Incidence, prevalence, patient characteristics, and treatment modalities
n 2011, the number of new patients starting therapy on hemodialysis declined 1.5 percent, the first decrease in more than three decades. The population initiating on peritoneal dialysis, in contrast, grew for the third year in a row, and now accounts for 6.6 percent of patients with a known dialysis modality. This change is associated with the new bundled payment system, with its clear incentives for peritoneal dialysis. The number of total incident dialysis patients was 112,788, while 2,855 patients received a preemptive transplant as their first ESRD modality; a total of 115,643 patients thus began ESRD therapy in 2011 — a level below that of the two prior years.

The rate of new ESRD cases per million population, relatively stable since 2000, fell 3.8 percent in 2011, to 357. Growth in counts and rates has dropped across all age groups, though, as late reporting of cases can cause slight changes in the numbers, this finding needs to be confirmed in coming years.

The incidence of ESRD in the black/African American population has been declining for the last five years. The rate also continues to fall among Native Americans, reaching a level just 13.5 percent higher than that in the Asian population — the smallest difference in more than three decades. By cause, rates of incident ESRD have fallen across each of the major primary diagnoses: diabetes, hypertension, glomerulonephritis, and cystic diseases. Among those whose ESRD is caused by diabetes, however, racial disparities persist, particularly among younger blacks/African Americans.

The December 31, 2011 prevalent population included 430,273 patients on dialysis and 185,626 patients with a functioning kidney transplant, and the one-year growth of 3.4 percent — to 615,899 — was the smallest in 30 years. The rate of prevalent ESRD cases per million population reached 1,901, an increase of 1.3 percent from 2010, and also the slowest growth in the last three decades. The number of patients receiving home hemodialysis continued to grow, though at a slower pace in 2011.

Insurance coverage in the dialysis population continues to change, with more incident dialysis patients now covered by Medicare Advantage. Private insurance, in contrast, is dominant among patients who receive a preemptive kidney transplant. In the 2011 prevalent population, 84 percent of hemodialysis patients and 81 percent of those on peritoneal dialysis had some type of primary Medicare coverage, compared to just 53 percent of those with a transplant.

Since 2005, when new fields on the revised Medical Evidence form (2728) made it possible to analyze pre-ESRD treatment, there has been little improvement in the care patients receive prior to initiation of therapy. Forty-two percent of new ESRD patients in 2011, for example, had not seen a nephrologist prior to beginning therapy. And among these patients, 51 percent of those on hemodialysis began therapy with a catheter only, compared to 19 percent of those who had received more than a year of nephrology care. Among those with a year or more of pre-ESRD
nephrologist care, 30 percent began therapy with a maturing fistula and 50 percent had a mature fistula—a rate five times greater than that seen among non-referred patients.

The percentage of patients receiving an erythropoiesis stimulating agent (ESA) prior to initiation continues to change, from 33 percent in September, 2002 to 18.1 percent in 2011. This may reflect concern over potential adverse events when hemoglobin levels are targeted to a level above 11 g/dL. The mean hemoglobin at initiation of ESRD treatment also continues to change, and was 9.63 g/dL at the end of 2011. These changes place different demands on care after the initiation of dialysis. The current FDA recommendations indicate that "In controlled trials, patients experienced greater risks for death, serious adverse cardiovascular reactions, and stroke when administered erythropoiesis-stimulating agents (ESAs) to target a hemoglobin level of greater than 11 g/dL." “No trial has identified a hemoglobin target level, ESA dose, or dosing strategy that does not increase these risks.” The FDA recommends that clinicians “Use the lowest dose that will maintain a hemoglobin level sufficient to reduce the need for RBC transfusions.”

The percentage of dialysis patients beginning therapy with an estimated glomerular filtration rate (eGFR, calculated with the CKD-EPI formula) above 15 ml/min/1.73 m² fell in 2011, to 15.3 percent — still, however, almost three times higher than in 1996. It is not clear if the generally progressive increase has been the result of severe comorbidity or of a simple numerical starting point based on the ability to calculate the eGFR. Concerns have recently been raised about the usefulness of eGFR at ESRD initiation, as the lower serum creatinine used to calculate the rate may be impacted by low muscle mass in older, frail patients. Hopefully, symptoms and complications of uremia are still the primary indications for starting renal replacement therapy rather than a simple number, one which has been brought into question in recent years in controlled trials of early versus later dialysis initiation.

Biochemical data, collected on the Medical Evidence form since 2005, show that 57 percent of new patients in 2011 had an albumin less than the lower limit of normal, and the mean hemoglobin at initiation was 9.7 g/dL. Total cholesterol was greater than 200 mg/dL in 16 percent of patients, while 28 percent had an LDL level greater than 100 mg/dL, and 56 percent had an HDL level less than 40 mg/dL. Among patients with diabetes, 29 percent had a hemoglobin A1c level greater than 7 percent.

Recent changes and new incentives in the bundled Prospective Payment System for dialysis patients, introduced in January, 2011, may alter several characteristics of the incident and prevalent populations. The mix of peritoneal dialysis and hemodialysis patients, for example, has clearly changed. It is unclear how the expansion of peritoneal dialysis will affect patient outcomes, and how the new incentives will impact the emerging daily home hemodialysis population; provider incentives for this therapy are less clear, particularly as related to training. A more detailed assessment of the bundled payment system is presented in Chapter Ten.

Incident & prevalent patient counts (USRDS), by modality

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Figure 1.1: see page 430 for analytical methods. Incident & December 31 point prevalent ESRD patients; peritoneal dialysis consists of CAPD & CCPD.
After a 1.9 percent decrease in 2010, the incident rate of ESRD (adjusted for age, gender, and race) continued to decline, falling 3.8 percent in 2011 to 357 per million population. Since 2000, changes in the adjusted rate have shown little variation, but the 2011 adjusted rate is the lowest since 1998. Ethnicity was added to the Medical Evidence form in 1995. When adjusted for Hispanic ethnicity, rates differ little from those adjusted for age, gender, and race alone. In 2005, for example, the incident rate including ethnicity was 0.5 percent greater, and in 2011 it was 0.2 percent less, at 356.4 per million population compared to 357.1.

In 2011, the adjusted incident rate of ESRD averaged 449 per million population in the upper quintile and was highest in areas of the Ohio Valley, and in portions of Texas and California. • Figure 1.2; see page 430 for analytical methods. Incident ESRD patients. Adj: age/gender/race; ref: 2010 ESRD patients.

With an overall rate for incident dialysis patients of 349 per million population in 2011, rates by network range from 228 in Network 16 to 427 in Network 8. The distribution of patients by race continues to vary widely across the country. Blacks/African Americans, for example, constitute just 6.4 percent of the new dialysis population in Network 16, but 54 percent of patients in Network 6. • Table 1.3; see page 430 for analytical methods. Incident dialysis patients, 2011. Adj: age/gender/race; ref: 2010 patients.
Since 2000, the adjusted incident rate of ESRD has grown 7.1 percent for patients age 75 and older, to 1,707 per million population in 2011, while rates for those age 0–19 and 20–44 have increased 10.1 and 4.1 percent, respectively, to 15.6 and 127. Rates for patients age 45–64 and 65–74, in contrast, though rising slightly during the decade, are now 8.1–8.3 percent lower than in 2000, at 571 and 1,307 per million, respectively.

By race, rates for blacks/African Americans and Native Americans in 2011 were 940 and 453 per million population, respectively — 3.4 and 1.6 times greater than the rate of 280 found among whites. After rising in the middle of the decade, rates for both whites and Asians are now near the levels seen in 2000, while rates for blacks/African Americans and Native Americans are now 10.2 and 36 percent lower.

Fourteen percent of new ESRD patients in 2011 were Hispanic, up from 12.6 percent in 2007. While the rate of ESRD among Hispanics fell 3.0 percent between 2010 and 2011, to 518, it remains 1.5 times greater than that seen in the non-Hispanic population.

At 157 per million population in 2011, the rate of new ESRD cases due to diabetes is 4.2 percent lower than in the previous year, and has now fallen back to a level not seen since 1998. The rate of ESRD due to hypertension, while down 4.9 percent in 2011, is 2.6 percent higher than the 2000 rate, at 101, while the rate of ESRD due to glomerulonephritis has fallen 29 percent, to 23 per million.

*Figures 1.4–7; see page 430 for analytical methods. Incident ESRD patients. Adj: gender/race (1.4), age/gender (1.5–6), age/gender/race (1.7); ref: 2010 ESRD patients.*
Both the rates of incident ESRD caused by diabetes and their growth over time continue to vary widely by age and race/ethnicity. Among whites age 30–39, for example, the rate (adjusted for gender) has increased just 3.5 percent since 2000, reaching 37 per million population in 2011. For blacks/African Americans of the same age, in contrast, the rate has increased 72 percent since 2000, to reach 136.

Among blacks/African Americans age 40–49, the rate of incident ESRD has increased just 8.2 percent since 2000; among Native Americans of the same age, the rate is 11 percent lower than in 2000 (though rising after reaching a low in 2007). Among both populations, however, the current rates of 309 and 321 per million population, respectively, remain 3.5–3.6 times greater than among their white counterparts.

While rates in the Asian population remain comparatively low in these younger populations, they have increased since 2000, with growth of 58 percent among those age 20–29, 85 percent for those 30–39, and 46 percent for ages 40–49.

Different patterns are seen among older populations. The 2011 rate of incident ESRD due to diabetes among whites age 50–59 is nearly the same as in 2000, while rates have fallen 27 and 50 percent, respectively, among blacks/African Americans and Native Americans of the same age.

Rates among Hispanics age 50–59 and 60–69 have fallen 13 and 19 percent, respectively, since 2000; they remain, however, 2.8–2.9 times greater than those seen in white populations of the same age. And while rates among Hispanics younger than 50 have consistently been below those seen in the Native American population, the rates among older Hispanics have now reached levels higher than those seen in their Native American counterparts. • Figure 1.8; see page 430 for analytical methods. Incident ESRD patients; rates are three-year rolling averages. Adj: gender; ref: 2010 ESRD patients.
As with diabetic ESRD, there are significant disparities by age, race, and ethnicity in the incidence of ESRD due to hypertension. Among whites age 40–49, for example, the rate per million population (adjusted for gender) rose 61 percent between 2000 and 2011, to 28.1. The rate for blacks/African Americans of the same age fell 5.8 percent to 304 per million population — nearly 11 times greater than that of their white counterparts.

In the population age 50–59, the rate of ESRD due to hypertension rose 31 percent among whites between 2000 and 2011, while falling 2.2 percent among blacks/African Americans. In the latter population, however, the 2011 rate of 534 per million population was nearly 9 times greater than the rate of 61 among whites.

Between 2000 and 2011, rates rose 16.3 and 7.8 percent in whites and blacks/African Americans age 70 and older, to reach 537 and 1,578. Among Native Americans, Asians, and Hispanics of the same age, in contrast, rates fell 5.3, 8.7, and 6.1 percent, to reach 372, 765, and 695 per million population.

Figure 1.9; see page 430 for analytical methods. Incident ESRD patients: rates are three-year rolling averages. Adj: gender; ref: 2010 ESRD patients.
The adjusted rate of prevalent cases of end-stage renal disease rose 1.3 percent in 2011 — slightly lower than the growth of 1.8 percent in 2010 — to 1,901 per million population. This rate is 26 percent higher than that seen in 2000. Until 2011, the annual rate of increase had remained between 1.7 and 2.2 percent since 2004. • Figure 1.10; see page 430 for analytical methods. December 31 point prevalent ESRD patients. Adj: age/gender/race; ref: 2010 ESRD pts.

In 2011, patterns of ESRD prevalent rates generally followed those found in the incident population, with an additional area of higher rates in the Dakotas and Minnesota. Rates averaged 2,342 per million population in the upper quintile. • Figure 1.11; see page 430 for analytical methods. December 31 point prevalent pts. Adj: age/gender/race/Hispanic ethnicity; ref: 2010 ESRD pts.

For December 31, 2011 point prevalent transplant patients, the adjusted rate per million population is lowest in Network 6, at 465, and greatest in Network 11, at 833. As in the incident population, racial disparities persist. In Network 6, for example, blacks/African Americans account for 67 percent of prevalent transplant population.

In 2011, the overall rate for December 31 point prevalent dialysis patients was 1,329 per million population, and ranged by network from 841 in Network 16 to 1,686 in Network 8. • Table 1.b; see page 430 for analytical methods. December 31 point prevalent dialysis patients, 2011. Adj: age/gender/race; ref: 2010 patients. Zero values in this cell.
Reaching 6,307 per million population in 2011, the adjusted rate of prevalent ESRD for patients age 65–74 has increased 31 percent since 2000, while the rate among those age 75 and older has grown 48 percent, to 6,007. Among those age 20–44 and 45–64, in contrast, growth has been 16 and 20 percent, respectively, to 955 and 3,483 per million.

By race, rates of prevalent ESRD remain greatest in the black/African American and Native American populations, at 5,584 and 2,701 per million population in 2011, compared to 1,396 and 2,265 among whites and Asians. The rate among Hispanics reached 2,818 in 2011.

The size of the prevalent dialysis population increased 3.2 percent in 2011, reaching 430,273, and is now 52 percent larger than in 2000. The size of the transplant population rose 3.7 percent, to 185,626 patients, while the number of incident ESRD patients fell 1.5 percent, to 115,643. The prevalent transplant and incident ESRD populations are now 22 and 71 percent larger, respectively, than in 2000. • Figures 1.12–16; see page 430 for analytical methods. 1.12–1.15: December 31 point prevalent ESRD patients. Adj: gender/race (1.12); age/gender (1.13–14); age/gender/race (1.15); ref: 2010 ESRD patients. 1.16: Incident & December 31 point prevalent ESRD patients.
In 2011, 101,683 new patients began ESRD therapy on hemodialysis, 7,323 were placed on peritoneal dialysis, and 2,597 received a preemptive transplant (these data exclude patients with missing demographic information).

Past studies have suggested high mortality and significant movement between modalities in the first 90 days after initiation. The total number of 2011 incident patients with a known modality fell 10.8 percent between initiation and day 90. The hemodialysis population at day 90 was 13 percent smaller than at initiation; the peritoneal dialysis and transplant populations, in contrast, gained 8 and 21 percent, respectively. The rate per million population for hemodialysis fell from 322 to 280, while the rate for transplant rose from 8.3 to 10.0, and that for peritoneal dialysis rose from 23.3 to 25.1. * Table 1.d; see page 430 for analytical methods. Incident ESRD patients, 2011; unknowns dropped. Adj: age/gender/race; ref: 2010 ESRD patients.

Forty-four percent of new hemodialysis patients in 2011 were covered solely by Medicare, 14 percent had dual Medicare/Medicaid coverage, and 16 percent were covered by a Medicare HMO provider. Medicare covered 43 and 21 percent of new peritoneal dialysis and transplant patients, while 11.6 and 3.9 percent were dually-enrolled, and 10.3 and 3.9 percent had HMO coverage. * Figure 1.17; see page 430 for analytical methods. Incident ESRD patients; peritoneal dialysis consists of CAPD & CCPD only.

Of the 8,208 incident patients who received renal replacement therapy at home in 2011, 9.4 percent were treated with hemodialysis, 64.7 percent were treated with CAPD, and 26 percent used CCPD. * Figure 1.18; see page 430 for analytical methods. Incident dialysis patients.
On December 31, 2011, nearly 388,000 ESRD patients were receiving hemodialysis therapy, 31,200 were being treated with peritoneal dialysis, and 180,317 had a functioning graft. Rates of ESRD in the prevalent population continue to be highest among blacks/African Americans, at 4,353 per million population for hemodialysis, 220 for peritoneal dialysis, and 993 for transplant. Prevalent rates for Asian patients on peritoneal dialysis or with a transplant are higher than those of their Native American counterparts. At 1,986, however, the rate of Native Americans receiving hemodialysis is 43 percent greater than that found in the Asian population, and two and a half times greater than that found among whites.

### Table 1.c

<table>
<thead>
<tr>
<th>Number of patients</th>
<th>Rate per million population</th>
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<th>Asian</th>
<th>Hispanic</th>
<th>Non-Hispanic</th>
<th>Diabetes</th>
<th>Hypertension</th>
<th>Glomerulonephritis</th>
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<td>170,047</td>
<td>213,942</td>
<td>148,509</td>
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<td>19,580</td>
<td>216,867</td>
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<td>148,509</td>
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<td>88.3</td>
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<td>220.9</td>
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<td>135.7</td>
<td>708.5</td>
<td>88.3</td>
<td>78.6</td>
<td>220.9</td>
<td>115.2</td>
<td>135.7</td>
<td>571.4</td>
<td>133.8</td>
<td>93.3</td>
<td>146.3</td>
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Thirty-nine percent of prevalent hemodialysis patients were covered solely by Medicare in 2011, 33 percent had dual Medicare/Medicaid coverage, and 11.6 percent were covered by a Medicare HMO provider. Among patients on peritoneal dialysis, 47 percent were covered by Medicare alone compared to 32 percent in patients with a transplant.

### Figure 1.19

Prevalent patients using home dialysis, by therapy type

Thirty-seven thousand prevalent dialysis patients received renal replacement therapy at home in 2011. Of these patients, 5,535 were treated with hemodialysis, 10,147 with CAPD, and 21,537 with CCPD.

### Figure 1.20

Prevalent patients using home dialysis, by therapy type.
Forty-two percent of patients starting ESRD therapy in 2011 had not seen a nephrologist prior to initiation. Of these patients, 51 percent initiated with a catheter and only 10.5 percent with a mature fistula; 32 and 37 percent, respectively, had either a maturing fistula or maturing graft. Patients with more than one year of pre-ESRD nephrologist care, in contrast, were far more likely to initiate with a mature fistula, at 50.2 percent. • Table 1.15 see page 430 for analytical methods. Incident ESRD patients, 2011; eGFR calculated using the CKD-EPI equation.

Data from the Medical Evidence form indicate that nearly 80 percent of 2011 incident hemodialysis patients initiated treatment with a catheter as their vascular access, 16.8 percent started with an arteriovenous (AV) fistula, and 3.4 percent initiated with an AV graft. By month four (day 91) of treatment, claims data show rates of catheter, AV fistula, and AV graft use were 52, 17.6, and 5.6 percent, respectively. • Figure 1.21; see page 430 for analytical methods. Incident hemodialysis patients, 2011.

Among hemodialysis patients who have seen a nephrologist for more than a year prior to starting ESRD therapy, 41 percent initiate treatment using a catheter only; patients with this amount of care have the greatest likelihood at initiation of having an arteriovenous fistula (AV) or maturing fistula, at 31.9 and 20.8 percent, respectively. Patients with no pre-ESRD nephrology care most frequently start treatment with a catheter, at 81 percent, while only 16.3 percent initiate with either a mature or maturing AV fistula or graph. • Figure 1.22; see page 430 for analytical methods. Incident hemodialysis patients, 2011.
Mean hemoglobin levels at initiation have fallen from their peak in 2006 (10.24 g/dl), reaching 9.63 g/dl overall at the end of 2011, and they no longer vary between patients who receive pre-ESRD ESA treatment and those who do not. The number of patients receiving ESA treatment prior to initiation has changed 34 percent in 2002–2004 to 18–20 percent during 2011. *Figure 1.23; see page 430 for analytical methods.

**Incident ESRD patients.**

Comparisons of estimated glomerular filtration rates (eGFRs) at the initiation of ESRD therapy indicate that patients continue to start treatment sooner than in the past. In 2011, 29 percent initiated treatment with an eGFR of 10–<15 ml/min/1.73 m², compared to 18 percent in 2000. And 16 percent started with an eGFR of 15 or greater, in contrast to 7.2 percent in 2000. *Figure 1.25; see page 430 for analytical methods. Incident ESRD patients; eGFR calculated using the CKD-EPI equation.

The likelihood of starting dialysis with laboratory values outside the normal limit varies across demographic and disease categories. Nearly 64 percent of male patients, for example, and 61 percent of whites, have a high density lipid (HDL) level below the Adult Treatment Panel (ATP) III target of 40 mg/dl, compared to 46 percent of women and 47 percent of blacks/African Americans. The mean hemoglobin at initiation varies from 9.8 g/dl among whites and Asians to 9.4 among blacks/African Americans and 9.6 among Native Americans and Hispanics. And 69 percent of Native American patients have a serum albumin level below the test’s lower limit, compared to 51 percent of Asians. *Table 1.8; see page 430 for analytical methods. Incident ESRD patients, 2011.
Incident Counts & Rates
Number of New ESRD Patients, 2011 (Figures 1.5–7)
white: 74,311; black/African American: 31,578; Native American: 1,355; Asian: 5,568
Hispanic: 15,637; non-Hispanic: 97,175
diabetes: 49,603; hypertension: 31,831; glomerulonephritis: 7,215; cystic kidney disease: 2,502

Adjusted Rates of Incident ESRD, 2011 (Per Million Population; Figures 1.5–7)
overall: 357
white: 280; black/African American: 940; Native American: 453; Asian: 343
Hispanic: 157; diabetes: 101; hypertension: 101; glomerulonephritis: 23; cystic kidney disease: 8.0

Incident Rates & Racial Differences
Adjusted Incident Rates of ESRD Due to Diabetes, by Age, 2011 (Per Million Population; Figure 1.8)

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<th>Native American</th>
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<td>7</td>
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<tr>
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<td>40–49</td>
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Adjusted Incident Rates of ESRD Due to Hypertension, by Age, 2011 (Per Million Population; Figure 1.9)

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<td>1,478</td>
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<td>695</td>
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Prevalent Counts & Rates
Number of Prevalent ESRD Patients, 2011 (Figures 1.13–15)
white: 365,828; black/African American: 194,032; Native American: 8,302; Asian: 33,639
Hispanic: 90,584; non-Hispanic: 511,217
diabetes: 228,114; hypertension: 151,317; glomerulonephritis: 86,307; cystic kidney disease: 28,932

Adjusted Rates of Prevalent ESRD, 2011 (Per Million Population; Figures 1.13–15)
overall: 1,901
white: 1,396; black/African American: 5,584; Native American: 2,701; Asian: 2,265
Hispanic: 2,818; non-Hispanic: 1,824
diabetes: 718; hypertension: 477; glomerulonephritis: 274; cystic kidney disease:

Incident & Prevalent Modality
Adjusted Rates of ESRD at Initiation & Day 90, 2011 (Per Million Population; Table 1.D)

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<th>Modality</th>
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<tr>
<td>Transplant</td>
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Patient Characteristics
Patients Using an Erythropoiesis Stimulating Agent at Initiation, by Pre-ESRD Nephrologist Care, 2011 (Table 1.F)
no nephrology care: 1.8%; 0–12 months: 28%; more than 12 months: 37%