# 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.

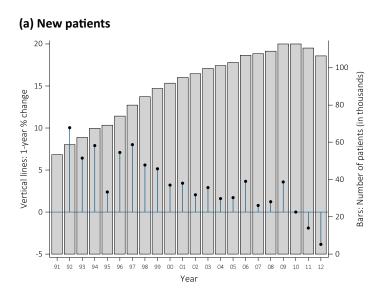
#### 2014 USRDS Annual Data Report | Volume 2 - ESRD

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

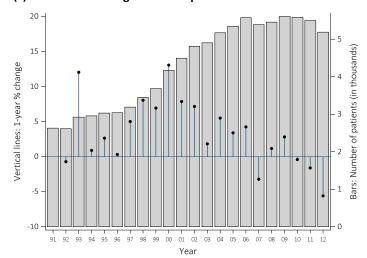
	Incidence <sup>a</sup>				December 31 point prevalence								
	Count	%	Adj. rate <sup>b</sup>	Count	%	Adj. rate <sup>b</sup>	Dialysis <sup>c</sup>	%	Tx °	%	Deceased donor	Living donor	ESRD deaths d
<b>0-19</b> <sup>e</sup>	1,163	1.0	13.1	7,545	1.2	83.1	2,060	0.5	5,485	2.9	549	350	84
20-44	13,162	11.5	122.2	101,994	16.0	938.0	59,045	13.1	42,949	23.1	2,918	1,925	3,929
45-64	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
65-74	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
75+	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
Unknown age											42	21	
White	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
Black/African American	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
Native American	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
Asian	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
Other	50	0.0		5,860	0.9		2,515	0.6	3,345	1.8	75	*	490
Unknown	163	0.1		2,682	0.4		283	0.1	2,399	1.3	77	48	
Hispanic	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
Non-Hispanic	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
Male	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
Female	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
Unknown gender	•	•	•	96	0.0	•	70	0.0	26	0.0	42	21	*
Diabetes	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
Hypertension	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
Glomerulonephritis	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
Cystic kidney disease	2,530	2.2	7.9	29,881	4.7	92.4	11,526	2.6	18,355	9.9	832	620	1,548
Urologic disease	538	0.5	1.6	7,447	1.2	22.9	3,576	0.8	3,871	2.1	133	91	589
Other known cause	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
Unknown cause	3,506	3.1	10.8	25,977	4.1	78.2	15,883	3.5	10,094	5.4	423	216	3,101
Missing cause	3,699	3.2	10.6	8,988	1.4	18.1	3,147	0.7	5,841	3.1	382	314	867
All	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
Unadjusted rate <sup>g</sup>			358.6			1,968.2					Total transplants <sup>h</sup>	17,330	

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 age, sex, and race. 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.

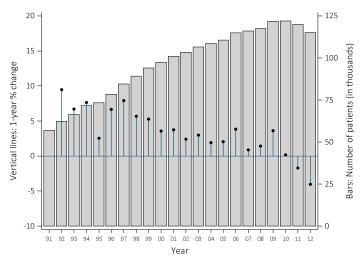
vol 2 Figure i.1 Counts of new & returning dialysis patients, 1991-2012



(c) Patients returning from transplant







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.

4

Bars: Number of patients (in thousands)

(b) Patients restarting dialysis

94 95 96

97 98 99 00 01 02 03 04 05 06 07 08 09 10 11 12

Year

20

15

10

5

0

-5

-10

91 92 93

Vertical lines: 1-year % change

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

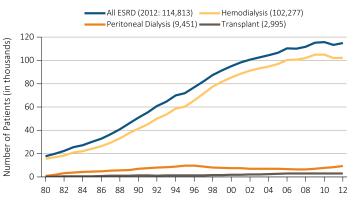
	New listings in 2012	N (as of 12/31/2012)	Median time on list (years) ª
0-17	633	564	0.30
18-44	8,195	20,547	3.19
45-64	15,336	45,159	3.55
65-74	4,271	14,088	3.76
75+	432	1,623	4.98
Unknown			
Male	17,750	49,230	3.21
Female	11,117	32,751	3.53
White	17,537	44,248	2.61
African American	8,895	29,987	4.14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

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

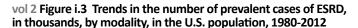
Chapter 1 analyses further examine current status and changes for the ESRD cohort, with a longitudinal view of trends over time. As evidenced by the data presented above, while prevalence of ESRD continues to increase, early trends indicate that the ESRD incidence rate may have begun to decrease after 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.

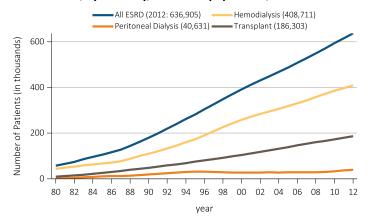
# vol 2 Figure i.2 Trends in the number of incident cases of ESRD, in thousands, by modality, in the U.S. population, 1980-2012



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.

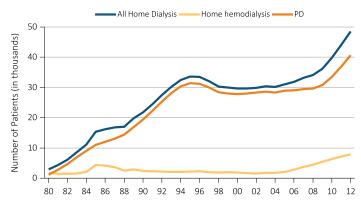




Data Source: Reference table D.1. Abbreviations: ESRD, end-stage renal disease. This graphic is also presented as Figure 1.10.

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

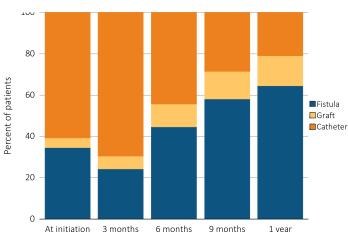
Chapter 2 provides an analysis of nine of the 14 Healthy People 2020 (HP2020) objectives (15 of 20 indicators) for the improvement of chronic kidney disease (CKD). Positive trends were observed for nearly all the CKD indicators that were examined. For 10 out of 15 indicators, the HP2020 target was met 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.

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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



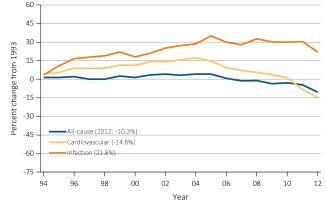
Data Source: Data Source: Special analyses, USRDS ESRD Database. Mean monthly Hgb level among ESA-treated HD patients within a given month (1995 through 2012) or all HD patients irrespective of ESA use (April to December 2012 only) if, within the given month, the patient had an Hgb claim, was on dialysis  $\geq$ 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. This graphic is adapted from Figure 3.2.

## **Chapter 4: Hospitalization**

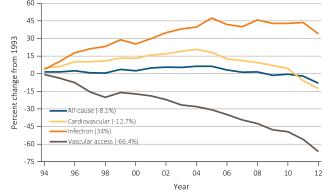
Hospital admissions among ESRD patients represent a significant societal and financial burden, and have a major negative impact on patients' well-being and quality of life. Among HD patients, the overall hospitalization rate in 2012 was 1.73 admissions per patient year—a reduction from 1.84 in 2011, and 1.87 in 2010 (see Figure 1.7).

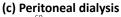
# vol 2 Figure i.7 Trends in adjusted all-cause & cause-specific hospitalization rates, by modality

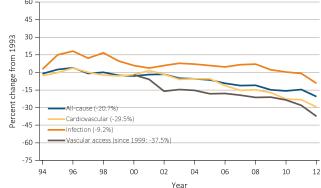
(a) All ESRD



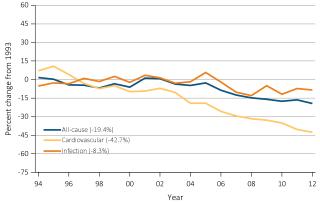






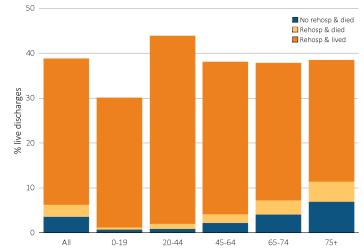






Data Source: Reference tables: G.1, G.3, G.4, G.5, and special analyses, USRDS ESRD Database. Period prevalent ESRD patients; adjusted for age, sex, race, & primary diagnosis; ref: ESRD patients, 2010. Percent changes from 1993 for the year 2012 are shown in parentheses. Abbreviations: ESRD, end-stage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

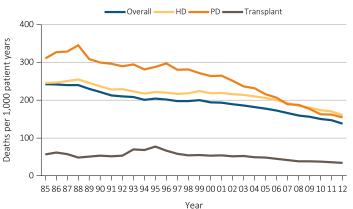


Data Source: Special analyses, USRDS ESRD Database. Period prevalent hemodialysis patients, all ages, 2012; unadjusted. Includes live hospital discharges from January 1 to December 1, 2012. Cause-specific hospitalizations are defined by principal ICD-9-CM codes. See Vol. 2, ESRD Analytical Methods for 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**

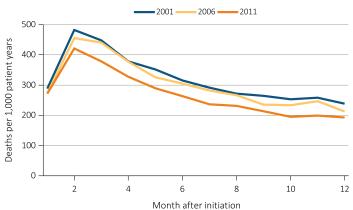
Overall mortality rates among ESRD patients continue to decline. Over the last two decades, the adjusted death rates fell by nine percent from 1993 to 2002, and by 26 percent from 2003 to 2012 (Figure i.9). Since 1993, the net reduction in mortality has been 28 percent for HD patients, 47 percent for 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



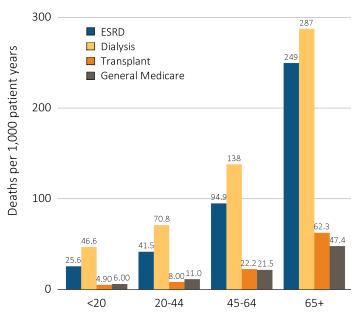
Data Source: Reference Tables H.2, H.8, H.9, and H.10, and special analyses, USRDS ESRD Database.Adjusted for age, sex, race, and primary diagnosis. Ref: 2011 patients. Abbreviations: HD, hemodialysis; PD, peritoneal dialysis. This graphic is also presented as Figure 5.1.

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

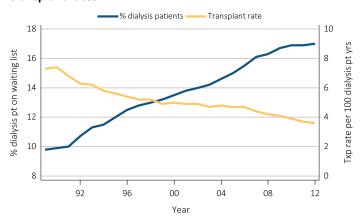


Data Source: Special analyses, USRDS ESRD Database and Medicare 5 Percent Sample. Adjusted for sex and race. Medicare data limited to patients with at least one month of Medicare eligibility in 2012. Ref: Medicare patients, 2012. Abbreviation: ESRD, end-stage renal disease. This graphic is also presented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

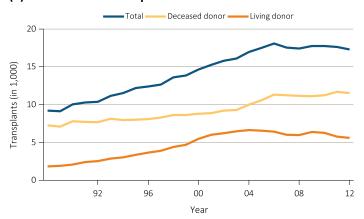
## **Chapter 6: Transplantation**

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





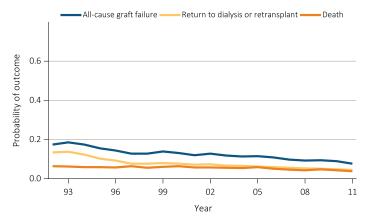


Data Source: Reference Tables E4, E9; E2, E3; E8, E8(2), E8(3); D9. Percent of dialysis patients on the kidney waiting list is for all dialysis patients. Unadjusted transplant rates are for all dialysis patients. Waiting list counts include all candidates listed for a kidney transplant on December 31 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 posttransplant 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

## **Chapter 7: Pediatric ESRD**



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.

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.

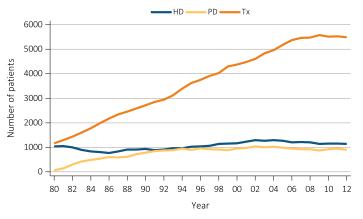
Hemodialysis remains the most common initial modality for renal replacement therapy in pediatric patients, at 45 percent in 2012 (Figure i.15). Kidney transplant patients form the majority of children with prevalent ESRD.

# 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)



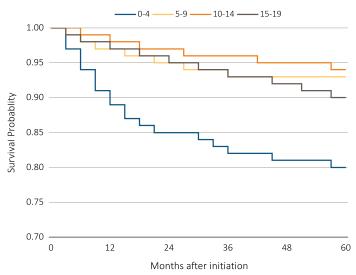
Data Source: Reference tables D3-D5, D7-D9, and special analyses, USRDS ESRD Database. Peritoneal dialysis consists of continuous ambulatory peritoneal dialysis and continuous cycling peritoneal dialysis. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.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

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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.

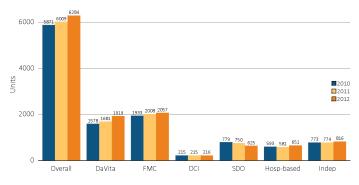
## **Chapter 8: Providers**

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



# $40 - \frac{414}{92} + \frac{427}{14} + \frac{427}{15} + \frac{427}{15} + \frac{414}{14} + \frac{417}{15} + \frac{414}{14} + \frac{414}{14} + \frac{417}{15} + \frac{414}{14} + \frac{414}{14}$

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.

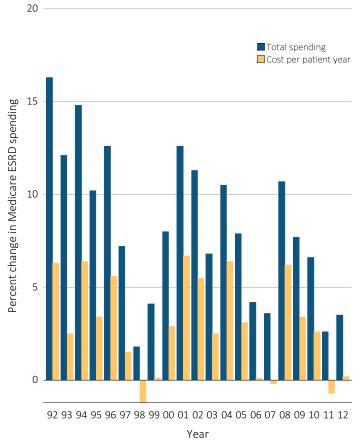
## **Chapter 9: Costs of ESRD**

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.

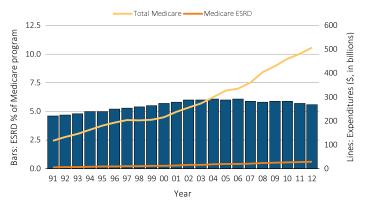
#### 88

# 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, endstage 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)

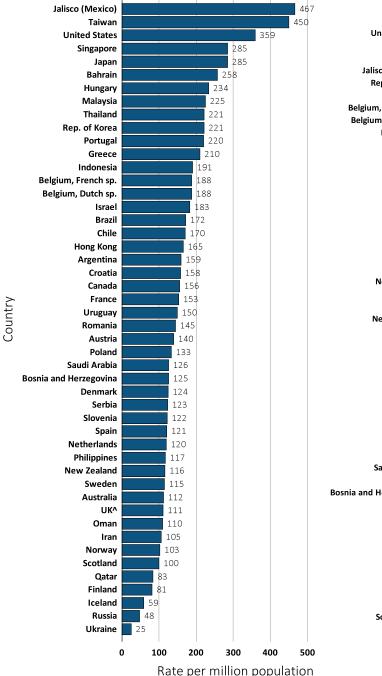


Data Source: USRDS ESRD Database. Total Medicare expenditures obtained from http://CMS.gov. Abbreviations: ESRD, end-stage renal disease. This graphic is also presented as Figure 9.2.

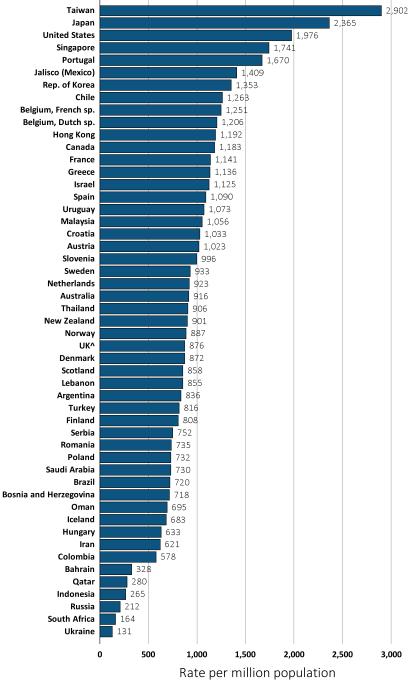
## **Chapter 10: International Comparisons**

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 patientcentered 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 m2), 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 heath 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.