## Introduction to Volume 2: ESRD in the United States

### Introduction

Volume 2 of the USRDS Annual Data Report (ADR) offers a detailed descriptive epidemiology of end-stage renal disease (ESRD) in the United States. Registration in the U.S. national ESRD database legally requires the completion of the ESRD Medical Evidence form (CMS 2728). 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 (RRT).

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 ADR, the Coordinating Center has previously relied on data from Medicare claims for its analyses; however, since the 2014 ADR, data from CROWNWeb is being included incrementally in several chapters.

Volume 2 of the 2016 USRDS ADR provides key statistics on ESRD in the United States and includes the following chapters: *Incidence, Prevalence, Patient Characteristics, and Treatment Modalities* (Chapter 1); *Healthy People 2020* (Chapter 2); *Clinical Indicators and Preventive Care* (Chapter 3); *Vascular Access* (Chapter 4); *Hospitalization* (Chapter 5); *Mortality* (Chapter 6); *Transplantation* (Chapter 7); *ESRD Among Children, Adolescents, and Young Adults* (Chapter 8); *Cardiovascular Disease in Patients With ESRD* (Chapter 9); *Dialysis Providers* (Chapter 10); *Medicare Expenditures for Persons With ESRD* (Chapter 11); *Part D Prescription Drug Coverage in Patients with ESRD* (Chapter 12); *International Comparisons* (Chapter 13); *USRDS Special Study Center on End-of-life Care for Patients With ESRD* (Chapter 14).

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

There were 120,688 newly reported cases of ESRD in 2014; the crude (unadjusted) incidence rate was 370 per million/year, representing a slight increase (1.1%) compared to 2013 (not shown, see Table 1.11 in Volume 2: Chapter 1). Adjusted incidence rate rose sharply in the 1980s and 1990s, but leveled off in the early 2000s, and has declined slightly since its peak in 2006 (Figure i.1). The rate of incident ESRD is roughly 3-fold higher for Black/African Americans than for other races, and approximately 1.4-fold higher for Hispanics versus non-Hispanics. Notably, there has been a rather dramatic decline in ESRD incidence in the Native American population.
Despite relative stability in ESRD incidence over the last 3 years, at the end of 2014, there were 678,383 prevalent dialysis and transplant patients receiving treatment for ESRD — a 3.5% increase from 2013. The number of ESRD prevalent cases continues to rise by about 21,000 cases per year, as does the adjusted prevalence (Figure i.2). Because the incidence of ESRD has plateaued, the ongoing rise in prevalence can be attributed to the decline in the mortality rate among ESRD patients.

Among prevalent ESRD cases, the use of home dialysis (peritoneal dialysis or home hemodialysis; Figure i.3) continues to show a rising trend.
vol 2 Figure i.2 Trends in the unadjusted and adjusted* ESRD prevalence (per million) (trend lines; scale on left), and annual percent (%) change in adjusted* prevalence of ESRD (vertical lines; scale on right), in the U.S. population, 1996-2014

Data Source: Reference Table B.2(2) and special analyses, USRDS ESRD Database. *Adjusted for age, sex, race, and ethnicity. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease. This graphic is adapted from Figure 1.10.
vol 2 Figure i.3 Trends in number of prevalent ESRD cases (in thousands) using home dialysis, by type of therapy, in the United States, 1996-2014

![Graph showing trends in number of prevalent ESRD cases using home dialysis, by type of therapy, in the United States, 1996-2014.]

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. This graphic is adapted from Figure 1.19.

Wide geographic variations by Health Service Area and Dialysis Networks were notable with respect to incidence, prevalence, home dialysis use, eGFR, hemoglobin values at start, and duration of pre-ESRD care prior to ESRD.

Nationally, 24% of patients starting ESRD therapy in 2014 were reported on the CMS 2728 form as not having received nephrology care prior to ESRD onset. This reflects little change from 2013. An additional 13% had unknown duration of pre-ESRD nephrology care.
Chapter 2: Healthy People 2020

We present data for 10 Healthy People 2020 (HP2020) Objectives, spanning 19 total indicators overall, stratified by race, gender, and age group. In 2014, 12 of 19 indicators met HP2020 goals, and most of the remaining objectives continue to show improvement. We include maps for some of the indicators to illustrate geographic variation. Specifically, we present state-level comparison maps for HP2020 objectives CKD-10 (proportion of chronic kidney disease (CKD) patients receiving care from a nephrologist at least 12 months before the start of RRT) and CKD-13.1 (proportion of patients receiving a kidney transplant within three years of end-stage renal disease; not shown, see Figure 2.2 in Volume 2: Chapter 2). More than 80% of states achieved the HP2020 target for CKD-10, while just over 20% achieved the target for CKD-13.1. For both these objectives there was significant geographic variation, with percentages varying between states by greater than 50% from the lowest to highest quintiles. For HP2020 objectives relating to vascular access, we present data from CROWNWeb. Until 2013, USRDS annual data reports had relied on data from the clinical performance measures project, which only collected information through 2007. Using CROWNWeb, we continue to present data from 2012 and 2014 for HP2020 objectives CKD 11-1 (proportion of adult hemodialysis patients who use an arteriovenous (AV) fistula as the primary mode of vascular access) and CKD 11-2 (proportion of adult hemodialysis patients who use a catheter as the only mode of vascular access). In 2014, we continued to observe an increasing trend in proportion of patients using AV fistulas, reaching 63.9% overall; notably, this trend was observed across nearly all subgroups. In 2014, we continued to observe a trend towards decreasing all-cause mortality among prevalent dialysis patients. The total death rate fell to 172.8 deaths per 1,000 patient years, decreasing more than 25% from 233.7 deaths per 1,000 patient years in 2001.

vol 2 Figure i.4  HP2020 CKD-10 Geographic distribution of the adjusted proportion of chronic kidney disease patients receiving care from a nephrologist at least 12 months before the start of renal replacement therapy, by state, in the U.S. population, 2013: Target 29.8%

Data Source: Special analyses, USRDS ESRD Database. Incident hemodialysis patients with a valid ESRD Medical Evidence CMS 2728 form; nephrologist care determined from Medical Evidence form. Adjusted for age, sex, and race. Abbreviations: CDC, Centers for Disease Control and Prevention; CKD, chronic kidney disease; ESRD, end-stage renal disease. This graphic is adapted from Figure 2.1.
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. Owing to recent availability of data from CROWNWeb, national trends in serum calcium, phosphorus, ferritin, and transferrin saturation levels are reported in the ADR, providing a more representative view of Kt/V (Figure i.5.a) and Hgb levels (Figure i.5.b) for the dialysis population than was previously possible, as it includes data from both Medicare and non-Medicare insured patients. Figure i.5.a shows that achievement of dialysis adequacy targets for hemodialysis is nearly universal, with 96.4% of patients obtaining a single pool Kt/V ≥1.2 (for more information about Kt/V see the Glossary in the ADR Appendices). Achievement of the dialysis adequacy target for peritoneal dialysis (a weekly Kt/V ≥1.7) is somewhat lower, at 89.0% (Figure i.5.a). As of December 2015, the majority (63.3%) of hemodialysis patients in December 2015 had Hgb levels between 10-12 g/dL, while 14.7% had Hgb ≥12 g/dL, 6.8% had Hgb less than 9 g/dL, and 15.2% had Hgb between 9-10g/dL, with the mean Hgb being 10.8/dL. About 2% of patients receiving either dialysis modality had calcium levels >10.2 mg/dL (Figure i.5.c). Avoidance of this threshold is currently being utilized as a quality indicator in CMS programs such as Dialysis Facility Compare and the Quality Incentive Program given concerns about associations between hypercalcemia and vascular calcifications or cardiovascular events. The percent of patients with hypercalcemia for both modalities has declined compared to December 2014.
vol 2 Figure i.5 ESRD clinical indicators: CROWNWeb data, December 2015 (continued)

(b) Percent distribution of Hgb levels among prevalent hemodialysis and peritoneal dialysis patients

![Graph showing percent distribution of Hgb levels among prevalent hemodialysis (HD) and peritoneal dialysis (PD) patients.]

(c) Percentage of dialysis patients with serum calcium >10.2 mg/dL by modality

![Graph showing percentage of dialysis patients with serum calcium >10.2 mg/dL.]

Data Source: Special analyses, USRDS ESRD Database. Results shown are for laboratory values reported to CROWNWeb for December 2015, restricted to patients as follows: (a) dialysis patients initiating treatment for ESRD at least 1 year prior to December 1, 2015, and who were alive through December 31, 2015; (b) dialysis patients initiating treatment for ESRD at least 90 days prior to December 1, 2015, who were ≥18 years old as of December 1, 2015, and who were alive through December 31, 2015; and (c) hemodialysis and peritoneal dialysis patients initiating treatment for ESRD at least 90 days prior to December 1, 2015, who were ≥18 years old as of December 1, 2015, and who were alive through December 31, 2015. Abbreviations: CROWNWeb, Consolidated Renal Operations in a Web-Enabled Network; ESRD, end-stage renal disease; HD, hemodialysis; Hgb, hemoglobin; Kt/V, see Glossary; PD, peritoneal dialysis. This graphic is adapted from Figure 3.1.
From December 2013 to December 2014, EPO doses increased by 1.5% in hemodialysis patients and 4.5% in peritoneal dialysis patients. In 2014, average monthly EPO doses were approximately 10,524 units/week and 9,716 units/week for hemodialysis and peritoneal dialysis patients, respectively (Figures i.6 and i.7).

**vol 2 Figure i.6** Anemia measures among adult hemodialysis patients on dialysis ≥90 days: mean monthly Hgb level and mean weekly EPO dose (averaged over a month), Medicare claims, 1995-2014

*Data Source: Special analyses, USRDS ESRD Database. Mean monthly Hgb level among ESA-treated adult hemodialysis patients on dialysis ≥90 days (1995 through 2014) or mean monthly Hgb level among all adult hemodialysis patients (April 2012 to December 2014 only) who, within the given month had a Hgb claim (only the first reported Hgb value in a month was used) and were on dialysis ≥90 days; analyses were restricted to patients ≥18 years old at the start of the month. Mean weekly EPO (epoetin alfa) dose is shown for hemodialysis 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. Abbreviations: EPO, erythropoetin; ESA, erythropoiesis-stimulating agents; Hgb, hemoglobin. This graphic is adapted from Figure 3.2.*
vol 2 Figure i.7  Anemia measures among adult peritoneal dialysis patients on dialysis ≥90 days: mean monthly Hgb level and mean weekly EPO dose (averaged over a month), Medicare claims, 1995-2014

Data Source: Special analyses, USRDS ESRD Database. Mean monthly Hgb level among ESA-treated adult peritoneal dialysis patients on dialysis ≥90 days (1995 through 2014) or mean monthly Hgb level among all adult peritoneal patients (April 2012 to December 2014 only) who, within the given month had a Hgb claim (only the first reported Hgb value in a month was used) and were on dialysis ≥90 days; analyses were restricted to patients ≥18 years old at the start of the month. Mean weekly EPO (epoetin alfa) dose is shown for peritoneal 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. Abbreviations: EPO, erythropoietin; ESA, erythropoiesis-stimulating agents; Hgb, hemoglobin. This graphic is adapted from Figure 3.8.

Approximately 71% of patients received an influenza vaccination in the 2013-2014 flu season, still below the Healthy People 2020 (HP2020) target of 90%. Although stable over the last two seasons, the percent vaccinated has increased from 58.4% a decade prior (Figure i.8).
Figure i.8 Percentage of ESRD patients with a claim for seasonal influenza vaccination (August 1-April 30 of subsequent year), overall, Medicare data, 2003-2014

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. Abbreviation: ESRD, end-stage renal disease. This graphic is adapted from Figure 3.19.

Chapter 4: Vascular Access

New since 2015, this chapter outlines the patterns of vascular access for incident and prevalent hemodialysis patients in the United States.

Figure i.9 displays trends in vascular access use among prevalent hemodialysis patients from 2003-2014. There has been a large rise in AV fistula use and AV fistula placement since 2003, with use increasing from 32% to 63%. In contrast, AV graft use has decreased from 40% to 18% over the same time period. Catheter use has also declined, albeit not as dramatically, decreasing from 27% to 18%. In 2014, only 9% of prevalent hemodialysis patients had been using a catheter for >90 days.
vol 2 Figure i.9  Trends in vascular access type use among ESRD prevalent patients, 2003-2014

Data Source: Special analyses, USRDS ESRD Database and Fistula First data. Fistula First data reported from July 2003 through April 2012, CROWNWeb data are reported from June 2012 through December 2014. Abbreviations: AV, arteriovenous; CROWNWeb, Consolidated Renal Operations in a Web-enabled Network; ESRD, end-stage renal disease. This graphic is adapted from Figure 4.6.

Figure i.10 shows cross-sectional data from both the Medical Evidence form (CMS 2728) (for vascular access information at initiation) and CROWNWeb (for follow-up data with respect to vascular access in use at 3, 6, and 9 months, and 1 year). At 90 days, most hemodialysis patients were still using a catheter, highlighting the importance of ongoing efforts to improve pre-dialysis access planning. The percentage of patients using an AV fistula exclusively at the end of 1 year on dialysis was 65%, up from 17% at initiation of hemodialysis. The proportion of patients with an AV graft for vascular access was 3% at initiation, and 15% at 1 year. Thus, at 1 year, 80% of patients were using either an AV fistula or AV graft without the presence of a catheter.
vol 2 Figure i.10 Change in type of vascular access during the first year of dialysis among patients starting ESRD via hemodialysis in 2014 quarterly: type of vascular access in use (cross-sectional), ESRD Medical Evidence form (CMS 2728) and CROWNWeb, 2014-2015

Data Source: Special analyses, USRDS ESRD Database. Data from January 1, 2014 to December 31, 2014: (a) Medical Evidence form (CMS 2728) at initiation and CROWNWeb for subsequent time periods. (b) ESRD patients initiating hemodialysis (N =102,367). Patients with a maturing AV fistula / AV graft with a catheter in place were classified as having a catheter. The apparent decrease in AV fistula and AV graft use at 1 month is related to missing data due to the different data sources used for incident and prevalent patients. Abbreviations: AV, arteriovenous; CMS, Centers for Medicare & Medicaid; CROWNWeb, Consolidated Renal Operations in a Web-enabled Network; ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis. This graphic is adapted from Figure 4.7.
Chapter 5: Hospitalization

On average, ESRD patients are admitted to the hospital nearly twice a year. About 30% of those have an unplanned rehospitalization within the 30 days following discharge. Hospitalization represents a significant societal and financial burden, accounting for approximately 40% of total Medicare expenditures for dialysis patients. Over the past decade, the frequency of hospital admissions and resulting number of hospital days for ESRD patients have declined gradually, but fairly consistently. In 2014, the adjusted rate of admission for hemodialysis patients decreased to 1.7 per patient year as compared to 2.1 in 2005, a reduction of 19.0% (Figure i.11). During that same period, admission rates for peritoneal dialysis patients fell by about 23.8%, to 1.6 in 2014 from 2.1 in 2005. For transplant patients this reduced by 27.2%, to 0.8 in 2014 from 1.1 in 2005.

Rehospitalization has also been recognized as 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. In this chapter, rehospitalization/readmission is defined as a hospital admission occurring within 30 days of a hospital discharge, excluding ER visits and those for rehabilitation purposes. Hospital readmissions with associated death were more common among patients with CKD or ESRD than in the general population.

Patients with CKD and ESRD experienced rehospitalization rates of 21.4% and 34.6%, respectively, as compared to only 15.3% of older Medicare beneficiaries without a diagnosis of kidney disease (Figure i.12). This held true for the combined outcomes of post-discharge death and/or rehospitalization—experienced by 27.6% of CKD patients and 40.1% of those with ESRD, versus only 19.8% of patients without diagnosed kidney disease.

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 cause of kidney failure & their two-way interactions; reference population, ESRD patients, 2011. Abbreviation: ESRD, end-stage renal disease. This graphic is adapted from Figure 5.1.
Chapter 6: Mortality

Increasing lifespan among ESRD patients is likely the main reason for continued growth in the prevalent ESRD population. Overall mortality rates among ESRD (dialysis and transplant) patients continue to decline, with steeper declines in more recent years. In 2014, adjusted mortality rates for ESRD, dialysis, and transplant patients, were 136, 166, and 30, per 1,000 patient-years, respectively (Figure i.13). By dialysis modality, mortality rates were 169 for hemodialysis patients and 157 for peritoneal dialysis patients, per 1,000 patient-years. Since 1996, crude mortality rates have decreased by 26% for dialysis patients and have increased by 2% for transplant recipients over the same period. However, when accounting for changes in population characteristics, adjusted mortality rates continue to decrease for dialysis and transplant patients, falling by 32% and 44%, respectively.
The conundrum of high mortality in the first year of dialysis remains. Patterns of mortality during the first year of dialysis differ substantially by modality. For hemodialysis patients, reported mortality is highest in month 2, but declines thereafter; this effect is more pronounced for patients aged 65 and over (Figure i.14). In contrast, mortality rises slightly over the course of the year for peritoneal dialysis patients.
vol 2 Figure i.14  Adjusted mortality (deaths per 1,000 patient-years) by treatment modality and number of months after treatment initiation among ESRD patients (a) under age 65 and (b) aged 65 and over, 2013

(a) Under age 65

(b) Aged 65 and over

Data Source: Special analyses, USRDS ESRD Database. Adjusted (age, race, sex, ethnicity, and primary diagnosis) mortality among 2013 incident ESRD patients during the first year of therapy. Reference population: incident ESRD patients, 2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis. This graphic is adapted from Figure 6.3.

The relationship between race and mortality differs considerably by age among dialysis patients. White dialysis patients younger than age 22 have mortality rates comparable to Black patients, but experience higher mortality than Blacks at older ages.
Dialysis patients continue to have substantially higher mortality, and fewer expected remaining life years, compared to the general population and Medicare populations with cancer, diabetes, or cardiovascular disease. However, the relative and absolute decline in mortality for dialysis patients in the past 15 years has been greater than for Medicare patients in these other diagnostic categories.

**Chapter 7: Transplantation**

During the year 2014, 17,914 kidney transplants, including 17,205 kidney-alone and 709 kidney plus at least one additional organ, were performed in the United States. Of these transplants, 5,574 were identified as coming from living donors and 12,328 from deceased donors.

As of December 31, 2014, the kidney transplant waiting list increased by 3% over the previous year to 88,231 candidates (dialysis patients only), 83% of whom were awaiting their first kidney transplant. Fifty-seven percent (50,692) of wait-listed candidates were in active status and 43% (37,539) were inactive. With less than 18,000 kidney transplants performed in 2014, the active waiting list was 2.8 times larger than the supply of donor kidneys, which presents a continuing challenge. An additional 15,498 (15%) patients not yet on dialysis were on the waiting list as of December 31, 2014.

The unadjusted transplant rate per 100 dialysis patient years has been falling, while the percentage of prevalent dialysis patients wait-listed for a kidney has risen, though it appears to have plateaued in recent years (Figure i.15).

![Image of Figure i.15](vol 2 Figure i.15  Percentage of dialysis patients wait-listed and unadjusted kidney transplant rates, 1997-2014)

*Data Source: Reference Tables E.4 and E.9. Percentage of dialysis patients on the kidney waiting list is for all dialysis patients. Unadjusted transplant rates are for all dialysis patients. Abbreviations: Tx, transplant; pt yrs, patient years. This graphic is adapted from Figure 7.1.*

The unadjusted transplant rate per 100 dialysis patient years has been falling, while the probable contributing causes include growing prevalent dialysis population, longer survival of ESRD patients on dialysis, and the growing imbalance between donor supply and demand, which in turn leads to longer kidney transplant waiting times. Waiting list counts and median waiting time to transplantation continue to grow for first-time listings. (Figure i.16).
vol 2 Figure i.16 Number of patients wait-listed for kidney transplant, 1997-2014, and median waiting time, 1997-2009

Data Source: Reference Tables E.2 and E.3. Waiting list counts include all candidates listed for a kidney transplant on December 31 of each year. Median waiting time is calculated for all candidates enrolled on the waiting list in a given year. This graphic is adapted from Figure 7.2.

The total number of kidney transplants has leveled off over the past decade (Figure i.17). During this period, a modest rise in deceased donor kidney transplants has been balanced by a small decrease in living donor transplants.
A relatively recent initiative aimed at increasing the availability of living donor transplants is the process of kidney paired donation (KPD). This typically applies when an otherwise willing potential living donor is incompatible with the recipient. In its simplest form, two living donors who are incompatible with their respective recipients perform an exchange whereby the donation goes to each other’s compatible recipient. More complex chains involving exchanges among three or more recipient-donor pairs are possible and have been performed. The counts of KPD transplants have risen sharply in recent years, with 552 performed in 2014, representing 10% of living donor transplants that year (Figure i.18).
Since 2010, Blacks have surpassed Whites in deceased donation rates (not shown, see Figure 7.18.b Donation rates by race in Volume 2, Chapter 7). The rate of deceased donors per 1,000 deaths among Blacks nearly doubled from 1999 to 2014. Notably, Asian or Pacific Islanders have had the highest donation rate, and Native Americans have had the lowest donation rates since 1999.

During 1997-2013, kidney transplant patients experienced improved health outcomes, with decreases in deaths and all-cause graft failure at one year post-transplantation. Among the recipients of deceased donor kidney transplants, the probability of all-cause graft failure in the first year following transplant decreased from 14% in 1997 to 8% in 2013, while the probability of death decreased from 6% in 1997 to 4% in 2013. Similarly, among those who received living donor kidney transplants, the probability of all-cause graft failure in the first year following transplant decreased from 7% in 1997 to 3% in 2013, while probability of death decreased from 3% to 1% over the same period.

Improvements in patient survival probabilities have persisted for most of the five- and ten-year outcomes (not shown, see Tables 7.3 and 7.4 in Volume 2, Chapter 7).

Chapter 8: ESRD Among Children, Adolescents, and Young Adults

A greatly expanded chapter on pediatric ESRD (renamed this year to ESRD Among Children, Adolescents, and Young Adults to emphasize its scope) is a notable feature since the 2015 ADR. ESRD affects children of all ages. The majority of this population will depend on renal replacement therapies over many decades. Consequently, children with incident ESRD often traverse the entire ESRD modality continuum of hemodialysis, peritoneal dialysis, and transplantation. Children with ESRD are subject to frequent hospitalizations and have a risk of mortality far exceeding the general pediatric population in the United States. They are quite different in disease etiology, transplant opportunities, morbidity and mortality when compared to adults with ESRD. Since 2015, The chapter includes information about vascular access in children as this can have far reaching implications into adulthood. Also, since 2015, this chapter also includes a section on young adults, providing an opportunity to improve our understanding of the issues surrounding “transitional” ages and outcomes in these patients.
The leading causes of ESRD in children during 2010-2014 are as follows: primary glomerular disease (25.3%), CAKUT [congenital anomalies of the kidney and urinary tract] (24.1%), cystic/hereditary/congenital disorders (14.3%), and secondary glomerular disease (12.4%) (not shown, see Table 8.1 in Volume 2, Chapter 8). The most common individual diagnoses associated with pediatric ESRD include renal hypoplasia/dysplasia (N=728), congenital obstructive uropathies (N=541), focal glomerular sclerosis (N=901), and systemic lupus erythematosus (N=489). In children with ESRD, sickle cell nephropathy, human immunodeficiency virus (HIV) nephropathy, and systemic lupus erythematosus are more common among Blacks compared with other racial groups. Figure i.19 shows the distribution of the most common causes of ESRD by age and by year (2010-2014) of onset of ESRD. CAKUT and Congenital/Hereditary/Cystic disorders cause more ESRD in young children, and primary and secondary glomerulonephritis and other etiologies become more common with advancing age.

In 2014, a total of 1,398 children had new onset ESRD, which was 6% less than in 2013. By the end of 2014, the point prevalence of children with ESRD was 9,721, which represented a 1.6% decrease from the previous year. Prevalence measures do not account for the large number of pediatric patients who have aged into adulthood. Approximately half of the pediatric ESRD population (50.4%) initiated renal replacement by hemodialysis, 420 (30.0%) by peritoneal dialysis, and 271 (19.4%) received kidney transplant as their first modality.

Peritoneal dialysis is the most common initial ESRD treatment modality for children aged 9 years and younger (Figure i.20.a). Hemodialysis becomes the most common initial modality at patient aged 9.5 years and older. Similarly, initial ESRD treatment modality is associated with patient weight. Peritoneal dialysis is most commonly the initial modality in small children weighing less than 20 kg. Hemodialysis is the least common initiating modality in small children and increases in frequency with increasing patient weight (Figure i.20.b).
vol 2 Figure i.20 Cross-sectional trends in pediatric ESRD modality at initiation, by patient (a) age and (b) weight, 1996-2014

Data Source: Special analyses, USRDS ESRD Database. Includes incident ESRD patients in the years 1996-2014. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant. This graphic is adapted from Figure 8.2.
Overall, 36.0% of children received a kidney transplant within the first year of ESRD care during 2010-2014. A total of 1,321 children were wait-listed for a kidney transplant in 2014, including 896 patients listed for the first time and 425 patients listed for repeat transplant. A total of 1,018 children received a kidney transplant in 2014. 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 (OPTN) organ allocation policy. The median waiting time for patients receiving their first kidney transplant has ranged between 150-220 days. Over the same time period, children receiving a repeat transplant have, on average, been on the waiting list at least 3-4 times longer than those awaiting their first transplant. The median waiting time to transplant for incident patients on dialysis has been improving over time. In 2002, the median waiting time peaked at 1.83 years and began to decline, with the most dramatic improvement occurring after 2005 (not shown, see Figure 8.15.a in Volume 2, Chapter 8), which coincides with the change in the OPTN organ allocation policy. Since 2005, the median waiting time for incident dialysis patients has continued to decrease and was at its lowest in 2013 at 1.04 years. Since 2007, the waiting times for incident patients on dialysis have been similar for hemodialysis and peritoneal dialysis. In 2013, the median waiting time to transplant for hemodialysis patients was 1.01 years, and for peritoneal dialysis patients it was 1.06 years.

Kidney grafts in pediatric transplant recipients were most commonly from living donors prior to 2005. There has been a decline in the number of pediatric patients receiving living donor kidneys since 2009. In 2014, living donors accounted for 40.0% of kidney transplants, which is a 2.1% decrease from 2013 and a 21% decrease since 2009.

Over time, transplant has become the most common prevalent ESRD treatment modality in children. Of the 9,721 children and adolescents between the ages of 0 and 21 years with prevalent ESRD as of December 31, 2014, kidney transplant was the most common modality (6,825 [70.2%]), followed by hemodialysis (1,745 [18.6%]) and peritoneal dialysis (1,122 [11.5%]). Over 80% of prevalent children ages 5 to 13 have a kidney transplant.

As a result of improvements in the care of pediatric patients with ESRD and kidney transplants, a larger percentage of these children are surviving into adulthood. The transition of these patients into adulthood represents a truly unique process and has resulted in the development of specific transition programs to improve health care for these individuals. Since the 2015 USRDS ADR, we continue to include a section in the pediatric chapter highlighting the young adult age group (defined in the USRDS as 22-29 years of age) that classically encompasses the transitional age groups. Despite their young age, cardiovascular disease remains the leading cause of mortality in this cohort, similar to older patients with ESRD.

Chapter 9: Cardiovascular Disease in ESRD Patients

This chapter was reintroduced in the 2015 ADR, as the USRDS special study dealing with cardiovascular disease in CKD/ESRD ended at the beginning of 2014. Patients with ESRD are among the highest risk populations for a number of cardiovascular diseases, and cardiovascular diseases are a major cause of death in ESRD patients. Cardiovascular disease is a significant comorbidity for patients along the entire spectrum of CKD and ESRD. Presence of ESRD often complicates disease management and treatment, as it can influence both medical and procedural options, thereby adversely affecting a patient’s prognosis. In this chapter, we focus on reporting the prevalence and outcomes of ESRD patients with diagnosed major cardiovascular conditions, stratifying by type of RRT received (hemodialysis, peritoneal dialysis, and kidney transplantation). For individual cardiovascular conditions, we compare the survival of patients with and without the condition. Given its role as the primary health care payer for ESRD patients, our analyses are based mostly on data from the national Medicare population.

Figure i.21 presents both the proportion of known causes of death and the proportion of total deaths among ESRD patients. As shown in Figure i.21.a,
cardiovascular diseases are a major cause of death in ESRD patients, contributing to more than half of all deaths with known causes. The category of arrhythmias and cardiac arrest alone is responsible for 38.7% of the deaths, excluding those with missing/unknown causes of death. Figure i.21.b provides an alternate analysis in which deaths with unknown and missing causes are included in the denominator and appear as separate categories. As shown in Figure i.21.b, the categories of arrhythmias and cardiac arrest, congestive heart failure (CHF), acute myocardial infarction (AMI), and atherosclerotic heart disease (ASHD) are responsible for over one-third of the total deaths. A significant proportion (24.7%) of the deaths is due to unknown causes or missing cause of death. We speculate that unidentified cardiovascular conditions may well be the true underlying causes of death in this category.

**vol 2 Figure i.21 Causes of death in ESRD patients, 2012-2014**

Data Source: Special analysis using Reference Table H.12. (a) Denominator includes other causes of death and excludes missing/unknown causes of death (24.7% of patients have unknown or missing causes of death). (b) Denominator includes other known causes, unknown causes of death, and records that are missing the cause of death. Unknown causes include records from the CMS 2746 ESRD death notification form that specifically designate an unknown cause of death. Missing includes records in the ESRD database that are missing the CMS 2746, or have the form but are missing or have recording errors in the primary cause of death field. Abbreviations: ASHD, atherosclerotic heart disease; AMI, acute myocardial infarction; CHF, congestive heart failure; CVA, cerebrovascular accident. This graphic is adapted from Figure 9.1.
ESRD patients have a high burden of cardiovascular disease across a wide range of conditions (Figure i.22). Not surprisingly, older ESRD patients tend to have a higher prevalence of cardiovascular conditions (not shown, see Figure 9.3 in Volume 2, Chapter 9). It is notable, however, that the prevalence of these conditions is high even among those 22-44 years of age (48.2%), although a much higher prevalence is observed among those 45 years or older (66.9% to 83.4%). ASHD is the most common condition, with its prevalence exceeding 50% in ESRD patients aged 65 years and older, followed by CHF, PAD, AFIB, CVA/TIA, and VHD. The presence of VTE/PE did not vary as much by age.

**vol 2 Figure i.22 Prevalence of cardiovascular diseases in adult ESRD patients, by age, 2014**

Data Source: Special analyses, USRDS ESRD Database. Point prevalent hemodialysis, peritoneal dialysis, and transplant patients aged 22 and older, with Medicare as primary payer on January 1, 2014, who are continuously enrolled in Medicare Parts A and B from January 1, 2013 to December 31, 2013, and ESRD service date is at least 90 days prior to January 1, 2014. Abbreviations: AFIB, atrial fibrillation; AMI, acute myocardial infarction; ASHD, atherosclerotic heart disease; CHF, congestive heart failure; CVA/TIA, cerebrovascular accident/transient ischemic attack; CVD, cardiovascular disease; PAD, peripheral arterial disease; SCA/VA, sudden cardiac arrest and ventricular arrhythmias; VHD, valvular heart disease; VTE/PE, venous thromboembolism and pulmonary embolism. This graphic is adapted from Figure 9.3.
Chapter 10: Dialysis Providers

At the end of 2014, there were 6,757 dialysis units (Figure i.23) and 460,675 dialysis patients (not shown, see Figure 10.2 in Volume 2, Chapter 10) in the United States. Together the two large dialysis organizations (LDOs), DaVita, and Fresenius, treated 317,587 of these patients (69%) in 4,362 dialysis units (65%). Nationwide, 748 dialysis units were added during the four-year period from 2011 to 2014, with Fresenius and DaVita accounting for 609 (81%) of the new units. For the 2016 ADR, we have avoided use of any formal classification system of dialysis providers, given the disproportionate size of the two largest dialysis providers, the heterogeneity in dialysis provider ownership type, and the evolving nature of mergers and acquisitions in the provider community. Nationwide, 608 dialysis units were added during the four-year period from 2010 to 2013, with most belonging to the LDOs; DaVita experienced the largest growth of all provider types in both facilities and patients. Small dialysis organizations experienced declines in the numbers of patients and units over the same period. Nearly 90% of all dialysis patients in 2013 received hemodialysis; hospital-based providers had the highest proportion of peritoneal dialysis patients at 21%, which is more than double the national average.

vol 2 Figure i.23 Dialysis unit counts, by unit affiliation, 2011–2014

Table i.1 provides the standardized mortality ratio for a sample set of dialysis providers for 2014. This example is designed to provide a simpler and more direct comparison of a given provider type to other providers and to the national value in a single year.
### vol 2 Table i.1  All-cause Standardized Mortality Ratio, by unit affiliation, 2014

<table>
<thead>
<tr>
<th>Affiliation</th>
<th>All (National average)</th>
<th>White (0.84-0.86)</th>
<th>Black/African American (0.68-0.72)</th>
<th>Asian (0.81-0.91)</th>
<th>Native American (0.77-0.80)</th>
<th>Hispanic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>1.00 (0.99-1.01)</td>
<td>1.12 (1.11-1.13)</td>
<td>0.85 (0.84-0.86)</td>
<td>0.70 (0.68-0.72)</td>
<td>0.86 (0.81-0.91)</td>
<td>0.79 (0.77-0.80)</td>
</tr>
<tr>
<td>LDOs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DaVita</td>
<td>1.02 (1.01-1.03)</td>
<td>1.14 (1.13-1.16)</td>
<td>0.85 (0.83-0.86)</td>
<td>0.71 (0.67-0.75)</td>
<td>0.82 (0.74-0.90)</td>
<td>0.79 (0.77-0.81)</td>
</tr>
<tr>
<td>Fresenius</td>
<td>0.98 (0.97-0.99)</td>
<td>1.10 (1.09-1.12)</td>
<td>0.81 (0.79-0.82)</td>
<td>0.77 (0.73-0.82)</td>
<td>0.88 (0.76-1.00)</td>
<td>0.79 (0.77-0.81)</td>
</tr>
<tr>
<td>DCI</td>
<td>0.92 (0.89-0.95)</td>
<td>1.06 (1.01-1.10)</td>
<td>0.78 (0.73-0.82)</td>
<td>0.66 (0.51-0.84)</td>
<td>0.70 (0.54-0.90)</td>
<td>0.77 (0.66-0.89)</td>
</tr>
<tr>
<td>Hospital-based</td>
<td>0.94 (0.91-0.97)</td>
<td>1.04 (1.00-1.08)</td>
<td>0.86 (0.80-0.91)</td>
<td>0.69 (0.58-0.81)</td>
<td>0.72 (0.58-0.89)</td>
<td>0.71 (0.63-0.79)</td>
</tr>
<tr>
<td>Independent</td>
<td>1.03 (1.01-1.04)</td>
<td>1.14 (1.11-1.16)</td>
<td>0.90 (0.87-0.93)</td>
<td>0.70 (0.65-0.75)</td>
<td>0.92 (0.81-1.03)</td>
<td>0.82 (0.78-0.85)</td>
</tr>
<tr>
<td>Others</td>
<td>1.02 (1.00-1.04)</td>
<td>1.12 (1.09-1.14)</td>
<td>0.87 (0.84-0.90)</td>
<td>0.75 (0.70-0.80)</td>
<td>1.27 (1.05-1.54)</td>
<td>0.81 (0.78-0.85)</td>
</tr>
</tbody>
</table>

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 race-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; Others, other dialysis organizations. This table is adapted from Table 10.2.

Dialysis providers of all types continued to experience declining Standardized Mortality Ratios between 2011 and 2014. However, all types of providers experienced relatively flat change trends in Standardized Hospitalization Ratios between 2011 and 2014.

### Chapter 11: Medicare Expenditures for Persons With ESRD

The Medicare program for the elderly was enacted in 1965. Seven years later, in 1972, Medicare eligibility was extended both to disabled persons aged 18 to 64 and to persons with irreversible kidney failure who required dialysis or transplantation. On January 1, 2011, CMS implemented the ESRD Prospective Payment System (PPS). This program bundled Medicare’s payment for renal dialysis services together with separately billable ESRD-related supplies (primarily erythropoiesis stimulating agents (ESAs), vitamin D, and iron) into a single, per treatment payment amount. The bundle payment supports up to three dialysis treatments per individual per week, with additional treatments covered on the basis of medical necessity. The reimbursement to facilities is the same regardless of dialysis modality, but is adjusted for case-mix, geographic area health care wages, and small facility size. This chapter presents recent patterns and longer-term trends in both total Medicare spending and spending by type of service. Data from 2014 is featured, which is the fourth full year under the expanded, bundled PPS.

Figure i.24 displays Medicare’s total annual paid claims for period prevalent ESRD patients from 2004-2014. These costs represent about three-quarters of all spending for the care of U.S. ESRD patients. Medicare fee-for-service ESRD spending rose by 3.3% from 2013 to 2014, marking the fourth year of modest growth relative to historical trends, and following the implementation of the bundled payment system. The Medicare patient obligation amount has also grown over the years in proportion to these paid claims. Patient obligations may be paid by the patient, by a secondary insurer, or may be uncollected. Overall, the patient obligation represented 14.8% of the total Medicare Allowable Payments in 2014.
As illustrated in Figure i.25, total Medicare fee-for-service spending in the general Medicare population increased by 3.8% in 2014 to $435.6 billion; $32.8 billion in spending for ESRD patients accounted for 7.2% of the overall Medicare paid claims costs in the fee-for-service system.
For the fifth consecutive year, the annual increase in total Medicare ESRD spending for beneficiaries with primary payer status was less than 4%. In 2014, total Medicare paid claims for ESRD services and supplies increased by 2.1% to $30.5 billion (Figure i.26; for total and specific values see Reference Table K.4).

In 2014, ESRD per patient per year (PPPY) spending increased by 0.3%. Given that these expenditures decreased or increased only minimally from 2009 to 2013, the growth in total ESRD costs during these years is almost entirely attributable to growth in the number of covered beneficiaries.

Total Medicare fee-for-service spending for ESRD patients is reported by type of service in Figure i.27. Compared to 2013, the costs of Part D claims and skilled nursing facility care in 2014 grew at the fastest rates of 21.0% and 5.5%, respectively. The increase in Part D (prescription drug) expenditures is consistent with drug cost trends nationally. All other categories of spending rose by less than 3%. The smallest share of Medicare spending for ESRD patients was for hospice care. It should be noted, however, that prior to 2013 hospice care had been experiencing one of the highest rates of growth of any category; this spending declined by 6.3% in 2014.
Chapter 12: Part D Prescription Drug Coverage in Patients With ESRD

The share of beneficiaries with ESRD that enrolled in Part D increased annually between 2011 and 2014 (Table i.2). Total enrollment was higher in the dialysis population than in the general Medicare population, but the growth between 2011 and 2014 was somewhat slower among beneficiaries on dialysis. Both the level and trend in Part D enrollment among beneficiaries with transplants mirrored that in the general Medicare population.
**vol 2 Table i.2** General Medicare & ESRD patients enrolled in Part D (%)

<table>
<thead>
<tr>
<th></th>
<th>General Medicare</th>
<th>All ESRD</th>
<th>Hemodialysis</th>
<th>Peritoneal dialysis</th>
<th>Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>60</td>
<td>70</td>
<td>74</td>
<td>62</td>
<td>59</td>
</tr>
<tr>
<td>2012</td>
<td>62</td>
<td>72</td>
<td>76</td>
<td>64</td>
<td>62</td>
</tr>
<tr>
<td>2013</td>
<td>67</td>
<td>75</td>
<td>79</td>
<td>67</td>
<td>66</td>
</tr>
<tr>
<td>2014</td>
<td>69</td>
<td>77</td>
<td>80</td>
<td>69</td>
<td>68</td>
</tr>
</tbody>
</table>

Data source: 2011-2014 Medicare data, point prevalent Medicare enrollees alive on January 1. Medicare data: general Medicare, 5% Medicare sample (ESRD, hemodialysis, peritoneal dialysis, and transplant, 100% ESRD population). Abbreviations: ESRD, end-stage renal disease; Part D, Medicare Part D prescription drug coverage. This table is adapted from Table 12.2.

More hemodialysis, peritoneal dialysis, and transplant patients with Part D receive the Low-income Subsidy (LIS) — 66%, 55%, and 52%, compared to 31% of the general Medicare population. About 15% of ESRD beneficiaries have no identified prescription drug coverage. By modality, peritoneal dialysis and transplant patients are least likely to have known coverage (see Figure i.28).

**vol 2 Figure i.28** Sources of prescription drug coverage in Medicare ESRD enrollees, by population, 2014

Data source: Special analyses, 2014 Medicare Data, point prevalent Medicare enrollees alive on January 1, 2014. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; LIS, Low-income Subsidy; Part D, Medicare Part D prescription drug coverage; PD, peritoneal dialysis; Tx, kidney transplant. This graphic is adapted from Figure 12.1.
Total Part D spending for beneficiaries with ESRD increased by 65% from $1.64 billion in 2011 to $2.71 billion in 2014 (Table i.3). These amounts do not include costs of medications subsumed under the ESRD prospective payment system (e.g. ESAs, IV vitamin D, and iron) or billed to Medicare Part B (e.g. immunosuppressants). Between 2011 and 2014, total estimated Part D spending increased by 63%, 91%, and 63% for hemodialysis, peritoneal dialysis, and kidney transplant patients. These rates of increase far outpaced the 26% spending growth that occurred in the general Medicare population.

<table>
<thead>
<tr>
<th></th>
<th>General Medicare</th>
<th>All ESRD</th>
<th>Hemodialysis</th>
<th>Peritoneal dialysis</th>
<th>Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>45.96</td>
<td>1.64</td>
<td>1.29</td>
<td>0.09</td>
<td>0.21</td>
</tr>
<tr>
<td>2012</td>
<td>40.08</td>
<td>2.00</td>
<td>1.59</td>
<td>0.12</td>
<td>0.23</td>
</tr>
<tr>
<td>2013</td>
<td>52.08</td>
<td>2.27</td>
<td>1.79</td>
<td>0.14</td>
<td>0.27</td>
</tr>
<tr>
<td>2014</td>
<td>58.07</td>
<td>2.71</td>
<td>2.10</td>
<td>0.17</td>
<td>0.35</td>
</tr>
</tbody>
</table>

Data source: 2011-2014 Medicare data, period prevalent Medicare enrollees alive on January 1, excluding those in Medicare Advantage Part D plans and Medicare secondary payer, using as-treated model (see ESRD Methods chapter for analytical methods). Part D spending represents the sum of the Medicare covered amount and the Low-income Subsidy amount. This table is adapted from Table 12.4.

By ESRD modality, hemodialysis patients had the highest PPPY Medicare Part D spending at $9,089, compared to $8,188 for peritoneal dialysis, and $6,284 for transplant patients. PPPY Part D spending was three times greater for beneficiaries with ESRD ($8,420) than for general Medicare beneficiaries ($2,830). As a proportion of total costs, however, out-of-pocket costs were lower for beneficiaries with ESRD representing 4%, 7%, and 8% of PPPY costs for hemodialysis, peritoneal dialysis, and transplant patients, compared to 13% in the general Medicare population (not shown, see Figure 12.5a in Volume 2, Chapter 12). A higher proportion of beneficiaries with ESRD receive the LIS relative to the general Medicare population, which substantially reduces out-of-pocket obligations.

Chapter 13: International Comparisons

This chapter examines international trends in treatment of ESRD. The number of countries and regions represented in this year’s ADR has increased to 60 (from 57 in last year’s ADR, and 54 countries in the 2014 ADR), with the addition of Morocco, Montenegro, and Sri Lanka.

This work is made possible through the substantial efforts of many individuals from all participating countries in collecting and contributing data for this international collaboration. The information provided is meant to serve as a resource for the worldwide ESRD community to inform health care policies, patient care, and application of resources, while stimulating meaningful research for improving ESRD patient care. The comparisons presented are intended to increase awareness of the international trends, similarities, and differences in key ESRD treatment measures. Data collection methods vary considerably across countries, and therefore direct comparisons should be made with caution. Data reflect “treated ESRD”. Unrecognized ESRD or poor access to RRT may result in reported ESRD incidence that substantially underestimates the true incidence of irreversible kidney failure. Furthermore, in some countries where RRT is widely available, true ESRD incidence also may be underestimated because some patients decline dialysis or transplantation.

Significant geographic variation is observed with respect to the incidence and prevalence of ESRD by country (Figures i.29, i.30, i.31, i.32). Taiwan had the highest incidence and prevalence of ESRD. The United States was ranked among the top three countries for both highest ESRD incidence and prevalence. Notably, males have a higher incidence of ESRD than females in all countries reporting data to the USRDS.
vol 2 Figure i.29 Geographic variations in the incidence rate of treated ESRD (per million population/year), by country, 2014

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. *United Kingdom: England, Wales, Northern Ireland (Scotland data reported separately). Data for Italy include 6 regions. Data for Indonesia represent the West Java region. Data for France include 22 regions. Data for Spain include 18 of 19 regions. Data for Canada excludes Quebec. Japan includes dialysis patients only. Abbreviation: ESRD, end-stage renal disease. This graphic is adapted from Figure 13.1.
vol 2 Figure i.30 Incidence rate of treated ESRD (per million population/year), by country, 2014

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. All rates are unadjusted. ^United Kingdom: England, Wales, Northern Ireland (Scotland data reported separately). Data for Italy include 6 regions. Data for Indonesia represent the West Java region. Data for France include 22 regions. Data for Spain include 18 of 19 regions. Data for Canada excludes Quebec. Japan includes dialysis patients only. Abbreviations: ESRD, end-stage renal disease; sp., speaking. This graphic is adapted from Figure 13.2.
vol 2 Figure i.31  Incidence rate of treated ESRD (per million population/year), by sex and country, 2014

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. ^United Kingdom: 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 Italy represent 6 regions. Data for Canada excludes Quebec. Japan includes dialysis patients only. Abbreviations: ESRD, end-stage renal disease; sp., speaking. This graphic is adapted from Figure 13.8.
Prevalence of treated ESRD per million population, by country, 2014

Data source: Special analyses, USRDS ESRD Database. Data presented only for countries from which relevant information was available. \(^\text{United Kingdom: England, Wales, Northern Ireland (Scotland data reported separately). The prevalence is unadjusted and reflects prevalence at the end of 2014. Switzerland includes dialysis patients only. Data for Indonesia represent the West Java region. Data for Spain include 18 of 19 regions. Data for France include 22 regions. Data for Italy includes 6 regions. Data for Canada excludes Quebec. Abbreviations: ESRD, end-stage renal disease; sp., speaking. This graphic is adapted from Figure 13.9.}
Significant variation was also observed with respect to the type of RRT used by ESRD patients across countries (Figure i.33), and the rate of kidney transplantation as a treatment modality.

**vol 2 Figure i.33** Percent distribution of type of renal replacement therapy modality used by ESRD patients, by country, in 2014

Data source: Special analyses, USRDS ESRD Database. Denominator is calculated as the sum of patients receiving HD, PD, Home HD, or treated with a functioning transplant; does not include patients with other/unknown modality. Data for Spain include 18 of 19 regions. Data for France include 22 regions. Data for Italy include 6 regions. Data for Canada excludes Quebec. Abbreviations: CAPD, continuous ambulatory peritoneal dialysis; APD, automated peritoneal dialysis; IPD, intermittent peritoneal dialysis; ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; sp., speaking. This graphic is adapted from Figure 13.12.
Chapter 14: 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.

Chapter 14 includes information on treatment practices, patterns of health care utilization, and costs at the end of life among decedents with ESRD over the 14-year period from 2000 through 2013. New to this year’s chapter is information on nursing facility use during the last year of life. Key findings include an upward trend over this time period in the percentage of Medicare beneficiaries with ESRD admitted to an intensive or coronary care unit and the percentage who received an intensive procedure in the last 90 days of life; an upward trend in the percentage of patients who received care in a nursing facility during the last year of life; an upward trend in the percentage of patients who discontinued dialysis before death, though with a downward trend in the last two years; an upward trend in the percentage of patients who were receiving hospice at the time of death; and a downward trend in the percentage of patients dying in the hospital. Receipt of hospice services occurred less than a week before death in most cases, was closely tied to dialysis discontinuation — with the most marked increases in hospice use occurring among those who discontinued dialysis before death — and was associated with lower costs during the last days and weeks of life.

The percentage of Medicare beneficiaries with ESRD receiving an intensive procedure to prolong life during the last 90 days of life increased from 27% to 35% (Figure i.34). The percentage of Medicare beneficiaries with ESRD receiving hospice care at the time of death increased from 11% to 25% (Figure i.35). Most patients receive hospice services only after discontinuing dialysis treatments. From 2004-2012, hospice use prior to death increased from 59% to 80% among patients who discontinued dialysis treatments, but from only 5% to 7% among those who did not (not shown, see Figure 14.7 in Volume 2, Chapter 14).
Figure i.34 Intensive procedures during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2013

Figure i.34 continued on next page.
vol 2 Figure i.34  Intensive procedures during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2013 (continued)

(c) Intensive procedures by race

(d) Intensive procedures by ethnicity

Figure i.34 continued on next page.
Figure i.34 Continued on next page.
vol 2 Figure i.34 Intensive procedures during the last 90 days of life among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, and modality, 2000-2013 (continued)

(g) Intensive procedures by state

Data Source: Special analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Intensive procedures were identified by ICD-9 procedure code search of Medicare Institutional claims from short- and long-stay hospitals. The yellow line in panel (a) denotes the percentage of patients who were intubated or received mechanical ventilation. This graphic is adapted from Figure 14.4.

vol 2 Figure i.35 Hospice utilization at the time of death among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, modality, and whether dialysis was discontinued, 2000-2013

(a) Hospice utilization by year, overall

Figure i.35 continued on next page.
vol 2 Figure i.35  Hospice utilization at the time of death among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, modality, and whether dialysis was discontinued, 2000-2013 (continued)

(b) Hospice utilization by age

(c) Hospice utilization by race

Figure i.35 continued on next page.
Hospice utilization at the time of death among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, modality, and whether dialysis was discontinued, 2000-2013 (continued)

(d) Hospice utilization by ethnicity

(e) Hospice utilization by sex

Figure i.35 continued on next page.
vol 2 Figure i.35 Hospice utilization at the time of death among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, modality, and whether dialysis was discontinued, 2000-2013 (continued)

(f) Hospice utilization by modality

(g) Hospice utilization by whether patients discontinued dialysis before death

Figure i.35 continued on next page.
vol 2 Figure i.35  Hospice utilization at the time of death among Medicare beneficiaries with ESRD overall, and by age, race, ethnicity, sex, modality, and whether dialysis was discontinued, 2000-2013 (continued)

(h) Hospice utilization by state

Data Source: Special Analyses, USRDS ESRD Database. Denominator population is all decedents with Medicare Parts A and B throughout the last 90 days of life. Receipt of hospice care at the time of death was defined as having a claim in the Hospice SAF on or after the date of death or Discharge Status from hospice=40, 41, or 42. This graphic is adapted from Figure 14.8.