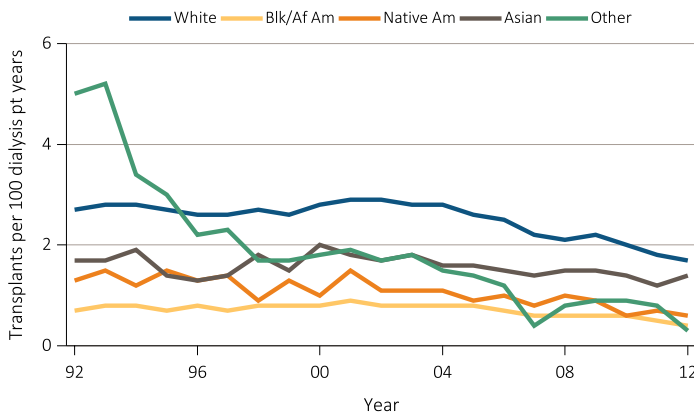
(a) Age



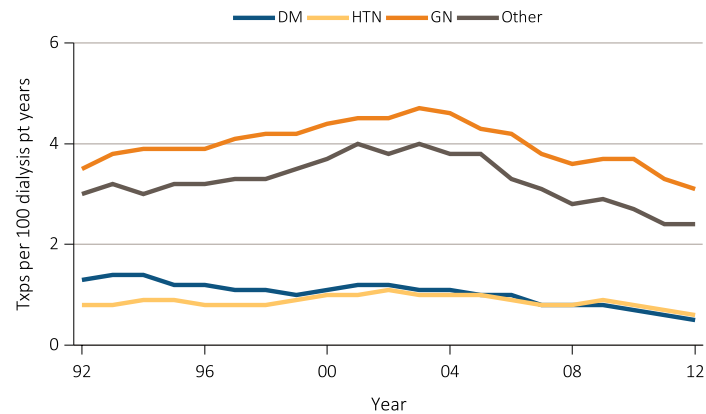
(b) Sex



(c) Race



(d) Primary diagnosis



Data Source: Reference Table E9(3). Unadjusted live donor kidney transplant rates by age, sex, race, primary diagnosis. Abbreviations: Blk/Af Am, Black/African American; DM, Diabetes Mellitus; GN, glomerulonephritis; HTN, hypertension; Native Am, Native American.

### Outcomes and Follow-up Care

Among recipients of a deceased donor kidney transplant in 2011, the probability of all-cause graft failure (including death with a functioning graft) in the first year following transplant was 0.08 (Figure 6.8.a, One-year), compared to 0.03 in those receiving a transplant from a living donor (Figure 6.9.a, One-year). The probability of death among the recipients who received a deceased donor kidney transplant in the first year post-transplant was 0.04 (Figure 6.8.a, One-year), compared to 0.01 (Figure 6.9.a, One-year) in those receiving a living donor transplant.

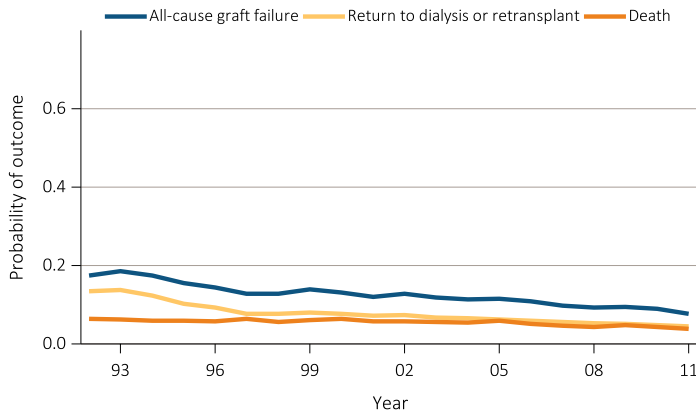
The one-year graft survival and patient survival advantage experienced by living donor transplant recipients persists at five and ten years post-transplant,

with probabilities of all-cause graft failure of 0.17 (Figure 6.9.b, Five-year) and 0.41 (Figure 6.9.c, Ten-year), compared to 0.29 (Figure 6.8.b, Five-year) and 0.54 (Figure 6.8.c, Ten-year), respectively, for those receiving a deceased donor transplant.

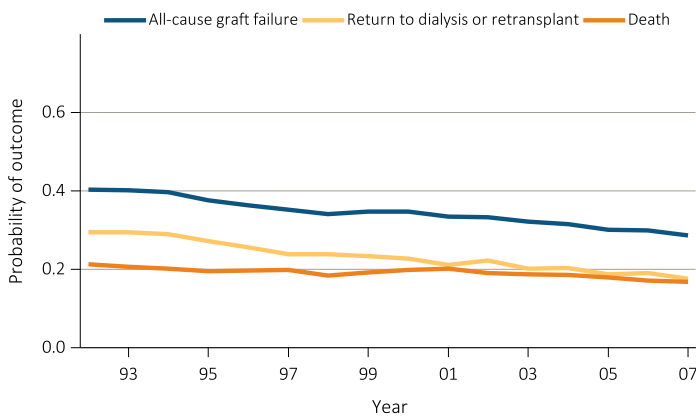
From 1991 to 2002, the probability of returning to dialysis or repeat transplantation by the tenth year post-transplant fell 10 and seven percent for deceased and living donor first-time kidney transplant recipients, respectively. The probability of death at 10 years post-transplant remained fairly stable for both deceased and living donor first-time kidney transplant recipients. The probability of death at one, five, and 10 years post-transplant is substantially higher for deceased donor transplant recipients than living donor transplant recipients.

vol 2 Figure 6.8 Outcomes: deceased donor transplants

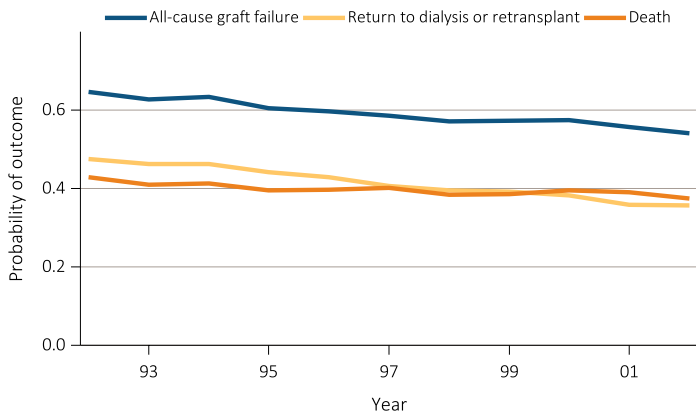
(a) One-year



(b) Five-year



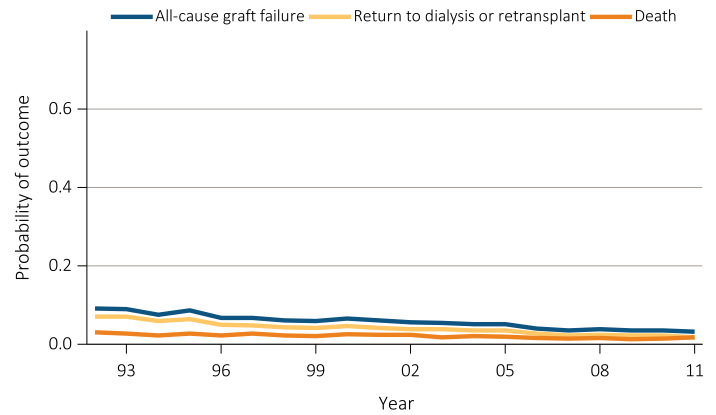
(c) Ten-year



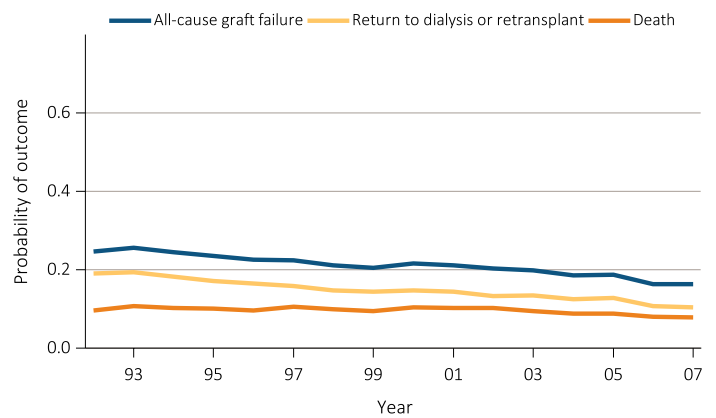
Data Source: Reference Tables F2, F14, I26; F5, F17, I29; F6, F18, I30. Outcomes among recipients of a first-time deceased donor kidney transplant; unadjusted.

vol 2 Figure 6.9 Outcomes: living donor transplants

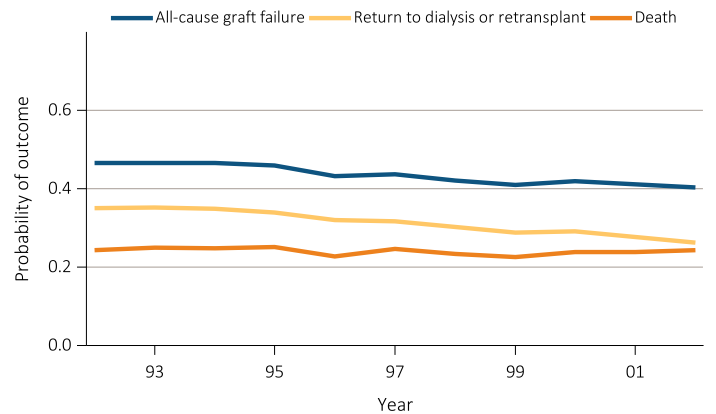
(a) One-year



(b) Five-year



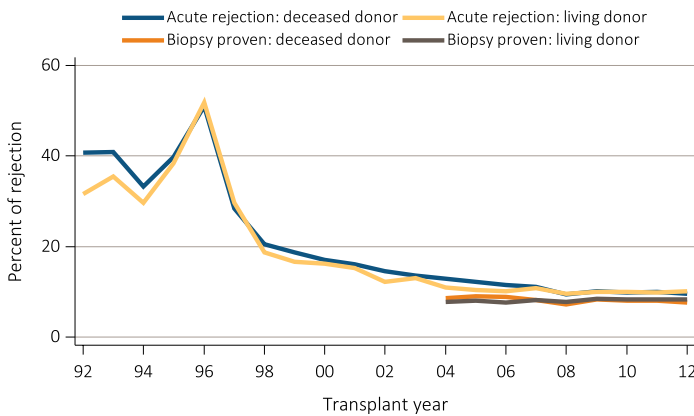
(c) Ten-year



Data Source: Reference Tables F8, F20, I32; F11, F23, I35; F12, F24, I36. Outcomes among recipients of a first-time live donor kidney transplant; unadjusted.

The percentage of kidney transplant recipients experiencing an acute rejection during the first year post-transplant has declined steadily since 1996 and stabilized in recent years (Figure 6.10). The risk of rejection is similar for living donor and deceased donor kidney transplants.

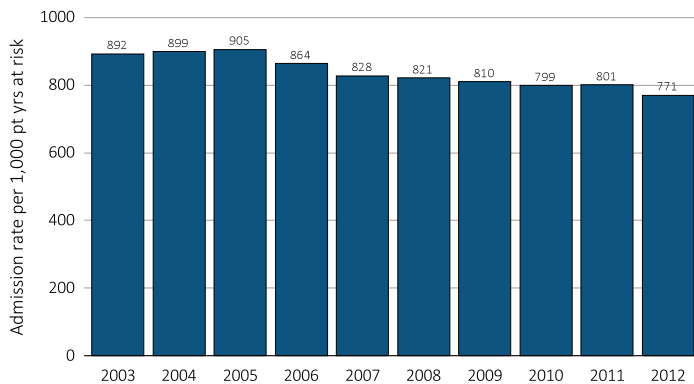
vol 2 Figure 6.10 Acute rejection within the first year post-transplant



Data Source: Special analyses, USRDS ESRD Database. Acute rejection rates during the first year post-transplant for recipients age 18 and older with a functioning graft at discharge.

The hospitalization rate for all kidney transplant recipients has declined steadily since 2005 (Figure 6.11).

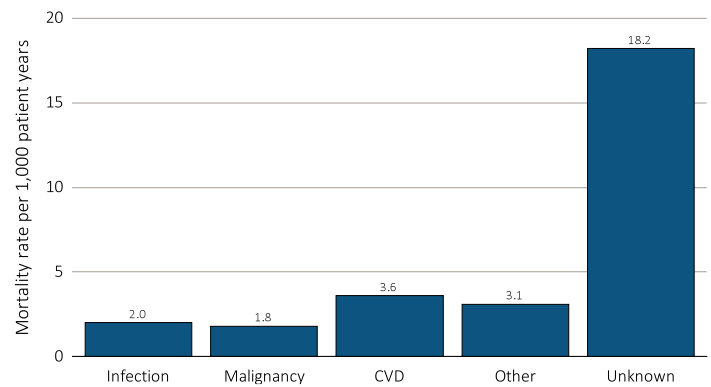
vol 2 Figure 6.11 Post-transplant total hospital admission rates



Data Source: Reference Table G5. All kidney transplant recipients.

Figure 6.12 displays post-transplant mortality rate by primary causes of death for patients who received a deceased or live donor kidney-alone or kidney plus an additional organ transplant during 2010–2012. The death rate from cardiovascular disease is nearly twice that observed for infection or malignancy.

vol 2 Figure 6.12 Mortality rate by causes of death



Data Source: Reference Table H12. Kidney transplant recipients who died.

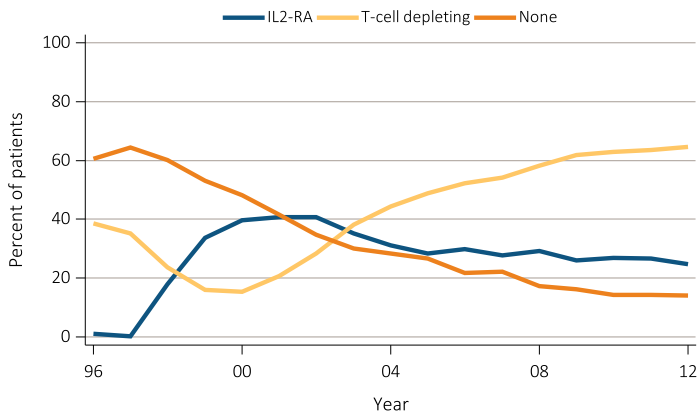
The majority (90 percent in 2012) of kidney transplant recipients received antibody induction. While the use of anti-IL2-RA (interleukin-2 receptor) antagonists has fallen from a peak of 41 percent in 2002, the use of T-cell depleting agents continues to increase, reaching 65 percent in 2012 (Figure 6.13.a, Induction agents).

Nearly all transplant recipients in 2012 received a calcineurin inhibitor (Figure 6.13.b, Calcineurin inhibitor at transplant) and an anti-metabolite (Figure 6.13.c, Anti-metabolites at transplant) as components of their initial immunosuppressive regimen. Ninety-two percent of these patients were prescribed tacrolimus as their first-line calcineurin inhibitor, and mycophenolate has almost completely replaced azathioprine as the anti-metabolite of choice. Use of mTOR inhibitors, both initially and at one year following transplantation, has declined to 2 and 4 percent, respectively, in 2012 (Figure 6.13.d, mTOR inhibitors), while steroid use seems to be stabilizing at about 67 percent (Figure 6.13.e, Steroids).

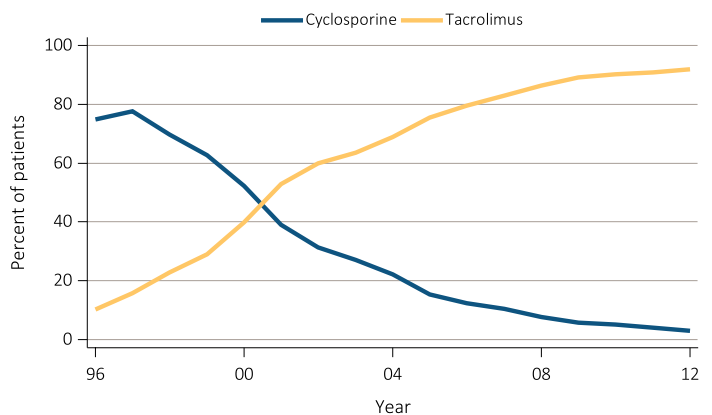
The trends in donation, access to transplantation, treatment and outcomes observed in kidney transplantation over the past 15 years deserve future monitoring.

vol 2 Figure 6.13 Immunosuppression use at transplantation (and one year post-transplant)

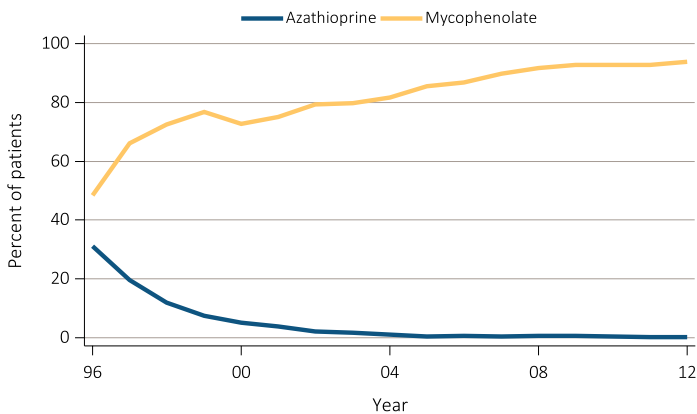
(a) Induction agents



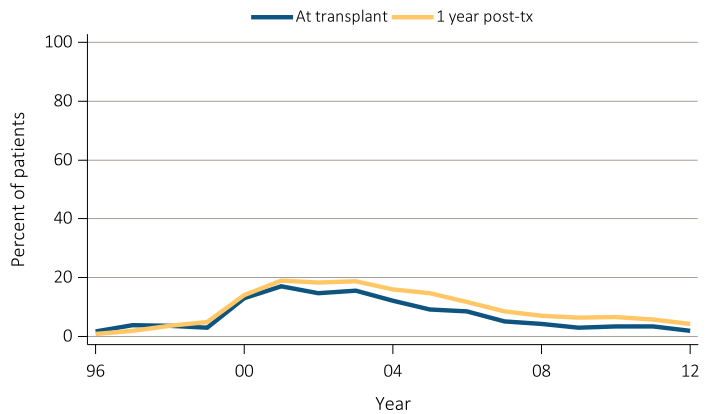
(b) Calcineurin inhibitors at transplant



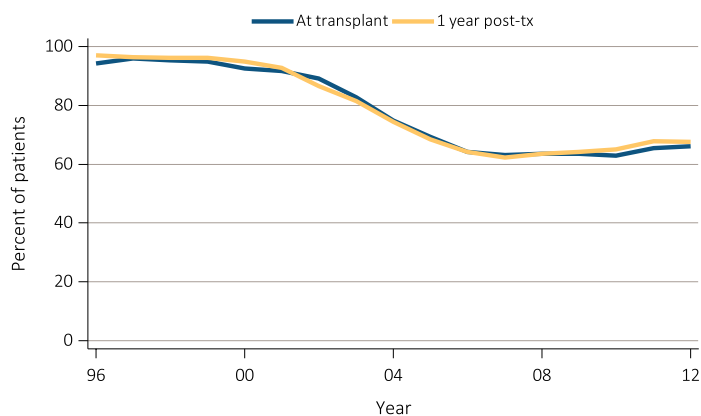
(c) Anti-metabolites at transplant



(d) mTOR inhibitors



(e) Steroids



Data Source: Special analyses, USRDS ESRD Database. All adult kidney transplant recipients. Abbreviations: IL2-RA, interleukin 2 receptor antagonist.

# Chapter 7: Pediatric ESRD

## Highlights

- 1,161 children began end-stage renal disease (ESRD) care in 2012
- 7,522 children were being treated for ESRD on December 31, 2012
- The most common initial ESRD treatment modality among children is hemodialysis (45 percent). However, 73 percent of the prevalent pediatric population had a functioning kidney transplant as of the end of 2012
- 43.6 percent of children are transplanted within the first year of ESRD care
- All-cause hospitalization rates are 1.5 per patient year among children with ESRD
- The number of children listed for kidney transplant was at an all-time high of 517 in 2012
- As of 2005, deceased donor transplants were more common than living donor transplants
- The five-year survival probability was 0.89 for children initiating ESRD care between 2003-2007

## Introduction

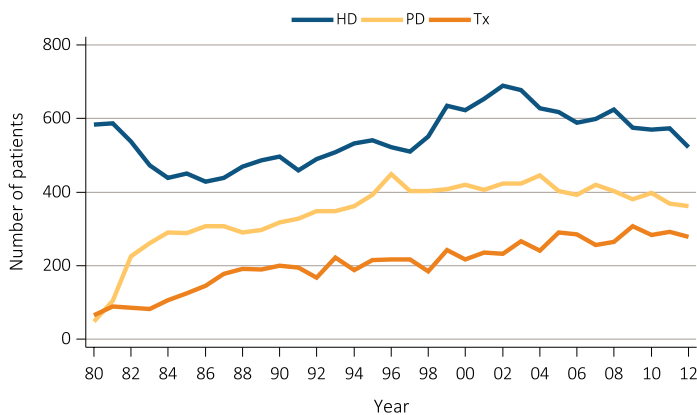
Pediatric ESRD affects children of all ages and with expected patient survival into adulthood. Consequently, children with incident ESRD often traverse the ESRD modality continuum of hemodialysis, peritoneal dialysis, and transplantation. These children are subjected to frequent hospitalizations and have a risk of mortality far exceeding the general pediatric population in the U.S. In the 2014 issue of the *United States Renal Data System (USRDS) Annual Data Report*, for the first time the Pediatric chapter includes the full spectrum of pediatric renal replacement therapy from dialysis to transplant.

## Epidemiology of End-Stage Renal Disease in Children

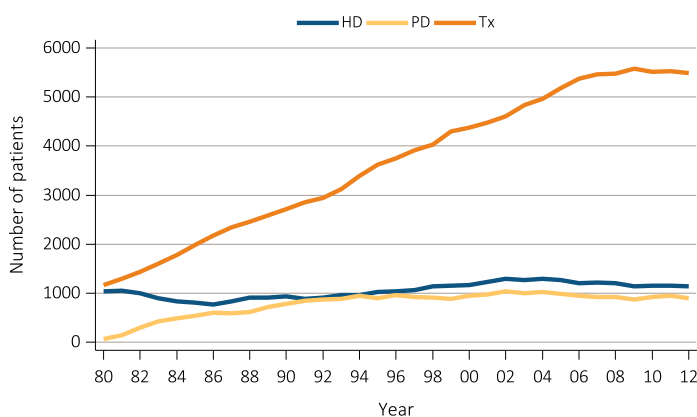
The incidence of ESRD in children has been slowly decreasing in the U.S. since 2008. The incidence peaked in 2003 across all treatment modalities. Between 2011 and 2012, 1,161 children had new onset ESRD. This figure represents a 5.8 percent reduction in incident cases from 2011. The overall prevalence of ESRD appears to have plateaued between 2008 and 2012. As of 2012, 7,522 children had prevalent ESRD, which represents a 1.3 percent decrease from the previous year. The plateau in the prevalence rate is a combination of a decline in the incident ESRD population and patients diagnosed as children who are transitioned to the adult cohort at the twentieth birthday.

vol 2 Figure 7.1 Incident & December 31 point prevalent ESRD patients (aged 0–19 years)

(a) Incidence of ESRD in children



(b) Prevalence of ESRD in children



Data Source: Reference tables D3-D5, D7-D9, and special analyses, USRDS ESRD Database. Peritoneal dialysis consists of continuous ambulatory peritoneal dialysis and continuous cycling peritoneal dialysis. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

## Etiology

The underlying etiologies of ESRD are generated from the ESRD Medical Evidence Form (CMS 2728) and summarized in Table 7.1. Consistent with previous years the leading causes of ESRD for 2008-2012 in children are: cystic/hereditary/congenital disorders (35.9 percent), glomerular disease (21.5 percent), and secondary causes of glomerulonephritis (GN) (10.6 percent). The most common individual diagnoses associated with ESRD include: renal hypoplasia/dysplasia (N=691), congenital obstructive uropathies of the ureteropelvic junction, ureterovesical junction and other locations (N=607), focal glomerular sclerosis (N=721), and lupus erythematosus (N=332). In children with ESRD, sickle cell nephropathy, human immunodeficiency virus (HIV) nephropathy and lupus erythematosus are more common among African Americans compared with other racial groups.

## Incidence and Prevalence by ESRD Modality

From the earliest reporting year, children have initiated ESRD therapy with hemodialysis more frequently than peritoneal dialysis or transplantation. 2012 data demonstrate the same pattern with 522 (45.0 percent) initiating with hemodialysis, 361 (31.1 percent) peritoneal dialysis, and 278 (23.9 percent) transplant. Over time, transplant has become the most common ESRD treatment modality in children. Of the 7,522 children and adolescents between the ages of 0 and 19 years with prevalent ESRD, kidney transplant was the most common modality (5,485 [72.9 percent]), followed by nearly equal distribution of hemodialysis (1,138 [15.1 percent]) and peritoneal dialysis (899 [12.0 percent]).



**Table 7.1 Distribution of reported incident pediatric ESRD patients by primary diagnosis (aged 0-19 years), 2003-2007 (period A) and 2008-2012 (period B) (continued on next page)**

	Total Patients		Incident %		Age Median		Male %		White %		African Am %		Other Race %		Transplant first year %		Died first year %	
	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B
<b>All ESRD (reference)</b>	6,544	6,204	100.0	100.0	14	14	57.0	56.5	64.3	65.7	24.7	23.0	11.0	11.3	41.4	43.6	3.7	3.3
<b>Diabetes</b>	58	57	0.9	1.0	18	16	46.6	52.6	55.2	57.9	37.9	36.8	6.9	5.3	8.6	15.8	12.1	12.3
Type 2	30	34	0.5	0.6	15	4	53.3	52.9	56.7	61.8	30.0	32.4	13.3	5.9	13.3	8.8	10.0	17.6
Type 1	28	23	0.4	0.4	19	19	39.3	52.2	53.6	52.2	46.4	43.5	0.0	4.3	3.6	26.1	14.3	4.3
<b>Glomerulonephritis (GN)</b>	1,541	1,336	24.7	23.0	16	16	54.9	52.8	58.5	64.1	33.2	29.0	8.4	6.9	35.4	36.5	2.2	1.7
GN (histologically not examined)	275	194	4.4	3.3	17	18	57.8	56.7	61.1	69.6	26.5	20.6	12.4	9.8	29.5	25.3	3.6	1.5
Focal glomerular sclerosis	824	721	13.2	12.4	15	15	56.8	54.4	51.8	59.2	42.0	36.1	6.2	4.7	37.6	39.4	1.9	1.9
Membranous nephropathy	31	34	0.5	0.6	15	17	48.4	58.8	58.1	47.1	32.3	44.1	9.7	8.8	35.5	41.2	0.0	0.0
MPGN GN type 1, diffuse MPGN	77	75	1.2	1.3	15	16	48.1	48.0	76.6	66.7	14.3	24.0	9.1	9.3	40.3	42.7	2.6	4.0
Dense deposit disease, MPGN type 2	26	20	0.4	0.3	12	15	38.5	60.0	96.2	75.0	3.8	10.0	0.0	15.0	30.8	20.0	3.8	0.0
IgA nephropathy	130	134	2.1	2.3	17	17	58.5	54.5	68.5	76.1	19.2	13.4	12.3	10.4	40.8	44.0	0.8	0.0
IgM nephropathy	*	14	0.1	0.2	16	18	57.1	64.3	42.9	71.4	42.9	21.4	14.3	7.1	42.9	14.3	0.0	0.0
Rapidly progressive GN	77	56	1.2	1.0	14	14	45.5	23.2	66.2	75.0	22.1	16.1	11.7	8.9	27.3	21.4	2.6	1.8
Post infectious GN, SBE	14	21	0.2	0.4	14	16	64.3	52.4	57.1	71.4	28.6	23.8	14.3	4.8	21.4	14.3	0.0	4.8
Other proliferative GN	80	67	1.3	1.2	15	16	41.3	43.3	66.3	65.7	26.3	26.9	7.5	7.5	31.3	43.3	2.5	1.5
<b>Secondary GN/vasculitis</b>	708	656	11.4	11.3	16	16	31.8	29.3	54.0	57.8	36.7	35.2	9.3	7.0	14.7	18.1	4.5	4.3
Lupus nephritis	405	332	6.5	5.7	17	18	22.7	21.7	38.3	32.8	50.4	59.0	11.4	8.1	6.9	7.2	5.9	4.5
Henoch-Schonlein syndrome	23	28	0.4	0.5	15	14	65.2	53.6	87.0	85.7	4.3	7.1	8.7	7.1	43.5	39.3	0.0	3.6
Scleroderma	*	*	0.1	0.1	18	18	25.0	66.7	50.0	66.7	50.0	33.3	0.0	0.0	0.0	33.3	25.0	33.3
Hemolytic uremic syndrome	119	113	1.9	1.9	6	8	47.1	37.2	77.3	82.3	17.6	12.4	5.0	5.3	27.7	35.4	3.4	4.4
Polyarteritis	11	21	0.2	0.4	14	13	18.2	19.0	72.7	85.7	9.1	4.8	18.2	9.5	9.1	19.0	0.0	0.0
Wegener's granulomatosis	60	56	1.0	1.0	15	16	56.7	42.9	70.0	89.3	23.3	7.1	6.7	3.6	20.0	23.2	3.3	1.8
Other vasculitis and its derivatives	58	54	0.9	0.9	15	13	25.9	33.3	69.0	72.2	25.9	16.7	5.2	11.1	24.1	29.6	1.7	5.6
Goodpasture syndrome	14	33	0.2	0.6	16	17	28.6	27.3	85.7	93.9	7.1	3.0	7.1	3.0	21.4	18.2	0.0	3.0
Secondary GN, other	14	16	0.2	0.3	14	17	42.9	37.5	78.6	81.3	7.1	18.8	14.3	0.0	21.4	25.0	0.0	6.3

Data Source: Special analyses, USRDS ESRD Database. Abbreviations: AIDS, acquired-immune deficiency syndrome; ESRD, end-stage renal disease; GN glomerulonephritis; IgA immunoglobulin A; IgM, immunoglobulin M; MPGN, membranoproliferative glomerulonephritis; SBE, sub-acute bacterial endocarditis.

**Table 7.1 Distribution of reported incident pediatric ESRD patients by primary diagnosis (aged 0-19 years), 2003-2007 (period A) and 2008-2012 (period B) (continued on next page)**

	Total Patients		Incident %		Age Median		Male %		White %		African Am %		Other Race %		Transplant first year %		Died first year %	
	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B
<b>Interstitial nephritis/pyelonephritis</b>	391	289	6.3	5.0	15	15	52.7	50.9	81.3	81.3	12.8	11.1	5.9	7.6	47.8	54.7	2.0	4.8
Nephropathy caused by other agents	41	37	0.7	0.6	15	14	56.1	56.8	82.9	83.8	14.6	10.8	2.4	5.4	53.7	29.7	9.8	10.8
Nephrolithiasis	*	11	0.1	0.2	12	16	44.4	27.3	100.0	90.9	0.0	0.0	0.0	9.1	100.0	81.8	0.0	9.1
Acquired obstructive uropathy	48	30	0.8	0.5	15	14	77.1	76.7	66.7	80.0	22.9	16.7	10.4	3.3	45.8	46.7	0.0	0.0
Chronic pyelonephritis, reflux nephropathy	201	143	3.2	2.5	15	15	44.3	45.5	88.6	84.6	6.5	7.0	5.0	8.4	48.3	60.8	0.5	2.8
Chronic interstitial nephritis	75	60	1.2	1.0	14	16	57.3	46.7	73.3	73.3	20.0	16.7	6.7	10.0	46.7	56.7	2.7	3.3
Acute interstitial nephritis	*	*	0.0	0.1	11	11	33.3	100.0	33.3	50.0	66.7	50.0	0.0	0.0	0.0	50.0	0.0	50.0
Disorders of calcium metabolism	*	.	0.1	.	15	.	20.0	.	80.0	.	20.0	.	0.0	.	20.0	.	0.0	.
<b>Hypertensive/large vessel disease</b>	283	260	4.5	4.5	17	18	55.8	57.3	52.3	54.6	41.3	41.5	6.4	3.8	23.7	19.6	5.3	3.8
Unspecified with renal failure	266	244	4.3	4.2	18	18	56.8	57.4	50.0	52.9	43.6	43.4	6.4	3.7	22.9	18.0	5.3	4.1
Renal artery stenosis	*	*	0.1	0.2	14	14	57.1	66.7	85.7	77.8	14.3	11.1	0.0	11.1	42.9	55.6	0.0	0.0
Renal artery occlusion	*	*	0.1	0.1	0	17	22.2	20.0	88.9	80.0	0.0	20.0	11.1	0.0	22.2	20.0	11.1	0.0
<b>Cystic/hereditary/congenital diseases</b>	2,088	2,229	33.5	38.3	10	10	68.1	67.4	75.2	74.8	18.0	18.5	6.8	6.6	51.1	51.1	3.2	2.8
Polycystic kidneys, adult type (dominant)	30	33	0.5	0.6	14	15	43.3	57.6	83.3	72.7	13.3	27.3	3.3	0.0	60.0	51.5	0.0	0.0
Polycystic, infantile (recessive)	142	150	2.3	2.6	9	1	56.3	44.7	76.1	78.0	16.9	16.7	7.0	5.3	53.5	39.3	7.0	11.3
Medullary cystic disease, incl. nephronophthisis	97	106	1.6	1.8	11	13	36.1	50.0	84.5	84.9	4.1	7.5	11.3	7.5	69.1	70.8	1.0	0.0
Tuberous sclerosis	*	*	0.1	0.1	17	18	37.5	40.0	50.0	40.0	50.0	60.0	0.0	0.0	25.0	20.0	0.0	0.0
Hereditary nephritis, Alport's syndrome	152	133	2.4	2.3	16	17	83.6	83.5	74.3	64.7	20.4	24.1	5.3	11.3	50.0	48.9	1.3	0.0
Cystinosis	62	49	1.0	0.8	12	13	51.6	59.2	90.3	91.8	9.7	8.2	0.0	0.0	77.4	75.5	0.0	0.0
Primary oxalosis	17	*	0.3	0.2	8	2	52.9	80.0	82.4	80.0	11.8	10.0	5.9	10.0	47.1	70.0	0.0	0.0
Congenital nephrotic syndrome	136	131	2.2	2.3	2	3	55.9	54.2	71.3	80.2	19.9	12.2	8.8	7.6	50.7	48.9	8.1	4.6
Drash syndrome, mesangial sclerosis	15	29	0.2	0.5	1	0	60.0	58.6	80.0	82.8	0.0	17.2	20.0	0.0	26.7	34.5	13.3	6.9
Congenital ureteropelvic junction obstruction	31	43	0.5	0.7	11	13	80.6	86.0	77.4	60.5	16.1	39.5	6.5	0.0	51.6	48.8	0.0	2.3
Congenital ureterovesical junction obstruction	25	50	0.4	0.9	13	11	88.0	86.0	72.0	70.0	28.0	20.0	0.0	10.0	52.0	50.0	0.0	2.0

**Table 7.1 Distribution of reported incident pediatric ESRD patients by primary diagnosis (aged 0-19 years), 2003-2007 (period A) and 2008-2012 (period B)**

	Total Patients		Incident %		Age Median		Male %		White %		African Am %		Other Race %		Transplant first year %		Died first year %	
	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B
Other congenital obstructive uropathy	514	514	8.2	8.8	11	10	84.6	81.5	68.5	71.8	23.5	23.7	8.0	4.5	45.1	48.2	2.7	1.2
Renal hypoplasia, dysplasia, oligonephronia	698	691	11.2	11.9	10	9	62.3	62.4	76.9	75.5	15.9	16.9	7.2	7.5	50.0	52.2	3.4	2.9
<b>Prune belly syndrome</b>	82	80	1.3	1.4	7	5	97.6	98.8	75.6	67.5	22.0	27.5	2.4	5.0	56.1	55.0	0.0	1.3
Other (congenital malformation syndromes)	79	204	1.3	3.5	14	12	50.6	56.4	83.5	78.9	13.9	10.3	2.5	10.8	55.7	51.0	2.5	4.4
<b>Neoplasms/tumors</b>	161	122	2.6	2.1	14	14	50.9	50.8	71.4	68.0	21.1	22.1	7.5	9.8	32.3	32.0	14.3	15.6
Renal tumor (malignant)	38	33	0.6	0.6	5	5	44.7	39.4	63.2	66.7	28.9	27.3	7.9	6.1	7.9	18.2	26.3	15.2
Renal tumor (unspecified)	*	*	0.1	0.0	17	1	0.0	100.0	50.0	0.0	25.0	100.0	25.0	0.0	50.0	100.0	0.0	0.0
Transplanted organ complication, unspecified	21	*	0.3	0.0	14	16	47.6	50.0	71.4	50.0	23.8	50.0	4.8	0.0	28.6	50.0	19.0	0.0
Transplanted kidney complication	46	13	0.7	0.2	15	17	58.7	76.9	73.9	84.6	19.6	15.4	6.5	0.0	58.7	23.1	0.0	0.0
Transplanted liver complication	*	*	0.1	0.1	17	15	62.5	25.0	62.5	62.5	25.0	12.5	12.5	25.0	50.0	87.5	0.0	0.0
Transplanted heart complication	20	25	0.3	0.4	14	15	55.0	52.0	80.0	64.0	15.0	24.0	5.0	12.0	30.0	48.0	20.0	16.0
Bone marrow transplant complication	12	25	0.2	0.4	12	17	50.0	60.0	91.7	64.0	8.3	28.0	0.0	8.0	8.3	12.0	33.3	12.0
<b>Miscellaneous conditions</b>	406	389	6.5	6.7	13	13	55.4	55.3	66.7	73.8	28.1	18.3	5.2	8.0	36.2	36.2	8.9	6.9
Sickle cell disease/anemia	14	*	0.2	0.2	18	18	64.3	90.0	0.0	10.0	100.0	90.0	0.0	0.0	14.3	10.0	21.4	0.0
Post-partum renal failure	*	*	0.1	0.1	17	19	11.1	0.0	66.7	71.4	33.3	14.3	0.0	14.3	33.3	0.0	0.0	0.0
AIDS nephropathy	44	15	0.7	0.3	16	18	47.7	53.3	13.6	0.0	86.4	100.0	0.0	0.0	0.0	0.0	13.6	20.0
Traumatic or surgical loss of kidney(s)	15	*	0.2	0.2	8	13	66.7	60.0	93.3	50.0	6.7	40.0	0.0	10.0	40.0	20.0	13.3	10.0
Hepatorenal syndrome	*	*	0.1	0.1	11	16	25.0	50.0	75.0	66.7	25.0	0.0	0.0	33.3	0.0	50.0	75.0	16.7
Tubular necrosis	114	131	1.8	2.3	2	11	51.8	60.3	78.9	79.4	14.0	14.5	7.0	6.1	15.8	20.6	9.6	10.7
Other renal disorders	205	210	3.3	3.6	13	12	60.5	52.4	74.1	80.0	19.5	11.0	6.3	9.0	57.6	51.4	5.4	3.8
<b>Etiology uncertain</b>	600	476	9.6	8.2	15	15	58.5	57.1	71.8	70.2	20.3	21.8	7.8	8.0	39.3	44.1	3.2	1.5
<b>Missing</b>	308	390	4.9	6.7	13	14	62.0	59.2	13.0	14.9	3.9	7.7	83.1	77.4	96.4	90.5	1.3	2.3

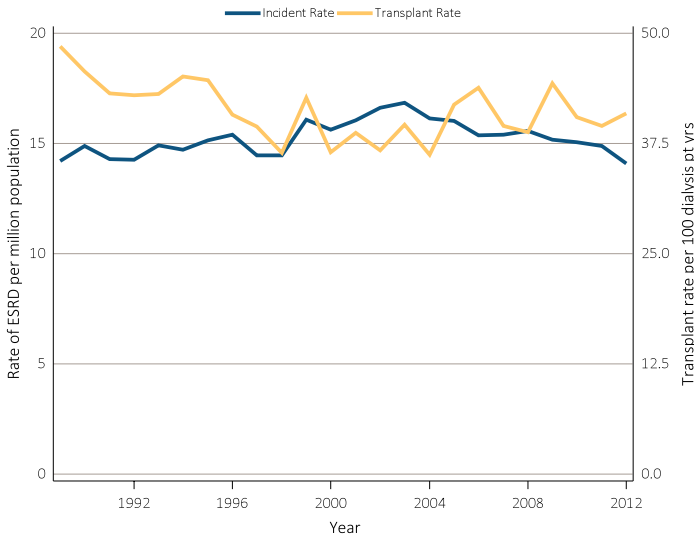
Data Source: Special analyses, USRDS ESRD Database. Abbreviations: AIDS, acquired-immune deficiency syndrome; ESRD, end-stage renal disease; GN glomerulonephritis; IgA immunoglobulin A; IgM, immunoglobulin M; MPGN, membranoproliferative glomerulonephritis; SBE, sub-acute bacterial endocarditis.

## Transplantation

Overall, 43.6 percent of patients were transplanted within the first year of ESRD onset in 2008-2012. This is an increase of 41.4 percent from the 2003-2007 period.

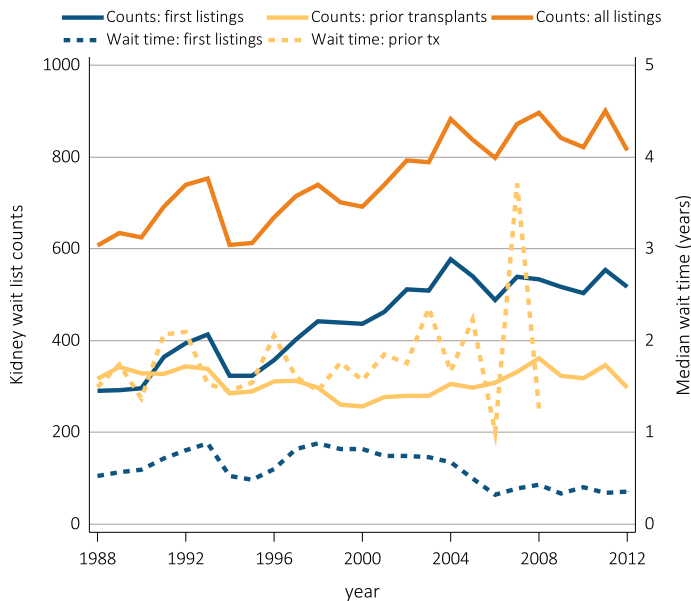
**vol 2 Figure 7.2 Trends in pediatric transplantation (aged 0-19 years)**

### (a) Incidence rate of ESRD and transplant rate in children



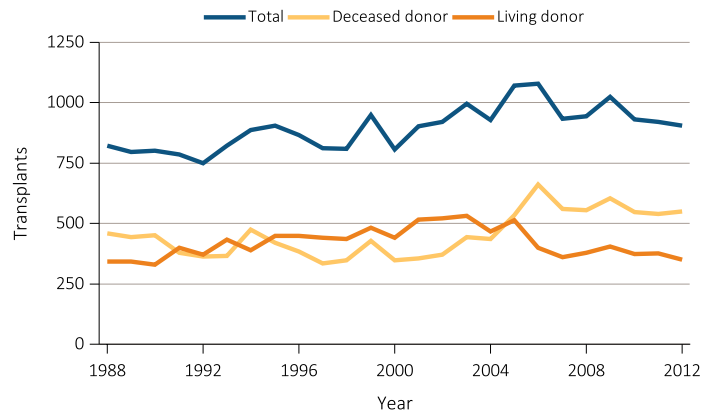
Data Source: Reference tables A1, E9, M1, and special analyses, USRDS ESRD Database. The rate of ESRD per million among the U.S. population aged 0-19 and the rate of transplantation in dialysis patients aged 0-19 at the time of transplant, 1989–2012. Abbreviation: ESRD, end-stage renal disease.

### (b) Waiting list count



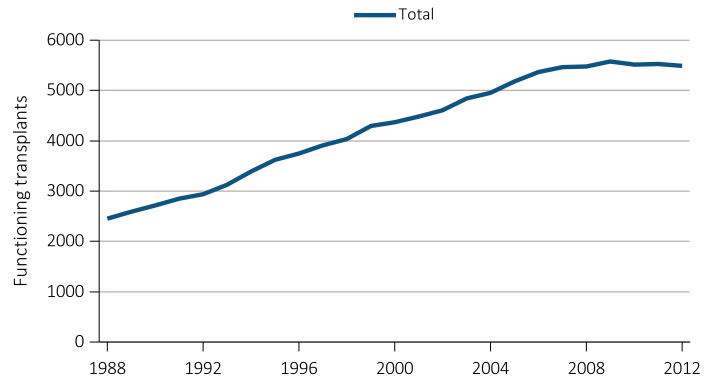
Data Source: Reference tables E2, E3, and special analyses, USRDS ESRD Database. The waiting list count provides the number of pediatric candidates aged 0-19 years on the Organ Procurement and Transplantation Network kidney transplant waiting list on December 31 of each year for first and subsequent kidney alone or kidney plus pancreas transplantation. Candidates listed at more than one center on December 31 are counted only once. There are no data available for median waiting list time for patients with prior transplants listed after 2008. Abbreviation: Tx, transplant.

### (c) Total transplants



Data Source: Reference tables E8, E8(2), E8(3), and special analyses, USRDS ESRD Database. This figure represents kidney alone and kidney plus pancreas transplant counts for all pediatric candidates.

### (d) Total functioning transplants



Data Source: Reference table D9. This is the cumulative count of functioning pediatric kidney and kidney-pancreas transplants.

The incident ESRD rate among the pediatric population peaked in 2003 and has been decreasing to 14.1 per million in 2012. The number of pediatric patients living with a kidney transplant has more than doubled from 2,455 in 1988 to 5,485 in 2012. The kidney transplant rate was highest in the initial reported years, with an average of 43.0 transplants per 100 dialysis patient years. In the most recent reporting window, 1999 to 2012, the transplant rate was 41.1 transplants per 100 dialysis patient years.

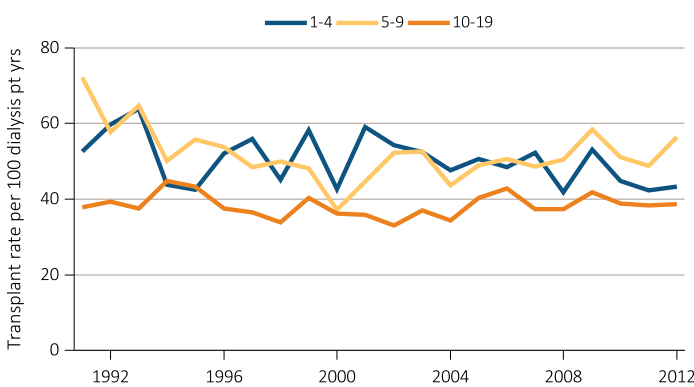
The total number of transplants plateaued in 2005. However, there has been a remarkable shift in donor characteristics coinciding with changes in the Organ Procurement and Transplantation Network organ allocation policy. Prior to 2005, most pediatric ESRD patients received living donor kidneys. After 2005, the majority of pediatric kidney transplants used deceased donor organs.

Over time, the pediatric kidney transplant waiting list has grown with patients awaiting their first transplant

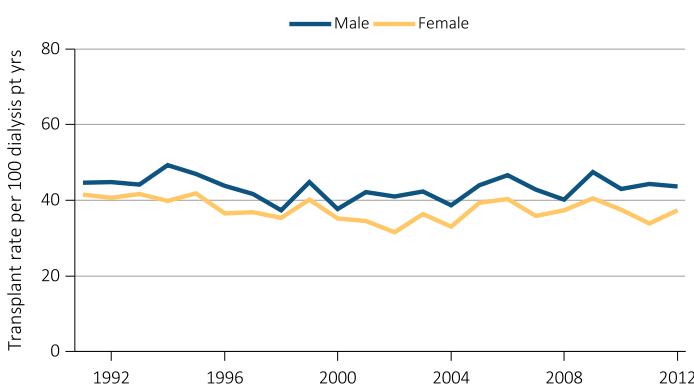
accounting for the majority of wait-listed patients. The number of patients with a previous transplant awaiting a kidney transplant remains stable. The median waiting time for patients who received their first transplant is shorter than those waiting for a repeat kidney transplant, reflecting the complex nature of repeat transplantation. Since 1997 there has been a decrease in the median waiting time for those listed for their first transplant with a flattening of the curve in 2005, which coincides with the change in the Organ Procurement and Transplantation Network organ allocation policy.

vol 2 Figure 7.3 Live and deceased donor transplants in pediatric patients (aged 0-19 years)

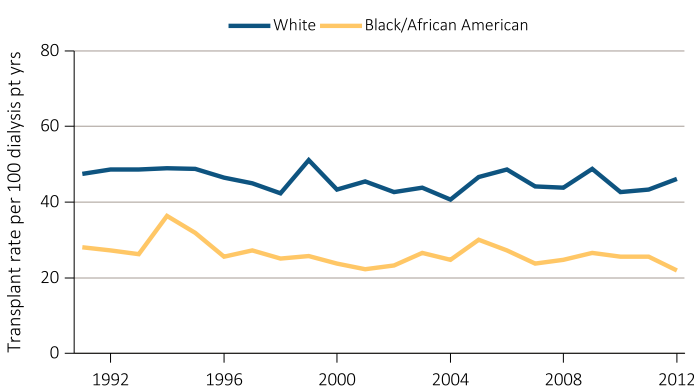
(a) Transplant rate in pediatric dialysis patients by age



(b) Transplant rate in pediatric dialysis patients by sex



(c) Transplant rate in pediatric dialysis patients by race



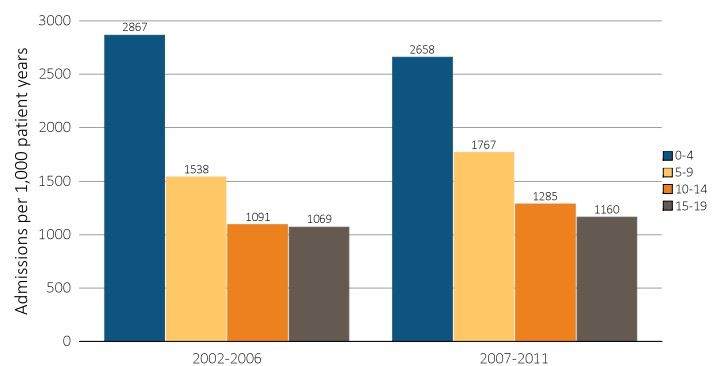
Data Source: Reference Table E9, and special analyses, USRDS ESRD Database. Includes transplant years between 1991–2012.

The transplant rate has been very stable in patients 10-19 years old, ranging from 33.1 to 44.9 per 100 dialysis patient years, and was 38.6 in 2012. Overall, transplant rates are very similar between the 1-4 year old and 5-9 year old cohorts. In 2012, there were 56.5 transplants per 100 dialysis patient years in 5-9 year olds and 43.3 transplants per 100 dialysis patient years in 1-4 year olds. Male dialysis patients have consistently been transplanted at a higher rate than female dialysis patients. The difference ranges from 2.1 transplants to 10.4 transplants per 100 dialysis patient years. There has been little change in the pediatric transplant rate in White and African American dialysis patients from 1991-2012. In 2012, the transplant rate was 46.2 per 100 White dialysis patient years and 22 per 100 African American dialysis patient years, for Whites and African-Americans respectively. The transplant rates are calculated using the number of pediatric dialysis patients. This analysis does not include up to 15 percent of the pediatric ESRD patients who receive pre-emptive transplants.

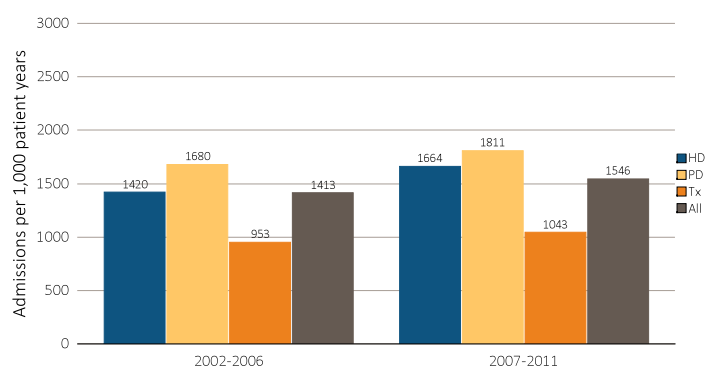
### Hospitalizations

vol 2 Figure 7.4 Hospitalization rates in pediatric patients (aged 0-19 years)

(a) One-year adjusted all-cause hospitalization rates in pediatric patients by age



(b) One-year adjusted all-cause hospitalization rates in pediatric patients by modality

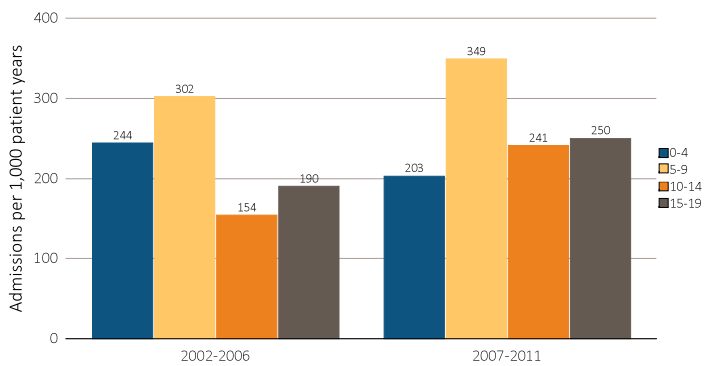


Data Source: Special analyses, USRDS ESRD Database. Includes incident ESRD patients in the years 2002-2011, surviving the first 90 days after ESRD initiation and followed from day 90. Adjusted for sex, race, primary diagnosis and Hispanic ethnicity. Ref: incident ESRD patients aged 0-19 years, 2010-2011. Abbreviations: HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

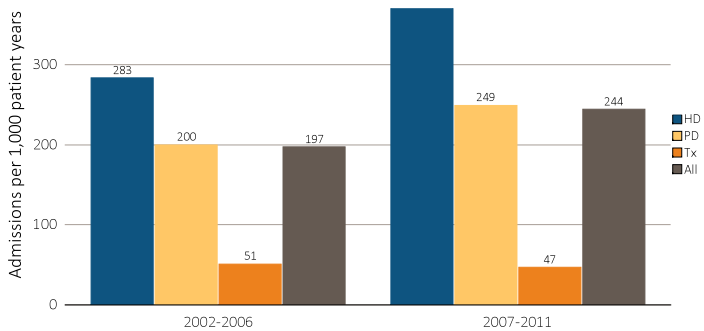
The one-year adjusted all-cause hospitalization rates from 2002–2006 to 2007–2011 in all children on renal replacement therapy rose 9.4 percent from 1,413 to 1,546 admissions per 1,000 patient years. In evaluating each modality the one-year adjusted all-cause hospitalization rates rose as follows: hemodialysis by 17.2 percent, peritoneal dialysis by 7.8 percent, and transplant by 9.4 percent between 2002–2006 and 2007–2011. In examining the rates of hospitalization by age, we find that the hospitalization rates were highest in those aged 0-4 years during both time periods. Despite significantly higher rates of hospitalization, children 0-4 years of age were the only age group that showed an improvement in hospitalization rates from 2002–2006 to 2007–2011.

**vol 2 Figure 7.5 Cardiovascular hospitalization rates in children (aged 0-19 years)**

**(a) One-year adjusted cardiovascular hospitalization rates in pediatric patients by age**



**(b) One-year adjusted cardiovascular hospitalization rates in pediatric patients by modality**



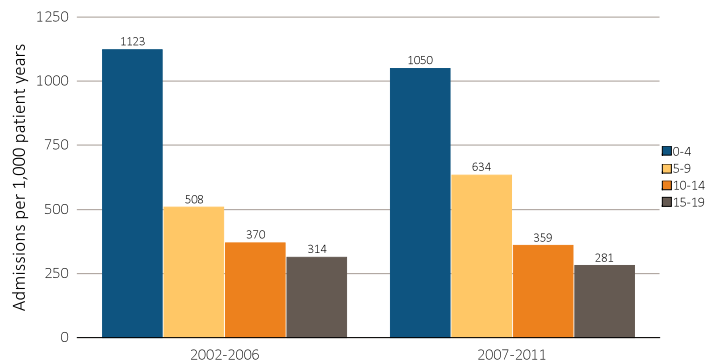
*Data Source: Special analyses, USRDS ESRD Database. Includes incident ESRD patients in the years 2002-2011, surviving the first 90 days after ESRD initiation and followed from day 90. Adjusted for sex, race, primary diagnosis and Hispanic ethnicity. Ref: incident ESRD patients aged 0-19 years, 2010-2011. Abbreviations: HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.*

The overall cardiovascular hospitalization rate per 1,000 patient years from 2007–2011 was 244, which is 23.9 percent higher than during 2002–2006. Rates rose by 15.6 percent in ages 5-9, 56.5 percent in ages 10-14, and 31.6 percent in ages 15-19 in the most recent

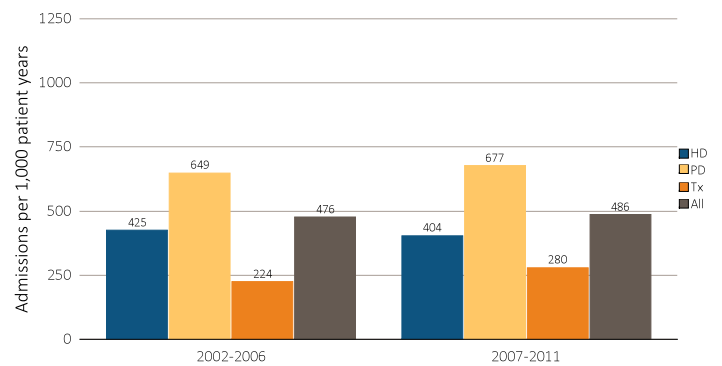
reporting window. Children less than 4 years of age showed a decrease of 16.8 percent in cardiovascular hospitalizations during the same time period. In evaluating modality, there was a 33.9 percent and 24.5 percent rise in cardiovascular hospitalization rates in hemodialysis and peritoneal dialysis patients, respectively. The rate of cardiovascular hospitalization in transplant patients fell by 7.8 percent, which was markedly less than dialysis-associated cardiovascular hospitalizations.

**vol 2 Figure 7.6 Infection hospitalization rates in children (aged 0-19 years)**

**(a) One-year adjusted hospitalization rates for infection in pediatric patients by age**



**(b) One-year adjusted hospitalization rates for infection in pediatric patients by modality**



*Data Source: Special analyses, USRDS ESRD Database. Includes incident ESRD patients in the years 2002-2011, surviving the first 90 days after ESRD initiation and followed from day 90. Adjusted for sex, race, primary diagnosis and Hispanic ethnicity. Ref: incident ESRD patients aged 0-19 years, 2010-2011. Abbreviations: HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.*

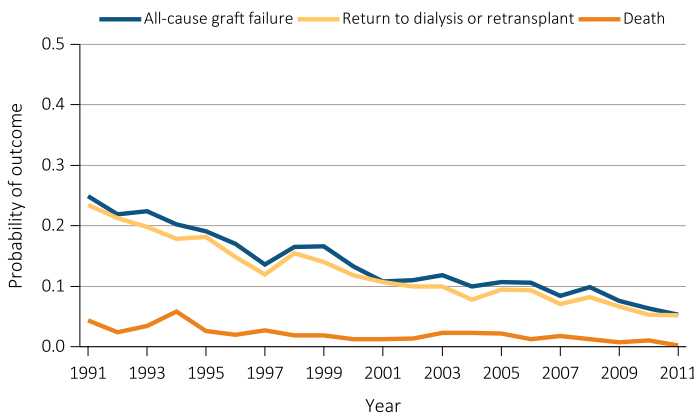
The overall rate of hospitalization for infection per 1,000 patient years was 486 during 2007–2011, which is 2.1 percent higher than during 2002–2006. The rates of infection-related hospitalizations fell by 6.5 percent in children 0-4 years of age, 3 percent in 10-14 years of age, and 10.5 percent in 15-19 years of age. Conversely, children between 5 to 9 years of age showed a rise in infection-related hospitalizations of 24.8 percent during the same time period. In examining modality, children on peritoneal dialysis had the highest rate of

infection-related hospitalization during 2002-2006 and 2007-2011. There was a decrease in infection-related hospitalization rates in hemodialysis patients from the 2002-2006 period to the 2007-2011 period by 4.9 percent. At the same time, there was an increase in infection-related hospitalization rates in patients on peritoneal dialysis and transplant patients by 4.3 percent and 25 percent respectively. While the rate of infection-related hospitalization rose the sharpest in transplant patients, the rates of infection-related hospitalizations in transplant patients were 69.3 percent of those on hemodialysis and 41.4 percent of those on peritoneal dialysis from 2007 to 2011.

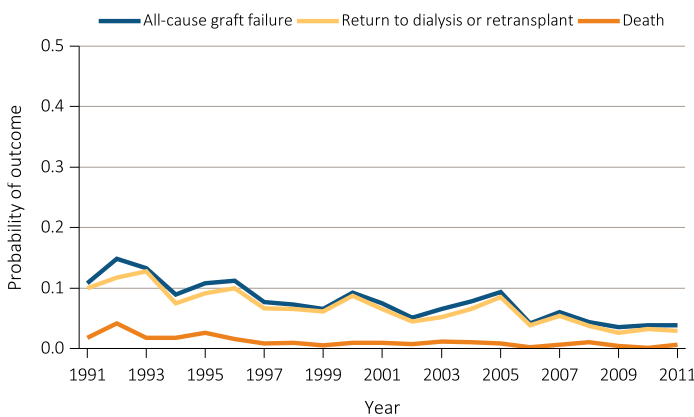
### Transplant Outcomes

vol 2 Figure 7.7 One-year transplant outcomes by donor type (aged 0-19 years)

(a) Outcomes: deceased donor transplants in pediatric patients, adjusted



(b) Outcomes: live donor transplants in pediatric patients, adjusted



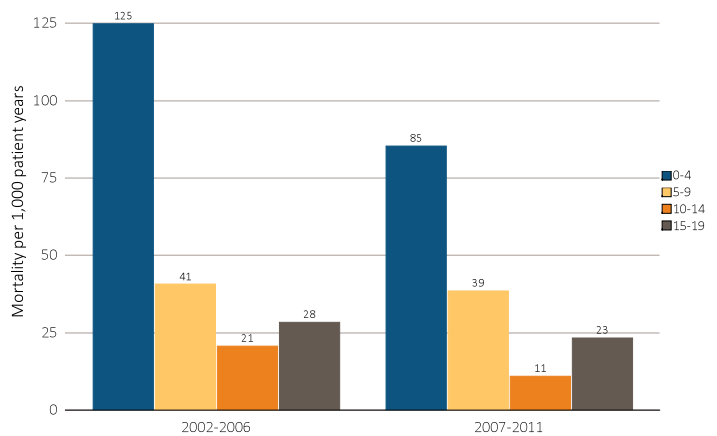
Data Source: 7.7a: Reference tables F2, F14, I26. 7.7b: Reference tables F8, F20, I32. Probabilities for all-cause graft failure and return to dialysis or retransplant are adjusted for age, sex, race, primary diagnosis, and first versus subsequent transplant. All-cause graft failure includes retransplant, return to dialysis, and death. The death outcome is not censored at graft failure, and includes deaths that occur after retransplant or return to dialysis. Probabilities of death are adjusted for age, sex, race, and primary diagnosis. The reference population for all-cause graft failure and return to dialysis or repeat transplantation is all pediatric patients receiving a kidney alone transplant in 2011. The reference population for death is incident pediatric ESRD patients in 2011.

The one-year deceased and living donor transplant outcomes for pediatric patients are presented in figures 7.7a and 7.7b, respectively. The first-year deceased and living donor transplant outcomes have steadily improved over the last 20 years. In the most recent reporting year, 2011, the probability of graft failure was 0.05 and of death was 0.01 for deceased donor transplants, while the one-year probability of graft failure was 0.04 and of death was 0.01 for living donor transplants. 2011 was the first year in which first-year mortality rates were the same for deceased and living donor pediatric transplant recipients.

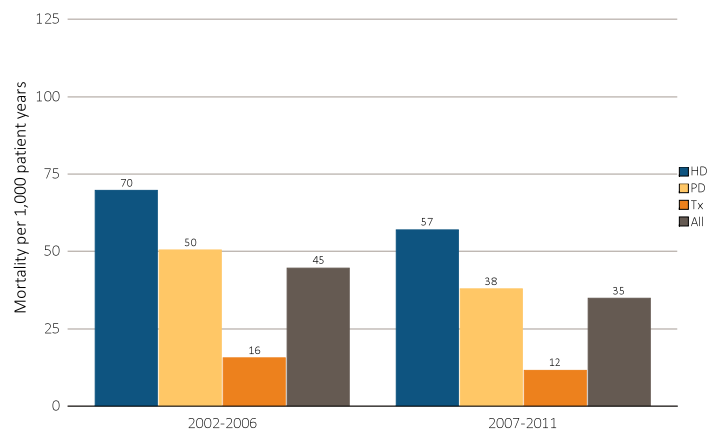
### Mortality

vol 2 Figure 7.8 Mortality rates in children with ESRD (aged 0-19 years)

(a) One-year adjusted all-cause mortality rates in pediatric patients by age



(b) One-year adjusted all-cause mortality rates in pediatric patients by modality



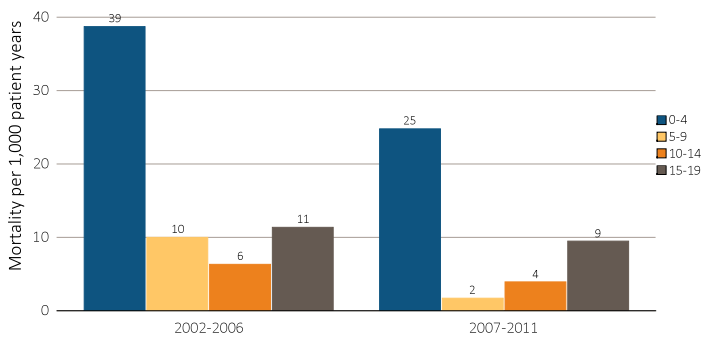
Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2012. Adjusted for age, sex, race, Hispanic ethnicity, and primary diagnosis. Ref: incident ESRD patients aged 0-19 years, 2010-2011. Abbreviations: HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

In 2007-2011, the one-year adjusted all-cause mortality was 35 per 1,000 patient years, which represents a

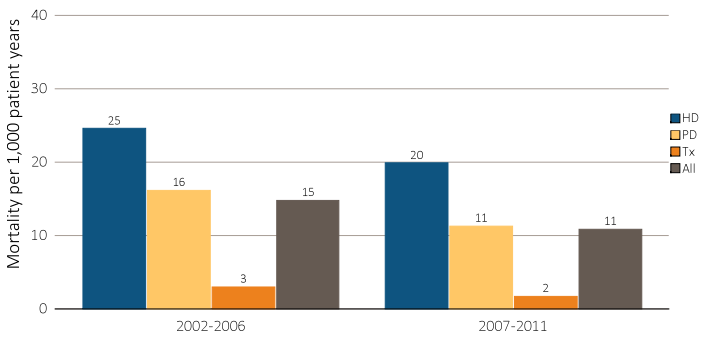
decrease of 22.2 percent from 2002-2006. The adjusted one-year all-cause mortality rates decreased in ages 0-4, 5-9, 10-14, and 15-19 by 32 percent, 4.9 percent, 47.6 percent, and 17.9 percent respectively. Adjusted one-year all-cause mortality rates by modality from 2002-2006 and 2007-2011 show decreases of 18.6 percent among hemodialysis patients, 24 percent among peritoneal dialysis patients, and 25 percent among transplant patients. Across all time windows, transplant-associated mortality is a small fraction compared with other modalities.

**vol 2 Figure 7.9 Cardiovascular mortality in children with ESRD (aged 0-19 years)**

**(a) One-year adjusted all-cause cardiovascular mortality rates in pediatric patients by age**



**(b) One-year adjusted all-cause cardiovascular mortality rates in pediatric patients by modality**



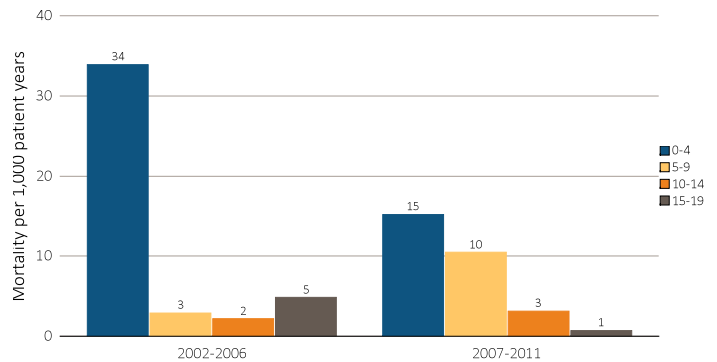
Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2012. Adjusted for age, sex, race, Hispanic ethnicity, and primary diagnosis. Ref: incident ESRD patients aged 0-19 years, 2010-2011. Abbreviations: HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

In 2007 to 2011, the one-year adjusted cardiovascular mortality was 11 per 1,000 patients years, which was a decrease of 26.7 percent from the 2002-2006 period. The adjusted one-year cardiovascular mortality decreased across all age groups: ages 0-4 years by 35.9 percent, ages 5-9 years by 80 percent, ages 10-14 years by 33.3 percent, and ages 15-19 by 18.2 percent. Those 0-4 years of age continued to have the highest adjusted one-year cardiovascular mortality. Examining adjusted one-year cardiovascular mortality across the periods 2002-2006

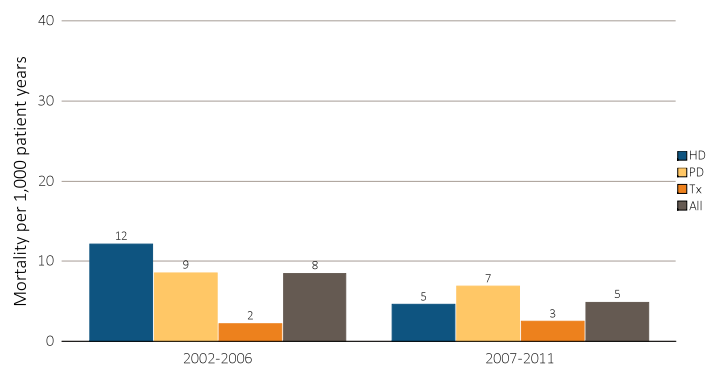
and 2007-2011 by modality, the rate decreased by 20 percent in hemodialysis, 31.3 percent in peritoneal dialysis, and 33.3 percent in transplant patients. During 2007 to 2011, one-year adjusted cardiovascular mortality rates in transplanted children were a fraction of the rates in dialysis-dependent children.

**vol 2 Figure 7.10 Infection-related mortality in children with ESRD (aged 0-19 years)**

**(a) One-year adjusted rates of mortality due to infection in pediatric patients by age**



**(b) One-year adjusted rates of mortality due to infection in pediatric patients by modality**



Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2012. Adjusted for age, sex, race, Hispanic ethnicity, and primary diagnosis. Ref: incident ESRD patients aged 0-19 years, 2010-2011. Abbreviations: HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

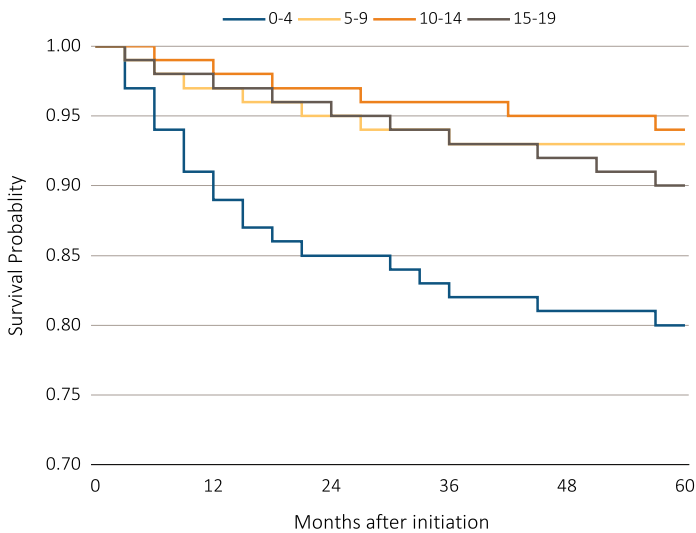
In 2007 to 2011, the one-year adjusted infection-related mortality rate decreased by 37.5 percent from that of the 2002 to 2006 period. The adjusted one-year infection-related mortality rate decreased in those 0-4 years of age by 55.9 percent. In the remaining age groups the overall rates remained low. Those 0-4 years of age continued to have the highest adjusted one-year infection-related mortality rate. Examining the adjusted one-year all infection-related mortality rates between the periods 2002-2006 and 2007-2011 by modality, the one-year infection-related mortality rate decreased by 58.3 percent in hemodialysis patients and 22.2 percent in peritoneal dialysis patients. During



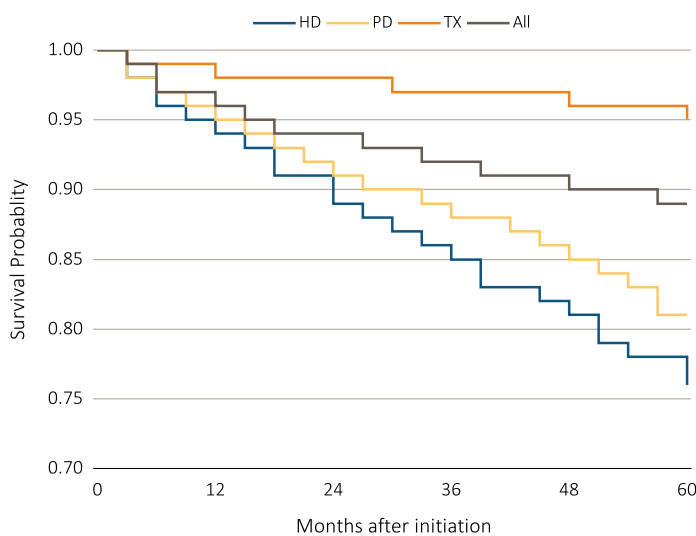
2007-2011, transplant patients had one-year adjusted infection-related mortality rates that were 60 percent of the hemodialysis patient mortality rates and 42.9 percent of peritoneal dialysis patient mortality rates.

**vol 2 Figure 7.11 Pediatric ESRD patient survival by age and modality (aged 0-19 years)**

**(a) Adjusted 5 year survival in pediatric patients from day 1 by age, 2003-2007**



**(b) Adjusted 5 year survival in pediatric patients from day 1 by modality, 2003-2007**



*Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2012. Adjusted for age, sex, race, Hispanic ethnicity, and primary diagnosis. Ref: incident ESRD patients aged 0-19 years, 2010-2011. Abbreviations: HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.*

For patients beginning ESRD therapy in 2003 to 2007, the probability of five year survival was 0.89. The probability of surviving five years by age was 0.8 for ages 0-4, 0.93 for ages 5-9, 0.94 for ages 10-14, and 0.9 for ages 15-19. Transplant patients had the

highest probability of surviving five years with 0.95, as compared to 0.76 in hemodialysis patients, and 0.81 in peritoneal dialysis patients.

## Summary

This pediatric chapter of the Annual Data Report includes over 20 years of ESRD care in children. In the most recent reporting year, there was a 5.8 percent decrease in the incidence and a 1.3 percent decrease in the prevalence of ESRD. Kidney transplantation remains the most common modality for treatment of prevalent ESRD. Pediatric kidney transplant recipients continue to have the best outcomes regarding hospitalization rates and mortality compared with other modalities. There are many opportunities to improve our understanding of the pediatric ESRD experience in future USRDS Annual Data Reports, special analyses and special studies including broad topics surrounding vascular access, acute kidney injury, and pre-ESRD chronic kidney disease.



# Chapter 8: Dialysis Providers

## Introduction

The 2013 ADR chapter on ESRD providers focused on potential associations between the bundled Prospective Payment System (PPS) and provider practices specifically related to anemia management, including decreased erythropoiesis stimulating agent (ESA) use, a fall in hemoglobin levels, and a slight increase in blood transfusion rates. Because more recent Medicare Part D data were not available in time to reassess ESA use for this year's ADR, we have chosen to highlight three other important areas of practice related to provision of care to patients on dialysis. These include (i) choice of dialysis modality by provider (2010–2012), (ii) patterns of vascular access type by provider for both incident and prevalent dialysis patients (2012), and (iii) the proportion of patients younger than age 70 who are wait-listed for kidney transplantation (2010–2012).

Overall, we note an increase in the utilization of peritoneal dialysis (PD). More than three-quarters of all new patients are beginning hemodialysis (HD) using an indwelling catheter as their vascular access, suggesting suboptimal preparation for ESRD, although not necessarily under the direct influence of dialysis providers. Over the period 2010–2012 and across providers, there was no observable change in the proportion of patients wait-listed for kidney transplantation, with only approximately one-quarter of those under the age of 70 years being wait-listed.

We conclude the chapter with an analysis of standardized mortality and hospitalization ratios by provider type, namely, large dialysis organizations (LDOs), small dialysis organizations (SDOs), and independent and hospital-based providers. Standardized mortality ratios (SMRs) and standardized hospitalization ratios (SHRs) in 2012 were similar between large and small dialysis

organizations and, for the most part, declined slightly from 2010 to 2012. Somewhat surprisingly, at hospital-based units the SMR was 11.4 percent lower than the national average, while the SHR was higher than the national average.

## Analytical Methods

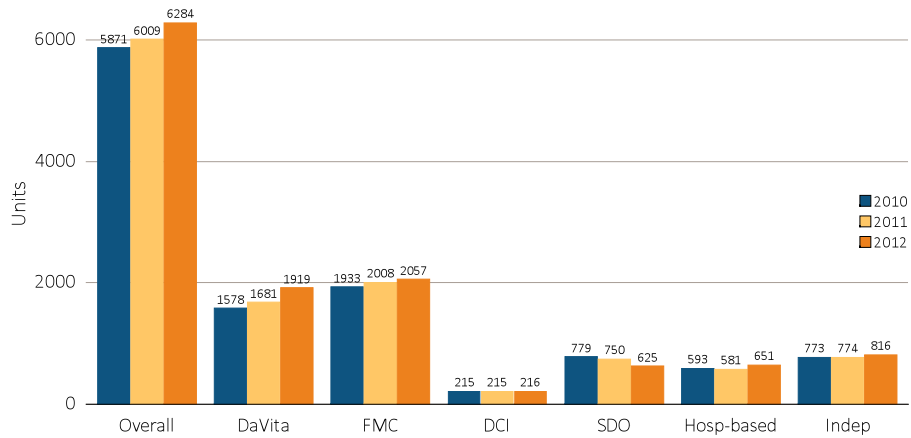
See the ESRD Analytical Methods chapter for an explanation of methods used to generate the figures and tables in this chapter.

## Provider Growth

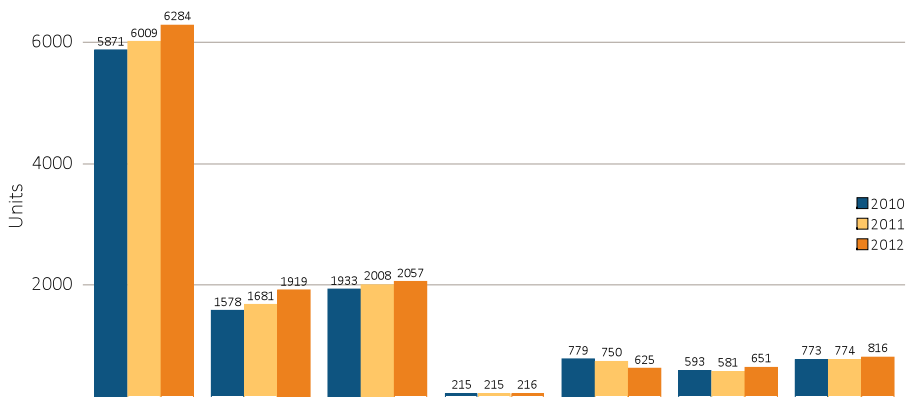
At the end of 2012, there were 6,284 dialysis units in the United States (Figure 8.1). Together, the three LDOs (DaVita, Fresenius [FMC], and Dialysis Clinic, Inc. [DCI]) treated 303,529 patients (71 percent) in 4,192 dialysis units (68 percent). SDOs treated 47,653 patients (10 percent) in 625 units (10 percent), whereas independent and hospital-based providers treated 56,319 (13 percent) and 19,959 (5 percent) patients, respectively, in 816 (13 percent) and 651 (10 percent) units. Nationwide, 413 dialysis units were added during the three-year period from 2010 to 2012, with most belonging to the LDOs. In the SDOs, the numbers of patients and units continued to decline over the same period.

vol 2 Figure 8.1 Dialysis units & patient counts, by unit affiliation, 2010–2012.

(a) Dialysis units



(b) Patient counts

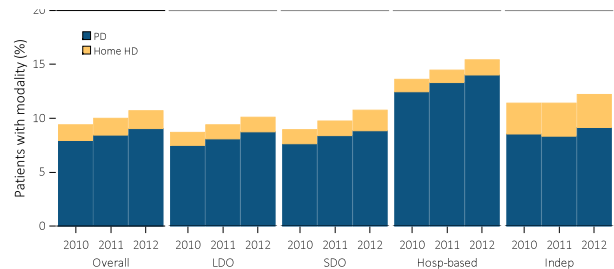


Data source: Special analyses, USRDS ESRD Database. Abbreviations: DCI, Dialysis Clinic, Inc.; FMC, Fresenius; Hosp-based, hospital-based dialysis centers; Indep, independent dialysis providers; SDO, small dialysis organizations.

## Key Practices: Dialysis Modality Choice, Vascular Access and Wait-listing for Kidney Transplantation

In 2012, nearly 90 percent of all dialysis patients received hemodialysis (Figure 8.2). This proportion was relatively consistent across provider types, with hospital-based providers having the lowest proportion of patients on HD at 84.6 percent, and the highest proportion of PD patients at 14 percent. Across all provider types, the modality type was relatively constant from 2010–2012. However, the nationwide prevalence of PD increased slightly, from 7.9 percent in 2010 to 9.0 percent in 2012. This indicates an encouraging, recent trend reversal (see Vol. 2, Chapter 1, *Incidence, Prevalence, Patient Characteristics, and Modalities*).

vol 2 Figure 8.2 Prevalence of home dialysis modality, by unit affiliation, 2010–2012



Data source: Special analyses, USRDS ESRD Database. Abbreviations: HD, hemodialysis; Hosp-based, hospital-based dialysis centers; Indep, independent dialysis providers; LDO, large dialysis organizations; PD, peritoneal dialysis; SDO, small dialysis organizations.

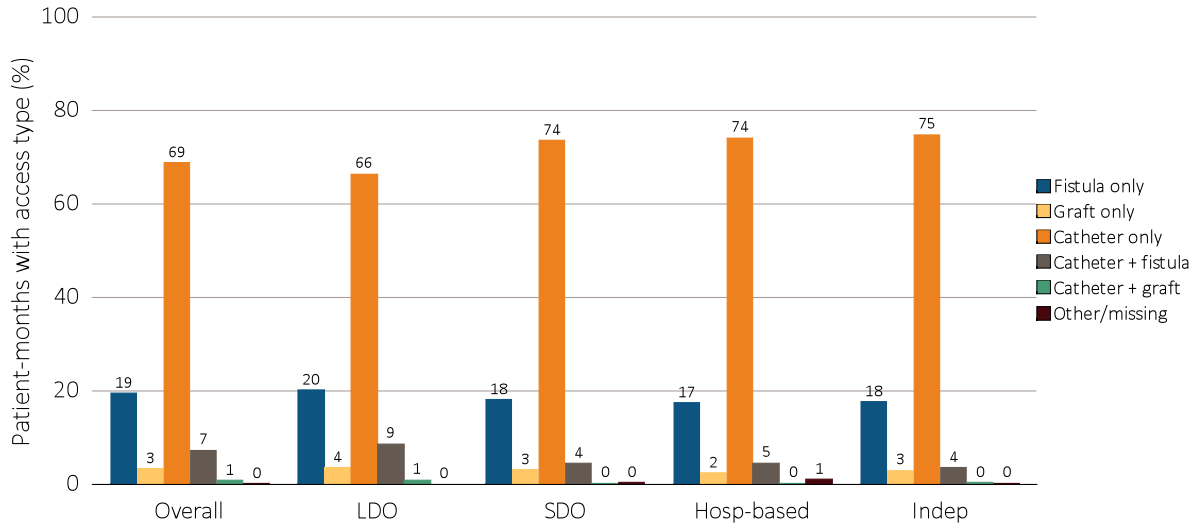
Nationally in 2012, 62 percent of HD patients received their treatment via an arteriovenous fistula and 19 percent via an indwelling catheter (Figure 8.3). Fistula use was highest among LDOs and independent providers at 62 percent; catheter use was highest at 28 percent in hospital-based providers. Among dialysis patients in their first 30 days of ESRD, most (77 percent) received dialysis via a catheter; LDOs had

the highest rate of fistula placement at 29 percent, compared with 27 percent overall nationally.

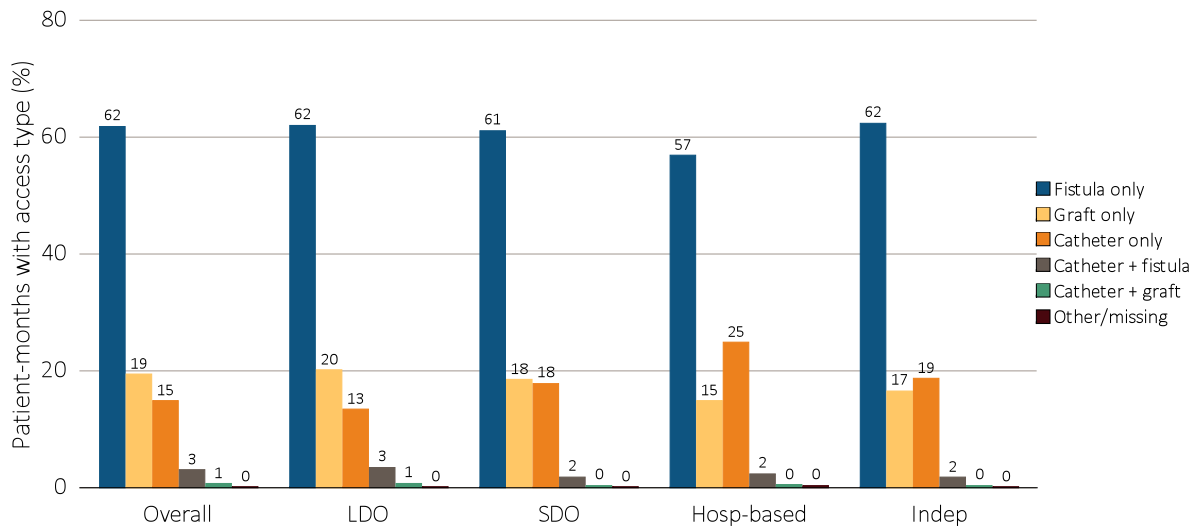
Kidney transplantation is the modality of choice for most individuals with ESRD and is associated with the highest quality of life and survival for this patient population. Nationally, the percentage of patients on a kidney transplant waiting list was fairly consistent

vol 2 Figure 8.3 Prevalence of vascular access type, by unit affiliation, 2012

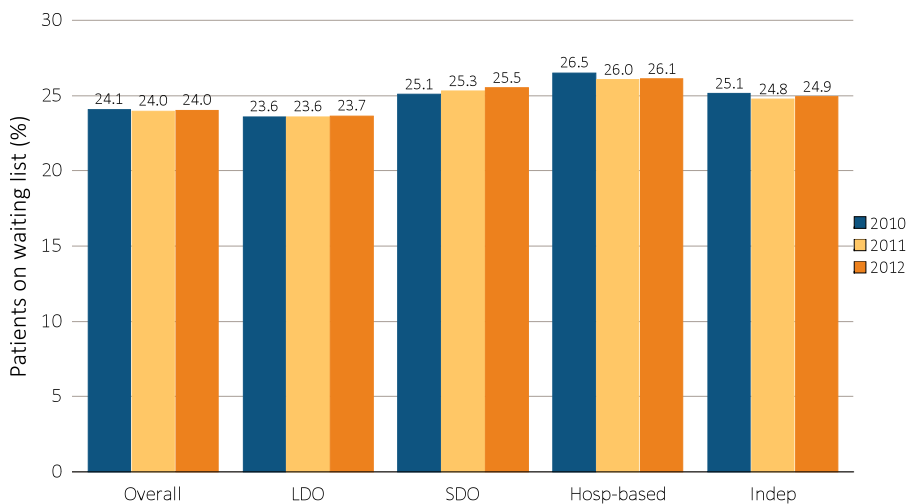
(a) Among incident dialysis patients



(b) Among prevalent dialysis patients



Data source: Special analyses, USRDS ESRD Database. Period prevalent hemodialysis patients. Abbreviations: Hosp-based, hospital-based dialysis centers; Indep, independent dialysis providers; LDO, large dialysis organizations; SDO, small dialysis organizations.

**vol 2 Figure 8.4 Percentage of patients younger than 70 on a kidney transplant waiting list, by unit affiliation, 2010–2012**

Data source: Special analyses, USRDS ESRD Database. Dialysis patients younger than 70 on December 31. Abbreviations: Hosp-based, hospital-based dialysis centers; Indep, independent dialysis providers; LDO, large dialysis organizations; SDO, small dialysis organizations.

between 2010 and 2012, with fewer than 25 percent of patients younger than 70 on a waiting list (Figure 8.4). This measure is limited to patients younger than 70 to be consistent with Vol. 2, Chapter 2, *Healthy People 2020* goals. SDOs and hospital-based providers had the highest rates of wait-listed patients in 2012, at 25.7 percent and 26.0 percent, respectively.

## Standardized Mortality & Hospitalization Ratios

All provider types experienced significant declines in SMRs (Table 8.1) between 2010 and 2012. Among the LDOs, DCI experienced a nonsignificant increase in SMR, from 0.94 in 2010 to 0.95 in 2012. In 2012, independent providers had the highest SMRs at 1.01.

Among the LDOs in 2012, DCI had the lowest SMR at 0.95, compared with 0.97 and 0.98, respectively, for DaVita and Fresenius (Table 8.1). Between 2010 and 2012, DaVita and Fresenius experienced significant declines in SMRs.

Between 2010 and 2012, White patients experienced decreases in SMR of similar magnitude as those in the overall population (Table 8.1). For these patients, SMR increased only among DCI facilities (nonsignificantly), by 1.6 percent, having fallen 3.9 percent overall.

Compared with the overall dialysis population, the decrease in SMR between 2010 and 2012 was of greater magnitude in the Black/African American population (Table 8.1). Among Black/African American patients, overall SMR decreased significantly by 7.6 percent, compared with a 5.0 percent overall decrease during the same time period. SMRs for Black/African American patients decreased among all provider types, significantly in DaVita, Fresenius, hospital-based and independent providers.

Compared with the overall dialysis population, the decrease in SMR between 2010 and 2012 was of greater magnitude in the Hispanic population (Table 8.1). Among Hispanic patients, overall SMR decreased significantly by 6.0 percent, compared with a 5.0 percent overall decrease during the same time period. SMR for Hispanic patients increased by 5.8 percent in units owned by DCI, but this change was not significant. Patients treated by all other provider types experienced decreases in SMR.

All types of providers experienced significant declines in SHRs (Table 8.2) between 2010 and 2012, with the exception of hospital-based providers, for which SHR increased significantly, by 1.7 percent. In 2012, hospital-based providers had the highest SHRs at 1.09.

Among the LDOs in 2012, DCI had the lowest SHR, at 0.91, compared with 1.02 and 1.01, respectively, for DaVita and Fresenius (Table 8.2). Between 2010 and 2012, all three LDOs experienced significant declines in SHRs.

Between 2010 and 2012, White patients experienced decreases in SHR of similar magnitude as those in the overall population (Table 8.2). For these patients, SHR increased only among hospital-based providers, from 1.04 to 1.06, which is a significant net change of 2.1 percent compared with the overall decrease among White patients of 2.5 percent.

vol 2 Table 8.1 All-cause standardized mortality ratio, by unit affiliation, 2010–2012

Affiliation	2010	2011	2012
<b>All patients</b>			
<b>Overall</b>	1.02 (1.02-1.03)	1.00 (1.00-1.01)	0.97 (0.97-0.98)
<b>LDO</b>			
Davita	1.05 (1.03-1.06)	1.02 (1.01-1.03)	0.97 (0.96-0.98)
Fresenius	1.03 (1.02-1.05)	1.02 (1.01-1.03)	0.98 (0.97-0.99)
DCI	0.94 (0.91-0.98)	0.92 (0.89-0.96)	0.95 (0.91-0.98)
<b>SDO</b>	1.02 (1.00-1.04)	1.03 (1.01-1.04)	1.00 (0.98-1.01)
<b>Hospital-based</b>	0.93 (0.91-0.95)	0.85 (0.83-0.87)	0.86 (0.84-0.88)
<b>Independent</b>	1.04 (1.02-1.05)	1.01 (1.00-1.03)	1.01 (0.99-1.02)
<b>White patients</b>			
<b>Overall</b>	1.14 (1.13-1.15)	1.13 (1.12-1.14)	1.10 (1.09-1.11)
<b>LDO</b>			
Davita	1.17 (1.15-1.19)	1.15 (1.14-1.17)	1.10 (1.08-1.11)
Fresenius	1.15 (1.14-1.17)	1.15 (1.14-1.17)	1.11 (1.10-1.13)
DCI	1.10 (1.05-1.15)	1.09 (1.04-1.14)	1.12 (1.07-1.17)
<b>SDO</b>	1.14 (1.11-1.16)	1.13 (1.11-1.16)	1.10 (1.07-1.12)
<b>Hospital-based</b>	1.05 (1.02-1.08)	0.96 (0.94-0.99)	0.96 (0.94-0.99)
<b>Independent</b>	1.14 (1.12-1.17)	1.12 (1.10-1.14)	1.13 (1.11-1.16)
<b>Black/African American patients</b>			
<b>Overall</b>	0.88 (0.87-0.89)	0.84 (0.83-0.85)	0.81 (0.80-0.82)
<b>LDO</b>			
Davita	0.89 (0.88-0.91)	0.84 (0.82-0.86)	0.80 (0.78-0.82)
Fresenius	0.87 (0.86-0.89)	0.84 (0.83-0.86)	0.81 (0.79-0.82)
DCI	0.79 (0.74-0.84)	0.75 (0.70-0.80)	0.75 (0.70-0.80)
<b>SDO</b>	0.87 (0.84-0.90)	0.88 (0.85-0.91)	0.85 (0.82-0.88)
<b>Hospital-based</b>	0.89 (0.85-0.92)	0.79 (0.75-0.82)	0.85 (0.81-0.89)
<b>Independent</b>	0.90 (0.87-0.93)	0.88 (0.85-0.91)	0.84 (0.81-0.87)
<b>Hispanic patients</b>			
<b>Overall</b>	0.80 (0.79-0.82)	0.80 (0.78-0.81)	0.75 (0.74-0.77)
<b>LDO</b>			
Davita	0.75 (0.73-0.78)	0.76 (0.74-0.79)	0.73 (0.71-0.75)
Fresenius	0.85 (0.82-0.87)	0.83 (0.81-0.86)	0.77 (0.75-0.80)
DCI	0.77 (0.65-0.91)	0.67 (0.56-0.79)	0.81 (0.69-0.95)
<b>SDO</b>	0.84 (0.80-0.87)	0.84 (0.81-0.88)	0.81 (0.77-0.85)
<b>Hospital-based</b>	0.67 (0.63-0.72)	0.64 (0.59-0.69)	0.61 (0.57-0.66)
<b>Independent</b>	0.83 (0.79-0.87)	0.81 (0.77-0.85)	0.78 (0.74-0.81)

Data source: Special analyses, USRDS ESRD Database. Period prevalent dialysis patients; 95% confidence intervals are shown in parentheses. The overall measure is adjusted for patient age, race, ethnicity, sex, diabetes, duration of ESRD, nursing home status, patient comorbidities at incidence, body mass index (BMI) at incidence and population death rates. The white- and black-specific measures are adjusted for all the above characteristics except patient race. The Hispanic-specific measure is adjusted for all the above characteristics except patient ethnicity. Abbreviations: DCI, Dialysis Clinic, Inc.; LDO, large dialysis organizations; SDO, small dialysis organizations.

vol 2 Table 8.2 All-cause standardized hospitalization ratio, by unit affiliation, 2010–2012

Affiliation	2010	2011	2012
<b>All patients</b>			
<b>Overall</b>	1.01 (1.01-1.02)	1.00 (1.00-1.01)	0.98 (0.98-0.98)
<b>LDO</b>			
Davita	1.02 (1.02-1.03)	1.01 (1.00-1.01)	0.98 (0.98-0.98)
Fresenius	1.01 (1.01-1.02)	1.00 (1.00-1.00)	0.97 (0.97-0.97)
DCI	0.91 (0.90-0.92)	0.91 (0.90-0.92)	0.89 (0.88-0.91)
<b>SDO</b>	1.02 (1.01-1.02)	1.02 (1.02-1.03)	0.98 (0.98-0.99)
<b>Hospital-based</b>	1.07 (1.06-1.08)	1.05 (1.04-1.06)	1.09 (1.08-1.10)
<b>Independent</b>	1.00 (0.99-1.00)	0.99 (0.99-1.00)	0.98 (0.97-0.98)
<b>White patients</b>			
<b>Overall</b>	1.03 (1.03-1.03)	1.02 (1.02-1.03)	1.00 (1.00-1.01)
<b>LDO</b>			
Davita	1.04 (1.03-1.04)	1.03 (1.02-1.04)	1.01 (1.00-1.01)
Fresenius	1.05 (1.04-1.05)	1.04 (1.03-1.04)	1.01 (1.00-1.01)
DCI	0.97 (0.95-0.99)	0.97 (0.95-0.99)	0.96 (0.95-0.98)
<b>SDO</b>	1.01 (1.00-1.02)	1.01 (1.00-1.02)	0.98 (0.97-0.99)
<b>Hospital-based</b>	1.04 (1.03-1.05)	1.02 (1.01-1.03)	1.06 (1.05-1.08)
<b>Independent</b>	1.00 (0.99-1.01)	1.00 (0.99-1.00)	0.99 (0.98-1.00)
<b>Black/African American patients</b>			
<b>Overall</b>	1.03 (1.02-1.03)	1.01 (1.01-1.01)	0.98 (0.97-0.98)
<b>LDO</b>			
Davita	1.04 (1.03-1.04)	1.01 (1.00-1.01)	0.98 (0.97-0.98)
Fresenius	0.99 (0.99-1.00)	0.98 (0.97-0.98)	0.94 (0.94-0.95)
DCI	0.87 (0.85-0.89)	0.86 (0.84-0.88)	0.85 (0.83-0.87)
<b>SDO</b>	1.09 (1.08-1.10)	1.09 (1.08-1.11)	1.03 (1.02-1.04)
<b>Hospital-based</b>	1.18 (1.16-1.19)	1.18 (1.16-1.19)	1.20 (1.18-1.22)
<b>Independent</b>	1.02 (1.01-1.04)	1.03 (1.01-1.04)	1.00 (0.99-1.01)
<b>Hispanic patients</b>			
<b>Overall</b>	0.95 (0.94-0.96)	0.91 (0.91-0.92)	0.91 (0.90-0.91)
<b>LDO</b>			
Davita	0.92 (0.91-0.93)	0.90 (0.89-0.91)	0.89 (0.88-0.90)
Fresenius	0.97 (0.96-0.98)	0.91 (0.90-0.92)	0.91 (0.90-0.92)
DCI	0.87 (0.82-0.91)	0.85 (0.80-0.89)	0.84 (0.80-0.89)
<b>SDO</b>	0.93 (0.91-0.94)	0.89 (0.88-0.91)	0.87 (0.86-0.88)
<b>Hospital-based</b>	1.06 (1.03-1.09)	1.05 (1.03-1.08)	1.11 (1.08-1.14)
<b>Independent</b>	0.97 (0.96-0.99)	0.93 (0.92-0.95)	0.94 (0.93-0.96)

Data source: Special analyses, USRDS ESRD Database. Period prevalent dialysis patients with Medicare as primary payer; 95% confidence intervals are shown in parentheses. Adjusted for patient age, race, ethnicity, sex, diabetes, duration of ESRD, nursing home status, patient comorbidities at incidence and body mass index (BMI) at incidence. The White- and Black-specific measures are adjusted for all the above characteristics except patient race. The Hispanic-specific measure is adjusted for all the above characteristics except patient ethnicity. Abbreviations: DCI, Dialysis Clinic, Inc.; LDO, large dialysis organizations; SDO, small dialysis organizations.



Compared with the overall dialysis population, the decrease in SHR between 2010 and 2012 was of greater magnitude in the Black/African American population (Table 8.2). Among Black/African American patients, overall SHR decreased significantly by 4.8 percent, whereas all dialysis patients experienced a 3.5 percent decrease. SHRs for Black/African American patients increased significantly by 2.2 percent in hospital-based units. In 2012, SHR was greater than one for Black/African American patients in SDO and hospital-based units, and less than one in DaVita, Fresenius, and DCI facilities.

Compared with the overall dialysis population, the decrease in SHR between 2010 and 2012 was also of greater magnitude in the Hispanic population (Table 8.2). Among Hispanic patients, overall SHR decreased significantly by 4.4 percent, whereas all dialysis patients experienced a 3.5 percent decrease. SHR for Hispanic patients increased significantly in hospital-based units, by 4.7 percent. Patients treated by all other provider types experienced decreases in SHR. In 2012, SHR was greater than one for Hispanic patients only in hospital-based providers, and less than one in all other provider groups.



# Chapter 9: Costs of ESRD

## Introduction

Since the Medicare end-stage renal disease (ESRD) entitlement was enacted by Congress in 1972, the size of the program, both in terms of number of patients served and total spending, has grown substantially. Even though the ESRD population remains less than one percent of the total Medicare population, it has accounted for about six percent of Medicare spending in recent years.

This chapter presents both recent patterns and longer-term trends in total Medicare spending, and spending by type of service. Medicare Part D prescription drug data were not available to the new USRDS Coordinating Center in time for inclusion in this Annual Data Report (ADR). In lieu, the current chapter focuses on Medicare spending for items other than outpatient prescription drugs. Please refer to the 2013 ADR for information on Part D, Medicare Health Maintenance Organizations (HMO; managed care), and private insurer spending through 2011 (USRDS, 2013). Analyses of these topics will be included in the 2015 ADR.

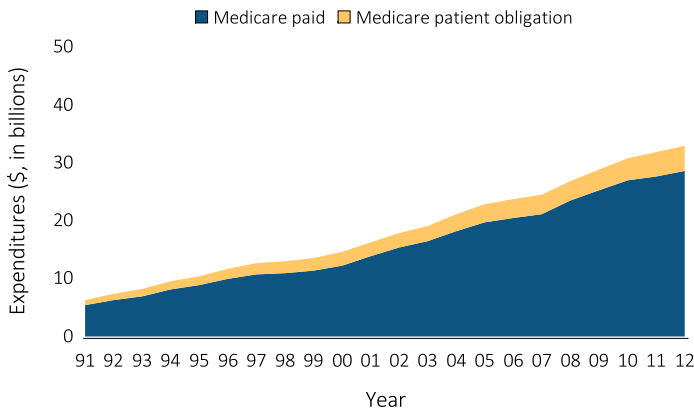
This report features data from 2012, the second full year under the expanded, bundled Prospective Payment System (PPS). Early research on the effects of the PPS showed substantial declines in the utilization of injectable medications and an increase in the use of peritoneal dialysis (Hirth et al., 2013; Civic Impulse, 2013). Savings from these changes, however, are not reflected in Medicare payments. Because the fixed, bundled payment rate was based on the higher utilization rates from 2007, any savings arising from lower utilization accrue to dialysis facilities. In response to these savings, Congress mandated in the American Taxpayer Relief Act of 2012 that CMS “re-base” the bundled payment rate to reflect these reductions in utilization. This action would have had the effect of transferring the savings to Medicare (and, hence, to taxpayers). To meet this mandate,

CMS proposed a 12 percent reduction in the per-dialysis session base rate. After accounting for an inflation adjustment of approximately three percent, net payments in 2014 would have fallen by about nine percent per treatment. Before the reduction could be implemented, however, it was rolled back by subsequent legislation in the Medicare Access to Rehabilitation Services Act of 2013 (Civic Impulse, 2013). That legislation also delayed the inclusion of more oral medications (primarily phosphate binders) into the bundle from the planned 2016 to no sooner than 2024. As a result, the bundled payment rate for 2014 was unchanged from 2013.

## Overall & per Person per Year Costs of ESRD

Total spending per year for Medicare paid claims, Medicare patient obligations, and non-Medicare expenditures for period prevalent patients from 1991-2012 is reported in Figure 9.1 (note that Medicare Part D spending is not included, see Reference Table K.2). Medicare spending and patient obligations represent about three quarters of all spending for the care of U.S. ESRD patients (USRDS, 2013). The non-Medicare share results from beneficiary cost-sharing for services, pre-Medicare coverage periods, legislated provisions for Medicare as Secondary Payer, and post-Medicare entitlement periods for transplant recipients. Medicare spending and patient obligations rose 3.5 percent and 2.8 percent, respectively, in 2012 as compared to 2011, marking the second year of modest growth relative to historical trends following the implementation of the bundled payment system.

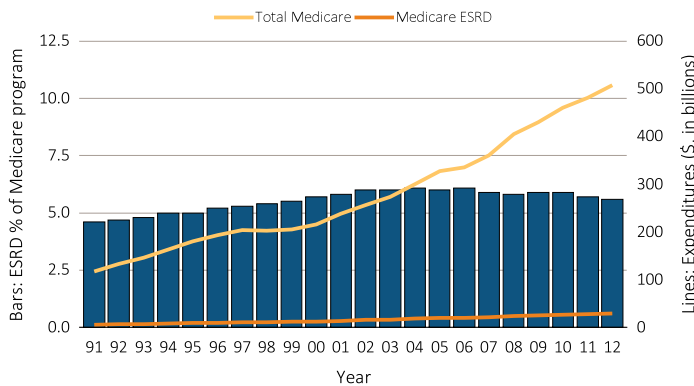
**vol 2 Figure 9.1 Medicare ESRD expenditures, Medicare and patient obligation**



Data Source: USRDS ESRD Database; Reference Table K.2. Abbreviations: ESRD, end-stage renal disease.

As illustrated in Figure 9.2, total Medicare spending (excluding Part D) rose 5.2 percent in 2012, to \$507 billion; spending for ESRD patients increased 3.2 percent, to \$28.6 billion, accounting for 5.6 percent of the Medicare budget costs (inflated by two percent), including estimated costs for HMO & organ acquisition. This continues the downward trend in the fraction of Medicare spending attributable to ESRD patients since that share peaked at 6.1 percent in 2006.

**vol 2 Figure 9.2 Costs of the Medicare & ESRD programs (excluding Part D)**

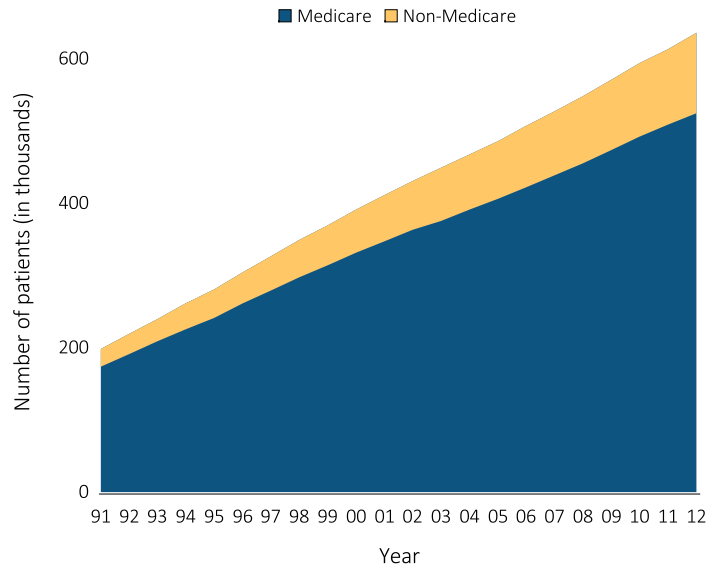


Data Source: USRDS ESRD Database. Total Medicare expenditures obtained from <http://CMS.gov>. Abbreviations: ESRD, end-stage renal disease.

The estimated number of point prevalent Medicare ESRD patients grew by 3.2 percent to 525,481 in 2012, while the non-Medicare ESRD population rose 6.0 percent, to 111,418 (see Figure 9.3). Data from the Medicare Enrollment Database (EDB), as well as dialysis claims information, are used to categorize payer status as Medicare primary payer (MPP), Medicare secondary payer (MSP), or non-Medicare.

Non-Medicare patients in the EDB include those who are pre- or post- Medicare entitlement. Medicare HMO patients are not included in either Medicare or Non-Medicare groups.

**vol 2 Figure 9.3 Estimated numbers of point prevalent ESRD patients**

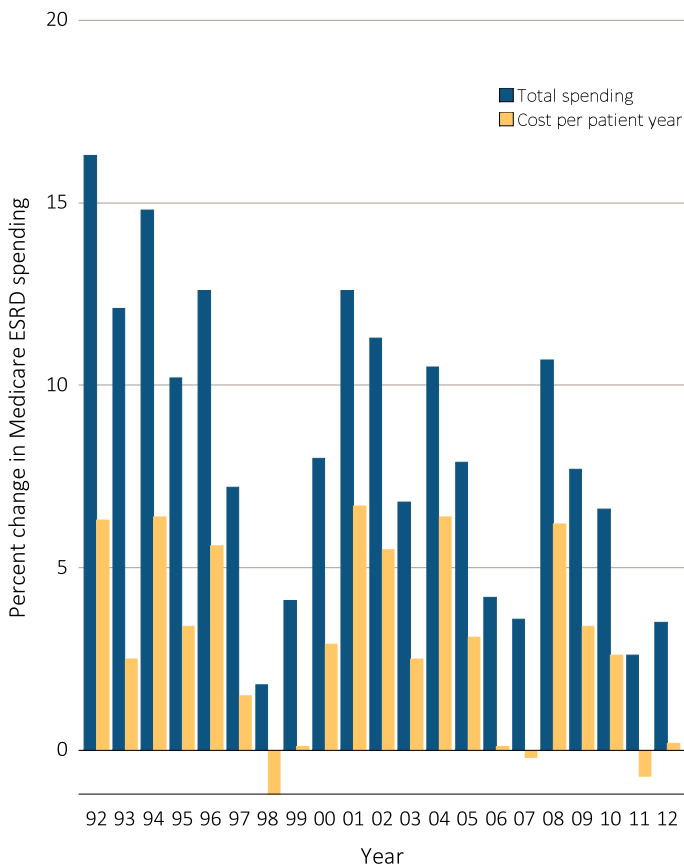


Data Source: USRDS ESRD Database. December 31 point prevalent ESRD patients. Abbreviations: ESRD, end-stage renal disease.

Annual percent change in Medicare ESRD spending for all ESRD patients for whom Medicare is either the primary or secondary payer is reported in Figure 9.4. Because Part D spending is excluded from these measures, total Medicare spending is not captured for years 2006-2012. However, the exclusion of Part D implies that the spending changes reported in Figure 9.4 reflect spending for a consistent set of services.

Total Medicare paid claims in 2012 were 3.5 percent higher than in 2011 (\$28.6 billion versus \$27.7 billion). An increased number of covered patients accounted for almost all of the cost growth, as spending per patient, per year (PPPY) was nearly flat (0.2 percent growth) for the second consecutive year.

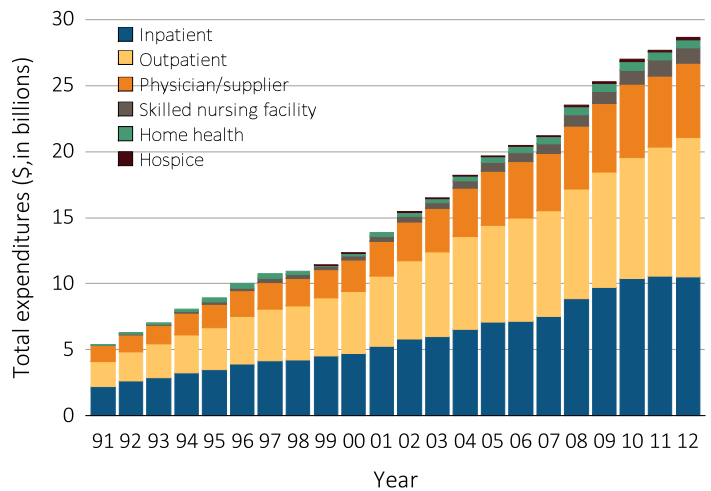
vol 2 Figure 9.4 Annual percent change in Medicare ESRD spending



Data Source: USRDS ESRD Database. Total Medicare ESRD costs from claims data; includes all Medicare as primary payer claims as well as amounts paid by Medicare as secondary payer. Abbreviations: ESRD, end-stage renal disease.

Total Medicare spending for ESRD patients by type of service is reported in Figure 9.5. Compared to 2011, outpatient services, physician/supplier services, and hospice care saw an increase in their shares of non-Part D Medicare spending, while inpatient and skilled nursing care saw decreases in their shares. Notably, inpatient spending has been essentially flat since 2010, consistent with the declines in hospitalization rates and hospital days reported in Chapter 4 of Volume 2, *Hospitalization*. Although hospice spending remains by far the smallest category, it continues to experience the highest rate of growth. Further exploration of end-of-life care for ESRD patients may be worthwhile.

vol 2 Figure 9.5 Total Medicare dollars spent on ESRD, by type of service



Data Source: USRDS ESRD Database. Total Medicare costs from claims data; includes all Medicare as primary payer claims as well as amounts paid by Medicare as secondary payer. Abbreviations: ESRD, end-stage renal disease.

### Conclusion

Medicare spending growth for ESRD patients continued to be moderate in the second year following the implementation of the dialysis bundled payment system. Inpatient spending remained essentially flat for the second consecutive year. The 2015 Annual Data Report will examine additional data for Medicare Part D spending, spending by modality, and spending for a large sample of privately insured patients.

### References

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# Chapter 10: International Comparisons

## Introduction

This chapter provides a worldwide view of end-stage renal disease (ESRD). The number of countries and regions represented in this Annual Data Report has increased by more than 25 percent, from 42 countries in 2013 to 54 this year. Forty countries provided updated data for 2012; 14 new countries provided data this year, including Bahrain, Hungary, Indonesia, Iran, Italy (for 2010), Kuwait, Lebanon, Oman, Poland, Qatar, Saudi Arabia, Slovenia, South Africa, and Ukraine. This chapter is made possible only through the great efforts of many people across all participating countries, in contributing data for this international collaboration. We sincerely thank all of the registries and providers for their efforts, and have included a list at the end of this chapter to further acknowledge their contributions.

We hope these comparisons provide helpful global perspectives and increase awareness regarding the various aspects of ESRD described within this chapter. We welcome any suggestions to further improve the content of this chapter for the international community, and invite all renal registries to participate in this data collection and collaboration. We realize there are many countries not yet represented in this chapter, and that an unmet need exists for availability of dialysis in some communities. Efforts toward enhanced, broadened, and meaningful outreach will be a continued focus of this chapter.

## Chapter Highlights

- In 2012, ESRD incidence rates varied more than 15-fold by country, ranging from 25 to 467 new ESRD patients per million population. In most countries, ESRD incidence rates are highest among elderly patients (aged 75 or greater). The highest rate of ESRD incidence in younger individuals (ages 20-44 years old) was observed in the United States (U.S.), at more than twice the

rate reported in the great majority of countries providing 2012 data.

- Comparisons of the change in country average ESRD incidence rates between 2006 and/or 2007 and 2011 and/or 2012 were varied. In 40 percent of countries, relatively small changes were seen over this time period ( $\pm$ five percent change). In some countries, however, incidence rates increased by 29 to 70 percent; in other areas ESRD incidence rates declined by seven to 30 percent over this time period.
- Prevalence of ESRD varied more than 20-fold across countries in 2012, from 131 per million population in Ukraine to 2,902 in Taiwan. In all countries reporting data from 2006 to 2011 or 2012, ESRD prevalence increased during this time period, ranging from a six to 135 percent overall rise (median rise of 17 percent; interquartile range: 13 to 35 percent).
- In 2012, the proportion of new ESRD patients with diabetes as the primary cause differed greatly across countries, ranging from 66 and 61 percent of patients in Singapore and Malaysia, respectively, to 12–16 percent of new ESRD patients in Ukraine, Romania, and the Netherlands. In approximately half of all countries, diabetes was the primary cause of ESRD for at least 31 percent of new ESRD patients.
- The number of ESRD patients receiving chronic dialysis per million population in 2012 varied more than 20-fold across countries, from 2,902 and 2,365 in Taiwan and Japan, respectively, to 133-185 in South Africa, Russia, and the Philippines. From 2006 to 2011 or 2012, the number of ESRD patients receiving dialysis per million population increased 1.5- to 2.5-fold across nearly 20 percent of reporting countries, and yet declined or reached an apparent plateau in nearly 25 percent of other reporting countries.

- Although hemodialysis (HD) was the most common form of dialysis provided to ESRD patients in the great majority of countries in 2012, peritoneal dialysis (PD) was used by 73 percent and 50 percent of dialysis patients, respectively, in Hong Kong and in Jalisco (Mexico). Thirty-one percent of patients received PD in New Zealand and Colombia, and 17–27 percent use was reported in Australia, Canada, Denmark, Finland, Iceland, Qatar, South Africa, Sweden, and Thailand; numerous other countries reported 5–16 percent PD use. Although recent increases have been seen in peritoneal dialysis in countries such as Argentina, Hungary, Portugal, Thailand, and the U.S., approximately 40 percent of countries reporting data for most years between 2006 and 2012 displayed an overall decline in the percentage of PD use during this time period.
- Home hemodialysis was provided to 19.0 percent and 9.2 percent of patients, respectively, in New Zealand and Australia in 2012. Furthermore, home HD was used by 3.0 to 5.7 percent of patients in Canada, Denmark, Finland, Sweden, the Netherlands, the United Kingdom (U.K.) and Scotland, with numerous countries providing such treatment for up to two percent of dialysis patients.
- Kidney transplantation rates varied 30-fold across countries, from two to 60 kidney transplants per million population in 2012 (median of 27 per million population). The highest kidney transplant rates were reported in Norway, Jalisco (Mexico), the Netherlands, the U.S., Croatia, and Spain, with 54–60 per million population. Substantial increases in kidney transplantation have been seen since 2006, in nearly 30 percent of reporting countries.
- Large international variations are seen in the prevalence of ESRD patients living with a functioning kidney transplant. In 2012, Norway, Portugal, and the U.S. reported the highest prevalence of such ESRD patients at 594 to 639 per million population. In contrast, in approximately 25 percent of other countries, the prevalence of ESRD patients living with a functioning kidney transplant ranged from two to 106 per million population.

### Analytical Methods

See the ESRD Analytical Methods chapter for the data collection form and for an explanation of the analytical methods used to generate the figures and tables in this chapter.

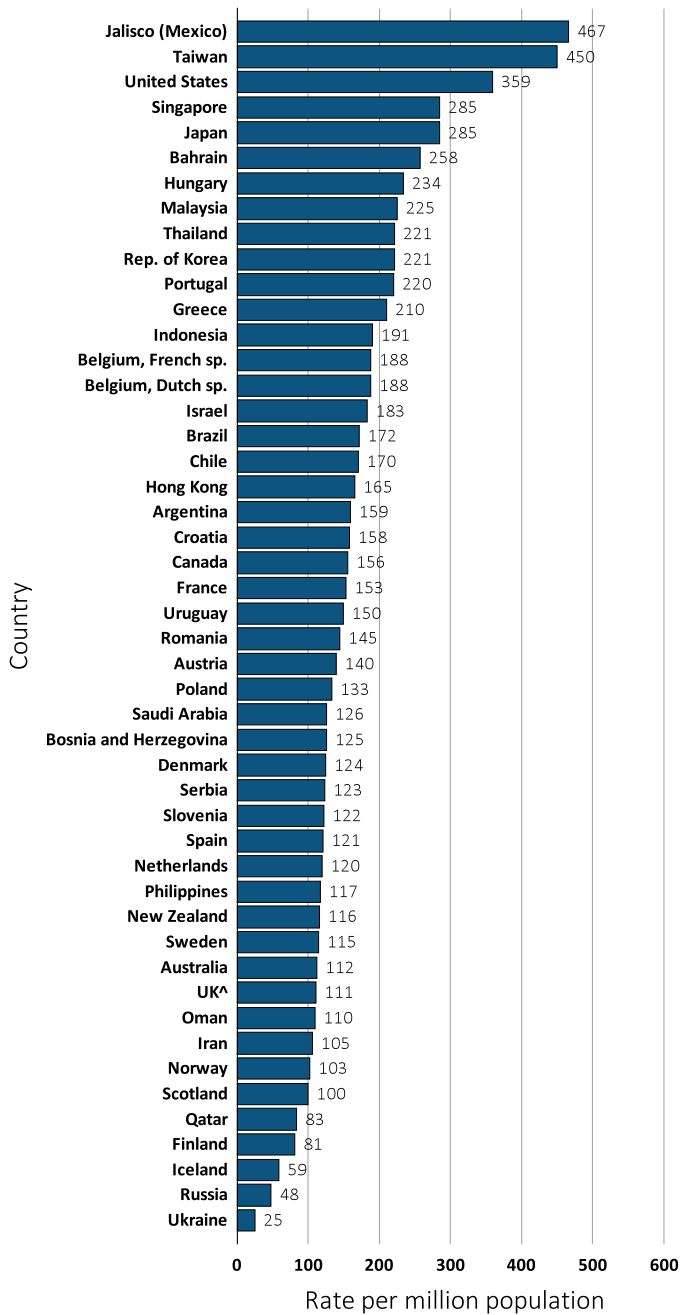
### Incidence of End-Stage Renal Disease

In 2012, reported rates of the incidence of ESRD varied greatly across countries (see Figure 10.1). Jalisco (Mexico), Taiwan, and the U.S. reported the highest rates of ESRD incidence at 467, 450, and 359 per million population, respectively. Below this, ESRD incidence rates of 210–285 per million population were reported for Japan, Singapore, Bahrain, Hungary, Malaysia, Republic of Korea, Thailand, Portugal, and Greece. Much lower ESRD incidence rates of 25 to 100 per million population were reported in Ukraine, Russia, Qatar, Iceland, Finland, and Scotland. In all other countries, incident ESRD rates ranged from 103 to 191 per million population.

As illustrated by Figure 10.2 and Table 10.1, substantial differences are seen across countries regarding the overall trend in ESRD incidence from 2006 to 2011 or 2012. In comparing the average ESRD incidence in 2006 and 2007 versus that in 2011 and 2012, rates increased by 29 to 70 percent in Romania, Russia, Malaysia, Thailand, the Philippines, Jalisco (Mexico), and Chile, while increasing seven to 16 percent in Uruguay, Argentina, Republic of Korea, Singapore, Hong Kong, and Turkey. In contrast, rates of ESRD incidence declined by seven to 14 percent over this time period in Finland, Sweden, Denmark, Scotland, Austria, and Bosnia and Herzegovina, with Colombia reporting a large 32 percent average decline during in the same time period. However, nearly 40 percent of all countries reported a relatively stable rate of ESRD incidence from 2006 to 2012, including the U.S., which showed little overall change (0.7 percent decline).



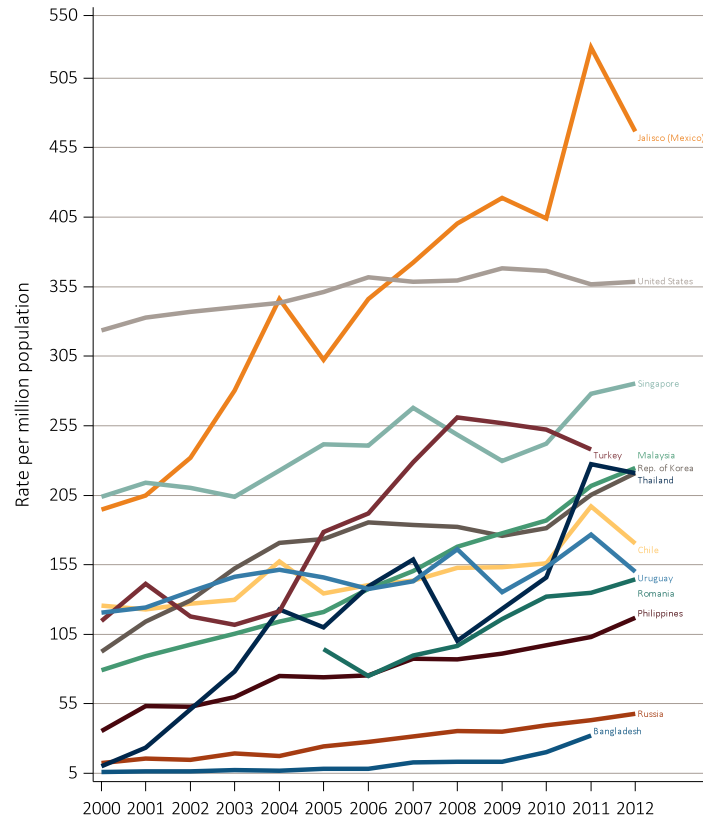
vol 2 Figure 10.1 Incidence rate of ESRD, per million population, by country, in 2012



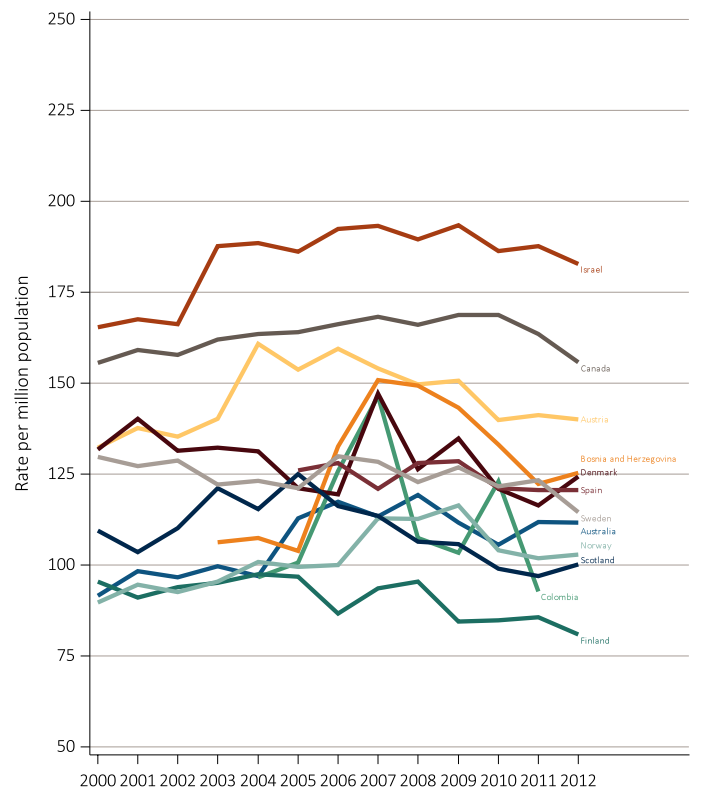
Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. ^UK: England, Wales, Northern Ireland (Scotland data reported separately). Japan and Taiwan are dialysis only. Data for Belgium do not include patients younger than 20. Data for Indonesia represent the West Java region. Data for France include 22 regions. Data for Spain include 18 of 19 regions. Abbreviations: ESRD, end-stage renal disease; sp., speaking.

vol 2 Figure 10.2 Temporal trends in the incidence rate of ESRD, per million population, by country, years 2000-2012

(a) Countries in which the incidence rate of ESRD increased at least 10% from 2006-2012



(b) Countries in which the incidence rate of ESRD decreased at least 3% from 2006-2012



Data source: Special analyses, USRDS ESRD Database. All rates are unadjusted. Data are shown for countries with incidence increase or decrease from 2006 to 2012 or 2011. Data for U.S. are shown for comparison purposes. Abbreviations: ESRD, end-stage renal disease.

vol 2 Table 10.1 Temporal trends in the incidence rate of ESRD, per million population, by country, years 2006-2012

Country	2006	2007	2008	2009	2010	2011	2012	% change from 2006-2012 <sup>a</sup>
Argentina	141.0	151.1	144.4	152.6	154.0	155.0	159.0	7.5
Australia	117.4	113.3	119.3	111.6	105.6	111.8	111.7	-3.1
Austria	159.5	154.0	149.7	150.7	139.8	141.2	140.0	-10.3
Bahrain	.	.	206.1	205.4	219.5	207.5	257.9	
Bangladesh	8.3	12.9	13.1	13.1	20.2	32.1	.	202.8
Belgium, Dutch sp.	192.4	189.8	192.6	207.5	196.4	184.9	188.2	-2.4
Belgium, French sp.	187.0	187.0	191.8	197.1	191.1	186.1	188.2	0.1
Bosnia and Herzegovina	132.6	150.8	149.3	143.3	133.1	122.3	125.4	-12.6
Brazil	184.9	140.1	145.4	98.9	150.3	176.0	171.5	6.9
Canada	166.3	168.2	166.1	168.7	168.7	163.6	155.7	-4.5
Chile	140.5	143.8	152.8	153.1	155.9	197.2	170.1	29.2
Colombia	125.9	146.4	107.4	103.4	122.9	92.8	.	-31.8
Croatia	.	.	.	.	.	.	158.1	
Czech Republic	185.7	184.6	181.9	180.5	197.8	171.9	.	-7.2
Denmark	119.4	147.2	126.3	134.8	121.0	116.4	124.3	-9.7
Finland	86.6	93.6	95.4	84.5	84.8	85.6	80.9	-7.6
France	144.0	140.8	148.2	151.3	152.4	151.0	153.4	6.9
Greece	197.6	191.6	201.2	205.0	190.8	203.3	209.7	6.1
Hong Kong	148.9	147.4	148.2	132.2	146.0	156.8	165.2	8.7
Hungary	.	.	235.8	264.5	228.6	241.2	234.3	
Iceland	69.1	83.7	72.5	87.9	106.9	103.4	59.2	6.4
Indonesia	.	.	.	.	.	.	190.7	
Iran	.	.	99.2	101.2	106.2	108.0	105.4	
Israel	192.4	193.2	189.5	193.4	186.4	187.6	182.8	-3.9
Italy	.	.	.	.	162.0	.	.	
Jalisco (Mexico)	345.9	372.2	400.4	419.0	403.9	527.1	466.5	38.4
Japan	275.4	285.2	287.7	287.5	290.6	294.6	285.3	3.4
Rep. of Korea	185.3	183.5	182.1	175.9	181.5	205.3	221.1	15.6
Kuwait	.	.	.	.	.	.	.	
Lebanon	.	.	.	.	.	.	.	

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. ^UK: England, Wales, Northern Ireland (Scotland data reported separately). Japan and Taiwan are dialysis only. Data for France include 15 regions in 2006, 18 regions in 2007, 20 regions in 2008, and 22 regions 2009-2012. Data for Spain include 18 of 19 regions. Data for Belgium do not include patients younger than 20. Data for Indonesia represent the West Java region. <sup>a</sup> % change is calculated as the percent difference between the average incidence in 2011 and 2012 and the average in 2006 and 2007. Abbreviations: ESRD, end-stage renal disease; sp., speaking; . signifies data not reported.

Table 10.1 continued on next page.

vol 2 Table 10.1 Temporal trends in the incidence rate of ESRD, per million population, by country, years 2006-2012 (continued)

Country	2006	2007	2008	2009	2010	2011	2012	% change from 2006-2012 <sup>a</sup>
Malaysia	137.8	150.3	168.2	177.5	186.9	211.6	224.6	51.4
Morelos (Mexico)	.	553.2	557.2	597.1	.	.	.	
Netherlands	112.8	117.4	120.8	118.8	117.7	117.7	120.1	3.3
New Zealand	119.5	110.9	116.4	135.3	117.9	110.1	115.7	-2.0
Norway	100.0	112.8	112.6	116.4	104.1	101.8	102.8	-3.9
Oman	.	.	102.1	103.0	106.1	108.0	110.0	
Philippines	-	87.5	87.2	91.1	97.3	103.0	116.8	35.0
Poland	.	.	129.9	134.3	134.3	131.9	133.1	
Portugal	.	.	231.9	239.5	238.5	226.4	219.9	
Poland	.	.	129.9	134.3	134.3	131.9	133.1	
Portugal	.	.	231.9	239.5	238.5	226.4	219.9	
Qatar	.	.	.	.	117.8	117.2	83.3	
Romania	74.9	89.9	96.7	115.9	132.3	134.9	144.5	69.5
Russia	27.7	.	35.5	34.9	39.5	43.1	47.7	63.9
Saudi Arabia	.	.	138.2	122.5	124.0	124.5	125.6	
Scotland	116.3	113.5	106.4	105.7	99.0	96.9	100.1	-14.3
Serbia	.	.	.	.	.	144.5	122.8	
Singapore	240.5	267.7	248.7	229.8	242.3	277.9	285.3	10.8
Slovenia	.	.	.	129.9	120.6	117.9	122.0	
South Africa	.	.	.	.	.	.	.	
Spain	128.0	120.9	128.1	128.5	121.1	120.7	120.6	-3.1
Sweden	129.9	128.4	122.8	126.9	121.7	123.4	114.5	-7.9
Taiwan	418.3	423.5	415.9	427.8	449.1	444.2	449.7	6.2
Thailand	139.4	158.9	100.3	123.2	146.0	227.4	221.1	50.4
Turkey	191.8	228.9	261.1	256.7	252.2	238.0	.	13.1
UK <sup>^</sup>	114.8	112.4	112.2	112.5	109.8	111.1	110.5	-2.5
United States	361.9	358.5	359.6	368.3	366.5	356.9	358.7	-0.7
Ukraine	.	.	.	.	.	.	24.8	

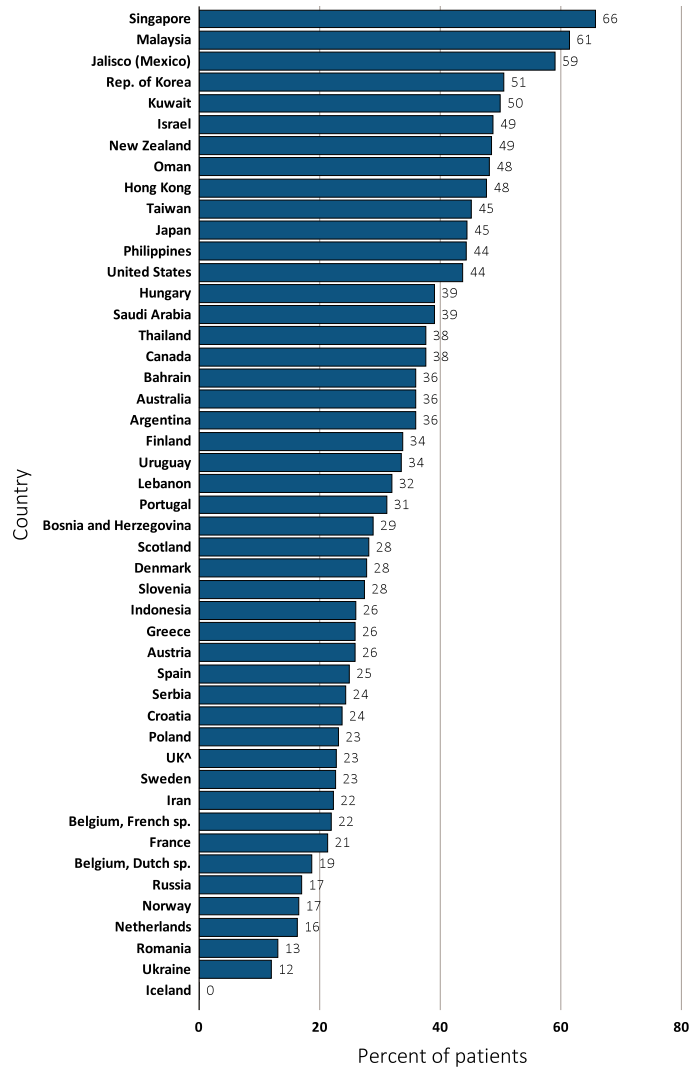
Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. <sup>^</sup>UK: England, Wales, Northern Ireland (Scotland data reported separately). Japan and Taiwan are dialysis only. Data for France include 15 regions in 2006, 18 regions in 2007, 20 regions in 2008, and 22 regions 2009-2012. Data for Spain include 18 of 19 regions. Data for Belgium do not include patients younger than 20. Data for Indonesia represent the West Java region. <sup>a</sup> % change is calculated as the percent difference between the average incidence in 2011 and 2012 and the average in 2006 and 2007. Abbreviations: ESRD, end-stage renal disease; sp., speaking; . signifies data not reported.

### Diabetes as Primary Cause of End-Stage Renal Disease in Incident Patients

The distribution of primary causes of ESRD varies substantially across countries (see Figure 10.3). Data on one of the key primary causes of ESRD, diabetes mellitus (DM), were provided by nearly 75 percent of the countries participating in this report. In 2012, Singapore and Malaysia reported the highest rate

of patients with new ESRD due to DM, at 66 and 61 percent, respectively in 2012. Furthermore, DM was the primary cause of new ESRD for 48 to 59 percent of patients in Jalisco (Mexico), Kuwait, Oman, Israel, Republic of Korea, Hong Kong, and New Zealand.

vol 2 Figure 10.3 Percentage of incident ESRD patients with diabetes as the primary ESRD cause, by country, in 2012



Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for Spain include 18 of 19 regions. Data for France include 22 regions. Data for Indonesia represent the West Java region. Data for Belgium do not include patients younger than 20. There were zero ESRD patients in Iceland with diabetes as the primary ESRD cause in 2012. Abbreviations: ESRD, end-stage renal disease; sp., speaking.

In contrast, in some countries, DM as the primary cause of ESRD was one-third to one-quarter that of the above countries. Thus, in Iran, Russia, Romania, Ukraine, France, Belgium, the Netherlands, and Norway, diabetes was the primary cause for less than 22 percent of new patients in 2012.

### Incidence of End Stage Renal Disease by Age Group

When examined across four age categories, the rate of new ESRD was typically highest among patients aged

vol 2 Figure 10.4 Incidence rate of ESRD, per million population, by age group and country, in 2012

(a) 20-44 years old

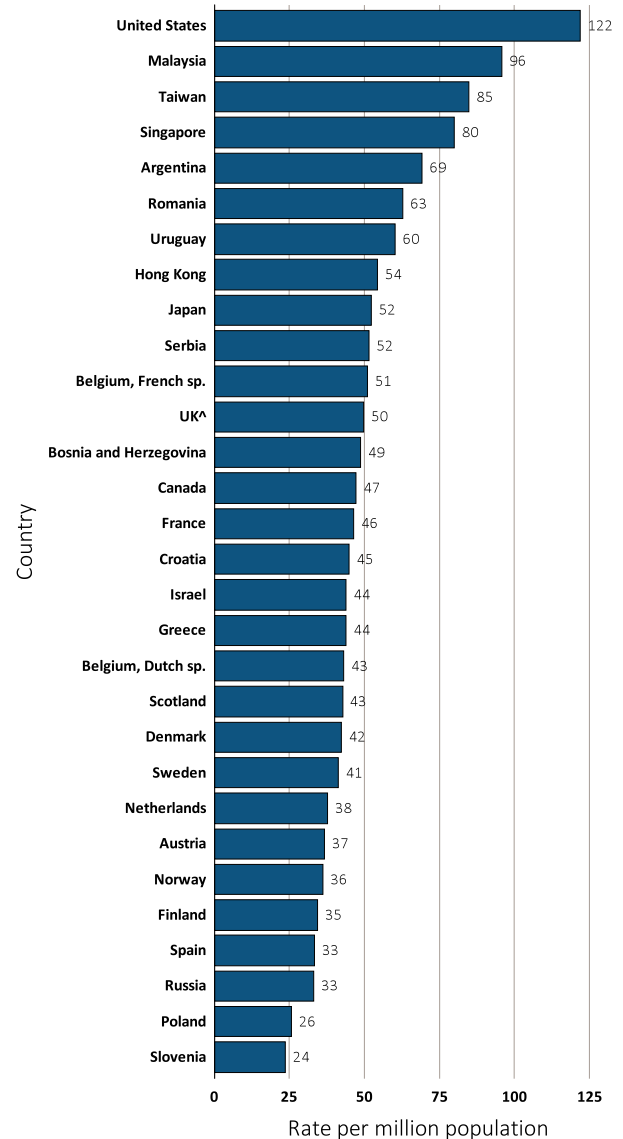
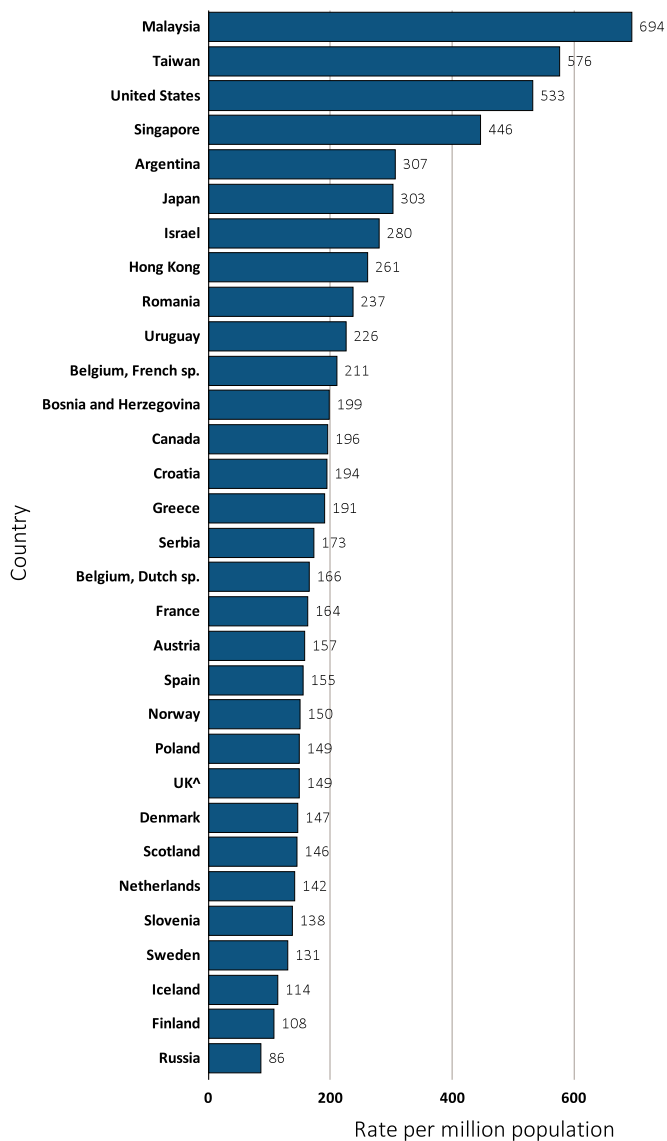


Figure 10.4 continued on next page.

75 years and older in the great majority of countries. In some cases the ESRD incidence rate was more than 1.5-fold higher for this older patient cohort, compared with those 65-74 years old (see Figure 10.4). The highest ESRD incidence rates were reported in Poland, Taiwan, and the U.S. for patients aged 75 years and older, amounting to 4,053, 2,840, and 1,415 per million population of older individuals, respectively, in 2012. Conversely, in Argentina, Hong Kong, Malaysia, Romania, Serbia, and Scotland, the ESRD incidence rate was lower among patients aged 75 years or older than for patients 65-74 years old. Furthermore, the highest rate of ESRD incidence in younger adults (ages 20-44 years old) was seen in the U.S., which was more than twice that reported in the great majority of countries reporting 2012 data.

vol 2 Figure 10.4 Incidence rate of ESRD, per million population, by age group and country, in 2012 (continued)

(b) 45-64 years old



vol 2 Figure 10.4 Incidence rate of ESRD, per million population, by age group and country, in 2012 (continued)

(c) 65-74 years old

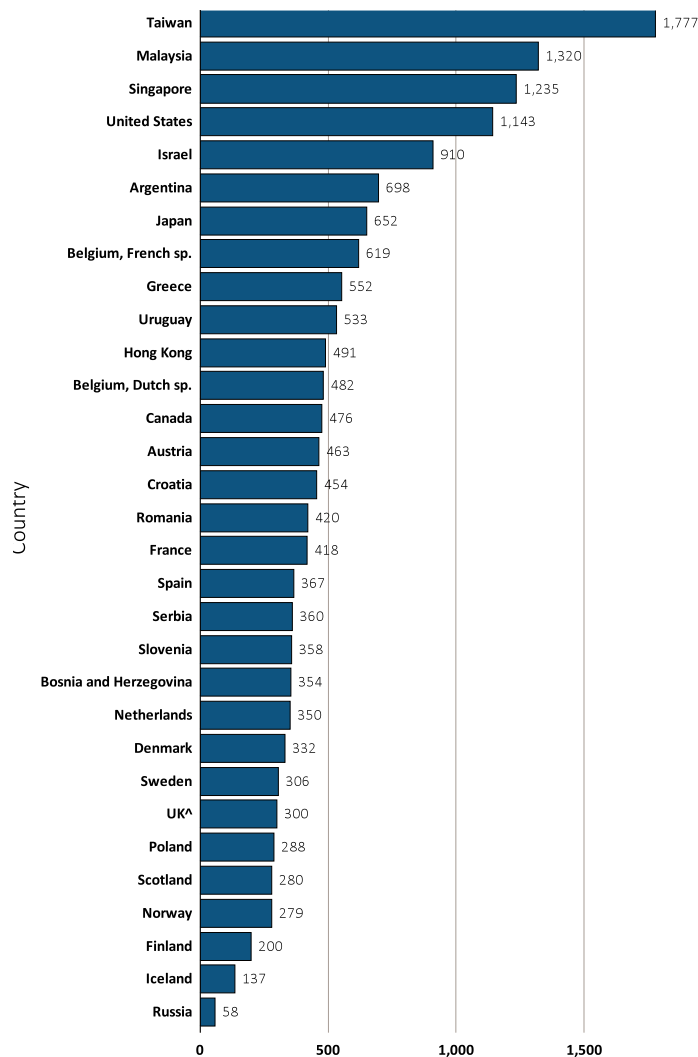
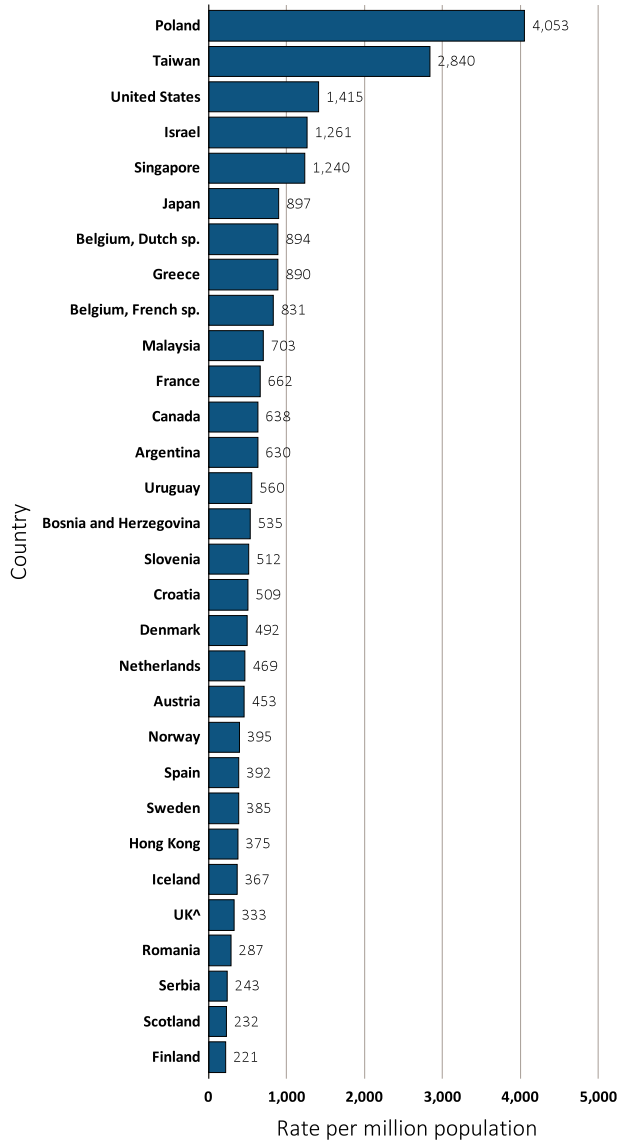


Figure 10.4 continued on next page.

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for Belgium do not include patients younger than 20. Data for Spain include 18 of 19 regions. Data for France include 22 regions. Abbreviations: ESRD, end-stage renal disease; sp., speaking.

vol 2 Figure 10.4 Incidence rate of ESRD, per million population, by age group and country, in 2012 (continued)  
(d) 75 years or older

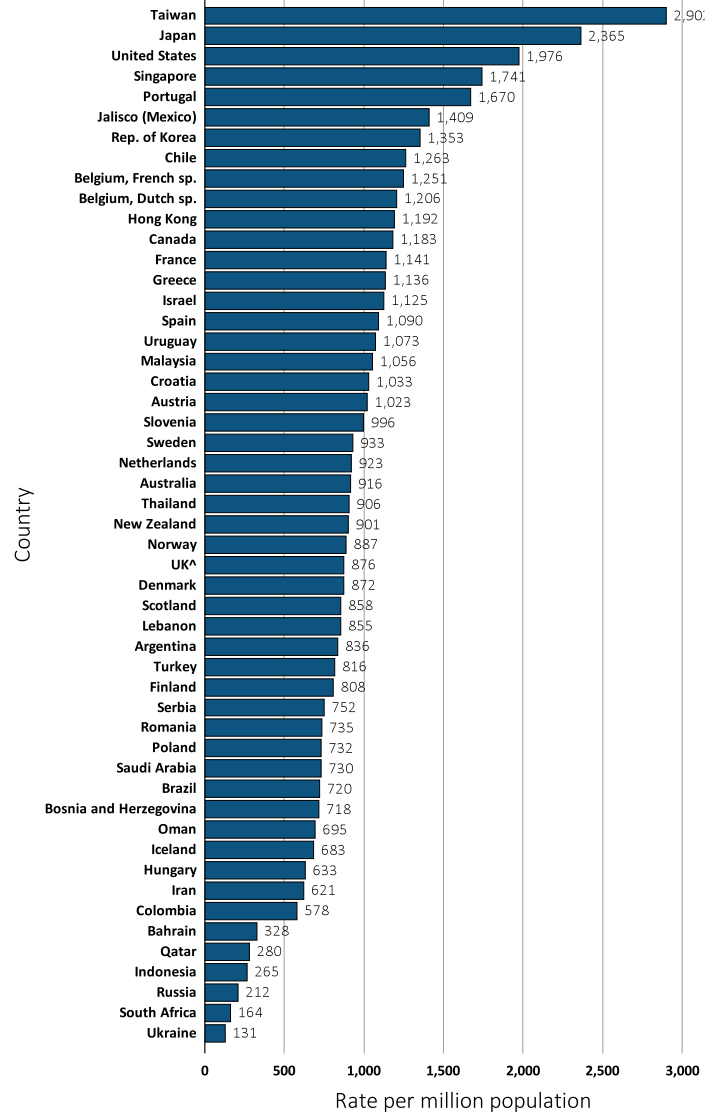


Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for Belgium do not include patients younger than 20. Data for Spain include 18 of 19 regions. Data for France include 22 regions. Abbreviations: ESRD, end-stage renal disease; sp., speaking.

### Prevalence of End-Stage Renal Disease

In 2012, ESRD prevalence, indicated as the number of treated ESRD patients per million population on December 31, 2012, was highest in Taiwan, Japan, and the U.S., at 2,902, 2,365, and 1,976 per million population, respectively. Furthermore, in 2012 ESRD prevalence ranged from 1,023 to 1,741 per million population in 33 percent of countries, and from 578

vol 2 Figure 10.5 Prevalence of ESRD, per million population, by country, in 2012



Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted and reflect prevalence at the end of 2012; rates for Colombia and Lebanon reflect prevalence at the end of June 2012. ^U.K: England, Wales, & Northern Ireland (Scotland data reported separately). Japan and Taiwan include dialysis patients only. Data for Belgium do not include patients younger than 20. Data for Indonesia represent the West Java region. Data for Spain include 18 of 19 regions. Data for France include 22 regions. Data for Turkey in 2012 was collected with the collaboration of the Ministry of Health, which collects patient-based data; however, in previous years center-based data were reported. Abbreviations: ESRD, end-stage renal disease; sp., speaking.

to 996 in 50 percent of countries (see Figure 10.5 and Table 10.2). The lowest rates were reported in Ukraine, Russia, Qatar, Bahrain, Indonesia, and South Africa, where treated ESRD prevalence rates varied from 131 to 328 per million population.

vol 2 Table 10.2 Number of ESRD prevalent patients and prevalence of ESRD, per million population, by country, years 2006-2012

Country	Prevalence rate, per million population								Prevalent patients, counts						
	2006	2007	2008	2009	2010	2011	2012	% change from 2006-2012 <sup>a</sup>	2006	2007	2008	2009	2010	2011	2012
Argentina	598.0	615.4	755.7	761.9	794.8	790.6	835.7	34.0	23,306	24,218	30,035	30,580	31,885	31,975	34,218
Australia	778.3	801.3	833.6	850.1	870.7	892.1	915.6	14.4	16,112	16,842	17,824	18,512	19,210	19,913	20,766
Austria	908.6	933.5	947.9	980.1	991.7	1000.6	1022.7	9.8	7,512	7,731	7,898	8,189	8,320	8,429	8,635
Bahrain	.	.	291.0	300.4	280.3	339.7	328.4	.	.	.	322	354	346	406	410
Bangladesh	87.8	101.3	112.8	137.1	157.7	191.5	.	102.5	12,864	15,089	17,068	21,067	24,618	28,729	.
Belgium, Dutch sp.	1033.1	1063.8	1096.0	1136.4	1160.8	1183.2	1206.2	13.9	6,300	6,531	6,779	7,080	7,289	7,488	7,679
Belgium, French sp.	1071.5	1110.7	1145.7	1142.1	1180.0	1211.2	1251.3	12.8	4,768	4,983	5,184	5,215	5,447	5,650	5,883
Bosnia and Herzegovina	551.9	601.8	637.0	646.4	675.1	709.0	718.1	23.7	2,115	2,306	2,441	2,477	2,587	2,487	2,519
Brazil	398.3	466.0	408.5	480.2	478.7	678.6	720.2	61.8	73,605	87,044	77,589	92,091	91,314	132,491	143,497
Canada	1039.1	1071.1	1094.1	1124.3	1142.3	1166.1	1182.7	11.3	33,898	35,274	36,465	37,934	38,981	40,209	41,252
Chile	929.6	985.7	1065.2	1108.8	1161.1	1235.7	1263.4	30.5	15,353	16,360	17,856	18,849	19,854	21,007	21,730
Colombia	.	.	455.3	441.3	544.2	536.3	578.4	.	.	.	20,239	19,846	24,760	24,692	26,942
Croatia	.	.	.	.	.	.	1033.0	.	3,799	3,932	4,009	4,124	4,257	4,348	4,410
Czech Republic	461.9	499.9	538.1	907.6	970.1	974.4	.	102.6	4,752	5,190	5,633	9,536	10,218	10,236	.
Denmark	781.8	832.2	832.1	843.8	847.8	857.0	872.3	7.1	4,295	4,592	4,619	4,708	4,751	4,823	4,927
Finland	727.1	747.4	769.2	782.2	796.0	805.5	807.7	9.4	3,829	3,953	4,087	4,176	4,269	4,340	4,373
France	962.6	953.9	993.1	1053.4	1089.7	1118.6	1141.3	17.9	34,835	49,679	54,627	62,070	64,225	66,245	68,350
Greece	986.1	1013.4	1038.9	1069.1	1083.0	1103.1	1135.7	12.0	10,994	11,343	11,674	12,062	12,246	12,466	12,598
Hong Kong	1003.0	1031.4	1067.4	1077.7	1106.3	1152.5	1191.7	15.2	6,930	7,171	7,460	7,580	7,857	8,197	8,549
Hungary	.	.	578.1	605.3	620.0	626.2	632.8	.	.	.	5,807	6,072	6,209	6,253	6,285
Iceland	483.9	518.5	523.0	543.2	600.6	667.7	682.8	34.7	147	161	166	173	191	213	219
Indonesia	.	.	.	.	.	.	265.0	.	.	.	.	.	.	.	.
Iran	.	.	490.6	528.8	556.4	585.5	621.2	.	.	.	35,248	38,575	41,192	43,969	47,336
Israel	1010.1	1040.7	1070.8	1086.6	1101.9	1120.2	1125.4	9.5	7,125	7,472	7,826	8,134	8,400	8,699	8,902
Italy	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.
Jalisco (Mexico)	928.9	986.2	1029.6	1314.3	1332.3	1381.5	1408.8	45.7	6,357	6,865	7,218	9,222	9,916	10,421	10,769
Japan	1954.5	2058.1	2126.0	2205.4	2277.4	2313.8	2365.2	16.6	249,718	262,968	271,471	281,212	289,415	295,706	301,545
Rep. of Korea	941.7	972.8	1031.7	1113.6	1144.4	1224.8	1353.3	34.7	46,730	48,675	51,989	56,396	58,860	63,341	70,211
Kuwait	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.
Lebanon	.	.	.	.	.	.	855.0	.	.	.	.	.	.	.	4,100
Malaysia	626.3	692.5	769.4	840.1	905.3	987.1	1056.4	55.0	16,805	18,825	21,191	23,435	25,574	28,184	30,991
Morelos (Mexico)	.	877.8	939.3	978.0	.	.	.	.	.	1,447	1,561	1,638	.	.	.

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for France include 15 regions in 2006, 18 in 2007, 20 in 2008, and 22 in 2009-2012. Data for Spain include 18 of 19 regions. Data for Belgium do not include patients younger than 20. Data for Indonesia represent the West Java region. a % change is calculated as the percent difference between the average prevalence in 2011 and 2012 and the average in 2006 and 2007. Abbreviations: ESRD, end-stage renal disease; sp., speaking; . signifies data not reported.

Table 10.2 continued on next page.

vol 2 Table 10.2 Number of ESRD prevalent patients and prevalence of ESRD, per million population, by country, years 2006-2012

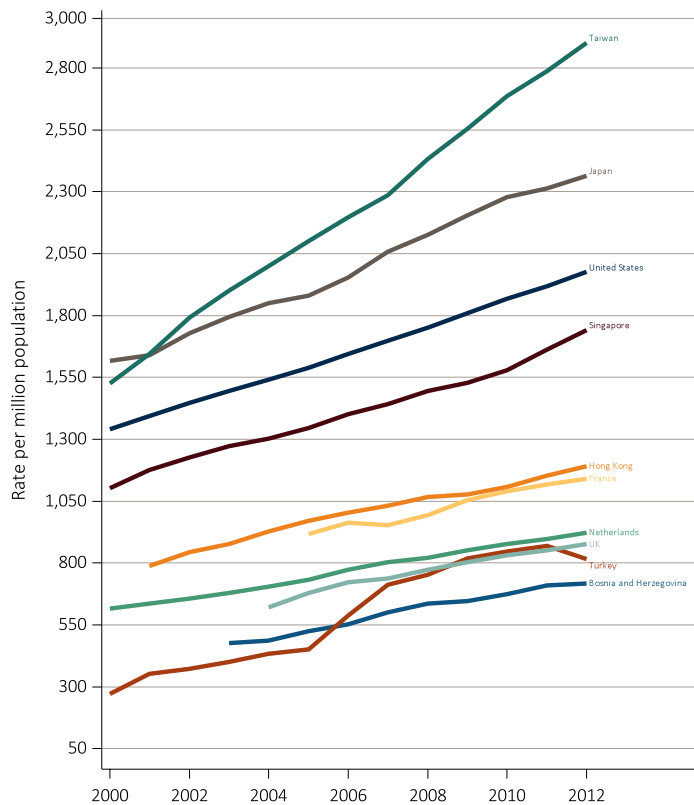
Country	Prevalence rate, per million population								Prevalent patients, counts						
	2006	2007	2008	2009	2010	2011	2012	% change from 2006-2012 <sup>a</sup>	2006	2007	2008	2009	2010	2011	2012
Netherlands	772.2	802.5	820.2	852.1	875.6	897.5	923.4	15.6	12,623	13,146	13,488	14,086	14,549	14,982	15,472
New Zealand	775.5	793.2	809.6	853.8	876.4	879.0	900.7	13.5	3,245	3,354	3,456	3,685	3,828	3,872	3,993
Norway	753.1	784.0	816.9	844.3	859.4	875.0	887.3	14.7	3,510	3,692	3,895	4,077	4,202	4,334	4,453
Oman	.	.	463.5	492.1	615.3	649.3	694.8	.	.	.	1,535	1,682	1,826	1,966	2,147
Philippines	80.6	84.6	109.8	114.0	132.9	159.4	.	93.0	7,437	7,967	10,552	11,172	13,275	16,230	.
Poland	.	.	647.5	672.5	665.5	706.6	732.2	.	.	.	24,783	25,665	25,635	27,236	28,226
Portugal	.	.	1406.8	1505.1	1589.5	1662.0	1670.3	.	.	.	14,965	16,011	16,788	17,553	17,641
Qatar	.	.	.	.	244.3	267.2	280.1	.	.	.	.	.	419	463	511
Romania	304.7	368.3	422.4	533.2	599.9	666.4	735.2	108.3	6,578	7,935	9,088	10,859	12,146	13,410	14,747
Russia	130.1	.	158.0	173.1	185.5	196.4	211.7	56.8	18,486	.	22,234	24,246	26,327	27,989	30,349
Saudi Arabia	.	.	797.5	792.7	763.9	731.7	730.3	.	.	.	19,334	20,113	20,731	20,764	21,321
Scotland	783.9	812.0	809.9	827.7	836.8	842.1	857.6	6.5	4,011	4,177	4,186	4,299	4,370	4,424	4,557
Serbia	.	.	.	.	.	722.4	752.0	.	.	.	.	.	.	5,244	5,414
Singapore	1400.1	1441.8	1494.8	1526.9	1578.6	1661.8	1741.4	19.8	4,936	5,165	5,445	5,701	5,954	6,297	6,648
Slovenia	.	.	.	980.6	986.5	984.5	995.5	.	.	.	.	2,000	2,021	2,021	2,048
South Africa	.	.	.	.	.	.	163.7	.	.	.	.	.	.	.	8,559
Spain	961.0	956.2	994.8	1033.5	1045.5	1074.7	1090.4	12.9	35,462	41,546	44,067	39,708	47,632	50,614	50,837
Sweden	850.7	866.7	875.7	893.5	912.2	931.1	933.0	8.5	7,725	7,929	8,074	8,308	8,555	8,798	8,882
Taiwan	2196.8	2285.1	2432.0	2554.4	2685.2	2785.9	2902.1	26.9	50,255	52,462	56,025	59,056	62,196	64,702	67,665
Thailand	286.0	419.8	496.9	552.8	639.3	749.8	905.9	134.6	17,967	26,457	31,496	35,112	40,845	47,987	58,385
Turkey	589.2	711.5	753.1	819.2	847.4	868.2	815.6	29.5	42,992	50,221	53,859	59,443	62,471	64,877	61,677
UK <sup>^</sup>	722.9	737.6	773.2	804.3	830.1	850.6	875.8	18.2	40,101	41,188	43,478	45,519	47,347	49,321	51,140
United States	1645.1	1697.9	1751.1	1809.6	1867.5	1918.0	1975.5	16.5	490,879	511,465	532,502	555,145	577,675	597,620	620,136
Ukraine	.	.	.	.	.	.	131.3	.	.	.	.	.	.	.	5,985

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. <sup>^</sup>UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for France include 15 regions in 2006, 18 in 2007, 20 in 2008, and 22 in 2009-2012. Data for Spain include 18 of 19 regions. Data for Belgium do not include patients younger than 20. Data for Indonesia represent the West Java region. a % change is calculated as the percent difference between the average prevalence in 2011 and 2012 and the average in 2006 and 2007. Abbreviations: ESRD, end-stage renal disease; sp., speaking; . signifies data not reported.

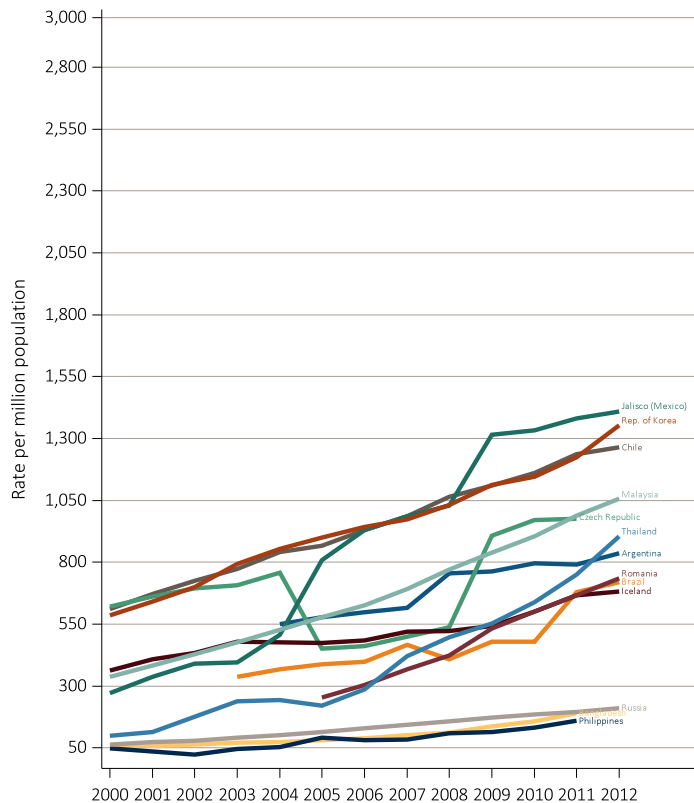


**vol 2 Figure 10.6 Temporal trends in the prevalence of ESRD, per million population, by country, years 2000-2012**

**(a) Countries in which the prevalence of ESRD increased by 15-31 % from 2006-2012**



**(b) Countries in which the prevalence of ESRD increased by greater than 31 % from 2006-2012**



Data source: Special analyses, USRDS ESRD Database. All rates are unadjusted. Data for U.S. are shown for comparison purposes. Abbreviations: ESRD, end-stage renal disease.

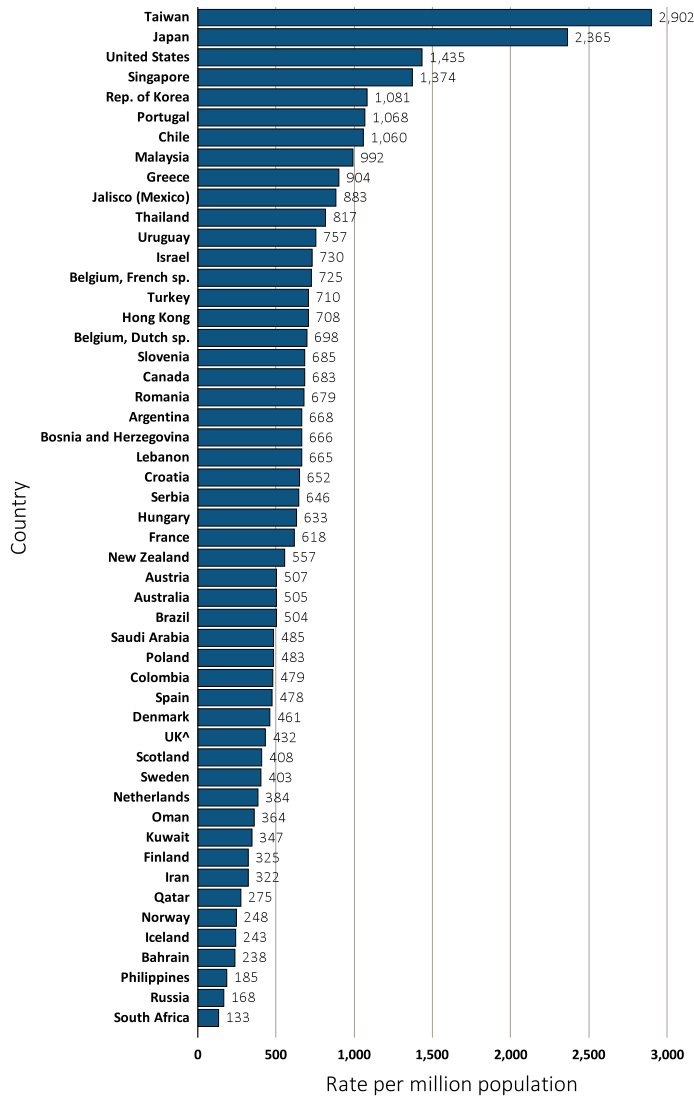
Since 2006, the prevalence of ESRD has been continually rising in nearly all of the countries that provided data for all or most of the 2006-2012 time frame. These results indicate the continuing worldwide need for additional resources and care on a broad, global level to meet the health needs of individuals with ESRD. As seen in Figure 10.6, some countries have shown particularly large rises in ESRD prevalence between 2006 and 2011 or 2012, including Malaysia, Russia, Brazil, the Philippines, the Czech Republic, Romania, and Thailand, where ESRD prevalence has increased 55 to 135 percent.

In 2012, the total number of patients treated for ESRD was by far the highest in the U.S., with nearly 600,000 treated patients, followed by Japan and Brazil with approximate cohorts of 301,000 and 144,000, respectively. France, Spain, Taiwan, Thailand, Turkey, and the U.K. reported between 50,000 to 70,000 treated ESRD patients in 2012, with all other countries treating smaller groups, with a median of approximately 9,000 treated patients.

### Dialysis Therapy for ESRD

Dialysis is the most commonly utilized therapeutic approach for treatment of ESRD, followed by kidney transplantation. The number of ESRD patients receiving chronic dialysis per million population in 2012 varied more than 20-fold across countries, from 2,902 and 2,365 in Taiwan and Japan, respectively, to a range of 133 to 185 in South Africa, Russia, and the Philippines (see Figure 10.7). Between 2006 to 2011 or 2012, a large 1.5- to 3.1-fold increase was reported in the number of ESRD patients receiving dialysis per million population in Thailand, the Philippines, Bangladesh, Malaysia, Romania, Russia, Oman (between 2008 to 2012), and Jalisco (Mexico). However, a plateauing or decline in the prevalence of treated ESRD patients receiving chronic dialysis is beginning to be seen in nearly a quarter of all countries reporting several years of data (see Figure 10.8 and Table 10.3). These countries include Austria, Slovenia, Denmark, Finland, Norway, Sweden, the Netherlands, Scotland, Spain, and Uruguay.

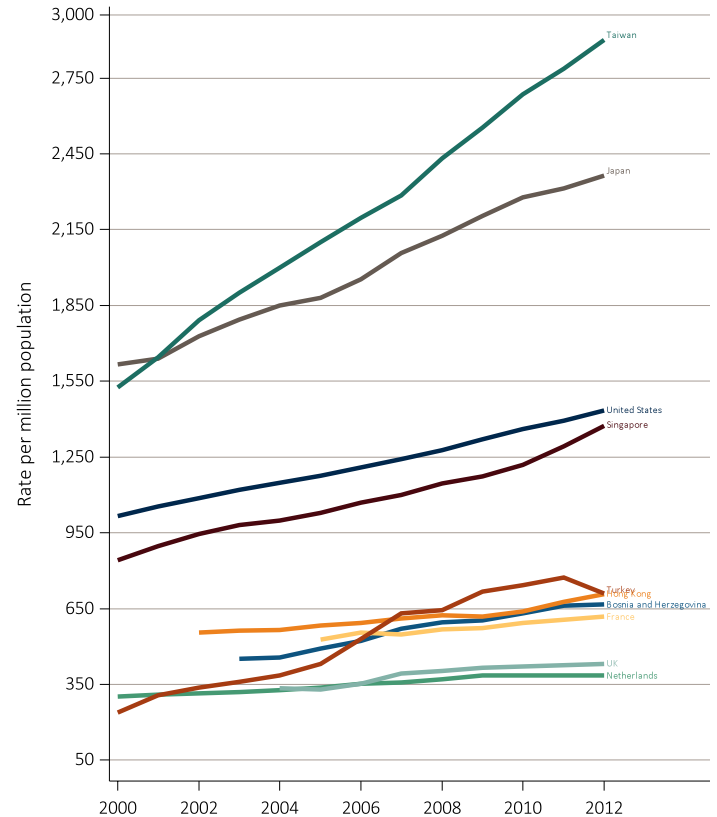
vol 2 Figure 10.7 Prevalence of dialysis, per million population, by country, in 2012



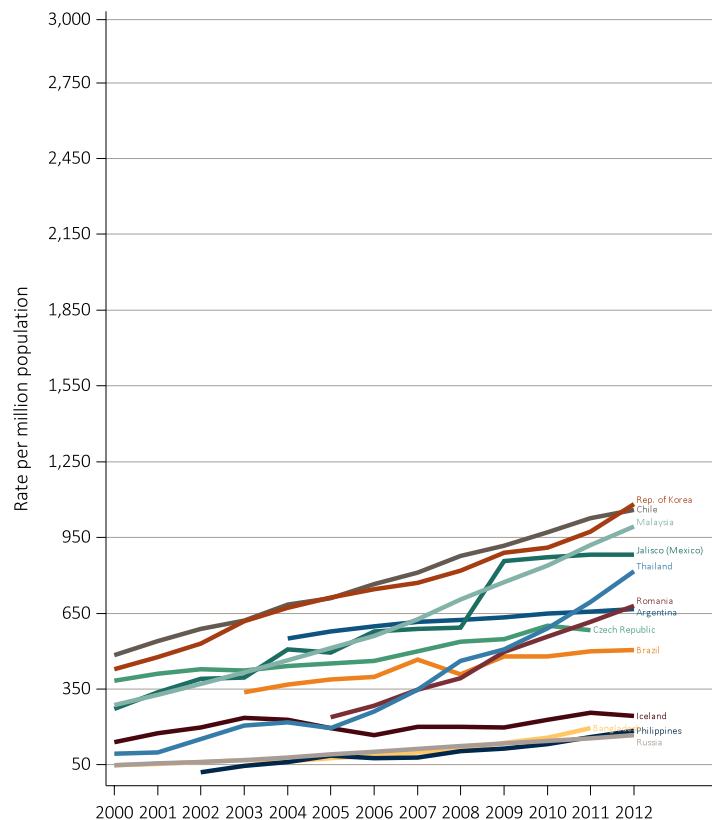
Data source: Special analyses, USRDS ESRD Database. All rates are unadjusted and reflect prevalence at the end of 2012. Japan and Taiwan include dialysis patients only. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for Spain include 18 of 19 regions. Data for France include 22 regions. Data for Belgium do not include patients younger than 20. Abbreviations: sp., speaking.

vol 2 Figure 10.8 Temporal trends in the prevalence of dialysis, per million population, by country, years 2000-2012

(a) Countries in which the prevalence of ESRD increased by 15-31% from 2006-2012



(b) Countries in which the prevalence of ESRD increased by greater than 31% from 2006-2012



Data source: Special analyses, USRDS ESRD Database. All rates are unadjusted and reflect prevalence of dialysis at the end of each year. Japan includes dialysis patients only. Abbreviations: ESRD, end-stage renal disease.

vol 2 Table 10.3 Temporal trends in the prevalence of dialysis, per million population, by country, years 2006-2012

Country	2006	2007	2008	2009	2010	2011	2012	% change from 2006 – 2012 <sup>a</sup>
Argentina	598.0	615.4	623.4	634.1	647.6	657.0	667.8	9.2
Australia	447.1	462.9	475.6	480.6	485.2	494.4	504.7	9.8
Austria	469.6	477.7	487.9	505.4	507.5	502.5	506.5	6.5
Bahrain	.	.	212.4	221.5	196.8	250.2	237.9	
Bangladesh	87.3	99.3	112.1	138.2	157.1	194.8	.	108.8
Belgium, Dutch sp.	609.9	624.3	644.4	672.5	686.2	692.7	698.4	12.7
Belgium, French sp.	637.8	657.6	673.0	671.5	690.8	699.5	724.9	10.0
Bosnia and Herzegovina	521.1	569.9	596.5	602.8	630.7	661.6	666.2	21.7
Brazil	398.3	466.0	408.5	480.2	478.7	499.8	503.9	16.1
Canada	629.9	643.1	652.4	667.5	671.3	680.9	682.7	7.1
Chile	764.9	810.2	876.3	917.9	969.6	1025.6	1059.9	32.4
Colombia	377.6	403.1	412.7	408.2	455.4	447.9	478.7	18.7
Croatia	.	.	.	.	.	.	651.7	
Czech Republic	461.9	499.9	538.1	548.7	599.8	584.1	.	21.5
Denmark	463.8	498.4	490.0	487.3	470.7	461.0	460.8	-4.2
Finland	292.4	302.0	319.8	322.9	327.6	331.1	325.3	10.4
France	554.0	546.7	567.4	573.8	592.8	606.0	617.7	11.2
Greece	793.6	811.1	824.0	851.5	867.6	881.9	904.4	11.3
Hong Kong	593.2	611.0	624.6	617.9	638.8	677.5	707.6	15.0
Hungary	.	.	578.1	605.3	620.0	626.2	632.8	
Iceland	167.9	199.7	201.6	197.8	229.5	257.0	243.2	36.1
Indonesia	.	.	.	.	.	.	.	
Iran	.	.	245.0	260.8	277.0	297.5	322.3	
Israel	652.4	668.4	684.8	703.8	721.2	728.3	730.2	10.4
Italy	.	.	.	.	792.7	.	.	
Jalisco (Mexico)	576.9	586.9	593.4	856.1	872.1	881.1	883.0	51.6
Japan	1954.5	2058.1	2126.0	2205.4	2277.4	2313.8	2365.2	16.6
Rep. of Korea	746.0	770.6	818.9	888.7	910.2	972.4	1081.0	35.4
Kuwait	.	.	.	.	.	.	346.6	
Lebanon	.	.	.	.	.	.	665.4	

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for France include 15 regions in 2006, 18 in 2007, 20 in 2008, and 22 in 2009-2012. Data for Belgium do not include patients younger than 20. Data for Spain include 18 of 19 regions. <sup>a</sup> % change is calculated as the percent difference between the average prevalence in 2011 and 2012 and the average in 2006 and 2007. Abbreviations: sp., speaking; . signifies data not reported.

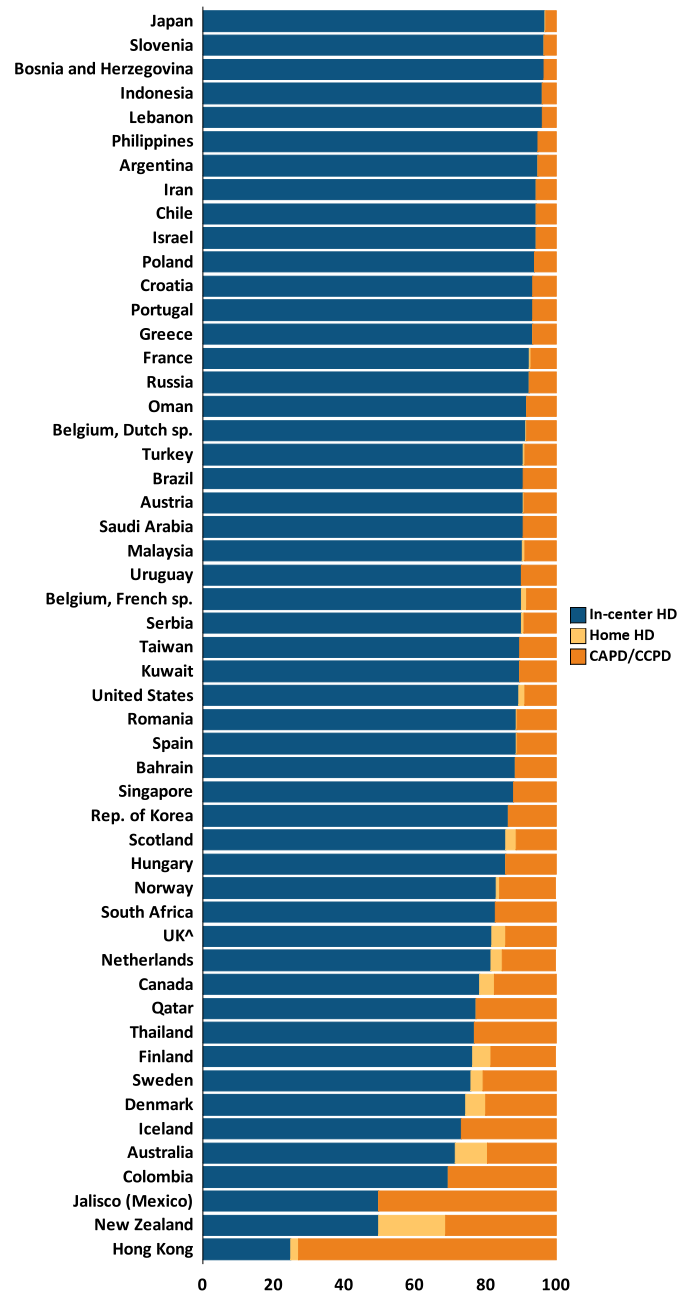
vol 2 Table 10.3 Temporal trends in the prevalence of dialysis, per million population, by country, years 2006-2012

Country	2006	2007	2008	2009	2010	2011	2012	% change from 2006 – 2012 <sup>a</sup>
Malaysia	560.8	627.1	703.8	773.7	838.7	920.5	992.2	61.0
Morelos (Mexico)	.	835.9	905.0	946.4	.	.	.	
Netherlands	353.4	356.3	369.5	384.3	384.8	384.8	384.2	8.4
New Zealand	477.5	489.8	493.3	528.5	546.7	542.3	557.0	13.6
Norway	216.5	232.3	243.7	252.0	249.9	245.9	248.1	10.1
Oman	.	.	231.0	250.7	318.8	333.9	363.7	
Philippines	75.8	79.4	104.6	114.0	132.9	159.4	184.7	121.7
Poland	.	.	417.5	432.8	446.3	466.1	483.2	
Portugal	.	.	922.6	960.5	1023.7	1052.2	1068.2	
Qatar	.	.	.	.	239.1	262.0	275.2	
Romania	285.0	346.2	393.8	497.1	557.7	616.5	679.4	105.3
Russia	101.6	.	124.4	135.4	144.3	154.8	168.3	59.0
Saudi Arabia	.	.	460.7	474.5	465.5	470.7	485.4	
Scotland	414.1	424.4	415.2	418.7	418.6	411.2	407.8	-2.3
Serbia	.	.	.	.	.	619.9	645.5	
Singapore	1070.5	1101.0	1145.9	1173.6	1218.5	1291.8	1373.6	22.7
Slovenia	.	.	.	715.3	702.9	688.3	685.4	
South Africa	.	.	.	.	.	.	132.9	
Spain	515.6	503.6	489.8	651.7	529.4	537.1	477.6	-0.4
Sweden	396.1	397.1	388.6	393.4	404.5	410.7	403.1	2.6
Taiwan	2196.8	2285.1	2432.0	2554.4	2685.2	2785.9	2902.1	26.9
Thailand	261.2	346.5	460.7	506.8	589.5	693.8	817.0	148.6
Turkey	530.8	631.5	643.7	717.6	742.9	772.8	709.8	27.6
UK <sup>^</sup>	352.7	391.8	402.8	415.1	420.1	426.0	431.7	15.2
United States	1210.0	1242.8	1278.0	1319.1	1360.1	1393.7	1435.4	15.3
Ukraine	.	.	.	.	.	.	.	
Uruguay	716.9	729.3	760.9	745.9	749.0	762.0	757.1	5.0

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. <sup>^</sup>UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for France include 15 regions in 2006, 18 in 2007, 20 in 2008, and 22 in 2009-2012. Data for Belgium do not include patients younger than 20. Data for Spain include 18 of 19 regions. <sup>o</sup> % change is calculated as the percent difference between the average prevalence in 2011 and 2012 and the average in 2006 and 2007. Abbreviations: sp., speaking; . signifies data not reported.

Hemodialysis continues to be the most common form of dialysis therapy in nearly all countries; in over 60 percent of reporting countries at least 80 percent of chronic dialysis patients were receiving HD (Figure 10.9). However, in 2012 PD was used by 73 percent of dialysis patients in Hong Kong, and 50 percent in Jalisco (Mexico). Furthermore, 31 percent PD use was reported in New Zealand and Colombia, and 17 to 27 percent in Australia, Canada, Denmark, Finland, Iceland, Qatar, South Africa, Sweden, and Thailand. As seen in Table 10.4, since 2006, an overall trend of increasing peritoneal dialysis use as a percentage of all chronic dialysis has been seen in such countries as Argentina, Hungary, Portugal, and Thailand. In contrast, PD use has declined over this same time period in countries such as the Flemish region of Belgium, Colombia, Denmark, Finland, France, Greece, Hong Kong, Israel, Jalisco (Mexico), Republic of Korea, the Netherlands, New Zealand, Norway, Romania, Scotland, Singapore, Turkey, and the U.K. Home HD therapy was provided to 19.0 and 9.2 percent of dialysis patients, respectively, in New Zealand and Australia in 2012. Home HD was also used by 3.0 to 5.7 percent of dialysis patients in Canada, Denmark, Finland, Sweden, the Netherlands, the U.K., and Scotland. However, in all other countries, home HD was either not provided, or used by fewer than two percent of dialysis patients.

vol 2 Figure 10.9 Distribution of the percentage of prevalent dialysis patients using in-center HD, home HD, and CAPD/CCPD, in 2012



Data source: Special analyses, USRDS ESRD Database. Denominator is calculated as the sum of patients receiving HD, PD, and Home HD; does not include patients with other/unknown modality. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for Spain include 18 of 19 regions. Data for France include 22 regions. Data for Indonesia represent the West Java region. Data for Belgium do not include patients younger than 20. Abbreviations: CAPD, continuous ambulatory peritoneal dialysis; CCPD, continuous cycling peritoneal dialysis; ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; sp., speaking.

vol 2 Table 10.4 Distribution of the percentage of prevalent dialysis patients using in-center HD, home HD, and CAPD/CCPD, years 2006-2012

Country	In-center HD								CAPD/CCPD								Home HD							
	2006	2007	2008	2009	2010	2011	2012	2006	2007	2008	2009	2010	2011	2012	2006	2007	2008	2009	2010	2011	2012			
Argentina	96.0	96.1	96.0	96.0	95.8	95.1	94.8	4.0	3.9	4.0	4.0	4.2	4.9	5.2	0.0	0.0	0.0	0.0	0.0	0.0	0.0			
Australia	68.2	68.3	68.6	69.6	71.3	72.2	71.4	22.1	22.0	22.0	21.0	19.5	18.8	19.5	9.6	9.8	9.4	9.3	9.2	9.0	9.2			
Austria	90.8	91.2	91.0	91.0	91.0	91.6	90.8	9.0	8.7	8.9	8.9	8.9	8.4	9.1	0.2	0.1	0.1	0.0	0.0	0.1	0.1			
Bahrain	.	.	95.7	95.8	95.5	95.3	88.4	.	.	4.3	4.2	4.5	4.7	11.6	.	.	0.0	0.0	0.0	0.0	0.0			
Bangladesh	99.6	98.4	98.3	98.3	98.3	98.3	.	0.4	1.6	1.7	1.7	1.7	1.7	.	0.0	0.0	0.0	0.0	0.0	0.0	.			
Belgium, Dutch sp.	89.1	89.2	89.7	89.8	90.6	90.9	91.5	10.7	10.6	10.1	9.9	9.1	9.0	8.2	0.2	0.2	0.3	0.3	0.3	0.1	0.3			
Belgium, French sp.	89.2	90.5	90.7	90.3	89.8	90.1	90.3	9.5	8.3	8.0	8.4	8.7	8.3	8.2	1.3	1.2	1.3	1.3	1.4	1.6	1.5			
Bosnia and Herzegovina	95.3	95.2	95.1	94.9	95.2	96.0	96.5	4.7	4.7	4.9	5.0	4.8	4.0	3.5	0.0	0.1	0.0	0.0	0.0	0.0	.			
Brazil	90.8	89.4	89.6	92.3	90.6	91.6	90.8	9.2	10.6	10.4	7.7	9.4	8.4	9.2	0.0	0.0	0.0	0.0	0.0	0.0	.			
Canada	78.9	78.6	78.4	78.4	78.5	78.9	78.4	18.4	18.4	18.4	18.1	17.8	17.1	17.5	2.8	3.0	3.3	3.5	3.7	3.9	4.1			
Chile	95.0	95.2	95.3	95.3	95.1	94.6	94.5	5.0	4.8	4.7	4.7	4.9	5.4	5.5	0.0	0.0	0.0	0.0	0.0	0.0	0.0			
Colombia	63.9	63.4	68.0	68.2	68.7	69.1	69.4	36.1	36.6	32.0	31.8	31.3	30.9	30.6	0.0	0.0	0.0	0.0	0.0	0.0	0.0			
Croatia	91.6	92.8	91.8	91.0	91.5	92.1	93.5	8.4	7.2	8.2	9.0	8.5	7.9	6.5	0.0	0.0	0.0	0.0	0.0	0.0	.			
Czech Republic	92.4	92.3	91.8	92.0	92.1	91.7	.	7.6	7.7	8.2	8.0	7.9	8.3	.	0.0	0.0	0.0	0.0	0.0	0.0	.			
Denmark	72.0	71.8	72.9	73.4	73.7	74.9	74.5	23.9	24.5	22.9	21.6	20.8	19.5	19.8	4.1	3.7	4.2	5.1	5.5	5.6	5.7			
Finland	76.0	75.8	74.3	75.0	77.1	77.4	76.4	21.2	20.4	21.7	21.3	19.0	18.4	18.2	2.9	3.8	3.9	3.7	4.0	4.1	5.3			
France	85.4	87.4	87.8	91.9	92.1	92.5	92.4	12.6	11.1	10.9	7.3	7.2	6.9	7.0	2.0	1.6	1.4	0.8	0.7	0.6	0.6			
Greece	91.5	91.7	91.7	92.0	92.3	92.8	93.4	8.4	8.3	8.3	7.9	7.7	7.2	6.6	0.0	0.0	0.0	0.0	0.0	0.0	0.0			
Hong Kong	18.8	19.8	20.4	21.5	23.5	24.4	25.0	81.1	80.0	79.2	77.9	75.6	74.1	72.9	0.0	0.2	0.4	0.6	0.9	1.5	2.1			
Hungary	.	.	88.3	87.2	86.5	85.8	85.7	.	.	11.7	12.8	13.5	14.2	14.3	.	.	0.0	0.0	0.0	0.0	0.0			
Iceland	70.6	72.1	76.6	87.3	83.6	80.5	73.1	29.4	26.2	21.9	12.7	16.4	19.5	26.9	0.0	1.6	1.6	0.0	0.0	0.0	.			
Indonesia	.	.	.	.	.	.	96.1	.	.	.	.	.	.	3.9	.	.	.	.	.	.	0.0			
Iran	.	.	93.8	93.6	93.7	93.6	94.5	.	.	6.2	6.4	6.3	6.4	5.5	.	.	0.0	0.0	0.0	0.0	0.0			
Israel	91.9	92.9	93.6	93.3	93.8	94.1	94.3	8.1	7.1	6.4	6.7	6.2	5.9	5.7	0.0	0.0	0.0	0.0	0.0	0.0	0.0			
Italy	.	.	.	.	90.0	.	.	.	.	.	.	10.0	.	.	.	.	.	.	.	.	.			
Jalisco (Mexico)	29.5	34.2	40.4	41.5	48.7	50.6	49.8	70.5	65.8	59.6	58.5	51.3	49.4	50.2	0.0	0.0	0.0	0.0	0.0	0.0	0.0			
Japan	96.8	96.7	96.8	96.7	96.7	96.8	96.9	3.2	3.3	3.1	3.2	3.2	3.1	3.0	0.1	0.1	0.1	0.1	0.1	0.1	0.1			
Rep. of Korea	78.4	80.2	81.0	83.1	84.4	84.7	86.5	21.6	19.8	19.0	16.9	15.6	15.3	13.5	0.0	0.0	0.0	0.0	0.0	0.0	0.0			
Kuwait	.	.	.	.	.	.	89.7	.	.	.	.	.	.	10.3	.	.	.	.	.	.	0.0			
Lebanon	.	.	.	.	.	.	96.0	.	.	.	.	.	.	4.0	.	.	.	.	.	.	.			

Data source: Special analyses, USRDS ESRD Database. Denominator is calculated as the sum of patients receiving HD, PD, and Home HD; does not include patients with other/unknown modality. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for France include 15 regions in 2006, 18 in 2007, 20 in 2008, and 22 in 2009-2012. Data for Spain include 18 of 19 regions. Data for Belgium do not include patients younger than 20. Data for Indonesia represent the West Java region. Abbreviations: CAPD, continuous ambulatory peritoneal dialysis; CCPD, continuous cycling peritoneal dialysis; HD, hemodialysis; PD, peritoneal dialysis; sp., speaking; . signifies data not reported.

Table 10.4 continued on next page.

vol 2 Table 10.4 Distribution of the percentage of prevalent dialysis patients using in-center HD, home HD, and CAPD/CCPD, years 2006-2012 (continued)

Country	In-center HD								CAPD/CCPD								Home HD							
	2006	2007	2008	2009	2010	2011	2012	2006	2007	2008	2009	2010	2011	2012	2006	2007	2008	2009	2010	2011	2012			
Malaysia	90.2	89.9	90.0	90.3	90.6	90.8	90.4	8.7	9.1	9.0	8.7	8.4	8.3	8.8	1.1	1.0	1.0	1.0	1.0	1.0	0.9			
Morelos (Mexico)	.	40.6	43.2	42.4	.	.	.	.	59.4	56.8	57.6	.	.	.	.	0.0	0.0	0.0	.	.	.			
Netherlands	74.8	76.0	77.4	79.0	79.5	81.5	81.7	22.9	21.7	20.1	18.5	17.8	15.8	15.2	2.3	2.3	2.5	2.5	2.7	2.7	3.0			
New Zealand	45.5	48.2	48.1	48.4	47.4	48.8	49.7	38.3	36.0	36.2	35.1	34.8	33.2	31.3	16.1	15.8	15.7	16.6	17.8	18.1	19.0			
Norway	80.5	80.6	83.4	80.7	81.3	84.2	83.1	19.1	19.1	16.4	18.8	18.0	15.3	15.8	0.4	0.3	0.3	0.5	0.7	0.6	1.0			
Oman	.	.	95.7	96.1	95.8	95.9	91.8	.	.	4.3	3.9	4.2	4.1	8.2	.	.	0.0	0.0	0.0	0.0	0.0			
Philippines	94.5	87.3	93.3	95.6	95.9	96.4	94.9	5.5	12.7	6.7	4.4	4.1	3.6	5.1	0.0	0.0	0.0	0.0	0.0	0.0	.			
Poland	.	.	93.1	93.3	93.5	94.1	94.0	.	.	6.9	6.7	6.5	5.9	6.0	.	.	0.0	0.0	0.0	0.0	0.0			
Portugal	.	.	94.8	94.4	93.9	93.7	93.4	.	.	5.2	5.6	6.1	6.3	6.6	.	.	0.0	0.0	0.0	0.0	.			
Qatar	.	.	.	.	70.9	73.5	77.4	.	.	.	.	29.1	26.5	22.6	.	.	.	.	0.0	0.0	0.0			
Romania	80.6	81.8	82.8	84.5	86.4	87.7	88.8	19.4	18.2	17.1	15.5	13.5	12.2	11.1	0.0	0.0	0.0	0.0	0.0	0.1	0.1			
Russia	91.0	.	91.0	91.3	91.4	91.6	92.3	9.0	.	9.0	8.7	8.6	8.4	7.7	0.0	.	0.0	0.0	0.0	0.0	0.0			
Saudi Arabia	.	.	92.2	90.8	90.5	90.7	90.6	.	.	7.8	9.2	9.5	9.3	9.4	.	.	.	.	.	.	.			
Scotland	79.0	80.7	82.6	83.8	84.8	85.3	85.7	19.3	17.5	15.1	13.7	12.8	12.0	11.2	1.7	1.9	2.2	2.5	2.4	2.7	3.1			
Serbia	.	.	.	.	.	90.5	90.2	.	.	.	.	.	8.8	9.1	.	.	.	.	.	0.7	0.7			
Singapore	81.1	82.5	85.6	86.3	87.4	87.2	87.9	18.8	17.4	14.4	13.6	12.5	12.8	12.0	0.1	0.1	0.1	0.1	0.1	0.1	0.1			
Slovenia	.	.	.	95.7	96.5	96.7	96.7	.	.	.	4.3	3.5	3.3	3.3	.	.	.	0.0	0.0	0.0	0.0			
South Africa	.	.	.	.	.	.	82.7	.	.	.	.	.	.	17.3	.	.	.	.	.	.	.			
Spain	90.1	89.4	90.6	90.6	89.8	89.3	88.7	9.7	10.5	9.2	9.2	10.0	10.6	11.1	0.2	0.1	0.3	0.2	0.2	0.2	0.2			
Sweden	75.5	73.0	73.3	73.6	74.7	75.6	76.0	21.9	24.2	23.9	23.6	22.5	21.3	20.6	2.6	2.9	2.8	2.8	2.8	3.1	3.4			
Taiwan	92.4	91.5	90.7	90.5	90.3	90.1	89.7	7.6	8.5	9.3	9.5	9.7	9.9	10.3	0.0	0.0	0.0	0.0	0.0	.	.			
Thailand	95.8	94.5	90.5	84.1	81.9	78.6	76.9	4.2	5.5	9.5	15.9	18.1	21.4	23.1	0.0	0.0	0.0	0.0	0.0	0.0	0.0			
Turkey	88.7	88.1	87.4	89.6	90.4	91.8	90.8	11.3	11.9	12.5	10.4	9.6	8.2	8.9	0.0	0.0	0.0	0.0	0.0	0.0	0.3			
UK	78.6	78.9	81.1	82.0	82.2	82.1	81.8	19.4	19.1	16.8	15.5	14.9	14.4	14.2	2.0	2.0	2.1	2.5	2.9	3.4	4.0			
United States	91.4	91.4	91.5	91.4	90.9	90.3	89.4	8.0	7.8	7.6	7.6	7.9	8.4	8.9	0.6	0.7	0.9	1.0	1.2	1.3	1.7			
Ukraine	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.	.			
Uruguay	92.6	90.6	91.1	90.8	90.1	90.1	90.3	7.4	9.4	8.9	9.2	9.9	9.9	9.7	0.0	0.0	0.0	0.0	0.0	0.0	0.0			

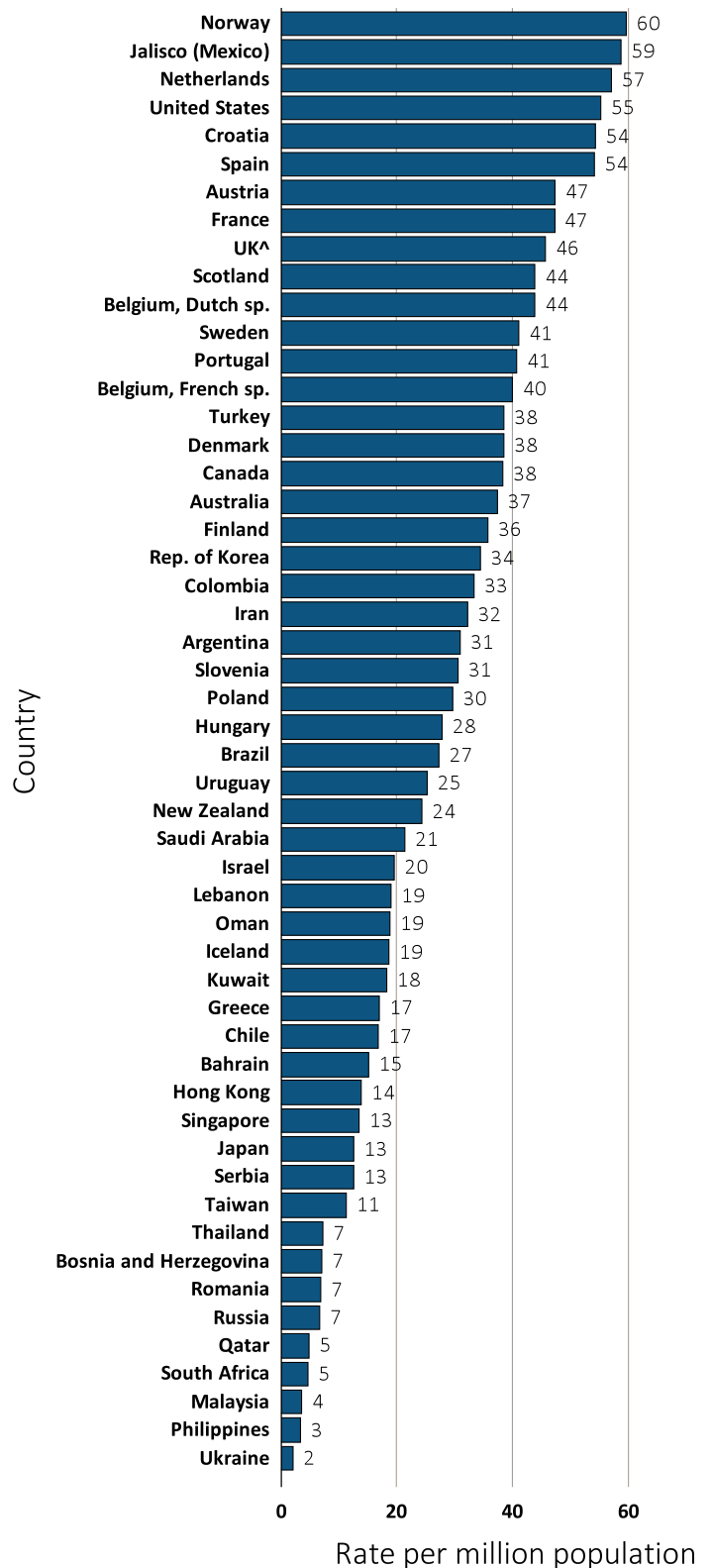
Data source: Special analyses, USRDS ESRD Database. Denominator is calculated as the sum of patients receiving HD, PD, and Home HD; does not include patients with other/unknown modality. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for France include 15 regions in 2006, 18 in 2007, 20 in 2008, and 22 in 2009-2012. Data for Spain include 18 of 19 regions. Data for Belgium do not include patients younger than 20. Data for Indonesia represent the West Java region. Abbreviations: CAPD, continuous ambulatory peritoneal dialysis; CCPD, continuous cycling peritoneal dialysis; HD, hemodialysis; PD, peritoneal dialysis; sp., speaking; . signifies data not reported.

## Transplantation

Kidney transplantation rates vary greatly across countries, which may reflect not only geographic variations in ESRD incidence and prevalence rates but also differences in national health care systems, infrastructure, organ availability, and cultural beliefs. Among the countries represented in this international chapter, kidney transplant rates varied 30-fold across countries, from two to 60 kidney transplants per million population in 2012 (see Figure 10.10). The highest kidney transplant rates were reported in Norway, Jalisco (Mexico), the Netherlands, the U.S., Croatia, and Spain with 54–60 kidney transplants per million population. Among other countries, kidney transplantation rates ranged from 30–47 per million population for 40 percent of countries, to 12–28 per million population for 30 percent of countries, and 2–7 per million population for 20 percent of countries. Countries reporting these lowest rates of kidney transplantation included Ukraine, Malaysia, the Philippines, South Africa, Qatar, Russia, Romania, Bosnia and Herzegovina, and Thailand. As shown in Table 10.5, since 2006 a substantial increase has been seen in kidney transplant rates in some countries, including Argentina, Australia, Brazil, Denmark, Saudi Arabia, Republic of Korea, Poland, Spain, Turkey, and the U.K. In contrast, kidney transplant rates appear to have declined over this time period in the Czech Republic, Greece, Malaysia, Israel, Singapore, and the Philippines.

In 2012, Norway, Portugal, and the U.S. reported the highest prevalence of ESRD patients living with a kidney transplant, at 594 to 639 per million population (Figure 10.11 and Table 10.6). Seventy percent of other participating countries reported distributions within the broad mid-range of 168 to 554 prevalent ESRD patients living with a kidney transplant per million population. The remaining 25 percent of countries had the lowest prevalence, ranging from two to 106 per million population.

vol 2 Figure 10.10 Kidney transplantation rate, per million population, by country, in 2012



Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for Belgium do not include patients younger than 20. Data for France include 22 regions. Data for Spain include all regions. There is underreporting of prevalent transplant patients in Turkey. Abbreviations: sp., speaking.



vol 2 Table 10.5 Kidney transplantation rates, per million population, by country, years 2006-2012

Country	2006	2007	2008	2009	2010	2011	2012	% change from 2006 – 2012 <sup>a</sup>
Argentina	21.7	23.0	25.1	26.4	28.4	28.9	30.9	33.8
Australia	31.0	29.3	38.0	35.5	38.3	37.0	37.3	23.2
Austria	47.9	43.7	39.5	47.4	44.6	45.0	47.3	0.8
Bahrain	.	.	10.8	18.7	11.3	6.7	15.2	
Bangladesh	0.2	0.5	0.5	0.6	0.6	0.8	.	128.6
Belgium, Dutch sp.	39.7	43.3	40.3	39.6	38.4	41.1	43.8	2.3
Belgium, French sp.	39.3	40.8	37.4	37.7	37.3	43.1	40.0	3.7
Bosnia and Herzegovina	6.8	8.4	9.1	7.0	6.0	6.3	7.1	-11.8
Brazil	17.8	18.5	20.1	22.3	24.4	25.5	27.2	45.2
Canada	38.4	39.5	38.3	37.7	37.9	37.7	38.3	-2.4
Chile	18.5	17.1	16.8	15.1	13.5	15.6	16.7	-9.3
Colombia	29.8	29.5	16.1	18.9	38.9	34.9	33.3	15.0
Croatia	.	.	.	.	.	.	54.3	
Czech Republic	41.6	38.0	31.9	34.0	27.2	31.6	.	-20.6
Denmark	30.8	31.4	34.9	40.7	41.2	44.2	38.4	32.8
Finland	39.7	32.3	28.0	33.0	32.8	33.0	35.8	-4.4
France	39.9	45.1	44.9	44.8	45.7	46.4	47.2	10.1
Greece	22.2	21.9	24.0	15.0	11.1	17.8	16.9	-21.3
Hong Kong	9.6	9.5	11.0	13.4	11.3	9.3	13.8	20.9
Hungary	.	.	25.7	27.1	30.7	25.1	27.8	
Iceland	26.3	22.5	25.2	31.4	31.4	50.2	18.7	41.2
Indonesia	.	.	.	.	.	.	.	
Iran	.	.	26.7	28.3	31.4	30.5	32.2	
Israel	43.2	37.7	33.1	28.6	23.7	36.7	19.5	-30.5
Italy	.	.	.	.	.	.	.	
Jalisco (Mexico)	52.2	59.3	54.3	58.1	60.1	62.2	58.7	8.4
Japan	.	.	.	.	11.7	12.5	12.6	
Rep. of Korea	18.8	18.5	22.7	24.5	25.1	31.7	34.4	77.2
Kuwait	.	.	.	.	.	.	18.3	
Lebanon	.	.	.	.	.	.	19.0	

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for France include 15 regions in 2006, 18 in 2007, 20 in 2008, and 22 in 2009-2012. Data for Belgium do not include patients younger than 20. There is underreporting of prevalent transplant patients in Turkey. <sup>a</sup> % change is calculated as the percent difference between the average rate in 2011 and 2012 and the average in 2006 and 2007. Abbreviations: sp., speaking; . signifies data not reported.

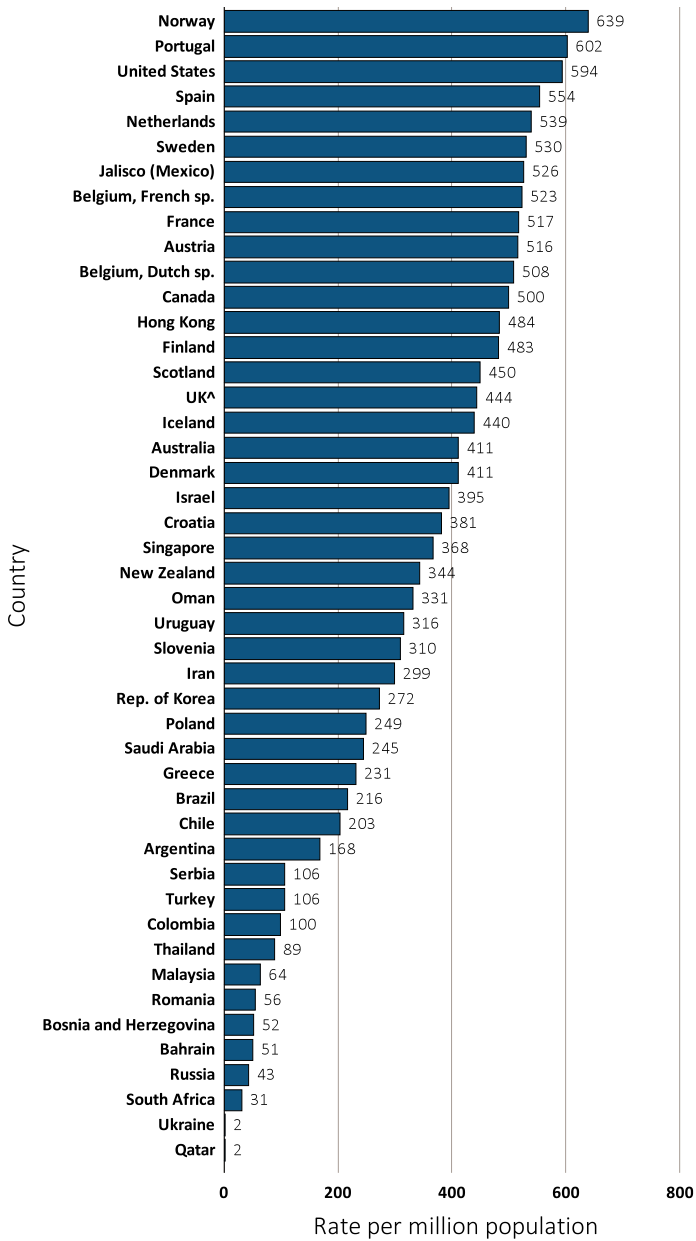
Table 10.5 continued on next page.

vol 2 Table 10.5 Kidney transplantation rates, per million population, by country, years 2006-2012 (continued)

Country	2006	2007	2008	2009	2010	2011	2012	% change from 2006 – 2012 <sup>a</sup>
Malaysia	11.1	8.2	4.7	5.1	4.5	4.3	3.6	-59.1
Morelos (Mexico)	.	54.6	44.5	41.8	.	.	.	
Netherlands	41.0	51.0	47.3	50.0	52.5	51.6	57.1	18.2
New Zealand	21.5	29.1	28.6	28.0	25.2	26.8	24.4	1.2
Norway	45.5	55.2	58.3	60.5	53.8	61.0	59.6	19.8
Oman	.	.	14.8	17.8	18.5	20.1	18.8	
Philippines	7.5	11.1	7.1	5.2	4.0	3.8	3.3	-61.8
Poland	.	.	21.2	20.6	25.9	27.0	29.7	
Portugal	.	.	49.4	55.7	54.3	50.2	40.6	
Qatar	.	.	2.1	1.2	5.2	5.2	4.9	
Romania	285.0	346.2	393.8	497.1	557.7	616.5	679.4	105.3
Russia	101.6	.	124.4	135.4	144.3	154.8	168.3	59.0
Saudi Arabia	.	.	460.7	474.5	465.5	470.7	485.4	
Scotland	414.1	424.4	415.2	418.7	418.6	411.2	407.8	-2.3
Serbia	.	.	.	.	.	619.9	645.5	
Singapore	1070.5	1101.0	1145.9	1173.6	1218.5	1291.8	1373.6	22.7
Slovenia	.	.	.	715.3	702.9	688.3	685.4	
South Africa	.	.	.	.	.	.	132.9	
Spain	515.6	503.6	489.8	651.7	529.4	537.1	477.6	-0.4
Sweden	396.1	397.1	388.6	393.4	404.5	410.7	403.1	2.6
Taiwan	2196.8	2285.1	2432.0	2554.4	2685.2	2785.9	2902.1	26.9
Thailand	261.2	346.5	460.7	506.8	589.5	693.8	817.0	148.6
Turkey	530.8	631.5	643.7	717.6	742.9	772.8	709.8	27.6
UK <sup>^</sup>	352.7	391.8	402.8	415.1	420.1	426.0	431.7	15.2
United States	1210.0	1242.8	1278.0	1319.1	1360.1	1393.7	1435.4	15.3
Ukraine	.	.	.	.	.	.	.	
Uruguay	716.9	729.3	760.9	745.9	749.0	762.0	757.1	5.0

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. <sup>^</sup>UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for France include 15 regions in 2006, 18 in 2007, 20 in 2008, and 22 in 2009-2012. Data for Belgium do not include patients younger than 20. There is underreporting of prevalent transplant patients in Turkey. <sup>o</sup> % change is calculated as the percent difference between the average rate in 2011 and 2012 and the average in 2006 and 2007. Abbreviations: sp., speaking; . signifies data not reported.

vol 2 Figure 10.11 Prevalence of ESRD patients with a functioning kidney transplant, per million population, by country, in 2012



Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. <sup>a</sup>UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for Spain include 18 of 19 regions. Data for France include 22 regions. Data for Belgium do not include patients younger than 20. Abbreviations: ESRD, end-stage renal disease; sp., speaking.

vol 2 Table 10.6 Temporal trends in the prevalence of ESRD patients with a functioning kidney transplant, per million population, by country, years 2006-2012

Country	2006	2007	2008	2009	2010	2011	2012	% change from 2006 – 2012 <sup>a</sup>
Argentina	.	.	132.3	127.9	147.2	133.6	168.0	
Australia	331.2	338.4	358.0	369.5	385.5	397.7	410.9	20.8
Austria	438.9	455.8	460.0	474.7	484.2	498.0	516.3	13.4
Bahrain	.	.	62.4	57.7	53.5	52.7	50.5	
Bangladesh	3.5	.	.	.	.	.	.	
Belgium, Dutch sp.	423.3	439.4	451.6	463.9	474.6	490.5	507.8	15.7
Belgium, French sp.	433.7	453.2	471.4	467.4	486.1	507.4	523.0	16.2
Bosnia and Herzegovina	31.6	31.8	40.4	43.6	42.3	47.0	51.6	55.5
Brazil	.	.	.	.	.	178.8	216.3	
Canada	409.2	428.1	441.7	456.8	471.0	485.1	499.9	17.6
Chile	164.8	175.4	188.9	190.8	191.5	210.1	203.4	21.5
Colombia	.	.	60.6	59.8	88.8	88.3	99.7	
Croatia	.	.	.	.	.	.	381.3	
Czech Republic	.	.	.	358.9	370.3	390.3	.	
Denmark	318.0	333.6	341.6	355.8	376.5	395.4	410.7	23.7
Finland	434.5	445.5	449.4	459.3	468.4	474.4	482.5	8.7
France	408.6	407.3	425.7	466.5	485.5	503.2	517.3	25.1
Greece	192.5	202.3	214.8	217.6	215.4	221.2	231.3	14.6
Hong Kong	409.7	420.4	442.8	459.8	467.5	474.9	484.1	15.5
Hungary	.	.	.	.	.	.	.	
Iceland	316.0	318.8	321.3	345.4	371.0	410.6	439.6	33.9
Indonesia	.	.	.	.	.	.	.	
Iran	.	.	245.7	268.0	279.4	288.0	298.9	
Israel	357.5	372.1	386.0	382.9	380.7	391.9	395.2	7.9
Italy	.	.	.	.	.	.	.	
Jalisco (Mexico)	352.0	399.4	436.2	458.2	460.2	500.4	525.8	36.6
Japan	.	.	.	.	.	.	.	
Rep. of Korea	195.7	202.2	212.8	224.8	234.1	252.4	272.3	31.9
Kuwait	.	.	.	.	.	.	.	
Lebanon	.	.	.	.	.	.	.	
Malaysia	11.1	8.2	4.7	5.1	4.5	4.3	3.6	-59.1
Morelos (Mexico)	.	54.6	44.5	41.8	.	.	.	
Netherlands	41.0	51.0	47.3	50.0	52.5	51.6	57.1	18.2

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. ^UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for France include 15 regions in 2006, 18 in 2007, 20 in 2008, and 22 in 2009-2012. Data for Belgium do not include patients younger than 20. There is underreporting of prevalent transplant patients in Turkey.

<sup>a</sup> % change is calculated as the percent difference between the average prevalence in 2011 and 2012 and the average in 2006 and 2007. Abbreviations: ESRD, end-stage renal disease; sp., speaking; . signifies data not reported.

Table 10.6 continued on next page.

vol 2 Table 10.6 Temporal trends in the prevalence of ESRD patients with a functioning kidney transplant, per million population, by country, years 2006-2012 (continued)

Country	2006	2007	2008	2009	2010	2011	2012	% change from 2006 – 2012 <sup>a</sup>
New Zealand	21.5	29.1	28.6	28.0	25.2	26.8	24.4	1.2
Norway	45.5	55.2	58.3	60.5	53.8	61.0	59.6	19.8
Oman	.	.	14.8	17.8	18.5	20.1	18.8	
Philippines	7.5	11.1	7.1	5.2	4.0	3.8	3.3	-61.8
Poland	.	.	21.2	20.6	25.9	27.0	29.7	
Portugal	.	.	49.4	55.7	54.3	50.2	40.6	
Qatar	.	.	2.1	1.2	5.2	5.2	4.9	
Romania	5.3	2.8	7.3	6.6	6.5	8.6	6.8	90.1
Russia	2.9	.	5.6	5.9	7.3	6.8	6.6	131.0
Saudi Arabia	.	.	16.3	15.1	18.6	19.5	21.4	
Scotland	26.4	37.7	41.0	40.6	35.4	37.5	43.8	26.8
Serbia	.	.	.	.	.	15.6	12.5	
Singapore	24.1	23.2	20.0	18.5	16.2	17.7	13.4	-34.2
Slovenia	.	.	.	22.6	31.2	23.4	30.6	
South Africa	.	.	.	.	.	.	4.7	
Spain	.	.	48.3	49.8	47.3	52.9	54.0	
Sweden	40.5	42.3	45.6	42.3	39.3	45.3	41.0	4.2
Taiwan	.	.	12.5	13.6	12.1	14.0	11.2	
Thailand	3.6	5.9	5.4	4.8	5.5	6.3	7.2	42.1
Turkey	11.6	18.6	18.1	26.3	34.5	39.3	38.4	157.3
UK <sup>^</sup>	34.1	38.3	40.3	42.4	44.4	44.2	45.7	24.2
United States	60.8	58.4	57.5	58.0	57.6	56.7	55.2	-6.1
Ukraine	.	.	.	.	.	.	2.1	
Uruguay	42.8	28.9	37.5	35.0	25.6	39.0	25.3	-10.3

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. <sup>^</sup>UK: England, Wales, & Northern Ireland (Scotland data reported separately). Data for France include 15 regions in 2006, 18 in 2007, 20 in 2008, and 22 in 2009-2012. Data for Belgium do not include patients younger than 20. There is underreporting of prevalent transplant patients in Turkey. <sup>a</sup>% change is calculated as the percent difference between the average prevalence in 2011 and 2012 and the average in 2006 and 2007. Abbreviations: ESRD, end-stage renal disease; sp., speaking; . signifies data not reported.

## Acknowledgements

We would like to greatly thank the following contributors—Australia and New Zealand Dialysis and Transplant Registry, Sergio Marinovich (Argentina), Anneke Kramer (Austria, Belgium, Bosnia and Herzegovina, Croatia, Denmark, Finland, Greece, Iceland, the Netherlands, Norway, Romania, Serbia, Slovenia, Sweden), Sumaya Al Ghareeb (Bahrain), Bangladesh Renal Registry, Jocemir Lugon (Brazil), Juliana Wu and Norma Hall (Canada), Hugo Poblete (Chile), Rafael Gomez and Cuenta de Alto Costo (Colombia), The Czech Registry of Dialysis Patients, Cecile Couchoud and Mathilde Lassalle (France), C.B. Leung and Yiu Wing Ho (Hong Kong), G.S. Reusz and Sandor Mihaly (Hungary), Afiatin Maman and Dheny Sarli (Indonesia), Mitra Mahdavi-Mazdeh and Katayoun Najafizadeh (Iran), Eliezer Golan (Israel), Maurizio Postorino (Italy), Ikuto Masakane (Japan), Ali Alsahow (Kuwait), Hafez Elzein (Lebanon),

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# Chapter 11: USRDS Special Study Center on Palliative and End-of-Life Care

Ann M. O'Hare<sup>1</sup> and Manjula Kurella Tamura<sup>2</sup>

## Introduction

Although it is often assumed that dialysis will restore health, this is not always the case. Patients who are disabled often become more disabled after initiation of dialysis (Kurella et al., 2009), and the prevalence of frailty and disability in the end-stage renal disease (ESRD) population is extremely high even among younger patients (Johansen et al., 2007). Despite improvements in survival among patients receiving maintenance dialysis over the past two decades, mortality rates in the ESRD population remain disturbingly high. When taken in this context, the limited survival of many patients with ESRD and their very high levels of disability, frailty and functional impairment provide a strong rationale for efforts to integrate a more palliative and patient-centered approach — focusing on relief of suffering and enhancement of quality of life — into traditional disease-based models of care (Kurella and Meier, 2013; Davison, 2011; Kurella and Cohen, 2010; Cohen et al., 2006; Moss, 2001). Key elements of a more palliative approach include a focus on symptom control, recognition of the importance of the role of family and caregivers and of efforts to coordinate care across settings, and a focus on delivering care that is congruent with each patient's goals, values and preferences (Morrison and Meier, 2004).

While palliative care is often viewed as a treatment of last resort to be offered only when all other treatment options have been exhausted, there is emerging evidence to suggest that disease-based and

palliative models of care can be complementary and synergistic rather than mutually exclusive (Temel et al., 2010). Support is now growing for a much broader deployment of palliative care within existing disease based-frameworks, beginning at the time of diagnosis and expanding to accommodate changing needs during the course of serious illness (National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for Quality Palliative Care, 2004).

## Intensive and Variable Patterns of End-of-Life Health Care Utilization in Patients with ESRD

Available information from existing USRDS and Medicare sources indicates that the majority of elderly dialysis patients receive aggressive care at the end of life that is focused on life prolongation (Figure 11.1). Almost half (44.5 percent) of older dialysis patients die in a hospital setting as compared with 35.2 percent of Medicare beneficiaries with other severe chronic illnesses (including congestive heart failure, advanced liver disease, dementia and chronic obstructive pulmonary disease) (Wong et al., 2012). Rates of hospitalization (76 percent) and ICU admission (49.0 percent) are also substantially higher than reported for other older Medicare beneficiaries, including those with cancer (of whom 61.3 percent are hospitalized and 24.0 percent are admitted to an ICU) and heart failure (of whom 64.2 percent are hospitalized and 19.0 percent are admitted to an ICU) (Wong et al., 2012). Older dialysis patients spend twice as many days in the hospital during the last month of life compared with Medicare beneficiaries with cancer (9.8 vs. 5.1 days), and are three times more likely than cancer patients to undergo an intensive procedure (29.0 percent vs. 9.0 percent). In contrast, rates of palliative care and hospice utilization among dialysis patients at the end of life are extremely low (Murray et al., 2006). Referral to hospice occurs much less commonly among dialysis patients than among cancer patients, even after a

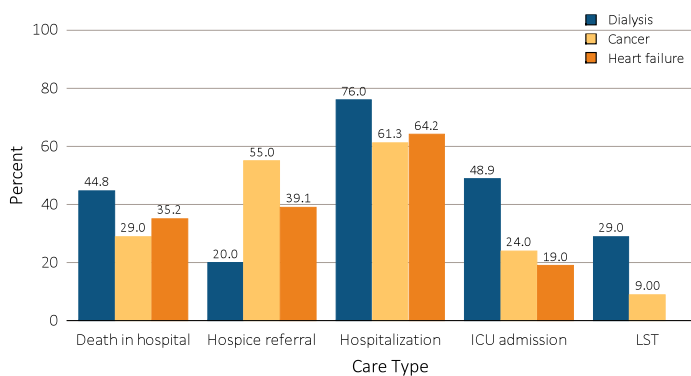
<sup>1</sup> Hospital and Specialty Medicine and Health Services Research and Development Center for Innovation for Veteran-Centered and Value-Driven Care, VA Puget Sound Health Care System and Department of Medicine and Kidney Research Institute, University of Washington, Seattle, WA.

<sup>2</sup> Geriatric Research and Education Clinical Center, VA Palo Alto Health Care System and Department of Medicine, Stanford University Medical Center, Palo Alto, CA.

decision has been made to discontinue dialysis. Fewer than 1 in 5 U.S. dialysis patients are referred to hospice before death compared with 55.0 percent of Medicare beneficiaries with cancer and 38.1 percent of those with heart failure (Murray et al., 2006).

Patterns of care at the end of life among older dialysis patients are highly variable, and seem to be shaped much more by regional treatment practices than by individual patient characteristics. Rates of referral to hospice and dialysis discontinuation before death vary by more than twofold across hospital referral regions, with the lowest rates observed in regions with the highest levels of end-of-life health care spending among Medicare beneficiaries (O'Hare et al., 2010). As for other populations, patterns of end-of-life care among patients with ESRD also vary dramatically by race. Rates of hospice referral and dialysis discontinuation among Black patients are less than half of those among White patients, with the most marked racial differences in patterns of end-of-life care observed in regions with the highest levels of end-of-life health care spending (O'Hare et al., 2010; Thomas et al., 2013).

**vol 2 Figure 11.1 Patterns of health care utilization during the last month of life among older Medicare beneficiaries with ESRD vs. other conditions (adapted from Wong et al., 2012 )**



Abbreviations: ICU, intensive care unit; LST, life-sustaining treatment.

## Unmet Palliative Care Needs of Patients With ESRD

Although dialysis is intended to address the signs and symptoms of advanced kidney disease, it is becoming increasingly clear that patients receiving maintenance dialysis have a high symptom burden, similar to that of patients with terminal cancer (Murtagh, 2007). A number of single center studies have now documented extremely high rates of untreated pain and other debilitating symptoms as well as a large unmet need for spiritual and palliative support (Davison, 2003; Davison and Jhangri, 2010). Patients treated with

maintenance dialysis face a singularly complex set of treatment decisions toward the end of their lives, often in a setting of great uncertainty about the relative benefits and harms of recommended interventions (Kaufman et al., 2006; Murtagh et al., 2007). Many ultimately discontinue this therapy before death (Murtagh et al., 2007).

Limited data suggest that patients with ESRD may not be aware of their prognosis and have unrealistic expectations about their expected disease course and appropriate treatment options (Wachterman et al., 2013). To date, no prior studies have provided nationally representative information about treatment preferences, palliative care needs, engagement in advance care planning (ACP) or prognostic expectations among patients with ESRD. Nor have prior studies evaluated the extent to which downstream patterns of care toward the end of life among patients with ESRD are congruent with their preferences.

## Study Rationale

Prior USRDS Special Study Centers have augmented existing registry data with detailed information relevant to several important domains of care not captured in standard CMS sources, including nutritional status, rehabilitation, disease burden and quality of life. However, these studies have not explicitly addressed palliative and end-of-life care — a domain with a high degree of relevance to this population and for which nationally representative data are currently lacking. Most single center studies of palliative and end-of-life care have been cross-sectional, and thus, have not examined the downstream effects of ACP or other interventions that may enhance the quality of end-of-life care in this population.

## Study Goals

The overarching goal of the USRDS Special Study Center (SSC) on Palliative and End-of-Life Care is to provide the nephrology community with innovative, rigorous and nationally representative information about a domain of ESRD care for which little information is currently available to guide policy and practice.

The SSC will conduct prospective surveys using previously validated instruments among patients with ESRD to obtain information across a range of domains related to palliative and end-of-life care. Specifically, we will collect information from patients on symptom



burden, palliative care needs, engagement in advance care planning, preferences for life-sustaining treatment, and knowledge of prognosis and treatment options, including hospice and dialysis discontinuation.

The SSC will also collect information from family members of patients with ESRD about their level of involvement in the patient's care, the impact of the patient's illness on their own health and their understanding of the patient's preferences for life sustaining treatment, readiness to engage in advance care planning and knowledge of treatment options. Ultimately, information collected prospectively from patients and family members will be linked to information for each patient on patterns of health care utilization at the end of their life.

In parallel with these prospective data collection efforts, the SSC will conduct secondary analyses of existing Medicare and USRDS sources to gain a broad understanding of patterns of health care utilization and costs during the final months and years of life among patients with ESRD, including trends over time, across regions, and among different subgroups of patients.

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# Chapter 12: USRDS Special Study Center on Transition of Care in CKD

Kamyar Kalantar-Zadeh, MD, MPH, PhD<sup>i</sup>,  
Csaba P Kovessy, MD<sup>ii</sup>, Steven S Jacobsen, MD, PhD<sup>iii</sup>,  
Elani Streja, MPH, PhD<sup>iv</sup>, John J Sim, MD<sup>v</sup>,  
Connie M Rhee, MD, MSc<sup>vi</sup>,  
Joline LT Chen, MD, MSc<sup>vii</sup>, Melissa Soohoo, MPH<sup>viii</sup>,  
Vanessa Ravel, MPH<sup>ix</sup>, Jennie Jing, MS<sup>x</sup>,  
Miklos Z Molnar, MD, PhD<sup>xi</sup>, and Tracy Nakata<sup>xii</sup>.

## Introduction

In patients with very-late-stage non-dialysis dependent chronic kidney disease (NDD-CKD; eGFR <25 ml/min/1.73 m<sup>2</sup>), the optimal transition of care to kidney replacement therapy (KRT, i.e., dialysis or transplantation) is not known. Significant knowledge gaps have persisted pertaining to differential or individualized transitions of care across varying age groups, sociodemographic status, and pre-KRT comorbid conditions and events in several key areas related to the (1) best timing for KRT transition, (2) the optimal KRT type and modality, and (3) the post-KRT impact of pre-KRT comorbid conditions and events including blood pressure and glycemic control, acute kidney injury (AKI) episodes, and pre-KRT management of CKD-specific conditions. Given the major changes occurring in our health care system, the escalating costs of dialysis therapy with persistently poor outcomes, and the heightened expenses and mortality risk particularly during the period of transition to KRT, there is an urgent need to answer these important questions related to transitions from NDD-CKD to KRT.

Given the limitations of prior United States Renal Data System (USRDS) reports that lacked most core data preceding the KRT transition intercept, this USRDS Special Study entitled “Transition of Care in CKD” (TC-CKD, 2014-2019) has been developed to provide innovative linkages between the USRDS and two exceptionally rich and large longitudinal databases of NDD-CKD patients, i.e., the national (entire United States [U.S.]) Veterans Affairs (VA) database and the regional (Southern California) Kaiser Permanente

(KP-SC) database, each consisting of thousands of NDD-CKD patients who transition to KRT each year. In the first phase of this Special Study, we will examine the recent national veterans and KP-SC cohorts of incident end-stage renal disease (ESRD) patients and provide pre-KRT data on all recent KRT transitions since 10/1/2007 among Veterans and since 1/1/2008 among KP-SC patients. In subsequent years we will provide annual linkages to projected data from thousands of incident ESRD patients who transition to KRT from 2013 to 2016. During this five-year USRDS project we will also examine the hypotheses that a pre-KRT data-driven individualized approach to the transition of care into KRT in very-late-stage NDD-CKD is associated with more favorable outcomes including greater survival, fewer hospitalizations and reduced costs, particularly if the decision is based on pre-KRT factors such as clinical and laboratory variables including the CKD progression rate, comorbid conditions, and demographics. We will also develop and validate scoring systems derived from these pre-KRT data to better ascertain the timing, preparation and modality of KRT associated with better outcomes.

Given the late project start of mid-2014, our report this year is limited to data from approximately 52,000 incident ESRD veterans who transitioned to KRT between 10/1/2007 and 9/30/2011. We will also present a brief overview of KP-SC data that will be examined in the following years.

## The Veterans Health Administration

The current U.S. veteran population is estimated to be approximately 22 million, of whom 8.9 million U.S. veterans are enrolled in the Veterans Health Administration (VHA), and of whom 5.8 million receive their healthcare in one of the VHA facilities. During the fiscal year of 2013 there were 86.4 million outpatient visits and 694,700 inpatient admissions at Veterans Affairs (VA) healthcare facilities <sup>1</sup>.

Whereas approximately 90 percent of the current U.S. veteran population consists of males, the sex distribution is changing, and it is estimated that by 2040 approximately 18 percent of the VA population will be females. Minority veterans made up about 21 percent of the total veteran population in 2011. The majority of minority veterans were Black (11 percent), with Hispanics as the second largest group (6 percent)<sup>2</sup>.

The VHA facility network consists of 150 hospitals, along with 820 community-based outpatient clinics and 300 veterans' centers<sup>3</sup>. Services provided by the VA department and VHA facilities include comprehensive medical care, life insurance, disability compensation, home loans, educational benefits, pensions and vocational rehabilitation training.

### Management of ESRD in the VHA

The VHA provides comprehensive medical care for patients with kidney disease, including acute kidney injury (AKI) and all stages of CKD. Management of kidney disease that does not require KRT is typically provided by VA personnel at one of the nationwide VHA facilities, or by local private providers (paid by the VHA) in cases where the VHA cannot provide adequate care (for reasons such as prohibitive distance or lack of adequate resources).

Veterans who develop ESRD are eligible to receive KRT from the VHA. Dialysis care is a covered benefit under VA's Medical Benefits Package for veterans enrolled in the VA, irrespective of their service connectedness<sup>4</sup>. For patients requiring in-center dialysis treatment, the VHA provides renal replacement therapy both through dialysis units maintained and operated by individual VA facilities, or by purchasing dialysis services from private dialysis providers (in cases where the distance from a VA facility is prohibitive for thrice-weekly dialysis, or when the capacity of the VA facility-operated dialysis unit is exceeded). There are currently 71 VA facilities nationwide which maintain and operate an in-house (in-center) dialysis center<sup>5</sup>. Most such dialysis units provide both chronic outpatient and acute inpatient dialysis treatments in the same center and simultaneously. The majority of ESRD veterans, however, receive dialysis treatment in non-VHA facilities including dialysis chains (see below).

Veterans who elect to perform home-based dialysis therapies and who are medically acceptable candidates are provided with the necessary training, medical equipment and supplies, and home support required

to perform home dialysis (home hemodialysis (HD) or peritoneal dialysis (PD) by the VHA. Both types must be made available to veterans by the VHA or through non-VA care if the VA facility is unable to provide that service<sup>6</sup>. Besides dialysis therapy, veterans are also eligible to receive kidney transplantation at one of four designated facilities<sup>7</sup>, and also post-transplant care including necessary medications.

In addition to providing KRT, other benefits offered by the VHA to veterans with kidney disease include beneficiary travel support, long term care in hospice services, respite care, domiciliary care, and adult day health care as needed, and assistance for home improvements necessary for the continuation of treatment under the Home Improvements and Structural Alterations (HISA) Program<sup>6</sup> (e.g. for veterans performing home HD).

### Highlights of Data of Incident ESRD Veterans between 10/1/2007 and 9/30/2011

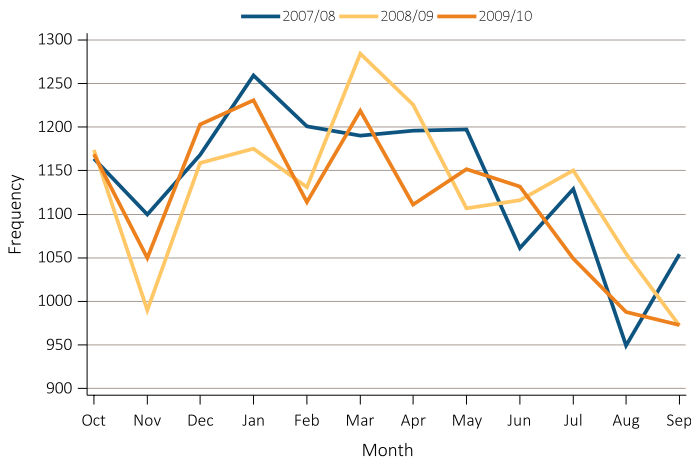
Between 10/1/2007 and 9/30/2011 (four fiscal years), a total of 52,172 veterans transitioned to KRT. Their mean  $\pm$  SD age was 70.3  $\pm$  12.1 years old, and they were comprised of 24.1 percent Blacks and six percent Hispanics. Diabetes mellitus (DM) and hypertension (HTN) were the cause of ESRD in 41.7 percent and 31.4 percent of patients, respectively. During the first three months of KRT, 10.4 percent of all incident ESRD veterans died and 1.4 percent received a kidney transplantation. At three months, 92.3 percent of the incident ESRD veterans were on HD and 6.1 percent on PD; less than one percent received home HD.

### ESRD Rate and Seasonal Variation Among Veterans

During the four-year observation periods, the average rate of transition to ESRD among veterans was 1,087 patients per months. During the four-year observation period, 13,668, 13,539, and 13,391 veterans transitioned to dialysis or preemptive transplantation in years one, two, and three, respectively, which yielded an ESRD transition rate of 1,128 patients per month for the first three years. The annual ESRD transition census for the fourth observation year (10/1/2010-9/30/2011) is slightly lower than prior years (n=11,573). Since it is not certain as to whether this is a true decline in trend versus under-reporting of data in the final months of the fourth year, the seasonal (month-by-month) variations are presented for the first three years (see Figure 12.1).

In general the highest transition rates are observed during the months of December through May, whereas the transition rates tend to be lower during June through November of each year.

vol 2 Figure 12.1 Monthly variation in patient enrollment in 52,172 incident ESRD veterans 10/1/2007-9/30/2011

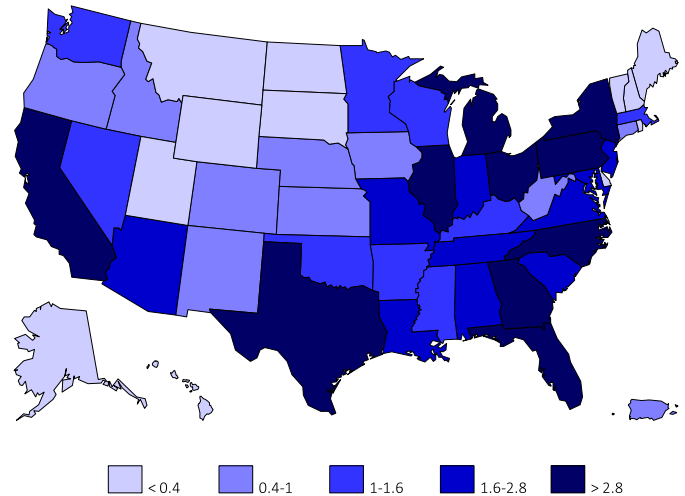


Data source: USRDS ESRD Database. Transition rates are reported for each month. Abbreviations: ESRD, end-stage renal disease.

### Distribution of Incident ESRD Veterans in the United States

One-third (n=17,951, 34.4 percent) of 52,172 veterans who transitioned to KRT during the four-year period (10/1/2007-9/30/2011), lived in five states including California (n=4,618, 8.9 percent), Florida (n=4,022, 7.7 percent), Texas (n=3,718, 7.1 percent), New York (n=2,915, 5.6 percent), and Pennsylvania (n=2,678, 5.1 percent). Less than five percent of the incident ESRD veterans resided in each of the other states and territories (see Figure 12.2).

vol 2 Figure 12.2 Distribution and density of the 52,172 incident ESRD veterans across states and territories of the United States 10/1/2007-9/30/2011

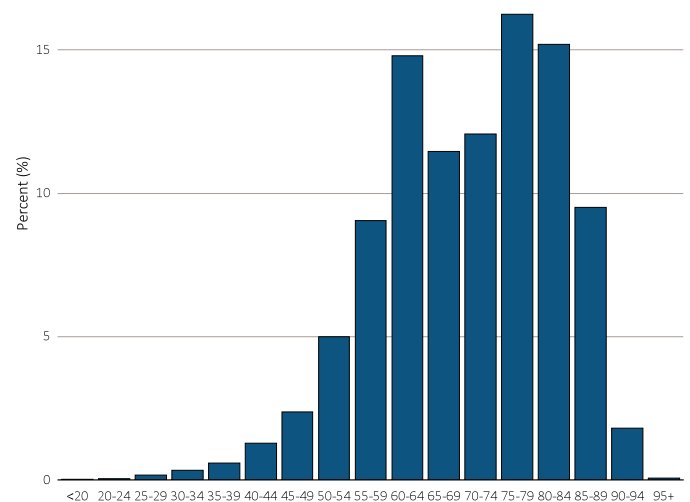


Data source: USRDS ESRD Database. States and territories of the United States of America. Abbreviations: ESRD, end-stage renal disease.

### Age, Sex and Race Distribution of Incident ESRD Veterans

The mean ± SD age of incident ESRD veterans are 70.3 ±12.1 years. A bimodal age distribution exists among 60-<65 and 75-<85 year old veterans (see Figure 12.3), whereas among the 22.3 million veterans a non-bimodal age distribution is observed with the mode in the 70-<75 year age group in 2011<sup>8</sup>. Among all states, Rhode Island, Massachusetts and Maine had the highest mean ages of 75.6, 75.4 and 73.8 years, respectively.

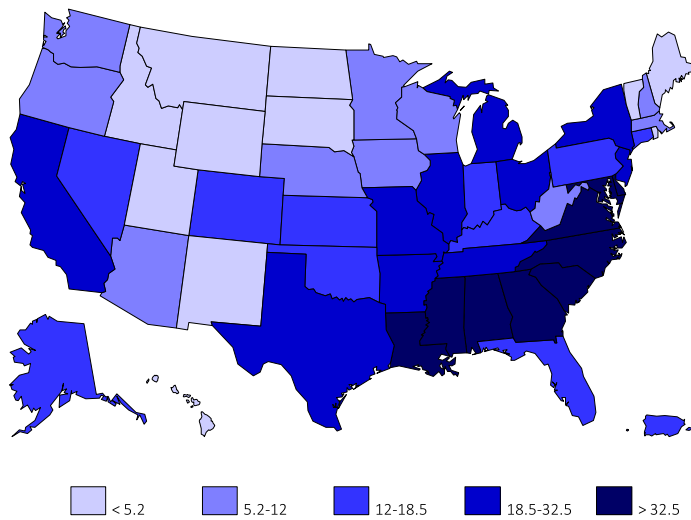
vol 2 Figure 12.3 Age in 5-year increments at first ESRD service in 52,172 incident ESRD veterans, 10/1/2007-9/30/2011



Data source: USRDS ESRD Database. Age groups are in 5-year increments except for <20 and >95 years or older. Abbreviations: ESRD, end-stage renal disease.

Only 5.7 percent of the ESRD veterans were women (n=2,955) during this period. Blacks constituted 24.1 percent of the incident ESRD population (n=12,584), as compared to 12.0 percent of all veterans being Black in 2011. There was a substantially smaller proportion of Asians (n=957, 1.8 percent) and Native Americans (n=543, 1.0 percent). Most Southeast states had larger proportions of Black incident ESRD veterans. Among mainland states and territories, District of Columbia had 91.7 percent Blacks, followed by Maryland (55.0 percent), Georgia (49.4 percent) and South Carolina (45.8 percent; see Figure 12.4).

vol 2 Figure 12.4 Distribution of Black incident ESRD veterans in the United States, 10/1/2007-9/30/2011

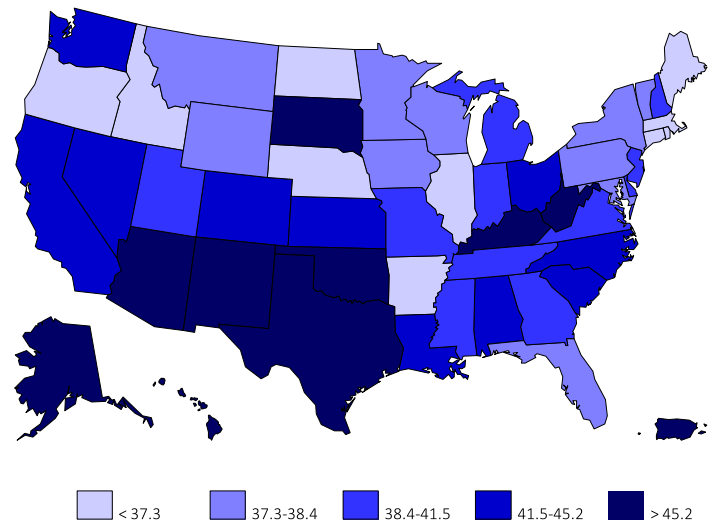


Data source: USRDS ESRD Database. States and territories of the United States of America. Abbreviations: ESRD, end-stage renal disease.

### Primary Disease Causing ESRD Among Veterans

Among all incident ESRD veterans, 41.7 percent (n=21,736) had DM and 31.4 percent (n=16,403) had HTN as the primary etiology of ESRD. Among states and territories with more than 100 incident ESRD veterans during the observation period, Hawaii (62.0 percent), Puerto Rico (59.8 percent) and West Virginia (50.2 percent) harbored the largest proportion of diabetic patients, followed by Southern states (see Figure 12.5).

vol 2 Figure 12.5 Distribution of diabetes mellitus as the primary cause of kidney disease among incident ESRD veterans in the United States, 10/1/2007-9/30/2011

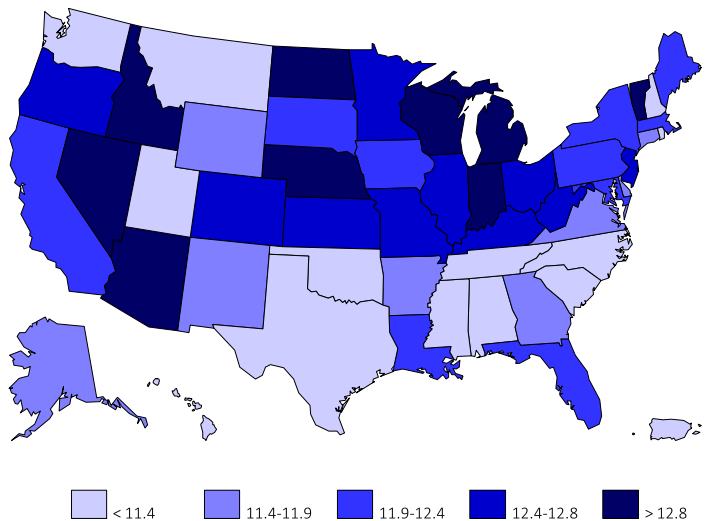


Data source: USRDS ESRD Database. States and territories of the United States of America. Abbreviations: ESRD, end-stage renal disease.

### Estimated GFR upon Transition to KRT

Among 52,172 veterans, the mean  $\pm$  SD eGFR upon transition to KRT was 12.1  $\pm$  5.1 (mean  $\pm$ SD) ml/min/1.73m<sup>2</sup>. There were geographic variations in the starting eGFR as shown in Figure 12.6. Among the 50 states, Hawaii, Rhode Island and South Carolina had the lowest eGFRs at the start of KRT, i.e., 9.5, 10.2 and 10.4 ml/min/1.73m<sup>2</sup>, respectively; whereas North Dakota, Idaho and Vermont exhibited the highest eGFRs of 14.1, 13.4 and 13.3 ml/min/1.73m<sup>2</sup>, respectively. These variations may suggest differences in practice patterns related to the timing of dialysis therapy initiation.

vol 2 Figure 12.6 Distribution of eGFR upon KRT in 52,172 incident ESRD veterans in the United States, 10/1/2007-9/30/2011



Data source: USRDS ESRD Database. States and territories of the United States of America. Abbreviations: ESRD, end-stage renal disease.

## First 90 Days after Transition to ESRD

Table 12.1 shows the status of incident ESRD veterans during the first 90 days after transition to KRT from 10/1/2007 to 9/30/2011. On Day 1 of ESRD service, over 80 percent of the 52,172 veterans received in-center HD treatment (n=43,256, 82.9 percent), whereas the number of PD patients at this time was less than five percent (n=2,552, 4.9 percent). There were 589 preemptive kidney transplant recipients (1.1 percent). Of note 201 veterans (0.4 percent) were already declared deceased on Day 1 of ESRD service initiation.

After 90 days of service, 44,320 of the original 52,172 incident ESRD veterans were still undergoing dialysis treatment, whereas 7,852 (15.2 percent) were not, including 10.3 percent who died in the first three months (n=5,348; see first-year mortality data below) and 1.3 percent who received a kidney transplantation (n=701). A total of 1,789 veterans (3.5 percent) recovered from ESRD and stopped dialysis therapy by the end of the 90 days, mostly during the second and third month after transition to ESRD.

**vol 2 Table 12.1 Status of 52,172 incident ESRD veterans during the first 90 days after transition to KRT, 10/1/2007-9/30/2011**

	Day 1		Day 30		Day 60		Day 90	
	n	%	n	%	n	%	n	%
<b>Dialysis modality</b>								
<b>In-center</b>	43,256	82.9	43,258	82.9	43,163	82.7	40,918	78.4
<b>Home HD</b>	260	0.5	260	0.5	259	0.5	258	0.5
<b>CAPD</b>	1,405	2.7	1,405	2.7	1,398	2.7	1,302	2.5
<b>CCPD</b>	1,174	2.2	1,174	2.2	1,182	2.3	1,395	2.7
<b>Uncertain*</b>	5287	10.1	3,495	6.7	612	1.2	447	0.9
<b>Outcomes**</b>								
<b>Death</b>	201	0.4	1,561	3	3,672	7	5,348	10.3
<b>Transplant</b>	589	1.1	654	1.3	679	1.3	701	1.3
<b>Lost to follow-up</b>	n/a	.	3	<0.1	3	<0.1	5	<0.1
<b>Recovered</b>	n/a	.	362	0.7	1,204	2.3	1,798	3.5
<b>Total</b>	<b>52,172</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>52,172</b>	<b>100</b>

Data source: USRDS ESRD Database. \* Uncertain groups have no known dialysis modality. \*\* n for outcomes is cumulative for subsequent periods after Day 1. Abbreviations: CAPD, continuous ambulatory peritoneal dialysis; CCPD, continuous cycling peritoneal dialysis ESRD, end-stage renal disease; HD hemodialysis.

## Dialysis Providers upon Transition to ESRD

Table 12.2 shows the status of incident ESRD veterans on Day 1 of ESRD service according to the type of dialysis provider. Upon transition to KRT among 52,172 veterans over the four-year period, only 9.9 percent (n=5,157) received dialysis therapy in one of the in-center dialysis units based at VHA medical centers. Over half of all veterans (52.1 percent) who transitioned to KRT received maintenance dialysis therapy in a for-profit “large dialysis organization” (LDO), which included Fresenius Medical Care (FMC, 27.6 percent) and DaVita (DVT, 24.5 percent); 13.1 percent of veterans underwent dialysis therapy in other dialysis chains and 21.1 percent received treatment in a dialysis unit that did not belong to any chain (i.e. free-standing and hospital based units). Among 3.9 percent of these veterans, the dialysis provider could not be identified on Day 1; over a quarter of the latter group (26.4 percent) had received a preemptive kidney transplantation and 10 percent of them were declared dead on Day 1.

The mean age of veterans who received dialysis treatment in a VHA medical center was on average 5.8 years younger than the mean age of all incident ESRD veterans, and only 43.4 percent of these patients were older than 65 years as compared to 66.3 percent of all incident ESRD veterans. VHA medical centers had a larger proportion of Black patients (41.3 percent) as compared to all incident ESRD veterans who received dialysis (24.1 percent).

vol 2 Table 12.2 Day 1 of ESRD service in 52,172 incident ESRD veterans upon transition to KRT, 10/1/2007-9/30/2011

	All veterans	VHA	FMC	DVT	Other Chains	Non-Chain	Provider not known
<b>Veterans, n (%)</b>	<b>52,172 (100%)</b>	5,157 (9.9%)	14,380 (27.6%)	12,766 (24.5%)	6,850 (13.1%)	11,007 (9.9%)	2,010 (3.9%)
<b>Number of facilities</b>	<b>5504</b>	68	1686	1352	793	1425	
<b>Age, year (SD)</b>	<b>70.3 (12.1)</b>	64.6 (11.4)	70.7 (11.8)	70.3 (12.1)	71.2 (11.9)	72.1 (11.8)	68.3 (13.6)
<b>Older than 85 yrs (%)</b>	<b>11.4</b>	4.6	11.1	11.3	12.2	14.3	12.3
<b>Females (%)</b>	<b>5.7</b>	2.5	6.1	6	6.1	5.7	7.6
<b>Race/ethnicity</b>							
Native American (%)	<b>1</b>	0.7	0.8	1.1	0.8	1.5	1.1
Asian (%)	<b>1.8</b>	1.8	1.3	1.7	3.4	1.2	5
Black/Af Am (%)	<b>24.1</b>	41.3	23.4	24.9	22.1	18.5	18.3
White (%)	<b>72.6</b>	55.7	74.3	72.1	73.6	78.6	69.9
Hispanic (%)	<b>6</b>	8.8	5.9	5.4	6.1	5.3	6.7
<b>Primary cause of ESRD</b>							
Diabetes (%)	<b>41.7</b>	47	42.6	42.7	41.7	40.1	23.7
Hypertension (%)	<b>31.4</b>	22.2	34.2	32.8	32.6	32.3	18.2
GN (%)	<b>5.5</b>	7.8	5.1	4.9	5.6	5	7.8
Cystic kidney (%)	<b>1.5</b>	1.6	1.5	1.5	1.3	1.4	3.7
<b>KRT modality</b>							
HD (%)	<b>82.9</b>	90.6	84.8	84.6	84.9	78.2	51.6
PD (%)	<b>4.9</b>	3.6	4.9	5.1	4.9	5.7	3.2
<b>Mortality (%)</b>	<b>0.4</b>	0	0	0	0	0	10
<b>Transplant (%)</b>	<b>1.1</b>	1.1	0	0	0	0	26.4
<b>Recovered function</b>	<b>n/a</b>	n/a	n/a	n/a	n/a	n/a	n/a
<b>Laboratory data</b>							
Hemoglobin (g/dL)	<b>10.0 (1.6)</b>	9.8 (1.6)	10.0 (1.6)	10.0 (1.6)	10.1 (1.6)	10.1 (1.5)	10.5 (1.7)
Albumin (d/dL)	<b>3.2 (0.7)</b>	3.2 (0.7)	3.2 (0.7)	3.2 (0.7)	3.2 (0.7)	3.2 (0.7)	3.4 (0.7)
Creatinine (mg/dL)	<b>6.0 (2.9)</b>	6.9 (3.1)	6.0 (2.9)	6.0 (2.9)	5.9 (2.9)	5.8 (2.8)	5.4 (2.6)
eGFR (ml/min/1.73m <sup>2</sup> )	<b>12.1 (5.1)</b>	10.9 (4.4)	12.1 (5.1)	12.2 (5.1)	12.3 (5.2)	12.4 (5.2)	13.1 (5.3)
BMI (kg/m <sup>2</sup> ) (SD)	<b>28.3 (6.7)</b>	28.6 (6.8)	28.6 (6.9)	28.2 (6.6)	28.0 (6.6)	28.0 (6.6)	28.6 (5.8)

Data source: USRDS ESRD Database. Percentages and standard deviation values are in parentheses. Abbreviations: Af Am, African American; BMI, body mass index; DVT, DaVita; eGFR, estimated glomerular filtration rate; ESRD, end-stage renal disease; FMC, Fresenius Medical Care; GN, glomerulonephritis; HD, hemodialysis; KRT, kidney replacement therapy; PD, peritoneal dialysis; SD, standard deviation; VHA, Veterans Health Administration.

Table 12.3 shows the status of the ESRD veterans on Day 90 of ESRD service according to their type of dialysis provider. This table also includes selected outcome data over the first three months of post-KRT including mortality, transplantation and recovered kidney function.

After three months among surviving ESRD veterans, over half of the veterans (52.4 percent) continued to receive dialysis therapy in a for-profit LDO (FMC or DVT), 13.2 percent in other dialysis chains, and 21.1 percent in independent (non-chain) dialysis centers; 10.7 percent received dialysis in one of the 68 VHA medical centers. Racial and sex differences continued to exist between VHA and non-VHA dialysis providers.



vol 2 Table 12.3 Status of ESRD service after 3 months among 44,220 ESRD veterans after transitioning to KRT, including selected outcomes over the first 3 months in veterans who transitioned to KRT during 10/1/2007-9/30/2011

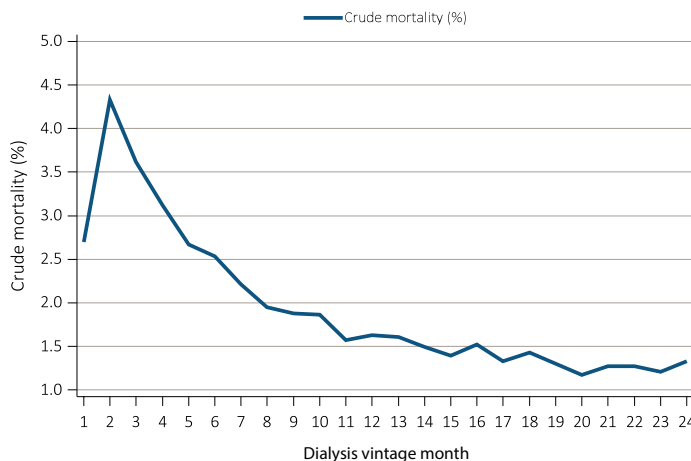
	All veterans	VHA	FMC	DVT	Other Chains	Non-Chain	Provider not known
<b>Veterans, n (%)</b>	<b>44,220 (100%)</b>	4,714 (10.7%)	12,313 (27.8%)	10,900 (24.6%)	5,838 (13.2%)	9,339 (21.1%)	1,116 (2.5%)
<b>Number of facilities</b>	<b>5494</b>	68	1686	1530	792	1418	.
<b>Age, year (SD)</b>	<b>69.8 (12.0)</b>	64.4 (11.2)	70.2(11.8)	69.8 (12.0)	70.7 (12.0)	71.6 (11.8)	69.6 (12.6)
<b>Older than 85 yrs (%)</b>	<b>10.3</b>	4.2	10	10.1	11.5	13.1	11.2
<b>Female (%)</b>	<b>5.7</b>	2.5	6.3	6.1	6.2	5.9	6
<b>Race/ethnicity</b>							
Native American (%)	1.1	0.6	0.9	1.2	0.9	1.6	0.6
Asian (%)	1.9	1.6	1.5	1.8	3.6	1.2	3.9
Black/Af Am (%)	25.9	42.6	24.9	26.6	23.8	19.6	22
White (%)	70.8	54.7	72.5	70.2	71.7	77.4	65.4
Hispanic (%)	6.3	9.1	6.2	5.8	6.1	5.5	8
<b>Primary cause of ESRD</b>							
Diabetes (%)	44	49.1	44.3	44.9	43.7	42	30.6
Hypertension (%)	31.9	22.5	34.4	33.2	33	32.3	21.5
GN (%)	5.7	8	5.5	5.2	6	5.4	4.1
Cystic kidney (%)	1.6	1.6	1.6	1.6	1.5	1.6	0.8
<b>KRT modality</b>							
HD (%)	92.3	96.1	93.5	92.8	93.3	91	65.1
PD (%)	6.1	3.9	5.9	6.4	6.2	7.3	4.7
<b>Mortality (%)</b>	<b>10.4</b>	5.9	10.3	10.3	10.7	4	48.8
<b>Transplant (%)</b>	<b>1.4</b>	1.2	0.1	0.2	0.1	0.1	24.6
<b>Recovered function</b>	<b>3.5</b>	0.9	4.1	4.3	4	3.1	0.8

Data source: USRDS ESRD Database. Percentages and standard deviation values are in parentheses. Abbreviations: Af Am, African American; DVT, DaVita; ESRD, end-stage renal disease; FMC, Fresenius Medical Care; GN, glomerulonephritis; HD, hemodialysis; KRT, kidney replacement therapy; PD, peritoneal dialysis; VHA, Veterans Health Administration.

### Mortality of Veterans after Transition to ESRD

As shown in Table 12.1 above, 10.4 percent (n=5,348) of all incident ESRD veterans died after three months of KRT. This is equivalent to an annualized mortality rate of 41.6 percent for these three months. Figure 12.7 shows monthly mortality during the first 24 months after transition to KRT. Mortality during the second, third, and fourth months were even higher than the first month mortality, but this discrepancy may be related to inadequate ESRD ascertainment of deceased patients during Month 1, since many of these patients might not have been registered under the ESRD program upon death.

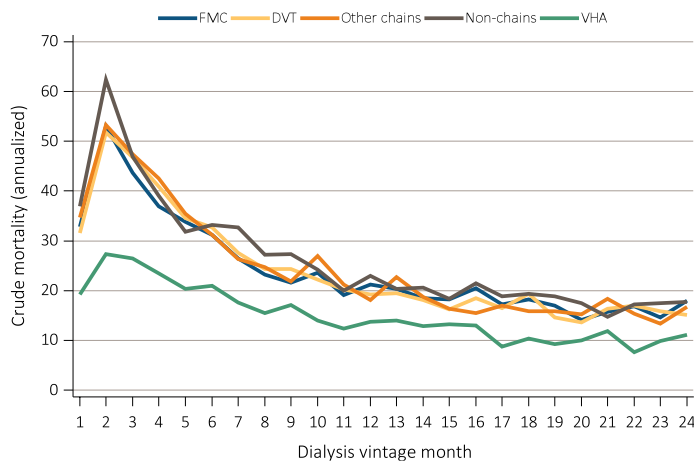
vol 2 Figure 12.7 Monthly crude mortality among 52,172 incident ESRD veterans who transitioned to KRT during 10/1/2007-9/30/2011 and who were followed for up to 24 months post-KRT



Data source: USRDS ESRD Database. All mortality rates are crude and without any adjustment. Abbreviations: ESRD, end-stage renal disease; KRT, kidney replacement therapy.

Figure 12.8 shows the annualized monthly mortality of the first two years post-KRT across dialysis providers. The second-month mortality was the highest (>60 percent per year) in non-chain units and lowest (<30 percent per year) in VHA based dialysis clinics. Nevertheless, the same pattern existed across dialysis providers such that the mortality was highest during the first several months after transition to KRT. It is important to note that the death rates are crude and do not account for differences in demographics or comorbid conditions.

**vol 2 Figure 12.8 Annualized monthly crude mortality of incident ESRD veterans who transitioned to KRT during 10/1/2007-9/30/2011 and who were followed for up to 24 months, by dialysis provider.**



Data source: USRDS ESRD Database. All mortality rates are crude and without any adjustment. Abbreviations: ESRD, end-stage renal disease; KRT, kidney replacement therapy.

### Recovered Kidney Function after Transition to ESRD

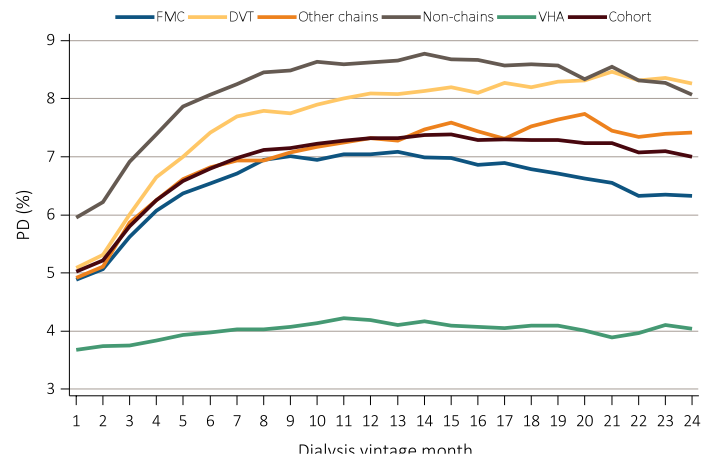
Over the first 24 months after KRT transition, 2,538 (4.9 percent) of the 52,172 incident ESRD veterans had recovered their kidney function and stopped dialysis therapy including 1,819 during the first 3 months (71.7 percent). Of those remaining until the end of the 24th month, 1,777 maintained recovered kidney function, whereas 761 veterans had alternative outcomes which included 192 patients who returned to dialysis with a known modality (188 HD, 4 PD) 41 patients who returned to dialysis with an unknown modality, 526 who died, and 2 who received kidney transplantation.

### Dialysis Modality in Veterans After Transition to ESRD

As shown in Table 12.1 above, only 4.9 percent of incident ESRD veterans transitioned to PD on Day 1 of

the ESRD service. This proportion, however, increased to above seven percent after six months and remained approximately seven percent over the first 24 months, as shown in Figure 12.9. Variations in practice were observed among dialysis providers, such that the rate of PD was the lowest among veterans who received dialysis therapy in a VHA based dialysis unit.

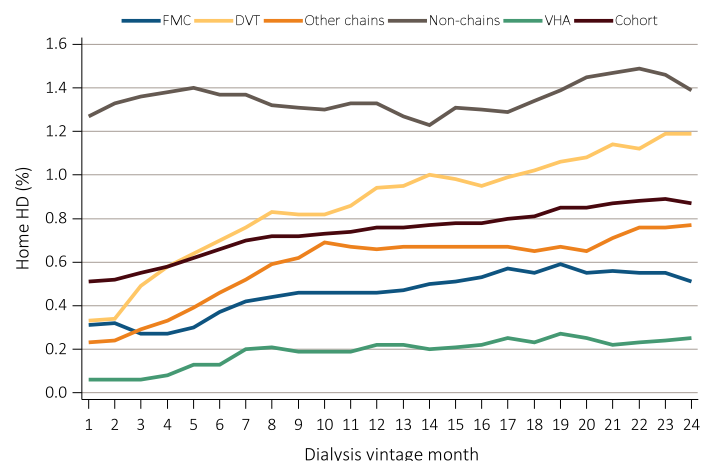
**vol 2 Figure 12.9 Peritoneal dialysis among incident ESRD veterans who transitioned to KRT during 10/1/2007-9/30/2011 and who were followed for up to 24 months according to dialysis provider.**



Data source: USRDS ESRD Database. All rates are crude and without any adjustment. Abbreviations: ESRD, end-stage renal disease; KRT, kidney replacement therapy.

Home HD constituted less than one percent of the dialysis modality throughout the entire first 24 months (Figure 12.10). Among dialysis providers, the lowest prevalence of home HD was observed in VHA based dialysis units (<0.3 percent) whereas the highest prevalence was observed among independent (non-chain) dialysis units (~1.4 percent).

**vol 2 Figure 12.10 Home hemodialysis among incident ESRD veterans who transitioned to KRT during 10/1/2007-9/30/2011 and who were followed for up to 24 months according to dialysis provider.**



Data source: USRDS ESRD Database. All rates are crude and without any adjustment. Abbreviations: ESRD, end-stage renal disease; KRT, kidney replacement therapy.

## Kaiser Permanente of Southern California

California is the most populous (38 million) and racially/ethnically diverse U.S. state. It is home to one out of eight Americans, and it possesses the largest economy in the nation and 8th largest in the world. Southern California (SC) is the most populous mega-region of California with 23 million people (60 percent of California's population), and bears four of the nation's 50 most populated cities (Los Angeles, San Diego, Fresno, and Long Beach), and encompasses Los Angeles Metropolitan (including LA and Orange Counties combined, with >17 million people and, the fifteenth largest economy in the world), Inland Empire, and Greater San Diego. In addition to substantial socioeconomic diversity, SC has remarkable racial/ethnic diversity (38 percent Hispanics, 14 percent Asians, and seven percent Blacks).

The Kaiser Permanente of Southern California (KP-SC) Health System is an integrated health care system that provides comprehensive health services for ~4 million residents of Southern California. The population served by KP-SC is socioeconomically diverse and broadly representative of the racial/ethnic groups in Southern California. KP-SC is one of KP's largest regions, which provides care at 13 hospitals and >190 medical offices by a partnership of >5,300 physicians who comprise the entire range of medical specialists (see Figure 12.11). The system provides an ideal environment for population-based epidemiologic, clinical and health services research, owing largely to the underlying population, model of care delivery and information infrastructure that can be leveraged for research purposes.

vol 2 Figure 12.11 Kaiser Permanente of Southern California (KP-SC) centers

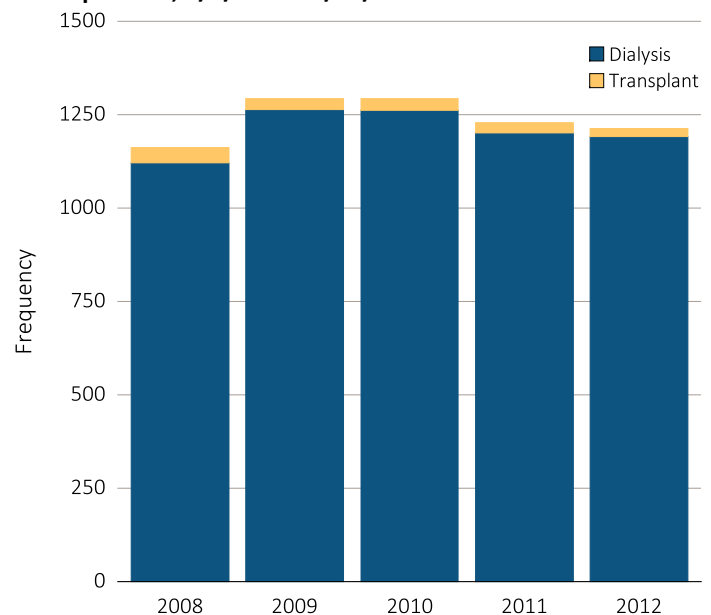


KP-SC has a state-of-the-art electronic health record (EHR) to support clinical management. Thus, information on virtually all aspects of care delivered is captured and routinely extracted for research.

## Transition to ESRD in Kaiser Permanente of Southern California

Between 1/1/2008 and 12/31/2012, 6189 KP-SC patients transitioned to KRT (see Figure 12.12). The rate of KRT transition was approximately 1100 to 1200 patients per year.

vol 2 Figure 12.12 Frequency of transition to KRT among 6,189 KP-SC patients, 1/1/2008-12/31/2012



Data source: Kaiser Permanente Southern California Electronic Health Records. Abbreviations: KP-SC, Kaiser Permanente of Southern California; KRT, kidney replacement therapy.

Table 12.4 shows the demographic of 6,189 patients who transitioned to ESRD in KP-SC between 1/1/2008 and 12/31/2012. Their mean age was 62.4 years and included 41.8 percent females, 20.7 percent Blacks and 35.3 percent Hispanics.

**vol 2 Table 12.4 Demographics of 6,189 KP-SC patients who transitioned to KRT, 1/1/2008-12/31/2011**

	Dialysis	Pre-emptive Transplant	Total
<b>n</b>	6,038	151	6,189
<b>Age, year (SD)</b>	62.8 (14.5)	45.1 (15.6)	62.4 (14.8)
<b>Gender</b>			
Female	2522 (41.8%)	65 (43.0%)	2587 (41.8%)
Male	3516 (58.2%)	86 (57.0%)	3602 (58.2%)
<b>Race/ethnicity</b>			
White	1852 (30.7%)	55 (36.4%)	1907 (30.8%)
Black/Af Am	1267 (21.0%)	11 (7.3%)	1278 (20.7%)
Hispanic	2126 (35.2%)	56 (37.1%)	2182 (35.3%)
Asian	708 (11.7%)	23 (15.2%)	731 (11.8%)
Other	39 (0.6%)	2 (1.3%)	41 (0.7%)
Unknown	46 (0.8%)	4 (2.7%)	50 (0.8%)

Data source: Kaiser Permanente Southern California Electronic Health Records. Abbreviations: Af Am, African American; KP-SC, KRT, kidney replacement therapy; Kaiser Permanente of Southern California; SD, standard deviation.

Table 12.5 shows the number of incident ESRD patients who had their serum creatinine measured prior to transition to KRT. The frequent serum creatinine measurements will allow for accurate estimation of eGFR and rates of CKD progression in years prior to ESRD transition. These data will be analyzed and presented during the TC-CKD Special Study.

**vol 2 Table 12.5 Number of serum creatinine tests and the eGFR prior to transition to KRT in 6,189 KP-SC patients, 1/1/2008-12/31/2012**

Years prior to KRT transition	Number of incidence ESRD patients having serum creatinine test	Mean number of tests per patient	Mean serum creatinine (ml/dL)	Mean eGFR (ml/min/1.73m <sup>2</sup> )
1	5,693 (92.0%)	7.2	4	20.9
2	5,076 (82.0%)	5.3	2.6	31.1
3	4,754 (76.8%)	4.6	2.2	38.1
4	4,429 (71.6%)	4.1	1.9	43.5
5	4,104 (66.3%)	3.8	1.8	48

Data source: Kaiser Permanente Southern California Electronic Health Records. Abbreviations: eGFR, estimated glomerular filtration rate; ESRD, end-stage renal disease; KRT, kidney replacement therapy.

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## Author Affiliations

- i. Harold Simmons Center for Kidney Disease Research and Epidemiology, Division of Nephrology and Hypertension, University of California Irvine Medical Center, Orange, CA; Veterans Affairs Long Beach Healthcare System, Long Beach, CA; and Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center, Torrance, CA
- ii. Nephrology Section, Memphis Veterans Affairs Medical Center and Division of Nephrology, Department of Medicine, University of Tennessee Health Science Center, Memphis TN
- iii. Department of Research and Evaluation, Kaiser Permanente Southern California, Pasadena, CA
- iv. Harold Simmons Center for Kidney Disease Research and Epidemiology, Division of Nephrology and Hypertension, University of California Irvine Medical Center, Orange, CA; Veterans Affairs Long Beach Healthcare System, Long Beach, CA
- v. Department of Research and Evaluation, Kaiser Permanente Southern California, Pasadena, CA
- vi. Harold Simmons Center for Kidney Disease Research and Epidemiology, Division of Nephrology and Hypertension, University of California Irvine Medical Center, Orange, CA
- vii. VA Long Beach Healthcare System, Long Beach, CA
- viii. Harold Simmons Center for Kidney Disease Research and Epidemiology, Division of Nephrology and Hypertension, University of California Irvine Medical Center, Orange, CA
- ix. Harold Simmons Center for Kidney Disease Research and Epidemiology, Division of Nephrology and Hypertension, University of California Irvine Medical Center, Orange, CA
- x. Harold Simmons Center for Kidney Disease Research and Epidemiology, Division of Nephrology and Hypertension, University of California Irvine Medical Center, Orange, CA
- xi. Division of Nephrology, Department of Medicine, University of Tennessee Health Science Center, Memphis TN
- xii. Harold Simmons Center for Kidney Disease Research and Epidemiology, Division of Nephrology and Hypertension, University of California Irvine Medical Center, Orange, CA



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## Introduction

In this appendix we present details on the USRDS database, its standardized working datasets and specialized code definitions, and our common data processing practices applied to the data used in the production of this Annual Data Report (ADR). We also describe the statistical methods used. The researcher's guide to the United States Renal Data Service (USRDS) database, available through [www.usrds.org](http://www.usrds.org), provides additional information about the database and standard analysis files (SAF).

## Data Sources

The USRDS maintains a stand-alone database of data on diagnostic and demographic characteristics of ESRD patients, supplemented with biochemical test results, dialysis claims and information on treatment and payer histories, hospitalization events, deaths, physician/supplier services, and providers.

### **Consolidated Renal Operations in a Web-enabled Network**

The major source of end-stage renal disease (ESRD) patient information for the USRDS is currently the Centers for Medicare and Medicaid Services (CMS) Consolidated Renal Operations in a Web-enabled Network (CROWN) data system. This database system contains demographic, diagnostic and treatment history information for all Medicare beneficiaries with ESRD. Data for non-Medicare patients have also been included since 1995, when ESRD Medical Evidence Report forms (ME; CMS 2728) became mandatory for all ESRD patients.

The original CMS ESRD database was called the Program Management and Medical Information System (PMMIS); this was replaced by the Renal Beneficiary and Utilization System (REBUS) in 1995. Having advanced its database technology, CMS migrated the REBUS database into an Oracle relational database in the fall of 2003. This database is known as the Renal Management Information System (REMIS). In 2003, the Standard Information Management System (SIMS) database of the ESRD networks was also established; SIMS includes information to track patient movement in and out of ESRD facilities, and their transitions from one treatment modality to another. Together, REMIS and SIMS comprise the CROWN system. In May 2012, internet-based access to the data system, CROWNWeb, was rolled

out nationally. It replaced the functionality of SIMS, interfaces with REMIS, and also provides new data to support calculation of clinical measures.

CMS updates the REMIS/CROWNWeb database on a regular basis, using the Medicare Enrollment Database (EDB), Medicare inpatient and outpatient claims, the Organ Procurement and Transplantation Network (OPTN) transplant database, ESRD Medical Evidence Report forms (ME; CMS 2728), and ESRD Death Notification forms (CMS 2746). CMS has also established data-integrity rules to ensure accurate identification of patients in the CMS databases.

### **CMS Medicare Enrollment Database**

The Medicare Enrollment Database (EDB) is the designated repository of all Medicare beneficiary enrollment and entitlement data, and provides current and historical information on residence, Medicare as secondary payer (MSP) and employer group health plan (EGHP) status, and Health Insurance Claim/Beneficiary Identification Code cross-referencing.

### **ESRD Medical Evidence Form**

The ESRD Medical Evidence Report form (ME; CMS 2728) is used to register patients at the onset of ESRD, and must be submitted by dialysis or transplant providers within 45 days of treatment initiation. The form establishes Medicare eligibility for individuals previously not Medicare beneficiaries, reclassifies previously eligible beneficiaries as ESRD patients, and provides demographic and diagnostic information on all new patients. The CMS, USRDS, and renal research communities rely on the form to ascertain patient demographics, primary diagnosis, comorbidities, and biochemical test results at the time of ESRD initiation. Prior to 1995, units were required to file the ME form only for Medicare-eligible patients. Since the 1995 revision, however, providers are required to complete the form for all new ESRD patients.

The third major revision of the ME form, in May 2005, remedied several shortcomings of the 1995 form and its earlier versions. Key additions target pre-ESRD care and vascular access use, and additional new fields collect information on glycosylated hemoglobin (HgbA1c) and lipid testing, on the frequency of hemodialysis (HD) sessions, and on whether patients are informed of transplant options.

This form is the only source of information about

the cause of a patient's ESRD. Because the list of diseases has been revised, the USRDS stores the codes from each version so that detail is not lost through conversion of one set of codes to the other.

### **ESRD Death Notification Form**

The ESRD Death Notification form (CMS 2746) is used to report the death of ESRD patients. According to CMS policy, this form must be submitted by dialysis or transplant providers within 30 days of a patient's death, and provides the date and causes of death (primary and secondary), reasons for discontinuation of renal replacement therapy, if applicable, and evidence of hospice care prior to death. It is the primary source of death information for CMS and the USRDS, identifying more than 99 percent of deaths. The USRDS also utilizes several supplemental data sources for ascertaining death (see the Death Date Determination section below for more details).

### **Organ Procurement and Transplantation Network Database**

In the early 1980s CMS began collecting data on all Medicare kidney transplants in the PMMIS data system. In 1984, the National Organ Transplant Act established the Organ Procurement and Transplant Network (OPTN) to collect data and maintain a registry for organ matching and transplantation. These two efforts were consolidated in 1994, and only OPTN continued to collect data on transplant donors and recipients. In addition to these sources, transplants are also identified from ME forms that indicate transplant as the initial modality, from CROWNWeb/SIMS transplant events, and from institutional inpatient claims. To resolve any conflicts among these sources, the USRDS uses the following algorithm, processing the transplants in the order listed below, and accepting a new transplant only if no transplant within the previous 63 days has already been accepted:

- OPTN transplants
- CROWNWeb/SIMS transplant events
- CMS transplants before 1988 are accepted
- CMS transplants from 1988 to 1993 are accepted if there is no OPTN transplant record for that patient within 63 days of the CMS transplant.
- Transplants indicated on ME forms as the initial

modality

- Transplants indicated on institutional inpatient claims

### **CMS Standard Analytical Files**

CMS Standard Analytical files (SAF) contain billing data from final action claims submitted by Medicare beneficiaries with ESRD in which all adjustments are resolved. For inpatient/outpatient (Part A) institutional claims, we use the following 100 percent SAF claims data: inpatient, outpatient, home health agency, hospice, and skilled nursing facility (SNF). For physician/supplier and durable medical equipment (DME) (Part B) claims, we also use the 100 percent SAF.

CMS SAFs are updated each quarter through June of the next year, when the annual files are finalized. Datasets for the current year are created six months into the year, and updated quarterly until they are finalized at 18 months. The USRDS also uses claims to supplement first service dates, transplant dates, and transplant failure dates.

### **CMS 5 Percent Standard Analytical Files**

CMS 5 percent SAFs contain billing data from final action claims submitted for Medicare beneficiaries in which all adjustments have been resolved. CMS and its contractors produce the 5 percent data sets by selecting all final action claims for Medicare beneficiaries whose CMS Health Insurance Claim (HIC) number ends in 05, 20, 45, 70, or 95. These five two-digit pairs were randomly selected to create a sample containing 5 percent of the total number of Medicare beneficiaries (Merriman and Asper, 2007). The sample design has the effect of creating a built-in longitudinal panel dataset. Once in the sample, a beneficiary will remain a part of all future year data files until death or a change to his/her HIC number. Since 2012, we receive the Master Beneficiary Summary File (formerly the Denominator file), containing demographic information on each beneficiary in the sample, as well as dates of enrollment in the various Medicare programs (Hospital Insurance [Part A], Supplemental Medical Insurance [Part B], Medicare Advantage managed care plans [Part C] and Prescription Drug Benefit [Part D]). Institutional claims for beneficiaries in the 5 percent sample are received in five files, based on type of medical service: inpatient, outpatient, home health agency, hospice,

and skilled nursing facility (SNF). Physician and supplier claims (also referred to as carrier claims) are received in one file for durable medical equipment and another for all other Part B covered services. These files collectively are referred to as the Medicare 5 percent files in this ADR.

### **Standard Information Management System Database**

The USRDS continues to collaborate with CMS and the ESRD networks to address data tracking issues relating to non-Medicare ESRD patients. Past ADRs have documented the lack of consistent Medicare claims data among these patients. Working solely with data from the ME form, the USRDS can establish the first ESRD service date but cannot generate a more detailed treatment history. With the integration of the SIMS event data into the USRDS database, however, we can better track patients beyond the initiation of treatment. The SIMS events data, along with the mandate for the ME form, allows us to include patients for whom there previously were no data on initial modality or death. We can now address issues in the non-Medicare ESRD population, such as the large and growing number of lost-to-follow-up patients. This data integration is detailed in the section on data management and preparation. In 2012, the functionality of SIMS was replaced by CROWNWeb.

### **CROWNWeb**

CROWNWeb is a web-based data collection system that captures clinical and administrative data from Medicare-certified dialysis facilities, and allows authorized users to securely submit, update, and verify data provided to Medicare. This system was rolled out nationally in June 2012. While CROWNWeb replaces the patient tracking functionality of SIMS, it also provides new data to support calculation of clinical measures.

### **CMS Dialysis Facility Compare Data**

The USRDS uses the CMS Dialysis Facility Compare data to define chain and ownership information for each renal facility. Prior to the 2003 ADR, similar data were extracted from the Independent Renal Facility Cost Report (CMS 265-94).

### **National Health and Nutrition Examination Survey**

The National Health and Nutrition Examination Survey (NHANES) is a series of health examination surveys conducted by the National Center for Health Statistics of the Centers for Disease Control and Prevention (CDC). Begun in 1960, NHANES is designed to monitor the health and nutritional status of the non-institutionalized civilian population in the United States. NHANES III was conducted in two phases between 1988 and 1994. In 1999, NHANES became a continuous annual survey to allow annual estimates, with release of public-use data files every two years. Both NHANES III and NHANES 1999–2012 were nationally representative cross-sectional surveys, and used a complex, stratified, multistage probability cluster sampling design that included selection of primary sampling units (counties), household segments within the counties, and sample persons from selected households. Survey participants were interviewed in their homes and/or received standardized medical examinations in mobile examination centers. Both surveys over-sampled Blacks/African Americans, Mexican Americans, and individuals aged 60 or older to improve the estimates for these subgroups.

### **Annual Facility Survey**

Independent ESRD patient counts are available not only from the CROWN database, but also from CMS's Annual Facility Survey (AFS; CMS 2744), which all Medicare-certified dialysis units must complete. The AFS reports the counts of patients being treated at the end of the year, new ESRD patients starting treatment during the year, and patients dying during the year. Both Medicare and non-Medicare end-of-year patients are counted. While AFS files do not carry patient-specific demographic and diagnosis data, they provide independent patient counts used to complement the CMS patient-specific records. Starting with the 2005 AFS, CMS stopped posting data from these surveys on the internet. Beginning with the 2007 ADR, the USRDS extracted the relevant facility survey data directly from the SIMS database. Beginning in 2012, when SIMS was replaced by CROWNWeb, the USRDS received the facility survey data directly from CROWNWeb.

## CDC Surveillance

The CDC used its National Surveillance of Dialysis-Associated Diseases to collect data from the United States (U.S.) dialysis facilities on patient and staff counts, membrane types, reuse practices, water treatment, therapy, vascular access use, antibiotic use, hepatitis vaccination and conversion rates, and the incidence of HIV, AIDS, and tuberculosis. No data are patient-specific. The CDC did not conduct a survey in 1998, and terminated this program after 2002.

## United States Census

In rate calculations throughout this year's ADR we use data from the 2000 and 2010 U.S. Census, and also incorporate CDC population estimates by race. Estimates for 1990–1999 were back-calculated based on the actual 2000 census. Later data, however, include racial groups that do not coincide with those in the ESRD data. For rate calculations throughout the ADR we thus use the CDC's Bridged Race Intercensal Estimates Dataset, which estimates White, Black/African American, Native American, and Asian populations. The data and methods for these estimates are available at <http://tinyurl.com/28kpp9j>. For state and network rates, we use Vintage 2013 Bridged-Race Postcensal Population Estimates. Both intercensal and postcensal estimate datasets are available at [http://www.cdc.gov/nchs/nvss/bridged\\_race/data\\_documentation.htm](http://www.cdc.gov/nchs/nvss/bridged_race/data_documentation.htm).

## Data Management and Preparation

For this ADR, data are reported through December 31, 2012.

## ESRD Patient Determination

A person is identified as having ESRD when a physician certifies the disease on the ME form, or when there is other evidence of chronic dialysis or a kidney transplant. Patients with acute kidney failure who are on dialysis for days or weeks, but who subsequently recover kidney function, are excluded from the database if their ME forms have not been submitted. Patients who die soon after kidney failure without receiving dialysis are sometimes miss inclusion in the dataset.

The ESRD first service date is the single most important data element in the USRDS database,

and each patient must, at a minimum, have a valid first service date. This date is used to determine the incident year of each patient and the first year in which the patient is counted as prevalent. The date 90 days after the first service date is used as the starting point for most survival analyses.

In most cases the first service date is derived by identifying the earliest date of various potential indicators:

- the start of dialysis for chronic kidney failure as reported on the ME form,
- the first CROWNWeb/SIMS event,
- a kidney transplant as reported on a CMS or OPTN transplant form, a ME form, or a hospital inpatient claim, or
- the first Medicare dialysis claim.

There are three exceptions to this rule:

- If the CROWNWeb/SIMS event and ME form agree (within 30 days of each other) and are more than 90 days after the first Medicare dialysis claim, and, if in addition, there is no transplant event between the first dialysis claim and the earlier of the CROWNWeb/SIMS event date and ME form date, then first service date is defined as the earlier of the CROWNWeb/SIMS event date and ME form date.
- If the ME form date is one year earlier than the first CROWNWeb/SIMS event date, and if the first claim date or first transplant date agrees with the first CROWNWeb/SIMS event date, then the CROWNWeb/SIMS first event date is used as the first service date.
- If all events for a patient are after January 1, 1995, and the modality of the first event is not “transplant” or “Center Self HD”, then the ME form is used to supply the first service date.

## Medicare and Non-Medicare Patients

Beneficiaries are enrolled in Medicare based on criteria defined in Title XVIII of the Social Security Act of 1965, and in subsequent amendments to the act. A person who meets one of these four criteria is eligible to apply for Medicare: aged 65 and over, who has certain disabilities and illnesses, who has ESRD, or who is eligible for services of the Railroad Retirement Board.

Most ESRD patients are eligible to apply for Medicare as their primary insurance payer. Some, however, are not immediately eligible for Medicare coverage because of their employment status and insurance benefits. These patients are usually covered by employer group health plans (EGHPs) and must wait 30–33 months before becoming eligible to have Medicare as their primary payer. Some of these patients, particularly new patients since 1995, have first service dates established by ME forms or CROWNWeb/SIMS events but have no dialysis claims or hospitalization events in the CMS claims database. In the REMIS database, all non-Medicare ESRD patients are assigned a code of ‘ZZ’ in the two-character Beneficiary Identification Code field. CMS does not generally include these patients in the datasets released to researchers.

The USRDS recognizes that these non-Medicare patients are true ESRD patients and should be included in patient counts for incidence, prevalence, and modality, as well as mortality and transplant rate calculations. Calculations of hospitalization statistics, however, should not include these patients because of the small number of claims available in the first 30–33 months after their first ESRD service.

The USRDS, in working with CMS, has been able to resolve most of the non-Medicare ESRD patients since the release of the ESRD Patient Database, REMIS, in the fall of 2003. According to our most recent assessment—performed during production of the 2007 ADR—we have determined that at least 99 percent of these patients have been resolved due to significant advancements in the REMIS database system.

### **Death Date Determination**

After the ESRD first service date, the date of death is the most critical piece of information in the ESRD database. Death dates are obtained from several sources, including the CMS Medicare Enrollment Database, CMS forms 2746 and 2728, the OPTN transplant follow-up form, CROWNWeb/SIMS database, the Social Security Death Master File, and inpatient claims. Because multiple sources report death information for the same patient, one patient may have several reported dates. For these patients, we primarily use the median of the various death dates reported. However, in the small number of cases where

there are only two death dates and they are more than 70 days apart, we use instead the most recent of the two dates.

### **Integration of the CROWNWeb and CMS Claim Databases**

The USRDS uses all available data to create a treatment history for each patient in the database, including all modality events, their duration, and the renal providers involved in each patient’s care. The CROWNWeb/SIMS event database is the primary source of the modality sequence file, and the dialysis claims are used as a way of confirming placements and identifying problem cases. As described in previous sections, we use all available sources to determine first service dates, deaths, transplants, and transplant failures.

For patients who either do not appear in the CROWNWeb/SIMS events file or for whom the only event is “New ESRD Patient”, and patients who have transfer-out gaps, the Medicare dialysis claim file is used. For “Transfer Out” and “Transfer Out for a Transplant” events with large gaps (seven days or more), claims falling in gaps are included, with the exception that no claims data are included if the “Transfer Out for a Transplant” event has a corresponding transplant/transplant failure event that occurred within (before or after) 30 days. Claims data are also included for the periods after “Transplant Failure” events and “Discontinued Dialysis” modality if the periods are longer than seven days.

Because the claims data capture the modality “Center Self Hemodialysis” more accurately than the CROWNWeb/SIMS data, this claims-based designation overrides other dialysis modalities from CROWNWeb/SIMS. Any CROWNWeb/SIMS dialysis event that falls into a “Center Self Hemodialysis” period as determined by claims is recoded as “Center Self Hemodialysis.”

Some events that do not make sense are removed. These include events that occur before a patient’s first service date, those falling between “Transplant” and “Transplant Failure,” and “Transfer Out for A Transplant” events that occur 60 days or less after the corresponding “Transplant.”

We have identified errors in the CROWNWeb data modality conversion that cause the wrong coding for peritoneal subcategories, including continuous

ambulatory PD (CAPD), continuous cycling PD (CCPD) and intermittent PD (IPD). To correct this problem, we employ historical data (pre CROWNWeb conversion) for years prior to 2012, and a combination of historical data and more complete CROWNWeb data for 2012. In future ADRs, CROWNWeb data will be used exclusively for years 2013 and beyond.

### **Lost-to-follow-up Methodology**

Gaps frequently exist in the CROWNWeb/SIMS and billing data upon which modality periods are based. The USRDS assumes that a modality continues until death or the next modality-determining event. A patient with a functioning transplant is assumed to maintain it unless a new CROWNWeb/SIMS event, claim event, or death date is encountered in the data. A dialysis modality, in contrast, is assumed to continue for only 365 days from the date of the last claim, in the absence of a death date or dialysis claims. After this period the patient is declared lost-to-follow-up, until the occurrence of a new CROWNWeb/SIMS event, dialysis claim, or transplant event.

Patients are considered lost-to-follow-up beginning 365 days after a “Transplant Failure” event or “Discontinued Dialysis” modality. Patients for whom the only event is an first service date, and who do not exist in any other files were also treated as lost-to-follow-up, beginning one year after the first service date. A number of events can result in a lack of dialysis data and eventual reclassification of a patient as lost-to-follow-up:

- The patient may have recovered renal function (RRF) and no longer have ESRD. For a valid patient classification, this event must occur within 180 days of the first service date, and the RRF period must persist for at least 90 days.
- The patient may no longer reside in the U.S.
- The patient’s death may not have been reported to the Social Security Administration or to CMS.

### **60-day Stable Modality Rule: Treatment History**

This rule requires that a modality continue for at least 60 days before it is considered a primary or switched modality. It is used to construct a patient’s modality sequence, or treatment history, so that incident and prevalent patients are known to have stable and established modalities. Beginning with the 2003 ADR,

all descriptive data in the incident, prevalent, and modality sections are based on incident and prevalent cohorts produced from the modality sequence without applying this rule. In contrast, certain analyses of patient outcomes such as hospitalization and mortality do apply this rule, unless the cohort is strictly incident.

### **90-day Rule: Outcomes Analyses**

This rule defines each patient’s start date for data analyses as day 91 of ESRD. Allowing outcomes to be compared among all ESRD patients at a stable and logical point in time, it is used primarily to calculate survival rates and to compare outcomes by modality at several points in time. Use of the rule overcomes the difficulties of examining data from the first three months of ESRD service. This initial period of treatment is an unstable time for new patients as renal providers try to determine the best treatment modality. In addition, data are incomplete during this period because in-center HD patients who are younger than 65 and not disabled, cannot bill Medicare for their treatments and hospitalizations until 90 days after the first ESRD service date. Such patients receiving PD or home dialysis, or with transplant as the first modality, can bill immediately.

### **Serum Albumin Data**

The ME form reports albumin level along with the test’s lower limit, which indicates the testing method: bromcresol purple or bromcresol green, with lower limits of 3.2 and 3.5 g/dL, respectively.

In producing the 2004 ADR we found that in 1995–2003, almost 50 percent of patient forms contained lower limit values equal to “zero,” while another 25 percent reported values other than the expected 3.2 and 3.5 g/dL. Only 25 percent (n=173,000) of incident patients had legitimate lower limit values. Further analyses, however, showed that these patients form a representative cohort sample, with demographic distributions by age, sex, race, and cause of ESRD similar to those of the overall ESRD population. For all figures in the 2005 and later ADRs that present serum albumin data from the ME form, we therefore include only those incident patients with both an albumin lower limit of 3.2 or 3.5 g/dL and an albumin value.

## Database Definitions

### Modalities

The USRDS and the CMS ESRD groups have worked extensively on methods of categorizing patients by ESRD modality. The initial modality for a patient is determined using an algorithm based on a hierarchy of data sources. This hierarchy of sources used is also dependent on the specific year the patient was incident and entered the CMS ESRD program. For patients entering into the ESRD program before 1995, dialysis claim information is given first priority to supply the modality at first service date. In the absence of a claim date, other sources are evaluated in the following order: ME form, CROWNWeb/SIMS data, and transplant data. For patients entering the ESRD program in 1995 or later, the ME form is given first priority

While the ME form is the primary source of data identifying modality at ESRD initiation for patients incident in 1995 or later, the modality it indicates may be temporary, as patients often change to a new one during the first 90 days of treatment, and it can be difficult to track modality during this time. Patients aged 65 and older have Medicare claims in the first 90 days that contain revenue codes designating modality. Patients younger than 65 and in EGHPs or Medicare risk programs, however, have no such early claims. Thus, modality may not be determined until Medicare becomes the primary payer at day 91 or, for EGHP patients, at 30–33 months after the ESRD first service date. These limitations influence our ability to determine a patient’s modality at any one point in time.

Of particular concern are patients categorized as having an unstable modality (i.e., on a modality for fewer than 60 consecutive days) in the first 90 days of treatment, and who are thus not recognized as being HD or PD patients. Because these patients tend to have higher death and hospitalization rates, interpretations of modality-specific outcome data including them should be viewed with caution. These patients are included in the “all ESRD” category, which provides a more complete view of mortality and hospitalization with the least biasing of the data.

As mentioned earlier, a new modality/event—recovered renal function (RRF)—was introduced in the 2007 ADR. This event can be established only if it occurs within the first 180 days following the first

service date, and if the RRF period persists for at least 90 days. The RRF event is similar to the lost-to-follow-up event in that patients will not be included in the prevalent populations for outcomes analyses. However, as with lost-to-follow-up events, we retain them in the modality sequence so that subsequent renal failure episodes can be tracked closely and in a timely manner.

Individual analyses categorize modalities in different ways; these are defined in the methods sections for each chapter.

### Payers

Information on payers is obtained from the CMS Medicare Enrollment Database (EDB). We also examine Medicare outpatient claims to identify patients for whom the EDB does not indicate Medicare as primary payer (MPP) but who have at least three consecutive months of dialysis treatment covered by Medicare; these patients are also designated as having MPP coverage. From these two data sources we construct a payer sequence file to provide payer history, and, beginning with the 2003 ADR, we use this file to identify Medicare eligibility status and other payers.

The construction of this file is similar to that of the treatment history file. Payer status is maintained for each ESRD patient from the ESRD first service date until death or the end of the study period. Payer data are used to categorize a patient as MPP, Medicare as secondary payer (MSP) with EGHP, MSP non-EGHP, Medicare Advantage (Medicare + Choice), Medicaid, or a combination of payers. With this approach, the USRDS is now able to apply payer status information in all outcome analyses using the “as-treated” model (see the discussion of Chapter 9, Costs of ESRD).

### Primary Cause of Renal Failure

Information on the primary cause of renal failure is obtained directly from the ME form. For the ADR, we use eight categories, with corresponding ICD-9-CM codes as follows:

- diabetes: 250.00 and 250.01
- hypertension: 403.9, 440.1, and 593.81
- glomerulonephritis: 580.0, 580.4, 582.0, 582.1, 582.9, 583.1, 583.2, 583.4, and 583.81
- cystic kidney: 753.13, 753.14, and 753.16



- other urologic: 223.0, 223.9, 590.0, 592.0, 592.9, and 599.6
- other cause: all other ICD-9-CM codes covered in the list of primary causes on the ME form, with the exception of 799.9
- unknown cause: 799.9 and ICD-9-CM codes not covered in the list of primary causes on the ME form
- missing cause: no ICD-9-CM code listed

## Race and Ethnicity

Data on patient race and ethnicity are obtained from the ME form, the CMS Medicare Enrollment Database, the REMIS patient identification file, and the CROWNWeb/SIMS patient roster. Because they are addressed in separate questions on the ME form, racial and ethnic categories can overlap. Patient ethnicity became a required field on the 1995 revised ME form; because data for 1995 are incomplete, information on Hispanic patients is presented starting in 1996. The non-Hispanic category includes all non-Hispanics and patients with unknown ethnicity. Because of the small number of ESRD patients of some races, as well as the construction of the U.S. census data, we concentrate on White, Black/African American, Native American (including Alaskan Native), and Asian (including Pacific Islander) populations. Data on patients of other races will be presented as their numbers increase.

## Introduction to Volume 2—ESRD

Data sources are indicated in the footnotes of each table and figure in Volume 2. Additional information on these sources is available in the Data Sources section above. Methodology used for the figures and tables in Volume 2 is described below in the corresponding chapter or reference table section. When figure or table data come directly from a particular reference table, please refer to the appropriate reference table methods section for additional detail.

Wait list counts in Table i.3 are restricted to ESRD-certified patients. New waiting list counts include all ESRD-certified patients added to the list for a kidney-alone or kidney-pancreas transplant in 2012; patients added at multiple centers are counted once. The total number of patients on the waiting list includes all ESRD-certified patients listed for a kidney-alone as of

December 31, 2012, regardless of when the first listing occurred. If patients are added to the list early in the year and are removed before the end of the year, it is possible for a group to have more new patients than existing patients. Median waiting time is shown for patients on the kidney-alone waiting list on December 31, 2007.

Data for Figure i.1 (a-d) are from the CMS Annual Facility Survey.

Prevalence counts in Figure i.2 are based on patients alive on December 31 of the year.

## Chapter 1: Incidence, Prevalence, Patient Characteristics and Modalities

### INCIDENCE AND PREVALENCE

Here and throughout the ADR, the USRDS generally reports point prevalence as of December 31, while period prevalence is reported for a calendar year. Annual period prevalent data thus consist both of patients who have the disease at the end of the year and those who have the disease during the year and die before the year's end. Because the USRDS treats successful transplantation as a therapy rather than as a "recovery" from ESRD, patients with a functioning transplant are counted as prevalent patients.

Because data are available only for patients whose ESRD therapy is reported to CMS, patients who die of ESRD before receiving treatment or whose therapy is not reported to CMS are not included in the database. We therefore qualify the terms incidence and prevalence as incidence and prevalence of reported ESRD. Some ESRD registries use the term "acceptance into ESRD therapy." We believe, however, that "incidence of reported ESRD therapy" is more precise, because "acceptance" implies that remaining patients are rejected, when they may simply not be identified as ESRD cases or may not be reported to CMS. Beginning with the 1992 ADR, lost-to-follow-up patients are not included in the point prevalent counts; they are, however, reported in Table B.1 of the Reference Tables.

Rate adjustments in this chapter are as follows: overall rates (including those in the maps) are adjusted for age, sex, and race; rates by age are adjusted for sex and race; rates by race or ethnicity are adjusted for age and sex; and rates by primary diagnosis are adjusted for age, sex, and race. Census data rate and prevalence calculations are now based on intercensal estimates;

for details, see the section on the United States Census in the Data Sources section of this appendix.

For Figures 1.4-1.7, incident cases and incidence rates are taken directly from Reference Table A. More specifically, cases come from A.1 and rates come from A.2(2) and A.2(3). Similarly, data for Figures 1.12-1.15 come directly from Reference Table B. Specifically, prevalent cases correspond to those found in B.1 and prevalence corresponds to that found B.2(2) and B.2(3). For details on the methods used, refer to the sections for Reference Tables A and B and the section for statistical methods used for rate calculations.

Figures 1.19 and 1.20 show the patient distribution by modality and payer, among ESRD incident and point prevalent patients, respectively. For Figure 1.19, payer is determined at the time of incidence. For Figure 1.20, payer is determined on December 31 of each year. Consequent to the previous two statements, the payer type does not account for changes in payer within the year. The detailed discussion of payer categories can be found in the database definitions section at the beginning of this appendix.

Figures 1.17 and 1.18 report the home dialysis patient distribution, by therapy type and among incident and point prevalent populations, respectively.

#### PATIENT CARE AND LABORATORY VALUES

Table 1.6 includes data on pre-ESRD nephrologist care of incident ESRD patients who have ME forms.

Data for Figures 1.21(a), 1.21(b), and Table 1.7 are obtained from the ME form.

Data for Figure 1.23 results from the calculation of eGFR, using the Chronic Kidney Disease Epidemiology Collaboration (CKD-EPI) equation, from data acquired from the ME form.

#### REFERENCE SECTION A

The Reference Tables present parallel sets of counts and rates for incidence (Section A) and December 31 point prevalence (Section B). Section B also presents annual period prevalent counts and counts of lost-to-follow-up patients. Because the U.S. population figures (shown in Reference Section M) used in the ADR include only residents of the 50 states and the District of Columbia, tables also focus on patients from these areas. Exceptions are Tables A.1, A.6, A.8, and A.10, all

of which present data specific to patients in Puerto Rico and the U.S. territories, or include these patients in the patient population. Age is computed as of the beginning of ESRD therapy.

Rates in Table A.2, A.9 and A.11 are adjusted for age, sex, and race, with the 2011 national population as reference.

#### REFERENCE SECTION B

With the exception of Tables B.1, B.6, B.8, and B.10, these tables focus on patients in the 50 states and the District of Columbia. Age is calculated as of December 31. Rates in Table B.2, B.9 and B.11 are adjusted for age, sex, and race, with the 2011 national population as reference.

#### REFERENCE SECTION C

Data in these tables are based on information collected with the 1995 and 2005 ME forms. Table C.1 contains data on biochemical markers from 2004–2012. A new ME form was introduced in 2005 that included glycosylated hemoglobin (HbA<sub>1c</sub>), total cholesterol, low-density lipoprotein, and high-density lipoprotein. Because these data elements had not been collected on the previous form, values are not available for 2004 and the first few months of 2005. Data prior to 2005 on mean values reported for these markers may be unreliable due to low numbers of patients. Blood urea nitrogen was dropped from the new 2005 form.

#### TREATMENT MODALITIES

Modality figures and the associated reference tables describe the treatment modalities of all known ESRD patients, both Medicare and non-Medicare, who are not classified as lost-to-follow-up or having recovered renal function (RRF). The RRF event, introduced in the 2007 ADR, is defined as an event that occurs within the first 180 days of ESRD initiation and lasts for at least 90 days. By definition, patients classified as having RRF post-initiation are included in the incident counts. Unless noted otherwise, incident and point prevalent cohorts without the 60-day stable modality rule are used in the analyses. Treatment modalities are defined as follows:

- center hemodialysis: HD treatment received at a dialysis center
- center self-hemodialysis: HD administered by

the patient at a dialysis center; a category usually combined with center HD

- home hemodialysis: HD administered by the patient at home; cannot always be reliably identified in the database
- CAPD: continuous ambulatory peritoneal dialysis; usually combined with CCPD and other PD
- CCPD: continuous cycling peritoneal dialysis; usually combined with CAPD and other PD
- peritoneal dialysis: analyses typically consist of CAPD, CCPD and intermittent peritoneal dialysis (IPD)
- other peritoneal dialysis: primarily intermittent peritoneal dialysis (IPD), a small category except among very young children; usually combined with CAPD and CCPD to form PD category
- uncertain dialysis: a period in which the dialysis type is unknown or multiple modalities occur but none last 60 days; usually combined with unknown dialysis to form an other/unknown dialysis category
- unknown dialysis: a period in which the dialysis modality is not known (e.g. when dialysis sessions are performed in a hospital); usually combined with uncertain dialysis to form an other/unknown dialysis category
- renal transplantation: a functioning graft from either a living donor (a blood relative or other living person) or a deceased donor
- death: a category not appearing in the year-end modality tables, which report only living patients, but used as an outcome (e.g. in tables showing living patients followed for a period of time for their modality treatment history)

Facilities began submitting patient data via CROWNWeb beginning in 2012. This information was previously submitted by facilities via the ESRD Networks. The new method of data input and submission may lead to unanticipated changes in trends beginning in 2012.

#### REFERENCE SECTION D

Reference Section D is divided into four parts. The first, Tables D.1–11 and D.15–16, provides counts and

percentages—by demographics, geographic location, and treatment modality—of incident and prevalent patients alive at the end of each year. Age is computed as of the start of ESRD for incident patients and as of December 31 for point prevalent patients.

Table D.12 shows modality at day 90 and at two years after first service for all incident Medicare patients beginning renal replacement therapy from 2008 to 2010. The 90-day rule is used to exclude patients who die during the first 90 days of ESRD, and age is computed as of the first ESRD service date.

The third section, Tables D.13–14, presents counts of prevalent patients alive at the end of each year, by ESRD exposure time and modality. Table D.13 shows counts by the number of years of ESRD, while Table D.14 presents counts by the number of years on the end-of-year treatment modality. For the duration of ESRD exposure, zero should be read as less than one year, one as at least one full year but less than two, and so on.

The fourth section, Tables D.17–24, presents counts of incident and prevalent patients alive at the end of selected years (i.e. 2004, 2008, 2012), by demographic characteristics, payer category, and treatment modality. Again, age is computed as of the start of ESRD for incident patients and as of December 31 for point prevalent patients. The payer categories are:

- Medicare FFS (i.e., Medicare as primary payer)
- Medicare/Medicaid (i.e., dually eligible)
- MSP (i.e., Medicare as secondary payer): EGHP and non-EGHP
- HMO (i.e., Medicare Advantage or Medicare+Choice plans)
- other and unknown payers

The detailed discussion of payer categories can be found in the Database Definitions section at the beginning of this appendix.

**Chapter 2: Healthy People 2020****OBJECTIVE CKD-3**

Data for this objective include all patients in the 5 percent Medicare sample who are aged 65 and older and who have hospitalized acute kidney injury (AKI) events in the given year (1992–2012). Hospitalized AKI is defined by ICD-9-CM diagnosis code 584 in inpatient claims, and renal evaluation is identified by a microalbumin test. Patients are followed from the discharge date to the earliest date of death, ESRD, end of Medicare coverage, or six months after the discharge date. CPT codes for urinary microalbumin measurement are identified from HEDIS 2008 specifications (HEDIS 2008, an NCQA program, is used to monitor the performance of managed health care plans), and include 82042, 82043, 82044, and 84156.

**OBJECTIVE D-12**

The cohort includes general Medicare patients diagnosed with DM in each year, continuously enrolled in Medicare Parts A and B during the whole year, and aged 65 or older at the beginning of the year. CPT codes for urinary microalbumin measurement are those used in Objective CKD-3, above. Testing is tracked during each year. Diabetes is defined by a qualifying ICD-9-CM diagnosis code of DM on one or more Part A institutional claims (inpatient, skilled nursing facility, or home health agency), or two or more institutional outpatient claims and/or physician/supplier claims within a one year observation period. Qualifying ICD-9-CM codes for diabetes mellitus are 250.XX, 357.2, 362.0X, and 366.41.

**OBJECTIVE CKD-4.1**

The cohort here is similar to that used for Objective D-12, but includes all CKD patients. Testing is tracked during each year. Patients are excluded if they are enrolled in a managed care program (HMO), acquire Medicare as secondary payer, are diagnosed with ESRD during the year, have a missing date of birth, or do not live in the 50 states, the District of Columbia, Puerto Rico, or the U.S. territories. Racial and ethnic categories are mutually exclusive. Methods of defining CKD are described in the appendix of the CKD volume. Serum creatinine is identified through

CPT codes 80047–80050, 80053–80054, 80069, and 82565, while lipid testing is identified through CPT codes 80061, 82465, 82470, 83695, 83705, 83715–83721, 84478, 83700, 83701, and 83704. CPT codes for urinary microalbumin measurement are the same as those used for Objective CKD-3, above.

**OBJECTIVE CKD-4.2**

Methods and codes used to determine rates of HbA<sub>1c</sub> testing and eye examinations are taken from HEDIS 2008 specifications. CPT codes 83036 and 83037 are used to identify HbA<sub>1c</sub> testing. Codes used to identify diabetic eye examinations are as follows: CPT codes, 92002, 92004, 92012, 92014, 92018, 92019, 92225, 92226, 92230, 92235, 92240, 92250, 92260, 67101, 67105, 67107, 67108, 67110, 67112, 67141, 67145, 67208, 67210, 67218, 67227, 67228, 67028, 67030, 67031, 67036, 67038, 67039, 67041, 67042, 67043, 67113, 67121, 67221, 67228, S0625, S0620, S0621, and S3000; ICD-9-CM procedure codes, 14.1–14.5, 14.9, 95.02, 95.03, 95.04, 95.11, 95.12, and 95.16; and ICD-9-CM diagnosis code V72.0. The cohort is similar to that used for Objective CKD-4.1, but includes all diabetic CKD patients. Methods of defining DM are described in the appendix of the CKD volume.

**OBJECTIVE CKD-8**

Incident rates are calculated using the methods described for Chapter 1. Overall rates are adjusted by age, sex, and race; rates by age are adjusted for sex and race; rates by sex are adjusted for age and race; and rates by race and ethnicity are adjusted by age and sex.

**OBJECTIVE CKD-9.1**

Rates of kidney failure due to DM are also calculated using the methods described for Chapter 1, and adjustments are the same as those described for Objective CKD-8, above.

**OBJECTIVE CKD-9.2**

This table uses data from the National Health Interview Survey; all ages are included. Three-year data are used to estimate the prevalence of DM in the middle year, and the size of the population with DM is based on U.S. census data. The incident rate per million of ESRD caused by DM is calculated as the number

of incident ESRD patients with a primary diagnosis of DM, divided by the size of the population with DM in that group.

#### **OBJECTIVES CKD-10 & CKD-11.3**

These tables use data from the newest version of the ME form. The cohorts include incident HD patients, with CKD-11.3 limited to those aged 18 and older at initiation who have a known vascular access at that time. CKD-10 includes only patients for whom it is known whether they saw a nephrologist prior to initiation.

#### **OBJECTIVE CKD-12**

The cohort includes patients from 2000–2011 who are younger than 70 at the initiation of ESRD. Percentages are calculated as the number of patients placed on the deceased donor organ waiting list or receiving a deceased donor transplant within one year of initiation, divided by the number of patients without a living donor available (i.e., patients receiving a living donor transplant are excluded), and are estimated using the Kaplan-Meier methodology.

#### **OBJECTIVE CKD-13.1**

The cohort includes patients from 1998–2009 who are younger than 70 at the initiation of ESRD. Patients are followed for three years, from ESRD certification until the first event of death, transplant, or censoring at three years after the initiation of ESRD. Percentages are calculated using the Kaplan-Meier methodology.

#### **OBJECTIVE CKD-13.2**

The cohort includes patients from 2001–2012 who are younger than 70 at the initiation of ESRD. Pre-emptive transplants are those in which ESRD initiation date is the date of transplant. Percentages are calculated as  $100(N/D)$ , where  $N$ =the number of preemptive transplants in the year and  $D$ =the number of ESRD patients in the year.

#### **OBJECTIVES CKD-14.1 & CKD-14.3**

Cohorts for these tables include period prevalent dialysis patients in each calendar year, 2001–2011, whose first ESRD service date is at least 90 days prior to the beginning of the year (point prevalent patients on January 1) or who reach day 91 of ESRD treatment

during the year (incident patients). We exclude patients with unknown age or sex and those with an age calculated to be less than zero, as well as patients who are not residents of the 50 states, the District of Columbia, Puerto Rico, or the U.S. territories. Age is calculated on January 1, and race is defined from the ME form. Cardiovascular mortality is defined using codes from past and current Death Notification forms: 01, 02, 03, 04, 1, 2, 3, 4, 23, 25, 26, 27, 28, 29, 30, 31, 32, 36, and 37. Patients are followed from January 1 (for point prevalent dialysis patients) or day 91 of ESRD (for incident dialysis patients) until death, transplant, or December 31 of the year. Rates are estimated as the number of patients who die from any cause (Objective 14.1) and who die from cardiovascular disease (Objective 14.3) in each year, per 1,000 patient years at risk.

#### **OBJECTIVE CKD-14.2**

Cohorts here include incident dialysis patients in each calendar year, 2001–2011. In addition to applying the same exclusion criteria described for Objectives 14.1 and 14.3, we further exclude patients with recovered kidney function. Age is calculated on the first ESRD service date. Patients are followed from the first service date until death, transplant, or 90 days after ESRD. Rates are estimated as the number of patients who die from any cause per 1,000 patient years at risk.

#### **OBJECTIVES CKD-14.4–5**

Patient cohorts here include period prevalent transplant patients, 2001–2011, whose first ESRD service date is at least 90 days prior to the beginning of the year (point prevalent patients on January 1) or who reach day 91 of ESRD treatment (incident patients). Exclusion criteria are the same as those described for Objectives 14.1 and 14.3. Patients are followed from January 1 (for point prevalent dialysis patients) or day 91 of ESRD (for incident dialysis patients) until death or December 31 of the year. Rates are estimated as the number of patients who die from any cause (Objective 14.4) and who die from cardiovascular disease (Objective 14.5) in each year, per 1,000 patient years at risk.

### Chapter 3: Clinical Indicators and Preventive Care

In Figure 3.1, all data are obtained from CROWNWeb clinical extracts for December 2013. The adequacy analyses are restricted to patients at least 18 years old as of December 1, 2013. Patients must have been alive as of December 31, 2013 and must have had ESRD for at least one year as of the time of the measurement. If multiple measurements were available for a patient, the last one in the month was used. In Figure 3.1b, all adult (aged 18 or older) patients who are on dialysis for at least 90 days as of December 1, 2013 and alive as of December 31, 2013 are included. If multiple hemoglobin (Hgb) measurements were available for a patient, the last one in the month was used. The categorical distribution of Hgb is shown for both HD and PD patients. In Figure 3.1c, all HD patients who had ESRD at least 90 days at the time vascular access was reported were included. Patients must have been alive as of December 31, 2013.

#### ANEMIA TREATMENT

All of the findings in this section are based on Medicare claims data. Efforts have been made for the figures and tables to be as fully representative as possible of the U.S. dialysis patient population represented by CMS claims data, resulting in substantially larger sample sizes in some of the tables associated with this anemia section as compared with the 2013 ADR. The modality of the patient in each month is determined from the primary modality that is indicated on the claims file associated with each claim for Hgb, iron dose, and epoetin alfa (EPO) dose variables in the given month. For transfusion analyses, patients were assigned to HD or PD if having at least one claim for HD or PD therapy, respectively, in that month. There were very few patients having dual modality use within the same month. The frequency of a patient having dual modalities in a particular year-month ranges from 0.3 percent to 0.8 percent over 1995 to 2012.

Calculation of Hgb levels are shown in Figures 3.2A, 3.3, 3.5A, and 3.6. Hgb values were based upon the first reported claim in each month for HD patients (Figure 3.2A, 3.3) or for PD patients (Figure 3.5A, 3.6). When Hgb levels were not available in claims data, hematocrit values, if available, were divided by 3 to serve as a proxy estimate. Patients were excluded in a given month if the Hgb level (or Hgb values estimated from hematocrit values) was < 5 g/dL or >20 g/dL.

Results are shown for erythropoiesis-stimulating agent (ESA)-treated patients in Figures 3.2A, 3.3, 3.5A, and 3.6, in which case analyses were restricted to patients who: (1) within the indicated month had a claim for ESA use and a claim for either Hgb or hematocrit level, and (2) at the start of the month, were on dialysis for 90 days or more and were aged 18 or older. In Figures 3.2A and 3.5A, Hgb levels are also provided for all patients, in which case the same restrictions were used as described in the latter sentence, but not limiting to patients with an ESA claim within the given month in 2012.

Calculation of mean EPO dose levels is shown in Figures 3.2A and 3.5A. Mean monthly EPO dose is provided for HD patients in Figure 3.2A and for PD patients in Figure 3.5A. Mean monthly EPO dose is shown for patients who within a given month had an EPO claim, were on dialysis for 90 days or longer were 18 years or older at the start of the month. EPO dose is expressed as mean EPO units per week, averaged over all EPO claims within a given month. Patients were excluded from these calculations for a given month if their monthly average EPO dose was either less than 250 units per week (resulting in 0.4 percent excluded) or if their monthly average EPO dose was greater than 400,000 units per week; these criteria resulted in <0.001 percent of patients being excluded.

Calculation of intravenous iron use is shown in Figures 3.2B and 3.5B. Intravenous iron use for HD patients is presented in Figure 3.2B and for PD patients in Figure 3.5B. Monthly intravenous iron use was among patients on dialysis for 90 days or longer and 18 years or older at the start of the given month.

Calculations of the percentage of dialysis patients with one or more claims for a red blood cell (RBC) transfusion in a given month from 2010-2012 are shown in Figures 3.4 (HD patients) and 3.7 (PD patients). For this calculation, the numerator consisted of dialysis patients with one or more RBC transfusion claims in a given month; the denominator included all patients having a claim for at least one dialysis session during the month and who were 18 years or older at the start of the month.

vol 2 Table m.1 Transfusion codes used in defining a red blood cell transfusion

Code	Code Type	Code Description
36430	CPT	Transfusion, blood or blood components
P9010	HCPCS	Blood (whole), for transfusion, per unit
P9011	HCPCS	Blood, split unit
P9016	HCPCS	Red blood cells, leukocytes reduced, each unit
P9021	HCPCS	Red blood cells, each unit
P9022	HCPCS	Red blood cells, washed, each unit
P9038	HCPCS	Red blood cells, irradiated, each unit
P9039	HCPCS	Red blood cells, deglycerolized, each unit
P9040	HCPCS	Red blood cells, leukocytes reduced, irradiated, each unit
P9051	HCPCS	Whole blood or red blood cells, leukocytes reduced, cmv-negative, each unit
P9054	HCPCS	Whole blood or red blood cells, leukocytes reduced, frozen, deglycerol, washed, each unit
P9056	HCPCS	Whole blood, leukocytes reduced, irradiated, each unit
P9057	HCPCS	Red blood cells, frozen/deglycerolized/washed, leukocytes reduced, irradiated, each unit
P9058	HCPCS	Red blood cells, leukocytes reduced, cmv-negative, irradiated, each unit
99.03	ICD9	Other transfusion of whole blood; transfusion: blood NOS, hemodilution, NOS
99.04	ICD9	Transfusion of packed cells

Hgb levels were also calculated for adult ESRD incident patients—those aged 18 years or older at any time during 2012, who during that year were new to ESRD and initiated chronic dialysis therapy. Analyses were provided separately for incident HD and PD patients, with modality based on that reported on the ME form for the patient’s initial chronic dialysis session. Hgb values for incident patients were based upon that of the first reported claim within 2012, among Hgb values occurring within 30 days of a patient’s initial chronic dialysis treatment. For incident patient analyses, approximately 25 percent of incident HD patients and 22 percent of incident PD patients did not have a reported Hgb value within 30 days of starting dialysis in 2012 claims data.

**PREVENTIVE CARE**

Figure 3.8 presents data on diabetic preventive care. The ESRD population includes patients initiating therapy at least 90 days prior to January 1 of the first year of each study period and with DM in the first year.

Testing is tracked in the second year of each study period; tests are at least 30 days apart. ESRD patients without Medicare inpatient/outpatient and physician/supplier coverage during the entire study period are omitted, as are general Medicare patients enrolled in an HMO or diagnosed with ESRD during the study period. Also omitted are those who do not reside in the 50 states, the District of Columbia, Puerto Rico, or the U.S. territories; who have a missing date of birth, who do not survive the entire reporting period, who have ESRD for fewer than 90 days prior to the start of the reporting interval, or who are lost to follow-up during the study period. Age is calculated at the end of the study period.

Patients are defined as having DM either through medical claims (one inpatient/home health/SNF claim, or two outpatient or physician/supplier claims), or through a listing of DM on the ME form as the primary cause of ESRD or as a comorbid condition. ICD-9-CM diagnosis codes used to define DM are 250, 357.2, 362.0x, and 366.41. Methods and codes used to determine rates of HgbA1c testing and eye examinations are taken from HEDIS 2008 specifications. CPT codes 83036 and 83037 are used to identify HgbA1c testing. Codes used to identify diabetic eye examinations are as follows: CPT codes, 67028, 67030, 67031, 67036, 67038, 67039, 67040, 67041, 67042, 67043, 67101, 67105, 67107, 67108, 67110, 67112, “67113, 67121, 67141, 67145, 67208, 67210, 67218, 67220, 67221, 67227, 67228, 92002, 92004, 92012, 92014, 92018, 92019, 92225, 92226, 92230, 92235, 92240, 92250, 92260, So620, So621, So625, S3000; ICD-9-CM procedure codes, 14.1–14.5, 14.9, 95.02, 95.03, 95.04, 95.11, 95.12, and 95.16; and ICD-9-CM diagnosis code V72.0. Lipid testing is identified through CPT codes 80061, 82465, 82470, 83695, 83700, 83701, 83704, 83705, 83715, 83716, 83717, 83718, 83719, 83720, 83721, 84478. Comprehensive diabetic care includes at least one HgbA1c test, at least one lipids test, and at least one eye exam. HgbA1c and lipid tests occur at least 30 days apart.

Figures 3.9–3.12 present data on influenza vaccinations for prevalent ESRD patients by age, race/ethnicity, modality, and time period. The cohort for influenza vaccinations includes all ESRD patients initiating therapy at least 90 days prior to August 1 of the first year of the study period and alive on April 30 of the second year. Patients without Medicare inpatient/outpatient and physician/supplier coverage during the study period are omitted, as are those who do

not reside in the 50 states, the District of Columbia, Puerto Rico, or the U.S. territories. Also omitted are those who have a missing date of birth; who have ESRD for fewer than 90 days prior to the start of the study period; or who are lost-to-follow-up during the study period. Age is calculated at the end of the study period. Influenza vaccinations are tracked between August 1 of the first year and April 30 of the second year in the study period. Influenza vaccinations are identified by CPT codes 90724, 90657, 90658, 90659, and 90660, and HCPCS code G0008.

### VASCULAR ACCESS

Data for Figures 3.13-3.15 and Table 3.1 are obtained from the ME form; data are restricted to the most recent version. Figure 3.15 also includes data from CROWNWeb. Patients with missing vascular access data are excluded. Figure 3.13 presents data for patients who began dialysis from 2005 to 2012; Table 3.1 and Figure 3.14 present data for patients beginning dialysis in 2012. Age is calculated as of the date regular chronic dialysis began. Figure 3.14 excludes patients not living in the 50 states or the District of Columbia; Figure 3.15 includes a cross-section of patients alive at each time point. Vascular access at initiation includes data obtained from the ME form for patients beginning dialysis between January 1, 2012 and December 31, 2012; vascular access data for all other time points are obtained from CROWNWeb. The time points from initiation include three months (patients starting dialysis between October 1, 2012 and December 31, 2012), six months (starting dialysis between July 1, 2012 and December 31, 2012), nine months (between April 1, 2012 and December 31, 2012), and one year after initiation (starting dialysis between January 1, 2012 and December 31, 2012). For the three, six, and nine month time points, there is a 30 day look-back and 30 day look-forward time period to determine vascular access at that time point. For the one year time point, there is a three month look-back and 30 day look-forward time period to determine vascular access.

### Chapter 4: Hospitalization

Methods used to examine hospitalization in prevalent patients generally echo those used for the tables in Reference Section G (described below). Inclusion and exclusion criteria are generally the same, as are the methods for counting hospital admissions and days, and defining the follow-up time at risk. One

difference is the exclusion in Section G of patients of races that are unknown or other than White, Black/African American, Native American, or Asian; these patients are included in the Chapter 4 figures. Included patients have Medicare as primary payer, with Parts A and B coverage at the start of follow-up, and without HMO coverage. Rates include total admissions or hospital days during the time at risk, divided by patient years at risk. The period at risk begins at the latest of January 1 or day 91 of ESRD, and censoring occurs at death, end of Medicare Parts A and B coverage, or December 31, in addition to other censoring criteria which vary by modality as described below. Since a currently hospitalized patient is not at risk for admission, hospital days are subtracted from the time at risk for hospital admissions. Additionally, rehospitalization rates include the percentage of live hospital discharges that are followed by a subsequent hospital admission within 30 days.

Hospitalization data exclude inpatient stays for the purpose of rehabilitation therapy. Inpatient rehabilitation claims are identified by provider numbers; numbers for inpatient rehabilitation facilities include values 3025-3099 in the third through sixth positions or "R" or "T" in the third position.

Inpatient institutional claims are used for the analyses, and methods for cleaning claims follow those described for Section G. Adjusted rates are calculated using the model-based adjustment method on the observed category-specific rates. Predicted rates are calculated with a Poisson model, and adjusted rates are then computed with the direct adjustment method and a reference cohort. This method is described further in the discussion of Section G, and in the statistical methods section later in this appendix.

Methods in Figures 4.1-2 follow those for Reference Section G. Figure 4.1 shows the percent change in admission rates since 1993 for period prevalent ESRD patients. Included patients have Medicare as primary payer and are residents of the 50 states, the District of Columbia, Puerto Rico, and the U.S. territories. Patients with AIDS as a primary or secondary cause of death are excluded, as are patients with missing age or sex information. Rates are adjusted for age, sex, race, and primary diagnosis using the model-based adjustment method. The reference cohort includes period prevalent ESRD patients, 2010. New dialysis access codes for PD patients appeared in late 1998; dialysis access values are therefore shown



for PD patients as a change since 1999 rather than 1993. For PD patients, dialysis access hospitalizations are those defined as “pure” inpatient vascular/dialysis access events, as described for Tables G.11–15. For HD patients, vascular access hospitalizations include “pure” inpatient vascular access events, and vascular access for HD patients excludes codes specific to PD catheters (996.56, 996.68, and V56.2). Principal ICD-9-CM diagnosis codes are used to identify cardiovascular and infectious admissions. The cardiovascular category consists of codes 276.6, 394–398.99, 401–405, 410–420, 421.9, 422.90, 422.99, 423–428, and 440–459, while infection is indicated by codes 001–139, 254.1, 320–326, 331.81, 372–372.39, 373.0–373.2, 382–382.4, 383, 386.33, 386.35, 388.60, 390–393, 421–421.1, 422.0, 422.91–422.93, 460–466, 472–474.0, 475–476.1, 478.21–478.24, 478.29, 480–490, 491.1, 494, 510–511, 513.0, 518.6, 519.01, 522.5, 522.7, 527.3, 528.3, 540–542, 566–567.9, 569.5, 572–572.1, 573.1–573.3, 575–575.12, 590–590.9, 595–595.4, 597–597.89, 598.0, 599.0, 601–601.9, 604–604.9, 607.1, 607.2, 608.0, 608.4, 611.0, 614–616.1, 616.3–616.4, 616.8, 670, 680–686.9, 706.0, 711–711.9, 730–730.3, 730.8–730.9, 790.7–790.8, 996.60–996.69, 997.62, 998.5, and 999.3.

Figure 4.2 presents adjusted rates of total hospital admissions and days per patient year. Prevalent ESRD patients are included, and rates are adjusted for age, sex, race, and primary diagnosis, with the 2010 ESRD cohort used as the reference.

Table 4.1 presents unadjusted and adjusted admission rates among adult (aged 20 and older) period prevalent HD patients. Principal ICD-9-CM diagnosis codes are used to identify cause-specific admissions: codes for cardiovascular and infectious admissions are listed in the discussion of Figure 4.1, while codes for vascular access infection are 996.62 and 999.31. Rates are adjusted for age, sex, race, and primary ESRD diagnosis; values presented by one factor are adjusted for the other three. For adjusted rates, HD patients in 2010 are used as the reference cohort. Values by age, sex, race, and primary diagnosis are shown for 2011–2012 prevalent HD patients.

Figures 4.4–7 show adjusted infectious admission rates among period prevalent ESRD patients. These figures illustrate two different methods of classifying infection by diagnosis code type. The traditional method defines cause-specific admissions based on principal ICD-9-CM diagnoses, and these rates are interpreted as admissions for the reason of the stated

condition. The other method uses both principal and secondary inpatient ICD-9-CM diagnoses recorded for hospital stays. In contrast, these rates are interpreted as admissions with the condition, and by definition, are more inclusive than those restricted to principal diagnoses. ICD-9-CM codes for infectious hospitalizations are listed in the discussion of Figure 4.1, and those for vascular access infection are listed for Table 4.1. Other infectious groups are as follows: bacteremia/sepsis, 038.0–038.9 and 790.7; peritonitis (PD patients only), 567; and pneumonia, 480–486 and 487.0. Rates are adjusted for age, sex, race, and primary ESRD diagnosis. The reference cohort includes ESRD patients in 2010.

Figure 4.8 illustrates infectious hospital admission rates among period prevalent home HD and center HD patients. Rates are presented for admissions with infection and admissions for infection, by diagnosis code type as described for Figures 4.4–7 and using the ICD-9-CM codes for infection listed for Figure 4.1. Similar to Figures 4.4–7, analyses are intent-to-treat regarding dialysis modality, and patients are followed from January 1 or day 91 of ESRD until the earliest of death, three days prior to transplant, end of Medicare Parts A and B coverage, or December 31. Rates in Figure 4.8, however, are unadjusted.

Figures 4.3–9 show rates of rehospitalization and/or death among prevalent HD patients of all ages (aged 66 and older in Figure 4.9), 30 days after hospital discharge. Live hospital discharges from January 1 to December 1 of the year are identified as index hospitalizations; the latter date provides a 30-day period following the latest discharge to evaluate rehospitalization. The units of analyses include hospital discharges rather than patients. Hospitalization data exclude rehabilitation claims and transfers. Discharges with a same-day admission to long-term care or a critical access hospital are excluded. For HD patients in Figures 4.3–8, discharges with a transplant, loss to follow-up, or end of payer status before day 30 after discharge are excluded. For ESRD patients in Figure 3.9, the same exclusions apply except as related to transplant; discharges from transplant patients are excluded if they occur after two years and 11 months following the most recent transplant to ensure that complete claims are available during the 30-day post-discharge period.

Figures 4.3-5 and 4.7-8 indicate the percentage of discharges with readmission and/or death within 30 days after discharge. The groups indicate status at day 30 after discharge from the index hospitalization, and do not consider events after day 30. Figures 4.3-4 include all-cause index hospitalizations, while in 4.5, categories of cause-specific admissions are based on principal ICD-9-CM diagnosis codes of the index hospitalization. Codes for cardiovascular and infectious hospitalizations are listed in the discussion of Figure 4.1; vascular access infection codes are 996.62 and 999.31. Figures 4.7-8 include the codes for discharges from cardiovascular hospitalizations listed for Figure 4.1, and Figure 4.8 includes the codes for acute myocardial infarction (AMI), congestive heart failure (CHF), stroke and dysrhythmia. ICD-9 CM codes for AMI: 410.x0 and 410.x1; CHF: 398.91, 402.x1, 404.x1, 404.x3, 425, and 428; CVA/TIA: 430-437; stroke: 430-434 and dysrhythmia: 426-427. Figure 4.6 indicates the percentage of hospital discharges followed by a 30-day rehospitalization by cause-specific groups for both the index hospitalization and the rehospitalization. Categories of cause-specific rehospitalization also include non-vascular access infections, defined by infection codes excluding 996.62 and 999.31, and other, defined by codes other than cardiovascular and infectious.

Figure 4.9 shows overall percentages of discharges with 30-day rehospitalization and/or death in the general Medicare, chronic kidney disease (CKD), and ESRD populations. Data include point prevalent Medicare patients on December 31, 2011 who are aged 66 and older. For general Medicare patients with and without CKD, CKD is defined during 2011, and patients remain who are without ESRD, with continuous enrollment in Medicare Parts A and B, and without HMO coverage. Live hospital discharges from January 1 to December 1, 2012 are included.

### REFERENCE SECTION G

Hospitalization reference tables present adjusted total admission and hospital day rates, by year, 1993-2012. They begin in 1993 because Medicare inpatient claims are available beginning in 1991, and the model-based adjustment method uses data from the current and previous two years to obtain the predicted rates. This method is further discussed later in this section and in the statistical methods section at the end of this appendix.

Because hospitalization data for non-Medicare patients may be incomplete, analyses in this section include only patients with Medicare as their primary payer. Hospitalization data are obtained from institutional inpatient claims. As in Chapter 4, hospitalization data in Reference Section G also exclude inpatient stays for the purpose of rehabilitation therapy.

Tables G.1-15 include dialysis and transplant patients who are on their modality for at least 60 days, reaching day 91 of ESRD by the end of the year, and residing in the 50 states, the District of Columbia, Puerto Rico, and the U.S. territories. Excluded are patients with AIDS as a primary or secondary cause of death; patients with missing values for age, sex, or race; and patients of races that are unknown or other than White, Black/African American, Native American, or Asian. Age is determined on January 1 of each year. Patients are also classified according to their primary cause of ESRD, in which the "other" category includes patients with missing data or causes other than DM mellitus (DM), hypertension, or glomerulonephritis.

Patients are classified by modality at the beginning of the year:

- all dialysis: patients on HD, CAPD/CCPD, or dialysis of an unknown type, as well as those on more than one modality in the past 60 days
- hemodialysis: patients on HD for at least 60 days as of the start of the period at risk
- CAPD/CCPD: patients on CAPD/CCPD for at least 60 days as of the start of the period at risk
- transplant: patients with a functioning transplant, and who received the transplant less than three years prior to the start of the period at risk
- all-ESRD: all patients

To limit the contribution of patient years at risk from patients who do not have Medicare coverage but do have Medicare as a secondary payer or HMO coverage, and who therefore have incomplete hospitalization data, cohorts include only patients with Medicare Parts A and B coverage at the start of follow-up. The follow-up period is censored when a patient's payer status changes to no longer having Medicare Parts A and B coverage or Medicare as a primary payer.

For patients in the all-dialysis, HD, and PD categories, the period at risk for all hospitalization analyses is

from January 1 or day 91 of ESRD until the earliest of death, three days prior to transplant, end of Medicare Parts A and B coverage, or December 31. Modality change is considered a censoring event only in the case of a change from dialysis to transplant. For dialysis patients in the all-ESRD category, in contrast, the analysis period is censored only at death, end of Medicare Parts A and B coverage, or December 31 of the year; a modality change is not used as a censoring event. For transplant patients in the all-ESRD and transplant categories, the period is censored at the earliest of death, three years after the transplant date, end of Medicare Parts A and B coverage, or December 31 of the year. The censoring of transplant patients at three years following the transplant is necessary because Medicare eligibility may be lost and hospitalization data may be incomplete for these patients.

Time at risk is calculated differently for hospital days and total admissions. Since a hospitalized patient remains at risk for additional hospital days, rates for hospital days include hospital days in the time at risk value. Since a currently hospitalized patient is not, however, at risk for new admissions, hospital days for each year are subtracted from the time at risk for total admissions. In the case of a hospitalization in which admission occurs the same day as discharge, zero days are subtracted from the time at risk for total admissions. When hospitalizations span the start of the analysis period, only the days within the period are subtracted from the time at risk for total admissions.

All admissions and hospital days during the analysis period are included, respectively, in the total admissions and hospital days for each year. An admission for a hospitalization that occurs before and spans the start of the analysis period is excluded from the total admissions for that period, and only the hospitalization days within the period are counted in the total days for hospital day rates. The minimum length of stay is one day, and hospitalizations with an admission and discharge on the same day, as well as those with a discharge the day after admission, are both counted as one day.

As in previous ADRs, all overlapping and only certain adjacent hospitalizations are combined, due to the fact that many adjacent claims may actually be legitimate separate hospitalizations. Specifically, hospitalizations with an admission on the same day or the day after a previous discharge are combined only when there is a discharge transfer code or indication of an interim

claim. In the case of two hospitalizations combined into one, the principal diagnosis and procedure codes are retained from the first of the two hospitalizations, with the combined hospitalization extending from the first admission date to the last discharge date.

The methodology for computing adjusted total admission and hospital day rates uses the model-based adjustment method (discussed in the section on statistical methods). Predicted rates for each subgroup combination of age, sex, race, primary diagnosis, and year are obtained using a model with the Poisson assumption. For prevalent patient cohorts, this model uses data from the current and previous two years, with respective weights of 1,  $\frac{1}{4}$ , and  $\frac{1}{4}$ . Adjusted rates are then calculated using the direct adjustment method, with all 2010 ESRD patients as the reference cohort.

Tables G.11–15 show inpatient utilization in the period prevalent ESRD patients. Methods—including modality definitions, inclusion criteria, data cleaning, follow-up time definitions, and rate calculations—generally follow those described for the total admission rates in Tables G.1–5, but some differences do exist. While patients of races other than White, Black/African American, Native American, or Asian are excluded from G.1–5, they are included in G.11–15, except where rates are given by race. Rates are unadjusted and reflect total admissions per 100 patient years for 2004–2006, 2007–2009, and 2010–2012 (pooled) prevalent patients. While the rates for all causes are computed similarly to the unadjusted rates in G.1–5, the other nine cause-specific categories only include admissions for specific diseases. Vascular access and PD access hospitalizations are those classified as “pure” inpatient vascular/dialysis access events. Such access events are defined as admissions with a specified ICD-9-CM principal diagnosis code, or an ICD-9-CM principal procedure code in conjunction with a certain Diagnosis Related Group (DRG) code. Codes are listed in Table a.2. If an admission does not qualify as vascular/dialysis access, it is classified by the principal diagnosis code into one of eight other mutually exclusive groups. Categories and ICD-9-CM codes are as follows: circulatory diseases, 390–459; digestive diseases, 520–579; genitourinary diseases, 580–629; endocrine and metabolic diseases, 240–279; respiratory diseases, 460–519; infectious diseases, 001–139; and cancer, 140–172, 174–208, 230–231, and 233–234. Hospitalizations that do not fall under any of these categories are counted under all others.

**vol 2 Table m.2 DRG & ICD-9-CM codes for vascular access & peritoneal dialysis access variables****DRG codes<sup>a</sup>: prior to October 1, 2007**

112 Percutaneous cardiovascular procedure  
 120 Other circulatory system OR procedure  
 315 Other kidney and urinary tract OR procedure  
 442 Other OR procedure for injuries with complication  
 443 Other OR procedure for injuries without complication  
 478 Other vascular procedure with complication  
 479 Other vascular procedure without complication

**DRG codes<sup>a</sup>: after September 30, 2007**

252 Other vascular procedures with Major complicating conditions (MCC)  
 264 Other circulatory system O.R. procedures  
 673 Other kidney & urinary tract procedures with MCC  
 674 Other kidney & urinary tract procedures with CC  
 675 Other kidney & urinary tract procedures without CC/MCC  
 907 Other O.R. procedures for injuries with MCC  
 908 Other O.R. procedures for injuries with CC  
 909 Other O.R. procedures for injuries without CC/Medicare

**ICD-9-CM procedure codes<sup>a</sup>**

38.95 Venous catheterization for renal dialysis  
 39.27 Arteriovenostomy for renal dialysis  
 39.42 Revision of arteriovenous shunt for renal dialysis  
 39.43 Removal of arteriovenous shunt for renal dialysis  
 39.93 Placement of vessel-to-vessel cannula  
 39.94 Replacement of vessel-to-vessel cannula  
 86.07 Placement of totally implantable vascular access device

**ICD-9-CM diagnosis codes<sup>b</sup>**

996.1 Mechanical complication of vascular device, implant, graft  
 996.56 Mechanical complication due to peritoneal dialysis catheter  
 996.62 Infectious complication of vascular device, implant, graft  
 996.68 Infectious complication due to peritoneal dialysis catheter  
 996.73 Other complication due to renal dialysis device, implant, graft  
 999.31 Infection due to central venous catheter  
 V56.1 Fitting and adjustment of extracorporeal dialysis catheter  
 V56.2 Fitting and adjustment of peritoneal dialysis catheter

<sup>a</sup> DRG and procedure codes are used in conjunction to define inpatient pure vascular access events (both must be present).

<sup>b</sup> The presence of any of these diagnosis codes as the "Principal Diagnosis Code" is sufficient to define an inpatient pure vascular access or peritoneal dialysis access event.

Tables G.1.1–5.1 present adjusted rates similar to those shown in G.1–5, but include more patient subgroups. Additional Tables (G.1.2–5.2) display the counts of the total admissions, patient years at risk, and total patients that are used to calculate the total admission rates. Standard errors of the rates in Tables G.1–10 and G.1.1–5.1 are also available.

**Chapter 5: Mortality**

Unless otherwise specified, patient cohorts underlying the analyses presented in Chapter 5 include Medicare and non-Medicare patients living in the 50 states, the District of Columbia, Puerto Rico, and the U.S. territories.

Figure 5.1 shows trends in mortality rates by modality among incident ESRD patients during 1980–2011. Modalities include HD, CAPD/CCPD, and first transplant; results aggregating across modalities are also presented. Patients are classified by year based on date of ESRD onset. Dialysis patients are followed from ESRD onset (i.e., day one) censored at the earliest of date of transplant, loss to follow-up, recovery of native renal function or December 31, 2012. Transplant patients begin follow-up at the date of transplant and are censored on December 31, 2012. Adjusted mortality rates for each period after first treatment are computed separately by taking an appropriate weighted average of Cox-regression based predicted rates. The adjustment is made through model-based direct standardization, and is described later in the Statistical Methods section of this appendix. The Cox proportional hazard model serves as the basis for the predicted rates, adjusted for age, sex, race, and primary diagnosis. The reference population consists of 2011 incident ESRD patients. Figure 5.2 shows adjusted age-specific all-cause mortality for 2012 among prevalent ESRD patients and subpopulations (dialysis, transplant), as well as the general Medicare population. The rates are based on predicted values from a generalized linear mixed model, adjusted for sex and race using 2011 Medicare patients as the reference cohort.

Figure 5.3 displays adjusted all-cause and cause-specific mortality for incident HD patients. Patients are followed from ESRD onset (day one; as reflected by first service date) up to one year, and censored at loss to follow-up, transplant, or recovery of kidney function. Note that patients with unknown age, sex, or primary diagnosis are excluded from the analysis.

Rates are adjusted for age, sex, race, Hispanic ethnicity, and primary diagnosis, with the 2011 incident HD patients serving as the reference population

Figure 5.4 illustrates calendar time trends in mortality rates, by patient vintage. Within a given calendar year, patients begin follow-up on January 1 or the date of first ESRD service (if within that year) until death, transplantation, loss to follow-up, recovery of function, or the end of the year. Patients are excluded if their age or sex is unknown, or if they are of a race other than White, Black/African American, Native American, or Asian. All-cause rates are based on predicted values from a generalized linear mixed model, adjusted for age, sex, race, and primary diagnosis with the reference population being 2011 prevalent dialysis patients. Note that adjusted year-specific mortality rates are comparable across vintages.

Table 5.1 presents expected remaining lifetimes in years for the 2010 general U.S. population, and for 2012 prevalent dialysis and transplant patients. For period prevalent ESRD patients in 2012, expected lifetimes are calculated using the death rates from a generalized linear mixed model with 16 age groups, assuming a constant mortality rate within each age group. The method for calculating expected remaining lifetimes is described in the Statistical Methods section at the end of this appendix. Data for the general population are obtained from the CDC's National Vital Statistics Reports, Table 7 (Murphy et al., 2013; "Life expectancy at selected ages, by race, Hispanic origin, race for non-Hispanic population, and sex: United States, 2010").

Table 5.2 presents five-year survival by modality. Dialysis patients are classified by year of first service and initial modality. Transplants are classified by calendar year of transplantation, with only first transplants included. Patients with unknown age or sex are excluded. Dialysis patients are followed from day one until the earliest of death, transplantation, loss to follow-up, recovery of function, or the end of 2012, while transplant patients are followed from the date of transplantation until the earliest of death, or the end of 2012. All survival probabilities are adjusted for age, sex, Hispanic ethnicity, race, and primary diagnosis. The reference population consists of 2011 incident ESRD patients. Note that adjusted five-year survival probabilities are comparable across modalities.

Table 5.3 presents both unadjusted and adjusted all-cause mortality in the ESRD, dialysis, transplant,

and general Medicare patients with cancer, DM, CHF, cerebrovascular accident/transient ischemic attack (CVA/TIA), and AMI. All cohorts are defined on January 1, and include patients aged 65 and older. Follow-up for ESRD patients is from January 1 to December 31 of each year. For general Medicare patients, follow-up is from January 1 to December 31 of each year, censored at ESRD and at the end of Medicare entitlement. Adjusted mortality is adjusted for age, sex, and race, with 2011 ESRD patients serving as the reference. Figures 5.5–6 present adjusted all-cause mortality in the ESRD, dialysis, transplant, and general Medicare populations in 2012. The cohorts and adjustment method are same as those used in Table 5.3; 2012 ESRD patients are used as the reference cohort.

## REFERENCE SECTION H

Cohorts for tables in Section H include both Medicare and non-Medicare patients living in the 50 states, the District of Columbia, Puerto Rico, and the U.S. territories.

The cohorts in Tables H.1–12 are comprised of period prevalent patients, including those alive on January 1 and those incident during a calendar year. All patients are followed from either January 1 (for those alive on January 1) or from the date of onset of ESRD (for those patients incident in a calendar year). Follow-up is censored at loss to follow-up, date of transplant (for dialysis patients), recovery of function, or December 31 of the year. Age is defined at the beginning of follow-up. In calculating adjusted mortality, we have adjusted and reported for five race groups (White, Black/African American, Native American, Asian, and Other), and beginning in 1996, for Hispanics and non-Hispanics.

Tables H.1, H.2, and H.2.1 present mortality data for all ESRD patients. Total deaths are presented in Table H.1. Overall unadjusted and adjusted annual mortality rates by age, sex, race/ethnicity, primary diagnosis, and vintage are presented in Table H.2. Category-specific unadjusted mortality rates are calculated as total patient deaths divided by total follow-up time. Adjusted rates are computed by an appropriately weighted average of predicted category-specific rates, with the predicted rates based on generalized linear mixed models. Such methods, akin to direct standardization, are described in the Statistical Methods section later in this appendix. Overall

mortality rates are adjusted for age, sex, race, primary diagnosis, and vintage, while rates for each individual category are adjusted for the remaining four. The reference population includes 2011 prevalent ESRD patients. Table H.2.1 presents unadjusted mortality rates by age, sex, race, and primary diagnosis for 2011 prevalent ESRD patients; rates are again smoothed using a generalized linear mixed model.

The same methods are used for Tables H.3, H.4, and H.4.1 (dialysis); H.5 (dialysis patients, never on transplant waiting list); H.6 (dialysis patients on transplant waiting list); H.7 (dialysis patients, returned to dialysis from transplant); H.8 and H.8.1 (HD); H.9 and H.9.1 (CAPD/CCPD); and H.10 and H.10.1 (transplant).

### REFERENCE SECTION I

These tables present patient survival probabilities, based on incident cohorts. All causes of death are included, as are all non-Medicare patients and patients living in the 50 states, the District of Columbia, Puerto Rico, and the U.S. territories. Patients were excluded if sex is unknown, or if age is unknown or listed as greater than 110. All new ESRD patients with a first ESRD service date between January 1, 1980, and December 31, 2011 are included in the analysis. These patients are followed from day one (ESRD onset) until death, loss to follow-up, or December 31, 2012. For dialysis patients, both HD and PD, follow-up is also censored at recovery of native renal function and at receipt of a kidney transplant. Unadjusted patient survival probabilities are estimated using the Kaplan-Meier method, while adjusted survival is computed through model-based direct standardization using Cox regression. Incident 2011 ESRD patients served as the reference population for both overall and subgroup-specific adjusted survival.

## Chapter 6: Transplantation

### TRENDS IN KIDNEY TRANSPLANTATION

Figure 6.1 presents an overview of trends in kidney transplantation. Figure 6.1.a juxtaposes the percent of prevalent dialysis patients wait-listed for a kidney transplant with the falling rate of transplantation in dialysis patients at all ages, 1989–2012. Figure 6.1.b shows the number of ESRD-certified candidates on the OPTN kidney transplant waiting list on December 31 of each year, for first and subsequent kidney-alone

or kidney plus other organ transplants. Figure 6.1.b also shows the median waiting time from wait-listing to kidney transplantation for candidates for kidney-alone transplants (i.e., the time by which 50 percent of these candidates had received a kidney transplant). Candidates listed at more than one center on December 31 are counted only once. Median waiting time is reported for candidates newly listed in each given year. Figure 6.1.c presents transplant counts for all recipients, by donor type. Figure 6.1.d shows cumulative counts of functioning kidney-alone and kidney-pancreas transplants.

### WAITING LIST

Figure 6.2 shows the percentage of patients wait-listed or receiving a deceased or live donor kidney-alone or kidney plus other organ transplant within one year of ESRD initiation, stratified by age.

Figure 6.3 shows the annual mortality rates of dialysis patients who were wait-listed for a kidney-alone or kidney plus other organ transplant, per 1,000 dialysis patient years at risk, by time since listing.

### TRANSPLANT EVENTS

Figure 6.4 illustrates the number of deceased kidney-alone and simultaneous kidney-pancreas transplants. Figure 6.5 presents unadjusted rates of deceased kidney-alone and simultaneous kidney-pancreas transplants by age, sex, race, and primary diagnosis, per 100 dialysis patient years. Figure 6.6 portrays the number of live donor kidney-alone and simultaneous kidney-pancreas transplants. Figure 6.7 shows unadjusted rates of live kidney-alone and simultaneous kidney-pancreas transplants by age, sex, race, and primary diagnosis, per 100 dialysis patient years. Diagnosis of cystic disease is included in the other diagnoses.

### TRANSPLANT OUTCOMES

Figures 6.8 and 6.9 present one-, five-, and ten-year graft and patient outcomes for recipients who received a first kidney transplant from a deceased or living donor, respectively. Data are reported as unadjusted probabilities of each outcome, computed using Kaplan-Meier methods. All-cause graft failure includes repeat transplantation, return to dialysis, and death. The death outcome is not censored at graft failure, and assigns deaths that occur after repeat transplantation or return to dialysis to the transplant cohort.

Figure 6.10 presents the percent of acute rejections reported during the first post-transplant year in adult, first-time, kidney-alone transplant patients after discharge from the initial transplant hospitalization with a functioning graft. A recipient is assumed to have acute rejection if OPTN data collection forms note (1) acute rejection episodes, (2) that medications were given for acute rejection, or (3) that acute rejection was the primary cause of graft failure. Biopsy-proven rejection is available starting in 1991 on the OPTN Transplant Recipient Registration Form; it was not, however, added to the Transplant Recipient Follow-up form until April, 2003, so the incidence of biopsy-proven rejection is reported for 2004 and later. If multiple rejection episodes are reported during the first year, only one rejection is counted in the numerator.

Figure 6.11 presents the post-transplant total hospital admission rates per 1,000 patient years for all kidney transplant recipients by year.

Figure 6.12 displays mortality rate by primary cause of death for patients who received a deceased or live donor kidney-alone or kidney plus other organ transplant during 2010–2012. Causes of death are ascertained from the CMS 2746.

#### FOLLOW-UP CARE

Figure 6.13 presents data on immunosuppressive medications used in adult recipients at the time of transplantation, as reported to the OPTN. Recipients who received the same type of medication multiple times were counted once. Mycophenolate data include mycophenolate mofetil and mycophenolate sodium, and mTOR inhibitors include sirolimus and everolimus. Data on mTOR inhibitors and steroids are also shown at one year post-transplantation.

#### REFERENCE SECTION E

Tables E.1–5 present data regarding the kidney transplant waiting list. The OPTN began to collect waiting list data in 1987. Table E.1 presents counts of ESRD-certified candidates newly added to the waiting list for a kidney or kidney-pancreas transplant during the given year. Patients listed at multiple transplant centers are counted only once. Table E.2 presents waiting times, defined as the median time in days from listing to transplantation among ESRD-certified candidates newly added to the kidney-alone waiting

list during the given year, and estimated with the Kaplan-Meier method. Patients listed at multiple centers are counted from the time of the first listing. Table E.3 presents counts of ESRD-certified patients on the waiting list at any center on December 31 of the given year, regardless of when the first listing occurred. Table E.4 includes point prevalent dialysis patients wait-listed for a kidney on December 31 of the given year. Table E.5 presents the percentage of patients wait-listed or receiving a transplant within one year of ESRD initiation. Patients receiving a deceased donor kidney transplant are included in Tables E.5, E.5.3, and E.5.4, and patients receiving a deceased or live donor kidney transplant are included in Tables E.5.2, E.5.5, and E.5.6. Percentages in Tables E.2 and E.5 are calculated using the Kaplan-Meier method.

Transplant counts are presented in Tables E.6–8. All kidney transplants, including kidney-alone and kidney plus at least one other organ, are included unless specified in the footnote, and all counts include non-Medicare patients. Table E.8 illustrates the distribution of recipients by donor type and panel reactive antibody level, determined from the OPTN Recipient Histocompatibility form, and shows a cross-tabulation of recipients and donors in terms of cytomegalovirus antibody status, hepatitis C antibody status, and Epstein-Barr antibody status at the time of transplantation. A recipient/donor is considered positive for any of these antibodies if any applicable OPTN data source indicates positive. Unknown status is applied when no applicable data fields indicate “positive” or “negative.” Cold ischemia time (in hours; Table E.8.2) is reported for deceased donor transplants only, and is taken from the OPTN Transplant Recipient Registration form.

Transplant rates per 100 dialysis patient years are shown in Table E.9. All HD patients, PD (CAPD/CCPD) patients, and patients on an unknown form of dialysis are included, as are all non-Medicare dialysis patients. A patient’s dialysis days are counted from the beginning of the specified year, or day one of ESRD dialysis therapy if treatment begins within the specified year, until the first of transplant, death, or the end of the year. Dialysis time for patients returning to dialysis from transplant is counted. Transplant rates are calculated as the number of transplants, including kidney-alone and kidney plus at least one other organ, divided by the total number of dialysis patient years for each year.

## REFERENCE SECTION F

This section presents probabilities of graft survival and graft failure necessitating dialysis or repeat transplantation, by donor type, age, sex, race, ethnicity, primary diagnosis, and first versus subsequent transplant. Data are presented for outcomes at 90 days, one year, two years, three years, five years, and ten years post-transplant. This section seeks to address two major issues: the probability of graft survival at various times post-transplant, and the probability that a recipient will return to dialysis or require repeat transplantation at various times post-transplant. Recipients are followed from the transplant date to graft failure, death, or the end of the follow-up period (December 31, 2011). In the analysis of graft survival, death is considered a graft failure. In the analysis of graft failure necessitating dialysis or repeat transplantation, patients are followed until graft failure (excluding death), and patient follow-up is censored at death. To produce a standard patient cohort, patients with unknown age or sex are omitted. Unknown age is defined as a missing age at transplant, or an age calculated to be less than zero or greater than 100 years. Patients are also excluded if their first ESRD service date is prior to 1977.

Unadjusted survival probabilities are estimated using the Kaplan-Meier method, while the Cox proportional hazards model is used for adjusted probabilities. Probabilities are adjusted for age, sex, race, primary diagnosis, and first versus subsequent transplant, and standardized to 2011 recipient characteristics.

### Chapter 7: Pediatric ESRD

Information on pediatric patients is a subset of ESRD patient data reported in other chapters of the ADR; methods used for most figures are therefore the same as those described in the related chapter discussions.

## HOSPITALIZATION

Figures 7.4-6 present adjusted admission rates in the first year of ESRD, by age, and modality, for 2002-2006 and 2007-2011 incident patients younger than 20. The patients are divided into four age groups (age 0-4, 5-9, 10-14, and 15-19) or three modality groups (HD, PD, and transplant). Since in-center hemodialysis patients who are younger than 65 and not disabled cannot bill for hospitalizations until 90 days after ESRD initiation, the 90-day rule is applied. Patients

are required to survive the first 90 days after initiation, and are followed for admissions for up to one year after day 90. Data cleaning and counting of admissions and time at risk for admissions generally follow methods described for Reference Section G. Censoring occurs at death, loss to follow-up, end of payer status, December 31, 2012, or at one year. Censoring also occurs three days prior to transplant for dialysis patients, and three years after the transplant date for transplant patients. Rates are adjusted for sex, race, Hispanic ethnicity, and primary diagnosis. Adjusted rates are calculated with a model-based adjustment method and an interval Poisson model. The reference cohort includes incident ESRD patients aged 0-19 in 2010-2011. Principal ICD-9-CM diagnosis codes used for cardiovascular and infectious hospitalizations are listed in the discussion of Figure 4.1.

## MORTALITY AND SURVIVAL

Figures 7.8-10 present adjusted all-cause and cause-specific mortality in the first months of ESRD, by age, modality, and ethnicity, for 2002-2006 and 2007-2011 incident patients younger than 20. The patients are divided into four age groups (age 0-4, 5-9, 10-14, and 15-19) or three modality groups (HD, PD, and transplant). Dialysis patients are followed from the day of ESRD onset until December 31, 2012, and censored at loss to follow-up, transplantation, or recovered function. Transplant patients who receive a first transplant in a calendar year are followed from the transplant date to December 31, 2012. Rates by age are adjusted for sex, race, Hispanic ethnicity, and primary diagnosis; rates by modality are adjusted for age, sex, race, Hispanic ethnicity, and primary diagnosis. Incident ESRD patients who were younger than 20 years in 2010-2011 are used as the reference cohort.

Figure 7.11 presents five-year survival for 2003-2007 incident ESRD patients aged 0-19, by age, modality, and ethnicity. The patients are divided into four age groups (age 0-4, 5-9, 10-14, and 15-19) or three modality groups (HD, PD, and transplant). Dialysis patients are followed from the day of ESRD onset until December 31, 2012, and censored at loss to follow-up, transplantation, or recovered function. Transplant patients who receive a first transplant in a calendar year are followed from the transplant date until December 31, 2012. Probabilities by age are adjusted for sex, race, Hispanic ethnicity, and primary diagnosis; probabilities by modality are adjusted for age, sex, race, Hispanic ethnicity, and primary diagnosis. The



reference population consists of 2010–2011 incident pediatric ESRD patients.

### TRANSPLANTATION

Figure 7.2 presents an overview of the pediatric transplant population.

Figure 7.2.a shows the rate of ESRD among the U.S. population aged 0-19, and the rate of transplantation in dialysis patients aged 0-19 at transplant, 1988–2012.

Figure 7.2.b shows the number of ESRD-certified pediatric candidates (0-19 years old) on the OPTN kidney transplant waiting list on December 31 of each year, and the median waiting time from wait-listing to kidney transplantation for new candidates (i.e., the time by which 50 percent of newly wait-listed candidates had received a kidney). Candidates listed at more than one center on December 31 are counted only once. Median waiting time is reported for patients listed in each given year.

Figure 7.2.c presents transplant counts for all pediatric (0-19 years old) recipients, by donor type. Figure 7.2.d shows cumulative counts of functioning transplants in pediatric patients, ages 0-19.

### TRANSPLANT AND OUTCOMES

Figures 7.3 presents transplant rates per 100 dialysis patient years among pediatric patients on dialysis (ages 0-19). Figure 7.3a presents rates by age group. Figure 7.3b presents rates by sex, and Figure 7.3c presents rates by race. Rates were calculated among dialysis patient years in that specific subgroup.

Figure 7.7 presents one-year graft and patient outcomes for pediatric recipients (ages 0-19) who received a kidney transplant from a deceased or living donor, respectively. Death outcome probabilities are among first-time transplants. Data are reported as adjusted probabilities of each outcome, computed using Cox proportional hazards models. The death outcome is not censored at graft failure, and includes deaths that occur after repeat transplantation or return to dialysis. These probabilities are adjusted as described below.

For the all-cause graft failure analyses, data are reported as adjusted probabilities of each outcome, computed using Cox proportional hazards models. Probabilities are adjusted for age, sex, race, primary

diagnosis, and first versus subsequent transplant, and standardized to 2011 patient characteristics. All-cause graft failure includes retransplant, return to dialysis, and death.

For the probability of death analyses, the Cox model and the model-based adjustment method are used for adjusted probabilities. The adjusted survival probability for a cohort is based on expected survival probability for the cohort and the reference population. The survival/conditional probabilities are modeled separately for each period: 0–90 days, 91 day to one year, one year to two years, two years to three years, three years to five years, and five years to ten years. The expected survival probabilities for 90 days, one year, two years, and so on are calculated based on the survival/conditional survival probabilities. We fit one model for each cohort to obtain adjusted probabilities overall and for age, sex, race, and primary cause of ESRD. The reference population consists of 2011 incident ESRD patients. The death outcome is not censored at graft failure, and includes deaths that occur after retransplant or return to dialysis.

### Chapter 8: Providers

In Reference Section J, we define a chain-affiliated unit as a freestanding dialysis unit owned or operated by a corporation at the end of a year. The category of small dialysis organization (SDO) includes all organizations meeting our definition of a chain but not owned by DaVita, Fresenius Medical Care (Fresenius), or Dialysis Clinic, Inc. (DCI).

Data are obtained from CMS's Annual Facility Survey (1988 to the present), Renal Dialysis Facilities Cost Report (Form 265–94, 1994–2000), and Dialysis Facility Compare (DFC) database (2001 to the present), as well as the CDC National Surveillance of Dialysis-Associated Diseases in the United States (1988–2002, excluding 1998, when the CDC did not conduct a survey). The CDC discontinued the National Surveillance of Dialysis-Associated Diseases after 2002.

A facility's hospital-based or freestanding status is determined from the third and fourth digits of the provider number assigned to each unit by CMS. For years prior to 2001, we determine profit status through the ownership type field on the CMS survey. For subsequent years we use the profit status field of the DFC database.

Figure 8.1 shows the counts of units and patients for all provider types from the 2010—2012 Annual Facility Survey. Figure 8.2 presents the percentage of patients by provider type being treated by each type of dialysis: in-center HD, PD and home HD.

Figure 8.3 presents the percentage of patient-months in May—December 2012 during which a provider's patients had a particular type of access: catheter, fistula, graft or other/missing type. The figure shows these percentages among all patient-months ("Among Prevalent Dialysis Patients") and only among those patient-months during which a HD patient was new to dialysis ("Among Incident Dialysis Patients").

Figure 8.4 shows the percentage of dialysis patients on the kidney transplant waiting list in 2010, 2011 and 2012. This figure only measures wait-listing among patients younger than 70 because transplants in people aged 70 or older occur much less frequently.

#### HOSPITALIZATION AND MORTALITY

Tables 8.1 and 8.2 compare mortality and hospitalization among dialysis provider types and chains, using standardized mortality ratios (SMRs) and standardized hospitalization ratios (SHRs). Both are estimated using a two-stage Cox proportional hazards model (described below). SMR and SHR calculations include all 2010, 2011 and 2012 period prevalent dialysis patients; SHR calculations include only dialysis patients with Medicare as primary payer.

#### ADJUSTMENT

Both SMRs and SHRs are adjusted for patient age, race, ethnicity, sex, DM, duration of ESRD, nursing home status, patient comorbidities at incidence, and body mass index (BMI) at incidence. The SMR is additionally adjusted for race-specific population death rates.

Unlike previous ADRs reporting these standardized measures, to facilitate comparison of the SMR and SHR across years, this year's ADR reports these measures with the year adjustment removed from the model. That is, the measures are not standardized to a national norm annually, but are rather standardized across the reporting period (e.g., three years) in order to facilitate identifying short-term trends over time.

#### CONFIDENCE INTERVALS

Given the large number of observations that go into the SMR and SHR models, we choose to approximate rather than directly calculate the 95 percent confidence intervals for the respective measure. This approach gains efficiency with minimal loss of precision. In particular, the exact 95 percent confidence intervals are derived by applying the Wilson-Hilferty Approximation (Wilson and Hilferty, 1931), which approximates chi-square percentiles using percentiles of the standard normal distribution (Breslow and Day, 1987).

#### PATIENT PLACEMENT

We identified each patient's dialysis provider at each point in time using data from a combination of Medicare-paid dialysis claims, the ME, and paid dialysis claims. Starting with day 91 after onset of ESRD, we attribute a patient to a facility according to the following rules. A patient is attributed to a facility once the patient has been treated there for 60 days. When a patient transfers from one facility to another, the patient continues to be attributed to the original facility for 60 days and then is attributed to the destination facility. In particular, a patient is attributed to their current facility on day 91 of ESRD if that facility had treated him or her for at least 60 days. If on day 91, the facility had treated a patient for fewer than 60 days, we wait until the patient reaches day 60 of treatment at that facility before attributing the patient to the new facility. When a patient is not treated in a single facility for a span of 60 days (for instance, if there were two switches within 60 days of each other), we do not attribute that patient to any facility. Patients were removed from a facility's analysis upon receiving a transplant. Patients who withdrew from dialysis or recovered renal function remained assigned to their treatment facility for 60 days after withdrawal or recovery. If a period of one year passed with neither paid dialysis claims nor CROWNWeb/SIMS information to indicate that a patient was receiving dialysis treatment, we considered the patient lost to follow-up and did not continue that patient in the analysis. When dialysis claims or other evidence of dialysis reappeared, the patient was entered into analysis after 60 days of continuous therapy at a single facility.

## Chapter 9: Costs of ESRD

Data used to estimate HMO and EGHP costs as well as Medicare Part D Prescription Drug cost data were not available for inclusion in the 2014 ADR.

Figure 9.1 includes total costs to Medicare and expected patient obligation based on Medicare claims data. Figure 9.2 includes total Medicare spending for all programs and the fraction of total spending related to the ESRD program. Figure 9.3 presents counts of Medicare and Non-Medicare ESRD patients by year. These counts are also available in Chapter 1: Incidence, Prevalence, Patient Characteristics and Modalities.

Figure 9.4 describes the growth in total Medicare Part A and B spending each year; part D costs are not included. Figure 9.5 shows the Total Medicare ESRD expenditures by type of service (see also Reference Table K.2).

### REFERENCE SECTION K: MEDICARE CLAIMS DATA

Cost information in this section is derived from Medicare inpatient/outpatient, physician/supplier and Part D claims data in the CMS SAFs, which are created annually six months after the end of each calendar year. Claims data are obtained for all patient identification numbers in the USRDS database, and the Renal Management Information System (REMIS) is used to gather all CMS ID numbers under which patients may have claims. The claims data are then merged with patient demographic data and modality information in the USRDS database.

The economic analyses for this section focus on the claim payment amount, which is the amount of the payment made from the Medicare trust fund for the services covered by the claim record. These analyses also include the pass-through per diem amount, which applies to inpatient claims and reimburses the provider for capital-related costs, direct medical education costs, and organ acquisition costs.

The reference tables in section K include previously reported values for years prior to 2012. Values for 2012 are calculated using the same methods as in prior years with exceptions noted below. Values for 2012 exclude patients who were classified as MSP and individuals with missing values for demographics, modality, or payer status, unless otherwise specified.

### PAYER SEQUENCE

The payer sequence is similar in concept to the USRDS treatment history. Payer status is tracked for each ESRD patient from the first ESRD service date until death or the end of the study period. Data from the Medicare Enrollment Database and dialysis claims information are used to categorize payer status as Medicare primary payer (MPP), Medicare secondary payer (MSP), or non-Medicare. The claims database contains data only for MPP and MSP patients, so economic analyses are restricted to these categories. In addition, as it is impossible to determine the complete cost of care for ESRD patients with MSP coverage, analyses of costs per person per year exclude patients during the periods when they have this coverage.

### PAYMENT CATEGORIES

Medicare payments are broken into several categories. Estimates of costs from the outpatient SAF are derived for the individual services provided. For claims prior to 2000, actual payment amounts are provided only for the entire claim. Cost estimates for these years for dialysis, EPO, iron, and so forth are calculated from the claim-level “Total Charge,” the payment amount, and the revenue line-level “Total Charge,” as follows:

payment (line) = [total charge (line) / total charge (claim)] \* payment (claim). In August, 2000, CMS added to the outpatient SAF a field containing line-item payment amounts. According to CMS documentation, the total of these payments may not equal the total paid amount for the claim. In such cases, each line-item cost is discounted by the ratio of the sum of line-item payment amounts to the total paid amount for the claim. Since complete data on line-item payments are available starting with the 2001 outpatient SAF, the estimates for outpatient payment categories are taken directly from the claims data for calendar years 2001–2012, with adjustments as noted.

### Model 1: as-treated actuarial model

In an as-treated model patients are first classified by their modality at entry into the analysis, and retain that classification until a modality change. When a change is encountered in the data, the initial modality is censored, and a new observation with the new modality is created. Under this method, aggregation of Medicare payments is done on an as-treated basis, attributing all payments for a particular claim to the

patient's modality at the time of the claim.

Prior to 2012, the first 60 days after a change were attributed to the previous modality, to account for any carryover effects. This carryover period did not apply to changes from dialysis to transplant. For the 2012 calculations, no carryover period was used for any modality change. In Section K of the Reference Tables, we classify patients into four as-treated modality categories: HD, CAPD/CCPD, other dialysis, and transplant. The "other dialysis" category includes cases in which the dialysis modality is unknown or is not HD or CAPD/CCPD, while the transplant category includes patients who have a functioning graft at the start of the period, or who receive a transplant during the period. Some tables also include categories for all dialysis (HD, CAPD/CCPD, and other dialysis) and all ESRD (all-dialysis and transplant).

The study spans the 20 years from January 1, 1991, to December 31, 2011, and ESRD patients prevalent on January 1, 1991 or incident at any time during the period are potentially eligible for inclusion. The initial study start date for a given patient is defined as the latest of January 1, 1991, the first ESRD service date in the USRDS database for that patient, or the earliest Medicare eligibility date from the payer sequence. Patients who are non-Medicare or enrolled in a Medicare Advantage program are excluded until their payer status changes to Medicare (either as primary or secondary payer). Claims during periods that a patient is classified as MSP are included in Tables K.1-4, and are excluded for the rest of the tables in Section K.

For each modality period, Medicare payments are aggregated from the modality start date until the earliest of death, transplant, modality change, loss to follow-up, or December 31, 2010. Patients incurring no inpatient/outpatient or physician/supplier Medicare costs for the entire period are excluded. Prior to 2012, Medicare payment amounts are linearly prorated for claims that span the start or end date of a modality period or of the study itself; for 2012, the payment amount is included for the period in which the claim begins.

To express costs as dollars per year at risk, total costs during the follow-up period are divided by the length of the period. Costs per patient year at risk are calculated by patient category, and stratified by age, sex, race, modality, and diabetic status (based on the patient's primary diagnosis).

## Model 2: categorical calendar year model

This model, described in the Health Care Financing Administration (now CMS) research report on ESRD (1993-1995), is used for Reference Tables K.10-13. With this method, patients are classified into four mutually exclusive treatment groups:

- dialysis: ESRD patients who are on dialysis for the entire calendar year, or for that part of the year in which they are alive and with ESRD.
- transplant: ESRD patients receiving a kidney transplant during the calendar year.
- functioning graft: ESRD patients with a functioning graft for the entire calendar year, or for that part of the year in which they are alive and with ESRD.
- graft failure: ESRD patients who have had a transplant, but return to dialysis due to loss of graft function during the calendar year; patients with a graft failure and a transplant in the same calendar year are classified in the trans-plant category.

## Chapter 10: International Comparisons

### DATA COLLECTION

Each country was provided a data-collection form spreadsheet (Microsoft Excel) to complete for years 2008 through 2012. Countries were asked to report patient count data for each year, if available, for the entire population or by 5 different age categories (0-19, 20-44, 45-64, 65-74, 75+) for: (1) the country's or region's general population, (2) patients new to ESRD during the year, (3) patients new to ESRD during the year among new ESRD patients for whom DM was the primary cause of ESRD, (4) the point-prevalent count of ESRD patients living on December 31 of the given year, (5) total number of patients with a functioning kidney transplant on December 31st of the given year, (6) total number of kidney transplants performed during the year, by type of kidney transplant (cadaveric, living donor, other donor), (7) the number of dialysis patients, HD patients, CAPD/CCPD patients, and home HD patients on December 31st of the indicated year. Prevalence was reported for all patients at the end of the calendar year (December 31, 2012) except where otherwise noted. Data for Australia, New Zealand, Italy, South Africa, and Lebanon were

taken directly from the respective registry's annual report (McDonald et al., 2013; Italian Registry of Dialysis and Transplant, 2014; Davids et al., 2014; Elzein, 2012). Information for Ukraine was based on a recent publication of registry data from the Ukraine (Kolesnyk et al., 2014). Data provided by Argentina may be supplemented by Marinovich et al., 2013.

#### DATA LOADING AND CLEANING

The data were imported into SAS from Microsoft Excel and data quality checks were performed, with follow-up with registries as needed.

#### STATISTICAL ANALYSES

Rates were calculated as the count divided by the total population for that year, multiplied by one million. For age-specific categories, rates were calculated as the count in each category divided by the total population in the age category, multiplied by one million.

To contribute data from your country's registry, please contact [international@usrds.org](mailto:international@usrds.org).

#### Chapters 11 and 12: Special Studies

Methods for the creation of the figures and tables in Chapters 11, USRDS Special Study Center on Palliative and End-of-Life Care and 12, Transition of Care in Chronic Kidney Disease are described within the chapters themselves.

#### Vascular Access

##### REFERENCE SECTION L

Tables L.1-L.6 include period prevalent HD patients with Medicare as primary payer. Placements are identified from Medicare claims, and rates represent the total number of events divided by the time at risk. Follow-up is censored at death, change in modality, change in payer status, or the end of the prevalent year.

Tables L.7-L.8 include point prevalent PD patients with Medicare as primary payer. Complications are obtained from claims during the time at risk in the prevalent year, and rates represent the total number of events divided by the time at risk. Follow-up time is censored at death, a change in modality, a change in payer status, a claim for HD vascular access placement, or at the end of the prevalent year.

## Statistical Methods

### Methods for Calculating Rates

The calculation of observed rates is straightforward, with some rates based on counts and others on follow-up time. The ESRD incident rate in 2009, for example, is the observed incident count divided by the 2009 population size and, if the unit is per million population, multiplied by one million. The 2009 death rate for prevalent ESRD patients is the number of deaths in 2009 divided by the total follow-up time (patient years) in 2009 of the 2009 prevalent patients, and, if the unit is per thousand patient years, multiplied by one thousand. Standard errors of estimated rates are based on the assumption of the data; the observed count has a Poisson or binomial distribution. The count-based rate describes the proportion having the "event", and the time-based rate tells how often the "event" occurs.

#### MODEL-BASED RATES

Some patient groups may be very small, and their observed rates therefore unstable. If follow-up time is considered, the hazard of an event may change over time. A model-based method can improve the stability of these estimates and incorporate changes of hazard over time. In this ADR, for example, we have used the generalized linear mixed Poisson model to estimate prevalent patient mortality rates for Reference Section H.

#### MEASUREMENT UNIT FOR RATES

Both observed and model-based rates are calculated per unit of population (i.e., per 1,000 patients) or per unit of follow-up time (i.e., per 1,000 patient years). Calculating rates per unit of follow-up time can account for varying lengths of follow-up among patients. Patient years are calculated as the total number of years, or fractions of a year, of follow-up time for a group of patients.

Take, for example, a calculation of 2010 first hospitalization rates for two groups of patients, all receiving dialysis therapy on January 1, 2010. Group A consists of three patients: Patient one had a first hospitalization on March 31, 2010, Patient two was hospitalized on June 30, 2010, and Patient three was on dialysis through December 31, 2010, with no hospitalizations. Group B also has three patients: Patient four was first hospitalized on December 31,

2010, Patient five was hospitalized on September 30, 2010, and Patient six was on HD the entire year, with no hospitalizations through December 31, 2010.

Patients one to six contribute 0.25, 0.5, 1.0, 1.0, 0.75, and 1.0 patient years at risk, respectively. The first hospitalization rate per thousand patients is 667 for both groups in 2010. But the first hospitalization rate per thousand patient years at risk is 1,143 for Group A and 727 for Group B (calculated as  $[2 \text{ total events} / 1.75 \text{ total patient years at risk}] \times 1,000$  for Group A and  $[2 \text{ total events} / 2.75 \text{ patient years at risk}] \times 1,000$  for Group B). The resulting rate is lower for Group B because of the longer total follow-up time.

Rates per unit of population may be influenced by the proportion of patients who are followed for only a fraction of a year. The event rate per unit of population is likely to be lower, for example, in a group of patients followed for only one month until censoring than in a group whose patients are each followed for up to a full year. Rates per unit of follow-up time at risk, in contrast, count only the actual time that a patient is at risk for the event.

**Methods for Adjusting Rates**

Because each cohort contains a different patient mix, observed event rates may not be comparable across cohorts. Adjusted analyses make results comparable by reporting rates that would have arisen had each cohort contained patients with the same distribution of confounders—such as age, sex, race, and primary diagnosis—as the reference population.

**DIRECT ADJUSTMENT**

There are several rate-adjustment methods, but only the direct method allows rates to be compared (Pickle & White, 1995). Here the adjusted rate is derived by applying the observed category-specific rates to a single standard population (i.e., the rate is a weighted average of the observed category-specific rates, using as weights the proportion of each category in the reference population). Categories are defined by the adjusting variables. For example, if a rate is adjusted for race and sex and there are three race groups (White, Black/African American, and Other) and two sex groups, there are six categories: White males, White females, Black/African American males, Black/African American females, males of other races, and females of other races.

Suppose we try to compare state-level incidence rates in 2009 after removing the difference caused by race. To do this, we need to calculate the incidence rate, adjusted for race, for each state. Because racial distributions in each state are quite different, we use as reference the national population—here, the population at the end of 2009—with five race groups (White, Black/African American, Native American, Asian, and Other).

Assuming the incidence rate of state A in 2009 is 173 per million population, and the race-specific rates and race distribution of the national populations are as shown in the following table, the adjusted incidence rate of state A with the national population as reference is  $(153 \times 75.1\%) + (250 \times 12.3\%) + (303 \times 0.9\%) + (174 \times 3.6\%) + (220 \times 8\%) = 158.73$  per million population. This means that if state A had the same racial distribution as the entire country, its incidence rate would be 158.73 instead of 173. If state B had an adjusted incidence rate of 205, we could say that state B had a higher incidence rate than state A if they both had the same racial distribution as the whole country.

**vol 2 Table m.3 Example of adjusted incident rate calculation**

	Incidence rate of State A	National population (%)
White	153	75.1
Black/African American	250	12.3
Native American	303	0.9
Asian	174	3.6
Other	220	8.0

This method is used to produce some adjusted incidence and prevalence rates in Chapters 1 and 3, and in Reference Sections A and B, as well as in the model-based adjustment method.

**MODEL-BASED ADJUSTMENT**

Under some circumstances there are disadvantages to the direct adjustment method. Suppose we are calculating mortality rates for a set of groups, and adjusting for potential confounding variables. If one category in a group has only a few patients or deaths, its estimated category-specific mortality rate will be unstable, likely making the adjusted rate unstable as well. In addition, if one includes a category with no patients, the method is not valid for calculating an adjusted mortality rate for the group. An attractive alternative is a model-based approach, in which we find a good model to calculate

category-specific estimated rates for each group, and then calculate direct adjusted rates using these estimates with a given reference population. This method can also be extended to adjustments with continuous adjusting variables (Liu et al., 2006). As in previous ADRs, standard errors of the adjusted rates are calculated using a bootstrap approach. In general, the bootstrap approach works well, but is time consuming. Convergence problems occur in a few bootstrap replications and such cases are ignored in the calculation. In this ADR we use model-based adjustments to calculate adjusted mortality rates, adjusted hospitalization rates, and state-level adjusted incidence and prevalence rates using the Poisson model and some other rates, as described in the text on the individual figures.

**Survival Probabilities and Mortality Rates**

**UNADJUSTED SURVIVAL PROBABILITIES**

In this ADR, unadjusted survival probabilities are calculated using the Kaplan-Meier method, and corresponding standard errors are calculated with Greenwood’s formula (Kalbfleisch & Prentice, 2002.). Survival probabilities in Reference Section I are expressed as percentages from 0 to 100. The mortality/event rate in the period of (0,t) is calculated by  $-\ln(\text{Survivor at time } t)$ . This event rate will be the same as that estimated by event time divided by follow-up time after adjustment of the unit if the event rate is a constant over time.

**SURVIVAL PROBABILITY WITH COMPETING RISKS**

When competing risks exist, the estimate of the cumulative incidence function of a specific cause may be biased if the other competing risks are ignored. If we have K competing risks, the cumulative incidence function of cause k,  $k=1, 2, \dots, K$ , at time t,  $I_k(t)$ , is defined as the probability of failing from cause k before time t (including time t),  $\text{Prob}(T \leq t, D=k)$ . Then

$$I_k(t) = \int_0^t \lambda_k(s)S(s)ds$$

where  $\lambda_k(s)$  is the hazard of event from cause k at time s and  $S(s)$  is the survival probability at time s (the probability of no event happening). If we have failing time  $t_1, t_2, \dots, t_m$ , the cumulative incidence function of cause k at time t is estimated by

$$I_k(t) = \sum(\lambda_k)(t_j)\hat{S}(t_{j-1})$$

where  $\lambda_k(t_j)=D_{kj}/n_j$ ,  $\hat{S}(t_{j-1})$  is the Kaplan-Meier estimate of survival at time  $t_{j-1}$ ,  $D_{kj}$  is the number of patients failing from cause k at time  $t_j$ , and  $n_j$  is the number of patients at risk at prior time  $t_j$  (Putter et al., 2007).

**ADJUSTED SURVIVAL PROBABILITIES**

Adjusted survival probabilities are reported in Reference Section I, with age, sex, race, Hispanic ethnicity, and primary diagnosis used as adjusting risk factors. The model-based adjustment method is used, with survival probabilities/conditional survival probabilities predicted from the Cox regression model (Kalbfleisch & Prentice, 1980, 2002). This process yields estimates of probabilities that would have arisen in each year if the patients had had the same attributes as the reference population. Since the probabilities in each table are adjusted to the same reference set of patient attributes, any remaining differences among cohorts and years are due to factors other than age, sex, race, Hispanic ethnicity, and primary diagnosis. The adjusted mortality rates for incident cohorts in Reference Section H are calculated using similar methods.

**Generalized Linear Models**

**GENERALIZED LINEAR MIXED MODEL FOR MORTALITY RATES**

We use the generalized linear mixed model with log link and Poisson distribution to calculate mortality and first transplant rates for prevalent patients. While rates are reported for a year, data from the previous two years with different weights are also used to improve the stability of the estimates.

The generalized linear mixed model, which considers both fixed and random effects, is implemented using the SAS macro GLIMMIX. Rates for the intersections of age, sex, race, and diagnosis are estimated using the log linear equation  $\text{Log}(\text{rate}) = (\text{fixed effects}) + (\text{random effect})$ . Fixed effects include year, age, sex, race, and primary diagnosis, and all two-way interactions among age, sex, race, and primary diagnosis. Assumed to be independently and identically distributed with a normal distribution, the random effect is the four-way interaction of age, sex, race, and primary diagnosis. Age is used as a categorical variable.

For tables with mortality rates for both intersecting and marginal groups, we have used a single model to calculate all rates in each table. The marginal rates are simply the weighted averages of the estimated, cross-classified rates, with cell-specific patient years as weights. For this approach the use of a single model means that GLIMMIX cannot give the standard errors for some of these estimated rates; the bootstrap method is therefore used instead.

The adjusted mortality rates for prevalent cohorts in Section H are calculated using the direct adjustment method based on the category-specific mortality rates from the generalized linear mixed models.

#### **GENERALIZED LINEAR MODEL FOR HOSPITALIZATION RATES**

In this ADR, hospitalization reference tables present rates of total admissions and hospital days. We use a generalized linear model with log link and Poisson distribution; the model includes age, sex, race, primary diagnosis, and their two-way interactions.

To stabilize the estimates, three years of data are used with different weights. Year is also included in the model as a covariate. The adjusted hospitalization rates are calculated using the direct adjustment method, based on the category-specific admission rate from the generalized linear models.

#### **Standardized Mortality Ratios**

The standardized mortality ratio (SMR) compares the mortality of a group of patients relative to a specific norm, or reference, after adjusting for some important risk factors. For example, the dialysis chain-level SMR is used to compare mortality in prevalent dialysis patients—after adjusting for age, race, ethnicity, sex, DM, duration of ESRD, nursing home status, patient comorbidities at incidence and BMI at incidence in each dialysis chain. Qualitatively, the degree to which the facility's SMR varies from 1.00 is the degree to which it exceeds ( $>1.00$ ) or is under ( $<1.00$ ) the national death rates for patients with the same characteristics as those in the facility. For example, an  $SMR=1.10$  would indicate that the facility's death rates typically exceed national death rates by 10 percent (e.g., 22 deaths observed where 20 were expected,

according to the facility's patient mix). Similarly, an  $SMR=0.95$  would indicate that the facility's death rates are typically 5 percent below the national death rates (e.g., 19 observed versus 20 expected deaths). An  $SMR=1.00$  would indicate that the facility's death rates equal the national death rates, on average.

#### **METHOD OF SMR CALCULATION**

The SMR is designed to reflect the number of deaths for the patients at a facility, relative to the number of deaths that would be expected based on overall national rates and the characteristics of the patients at that facility. Specifically, the SMR is calculated as the ratio of two numbers; the numerator ("observed") is the actual number of deaths, excluding deaths due to abused drugs and accidents unrelated to treatment, over a specified time period. The denominator ("expected") is the number of deaths that would be expected if patients at that facility died at the national rate for patients with similar characteristics. The expected mortality is calculated from a Cox model (Cox, 1972; SAS Institute Inc., 2004; Kalbfleisch and Prentice, 2002; Collett, 1994). The model used is fit in two stages. The Stage I model is a Cox model stratified by facility and adjusted for patient characteristics. This model allows the baseline survival probabilities to vary between strata (facilities), and assumes that the regression coefficients are the same across all strata. Stratification by facility at this stage avoids biases in estimating regression coefficients that can occur if the covariate distributions vary substantially across centers. The results of this analysis are estimates of the regression coefficients in the Cox model and these provide an estimate of the relative risk for each patient. This is based on a linear predictor that arises from the Cox model, and is then used as an offset in the Stage II model, which is unstratified and includes an adjustment for the race-specific age-adjusted state population death rates.

#### **Standardized Hospitalization Ratios**

The Standardized Hospitalization Ratios (SHR) for Admissions is designed to reflect the number of hospital admissions for the patients at a dialysis facility, relative to the number of hospital admissions that would be expected based on overall national rates and the characteristics of the patients at that facility. Numerically, the SHR is calculated as the ratio of two numbers: the numerator ("observed") is the



actual number of hospital admissions for the patients in a facility over a specified time period, and the denominator (“expected”) is the number of hospital admissions that would have been expected for the same patients if they were in a facility conforming to the national norm.

The denominator of the SHR stems from a proportional rates model (Lawless and Nadeau, 1995; Lin et al., 2000; Kalbfleisch and Prentice, 2002). This is the recurrent event analog of the well-known proportional hazards or Cox model (Cox, 1972; Kalbfleisch and Prentice, 2002). To accommodate large-scale data, we adopt a model with piecewise constant baseline rates (e.g., Cook and Lawless, 2007) and the computational methodology developed in Liu, Schaubel and Kalbfleisch (2012). The modeling process has two stages. At Stage I, a stratified model is fitted to the national data with piecewise-constant baseline rates, stratification by facility and adjusting for age, sex, DM, duration of ESRD, nursing home status, comorbidities at incidence, BMI at incidence, and calendar year. The baseline rate function is assumed to be a step function with break points at 6 months, 1 year, 2 years, 3 years and 5 years since the onset of dialysis. This model allows the baseline hospitalization rates to vary between strata (facilities), but assumes that the regression coefficients are the same across all strata; this approach is robust to possible differences between facilities in the patient mix being treated. The stratification on facilities is important in this phase to avoid bias due to possible confounding between covariates and facility effects. At Stage II, the relative risk estimates from the first stage are used to create offsets, and an unstratified model is fitted to obtain estimates of an overall baseline rate function.

**Expected Remaining Lifetimes**

The expected remaining lifetime for a patient group is the average of the remaining life expectancies for the patients in that group. Some patients will live longer than, and some will live less than, the average. Although the average cannot be known until all patients in the cohort have died, the expected remaining lifetime can be projected by assuming that patients in the cohort will die at the same rates as those observed among groups of recently prevalent ESRD patients.

For a subgroup of ESRD patients of a particular age, the expected remaining lifetime is calculated using a survival function, estimated for the group. Let

$S(A)$  denote the survival function of patients at age  $A$ . Among patients alive at age  $A$ , the probability of surviving  $X$  more years is  $S(X|A) = S(A+X)/S(A)$ . For a given starting age  $A$ , the expected remaining lifetime is then equal to the area under the curve of  $S(X|A)$  plotted versus  $X$ . Because few patients live beyond 100, this area is truncated at the upper age limit  $A + X = 100$ .

**Half-lives (Median Time)**

**CONDITIONAL HALF-LIFE**

The conditional half-life is conditional on having survived a given period of length  $T_0$  without the event, the point at which 50 percent of patients who survived the given period remain alive. In other words, it is the median remaining lifetime conditional on surviving a given period  $T_0$ .

The conditional half-life is estimated using the Kaplan-Meier method if the median survival time falls in the duration of follow-up. Otherwise, the conditional half-life is estimated as the following:

Estimate the survival probabilities  $S(t_0)$  and  $S(t_1)$  using the Kaplan-Meier method from the data available, where  $t_0 < t_1$  and  $T_1$  is within the follow-up

$$\mu = (t_1 - t_0) / (\ln[S(t_0)] - \ln[S(t_1)])$$

the estimate of the conditional half-life =  $\mu \cdot \ln(2)$ .

This method can be used only when the hazard is a constant after  $t_0$  and  $t_1$  is chosen to be big enough to obtain a stable estimate of  $\ln(S(t_0)) - \ln(S(t_1))$ .

**Mapping Methods**

Throughout the ADR, data in maps and graphs are unadjusted unless otherwise noted. Because of area size and limitations in the mapping software, data for Puerto Rico and the U.S. territories are not included in the maps.

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