chapter TWO

incidence & prevalence

From far, from eve and morning
And yon twelve-winded sky,
The stuff of life to knit me
Blew hither: here am I.

A.E. Housman, A Shropshire Lad
Growth of the ESRD program is typically characterized by assessment of total patient counts at a single point in time (point prevalence), of new patients who are accepted for treatment (incidence), and of patients receiving transplants.

Disease rates are based on the number of patients per million people in the general population, and adjusted for age, gender, and race.

This year we highlight racial disparities in ESRD incidence, as illustrated on the next page. While rates of ESRD due to glomerulonephritis have declined among both whites and African Americans younger than 40, the same is not true for ESRD due to diabetes and hypertension in those age 20–39. The linear rate of increase in diabetic ESRD among African Americans is particularly noteworthy, in part because of its contrast to the decline seen among whites, for whom the rate has fallen to the level noted 15 years ago. Potential factors involved here include the rising prevalence — to a degree greater than among whites — of diabetes in the African American and other minority populations, itself linked to greater degrees of obesity in the population overall and particularly among minorities.

The size of the incident population, which had grown in 2006, declined in 2007 and again the following year, with rates returning to the flattened level seen since 2001. Although rates of incident ESRD due to diabetes have increased among younger minority patients, they have been stable or falling in older populations and among whites, showing that a detailed assessment of subpopulations is required to determine whether trends are consistent across all groups defined by age, gender, race, ethnicity, and primary cause of ESRD. Overall rates across all age groups have peaked, and have fallen in those age 65 and older. On the basis of absolute numbers, however, patients age 45–64 drive the total number of new ESRD cases. By race, data on incidence generally show the same flattening as the overall ESRD rates, though rates have been falling among Native Americans.

By primary cause, the adjusted rate of new ESRD cases due to diabetes fell 1.5 percent in 2008, to 152.8 per million population. The rate of ESRD due to glomerulonephritis continues to fall, returning to levels seen in the early 1990s. It is not clear if this finding is related to improved blood pressure control and greater use of ACEIs/ARBs/renin inhibitors, or if hypertension and diabetes are now so common that there is some misclassification of primary diagnosis. Additional investigations will be needed to assess the care of these patients, and to determine if detection and treatment continue to improve.
Data on the median age of incident patients show important trends; the slight decline in the age of white and Asian patients, for instance, may illustrate an increasing number of patients age 45–64 entering ESRD, a reflection of the expanding number of post-war baby boomers reaching their middle years. In 2008, the adjusted incident rate for patients age 45–64 fell to the same level seen in 1998 — 605 per million population. The rate for those age 75 and older declined 0.9 percent between 2007 and 2008.

Racial and ethnic discrepancies persist, with 2008 incident rates in the African American and Native American populations 3.6 and 1.8 times greater, respectively, than the rate among whites, and the rate in the Hispanic population 1.5 times higher than that of non-Hispanics.

Even after adjustments for age and gender, rates of ESRD continue to vary widely across the U.S. This year we update our data on ESRD in the major metropolitan statistical areas (MSAs) of the United States. Among African Americans, for instance, the incidence of ESRD is greatest in the Pittsburgh, Pennsylvania area, while for Hispanics the prevalence of ESRD is highest in the MSA centered around St. Louis, Missouri. These variations may reflect different burdens of CKD, as well as regional differences in the use of detection efforts and treatment interventions in populations at risk for kidney failure. (The 2009 ADR listed Denver as the leading MSA, but this was a typographical error.)

This year we also revisit data on trends in ESRD caused by rare diseases. The incidence of ESRD due to Fabry’s disease has changed little in the past decade, while that of IgA/IgM nephropathy and Berger’s disease appears to have risen slightly; these rates, however, are very low, at 2–3 cases per million population. There has been no change in the incidence of ESRD due to systemic lupus erythematosus over the last ten years, and rates of ESRD due to secondary glomerulonephritis, polycystic kidney disease, Alport’s and other hereditary and familial diseases, multiple myeloma/light chain disease, amyloidosis, and AIDS have also remained quite stable. Rates of ESRD due to post-transplant (non-kidney) complications, in contrast, have tripled. It is not clear if this is due to toxicity from immunosuppressive medications or to kidney disease already present and manifesting itself after the original organ failure. Long-term follow-up studies are needed to assess this rising rate.

Still to be determined is whether these data reflect short- or long-term trends. Even with moderations in disease rates, the aging of the baby boomers will continue to contribute to the growth of the ESRD population. The growth of diabetes in both the general Medicare population and among younger patients is a concern as well.

*Figure 2.1; see page 471 for analytical methods. *Incident ESRD patients. Adj: gender; ref: 2005 ESRD patients.*
After a 2.1 percent decline in 2007, the adjusted incident rate of end-stage renal disease fell 1.1 percent in 2008, to 350.8 per million population. Prior to the decline in these two years, the rate of new ESRD cases had increased or remained stable each year since 1996.

*Figure 2.2*; See page 47 for analytical methods. Incident ESRD patients. Adj: age/gender/race; ref: 2005 ESRD patients.

### Geographic variations in adjusted incident rates of ESRD (per million population), by HSA

#### Incident counts & adjusted rates of ESRD, by age

#### Incident counts & adjusted rates of ESRD, by race

#### Incident counts & adjusted rates of ESRD, by Hispanic ethnicity
The incident rate among patients with Medicare Advantage (formerly Medicare + Choice) coverage peaked in 2001, and by 2005 had fallen nearly 6 percent, reaching 1,411 per million population — 35 percent lower than the rate of 2,168 found in the fee-for-service population. More recent data are not yet available. *Figure 2.8; see page 471 for analytical methods. Incident ESRD patients: unadjusted.*

As in 2007, 13 percent of new ESRD patients in 2008 were Hispanic. The incident rate in this population continues to fall — 1.7 percent in 2008, to 501 per million population — yet remains 1.5 times greater than that seen among non-Hispanics. The incident rate of diabetic ESRD fell 1.5 percent between 2007 and 2008, to 153 per million population — a rate nearly unchanged from that of 2000. The rate of ESRD caused by hypertension, in contrast, has grown 8.1 percent since 2000, to 99.1 per million population, while that of ESRD due to glomerulonephritis has fallen 23.4 percent, to 23.7. *Figures 2.4–7; see page 471 for analytical methods. Incident ESRD patients.*
The adjusted rate of prevalent cases of end-stage renal disease rose 1.9 percent in 2008 — the same growth seen in 2007 — to 1,699 per million population. This rate is nearly 20 percent higher than that seen in 2000. The annual rate of increase has remained between 1.9 and 2.3 percent since 2003. *Figure 2.10; see page 471 for analytical methods. December 31 point prevalent ESRD patients. Adj: age/gender/race; ref: 2005 ESRD patients.*
The median age of the prevalent eSRD population has increased 3.2 percent since 2000, reaching 59.4 in 2008. By race and ethnicity, it varies from 57.4 in the African American population to 60.6 among whites. + Figure 2.14; see page 471 for analytical methods. December 31 point prevalent eSRD patients.

In 2008, the rate of prevalent eSRD was 1,699 per million population (see Table 31 point prevalent ESRD patients. Adj: December 31 point prevalent patients. Adj: age/gender/race; ref: 2005 ESRD patients. + Table 2.14; see page 471 for analytical methods. Incident & December 31 point prevalent eSRD patients, 2008. Adj: age/gender; ref: 2005 eSRD patients. *Values for cells with ten or fewer patients are suppressed.

Across races, incident and prevalent rates of eSRD in the Pittsburgh MSA are consistently among the highest in the U.S. High rates also occur in the St. Louis, Missouri area for African American and Hispanic populations, and in the Los Angeles and Riverside/San Bernardino areas for white populations. + Table 2.14; see page 471 for analytical methods. Incident & December 31 point prevalent eSRD patients, 2008. Adj: age/gender; ref: 2005 eSRD patients. *Values for cells with ten or fewer patients are suppressed.

Reaching 5,941 in 2008, the adjusted rate of prevalent eSRD for patients age 65–74 has increased 25 percent since 2000, while the rate among those age 75 and older has grown 31 percent, to 5,266. Among those age 20–44 and 45–64, in contrast, growth has been just 11.0 and 17.5 percent, respectively.

By race, rates of prevalent eSRD remain greatest in the African American and Native American populations, at 5,205 and 2,700 per million population in 2008, compared to 1,248 and 1,992 among whites and Asians. The rate of eSRD among Hispanics reached 2,458 in 2008, 1.5 times greater than that of the non-Hispanic population.

Rates of eSRD due to diabetes and hypertension increased 2.0–2.1 percent in both 2007 and 2008, while eSRD due to cystic kidney disease rose 2.6–3.1 percent, and eSRD due to glomerulonephritis remained stable. + Figures 2.12–15; see page 471 for analytical methods. December 31 point prevalent eSRD patients. Adj: gender/race (2.12); age/gender (2.13–14); age/gender/race (2.15); ref: 2005 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 incident rate (adjusted for gender) has fallen 7.0 percent since 2000, to 33.3 per million population. In African Americans of the same age, in contrast, the rate has increased 65 percent, to reach 131. The Native American population has seen a rise for this age group of 35 percent, to 121. And while rates of new ESRD cases among Asians remain comparatively low, among those age 30–39 they have increased 70 percent since 2000.

Different patterns are seen among older populations. Among those age 50–59, the rate has fallen more than 13 percent since 2000 for African Americans, and more than 42 percent for Native Americans; among whites and Asians, in contrast, it has increased 2 and 9 percent, respectively.

Compared to rates among whites, the incidence of ESRD remains significantly higher among African Americans: 3.8–3.9 times higher for those age 30–39 and 4.0 times higher for those age 50–59, and 4.6 times higher for those age 20–29. **Figure 2.17; see page 471 for analytical methods. Incident ESRD patients; rates are three-year rolling averages. Adj: gender; ref: 2005 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 30–39, for example, the rate per million population rose 51.5 percent between 2000 and 2008, to reach 12.9. The rate for African Americans of the same age rose at a far slower pace of 15.8 percent, but reached nearly 170 per million population—a rate 13.1 times greater than that of their white counterparts.

Similar patterns are visible among older age groups. In contrast, for instance, to a 42 percent rise among white patients age 40–49, the rate among African Americans of the same age fell 1.7 percent between 2000 and 2008, but it reached 316 per million population—13 times greater, once again, than the rate found among whites.

In the Native American population, rates of ESRD due to diabetes follow patterns by age and time period that are similar to those seen among African American patients. In terms of ESRD caused by hypertension, in contrast, these similarities disappear, with rates among Native Americans considerably lower than those found in the African American population. *Figure 2.18; see page 478 for analytical methods. Incident ESRD patients; rates are three-year rolling averages. Adj: gender; ref: 2005 ESRD patients.*
Since 1996–1998, the incidence of ESRD due to IgA/IgM nephropathy has risen modestly, to 3.2 cases per million population in 2006–2008. Prevalence has grown much more robustly, reaching 27.1 per million — more than three times the 1996–1998 rate. The incidence of ESRD due to Wegener’s granulomatosis rose to 1.2 per million in 2006–2008, while prevalence reached 5.4, nearly double that noted in 1996–1998. For ESRD due to systemic lupus erythematosus (SLE), incident rates have remained between 3.6 and 3.7 per million since 1996–1998, while prevalence has grown 56 percent to reach 31.1 per million in 2006–2008. The incidence of ESRD due to polycystic kidney disease has shown only a modest increase of 10.8 percent since 1996–1998, while prevalent rates have increased by 28.5 percent. *Figures 2.19–24* see page 471 for analytical methods. Incidence & December 31 point prevalent ESRD patients. Adj: age/gender/race; ref: 2005 ESRD patients.
The incidence of ESRD caused by Alport’s disease remains between 0.5 and 0.6 per million population; prevalence has grown 63.8 percent to reach 7.5 per million in 2006–2008. Rates of ESRD due to multiple myeloma or light chain nephropathy appear to have peaked, indicated by a slight downward trend in 2006–2008 for incident patients and only a slight increase in prevalence. New cases of ESRD due to amyloidosis have fallen 3.4 percent since 1996–1998, while prevalence has risen only slightly, to 2.4 cases per million population. The incidence of ESRD caused by AIDS has decreased 2.2 percent since 1996–1998, to 2.7, while prevalent rates have more than doubled, indicating that patients with this disease are living longer.

Network 14 had both the highest rate of diabetic ESRD in 2008 and the greatest ten-year growth, at 199 per million population and 55 percent, respectively. The rate of new ESRD cases due to hypertension rose just 9.1 percent in Network 12, but nearly 69 percent in Network 15. Rates of ESRD due to glomerulonephritis, in contrast, have fallen across the country, with the exception of a 5.2 percent growth in Network 16. + Figures 2.30–2.32; see page 471 for analytical methods. Incident ESRD patients. Adj: age/gender/race; ref: 2005 ESRD patients.

The mean age of both the incident and prevalent populations is greatest in areas of the Upper Midwest, the Northeast, and portions of Florida. In the lower quintile, the average age is 59.4 for incident patients compared to 56.4 in the prevalent population. Means in the upper quintile are 67.0 and 60.7, respectively. + Figure 2.33; see page 471 for analytical methods. Incident & December 31 point prevalent ESRD patients; unadjusted.
Patient demographics & adjusted rates, by ESRD network: December 31 point prevalent dialysis patients, 2008

<table>
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<th>% of total</th>
<th>Rate per million</th>
<th>Mean age</th>
<th>% DM</th>
<th>% White</th>
<th>% Af Am</th>
<th>% N Am</th>
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**Tables 2.8-2.10:** see page 471 for analytical methods. Incident dialysis patients (2.b); December 31 point prevalent dialysis patients (2.c); December 31 point prevalent transplant patients (2.d). \*Values for cells with ten or fewer patients are suppressed. Adj: age/gender/race; ref: 2005 patients.

These tables present patient demographics and adjusted disease rates by modality and esrd network. With an overall rate for incident dialysis patients of 343 per million population in 2008, rates by network range from 216 in Network 16 to 421 in Network 8. The distribution of patients by race continues to vary widely across the country. African Americans, for example, constitute just 6.9 percent of the new esrd population in Network 16, but 49–56 percent of patients in Networks 6 and 8.

In the 2008 prevalent population, the overall rate for December 31 point prevalent dialysis patients was 1,183 per million population. The percentage of prevalent patients with esrd caused by diabetes ranges from 39.5 in Network 1 to 52–53 in Networks 14 and 15.

For December 31 point prevalent transplant patients, the adjusted rate is lowest in Network 6, at 403 per million population, and greatest in Network 11, at 777. Racial differences are evident here as well. In Network 6, for example, African Americans account for 67 percent of prevalent dialysis patients. They represent, however, only 39 percent of the prevalent transplant population.
In 2008, the adjusted rate of new ESRD cases was 351 per million population. **FIGURE 2.2**

Since 2000, the adjusted incident rate of ESRD has grown 9.4 percent for patients age 75 and older, to 1,718 per million population in 2008. **FIGURE 2.4**

The rate of new ESRD cases among African Americans reached 983 per million population in 2008, 3.6 times greater than the rate of 272 found among whites. **FIGURE 2.5**

The adjusted rate of prevalent ESRD cases rose 1.9 percent in 2008, to 1,699 per million population. **FIGURE 2.10**

In the population age 65–74, the adjusted rate of prevalent ESRD cases is nearing 6,000 per million population, and has increased 25 percent since 2000. **FIGURE 2.12**

The Pittsburgh, Pennsylvania area has among the highest incident and prevalent rates in the country. **TABLE 2.A**

Both the incident rates of ESRD caused by diabetes and their growth over time continue to vary widely by age and race/ethnicity. **FIGURE 2.17**

The incidence of ESRD caused by AIDS has decreased 2.2 percent since 1996–1998, to 2.7 cases per million population, while prevalent rates have more than doubled. **FIGURE 2.28**

For December 31 point prevalent transplant patients, the adjusted rate of ESRD is lowest in Network 6, at 403 per million population, and greatest in Network 11, at 777. **TABLE 2.D**