chapter one

incidence, prevalence, patient characteristics, and treatment modalities

And in the naked light I saw
Ten thousand people, maybe more
People talking without speaking
People hearing without listening
People writing songs that voices never share
No one dare
Disturb the sound of silence

Paul Simon, “The Sound of Silence”
The number of incident dialysis cases rose 3.3 percent in 2009, to 113,636; with 2,759 patients receiving a pre-emptive transplant as their first ESRD modality, 116,395 total patients began ESRD therapy in 2009.

More than 106,000 dialysis patients started ESRD treatment on hemodialysis, and 7,094 started on peritoneal dialysis — 6.1 percent of patients with a known dialysis modality. The rate of new ESRD cases per million population has been relatively stable since 2000, and rose just 1.1 percent in 2009, to 355. Growth in the incident population continues to be driven by a linear increase in the number of patients age 45–64; growth in the population age 65 and older, in contrast, has slowed considerably.

The December 31, 2009 prevalent population included 370,274 patients on hemodialysis and 27,522 on peritoneal dialysis, as well as 172,553 with a functioning kidney transplant; the total treated ESRD population thus rose above 570,000. The rate of prevalent ESRD cases reached 1,738 per million population, an increase of 2.1 percent from 2008, and consistent with a similar rise per year since 2002.

In previous ADRs we have introduced comparisons that include matched hemodialysis and peritoneal dialysis populations. This year we more completely define these comparison populations, using 17 characteristics from the Medical Evidence form submitted for all new ESRD patients. As seen in the figure on the next page, the incident hemodialysis population is considerably different from the peritoneal dialysis population before the match; after the match, however, these differences are markedly reduced. These matched populations are used later in the ADR to compare hospitalization rates and the costs of patient care.

By primary diagnosis, the adjusted rate of new ESRD cases due to diabetes increased 0.5 percent in 2009, to 154.1 per million population. The rate of ESRD caused by glomerulonephritis was unchanged, and also consistent with levels seen in the early 1990s. It is not clear if these findings are related to improved blood pressure control and greater use of ACEIs/ARBs/renin inhibitors — data consistent with recent trends seen in NHANES data — or if hypertension and diabetes are now so common that there is some misclassification of primary diagnosis.

Racial and ethnic discrepancies persist, with 2009 incident rates in the African American and Native American populations 3.5 and 1.9 times greater, respectively, than the rate among whites, and the rate in the Hispanic population 1.5 times higher than that of non-Hispanics.

Insurance coverage of ESRD patients continues to shift. In the incident hemodialysis population, for example, coverage by the Medicare Advantage program has reached its highest level, at 15.3 percent in 2009. Dual Medicare/Medicaid coverage has fallen to 13.5 percent, and Medicare fee-for-service coverage is now at 45 percent, its lowest level. Medicare as primary payor now covers just 74 percent of incident hemodialysis patients — down from nearly 95 percent in 1978.

In the prevalent population, Medicare is the primary payor for 83 percent of hemodialysis patients, down nearly 2 percentage points since 1998. With private insurance covering a greater proportion of peritoneal dialysis and transplant patients, Medicare is the primary payor for just 78 and 53 percent of these patients, respectively.

Data on patient care at the start of ESRD therapy show that the percentage of patients receiving any erythropoi-
esis stimulating agent (ESA) prior to initiation continues to decline, most likely due to recent concern over potential adverse events when hemoglobin levels are targeted to a level above 12 g/dl. The mean hemoglobin at initiation of ESRD treatment is now 9.8 g/dl, with one patient in five treated with an ESA; in 2006, these numbers were 10.1 g/dl and 29 percent, respectively.

Whether calculated by the MDRD formula or the newer CKD-EPI formula, the increase in the estimated glomerular filtration rate (eGFR) at the initiation of ESRD therapy continued in 2009. Using the MDRD formula, for example, 54 percent of new patients had an eGFR greater than 10 ml/min/1.73 m²; with the CKD-EPI formula, this number falls to 45 percent.

Biochemical data, collected on the Medical Evidence form since 2005, show that 57 percent of new patients in 2009 had an albumin less than the lower limit of normal, and 52 percent had a hemoglobin lower than 10 g/dl. Total cholesterol was greater than 200 mg/dl in 16.3 percent of patients, while 70 percent had an LDL level lower than 100 mg/dl, and 58 percent had an HDL level less than 40 mg/dl. Among patients with diabetes, 28 percent had a hemoglobin A1c level greater than 7 percent.

Recent changes and new incentives in the bundled prospective payment system for dialysis patients, starting in January, 2011, may alter several characteristics of the incident and prevalent populations. The USRDS will continue to monitor these populations closely and assess the impact of this payment system on the ESRD population.

Figures 1.1–2; see page 379 for analytical methods. Incident & December 31 point prevalent ESRD patients (1.1); incident ESRD patients (1.2).
After a 0.9 percent decline in 2008, the adjusted incident rate of end-stage renal disease rose 1.1 percent in 2009, to 355 per million population. Prior to the slight decline in 2007 and 2008, the rate of new ESRD cases had increased or remained stable each year since 1996.  

Figure 1.3; see page 379 for analytical methods. Incident ESRD patients. Adj: age/gender/race; ref: 2005 ESRD patients.

In 2009, the adjusted incident rate of ESRD was 355 per million population, and geographically averaged 452 in the upper quintile. The highest adjusted rates occur in the Ohio Valley, portions of Texas and California, and the southwestern states. (Rates are not adjusted for ethnicity.)  

Figure 1.4; see page 379 for analytical methods. Incident ESRD patients. Adj: age/gender/race; ref: 2005 ESRD patients.

With an overall rate for incident dialysis patients of 348 per million population in 2009, rates by network range from 236 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 6.4 percent of the new dialysis population in Network 16, but 49–55 percent of patients in Networks 6 and 8.  

Table 1.a; see page 379 for analytical methods. Incident dialysis patients.*Values for cells with ten or fewer patients are suppressed. Adj: age/gender/race; ref: 2005 patients.
Since 2000, the adjusted incident rate of ESRD has grown 12 percent for patients age 75 and older, to 1,762 per million population in 2009, while rates for those age 0–19 and 20–44 have increased 9.6 and 9.8 percent, respectively, to 15.5 and 131. Rates for patients age 45–64 and 65–74, in contrast, though rising slightly during the decade, are now the same as in 2000, at 610 and 1,407.

By race, rates for African Americans and Native Americans in 2009 were 976 and 523 per million population, respectively — 3.5 and 1.9 times greater than the rate of 277 found among whites. Since 2000, the rate of new ESRD cases has grown 7.2 percent among whites and 6.4 percent among Asians, while remaining stable in the African American population.

As in the previous two years, 13 percent of new ESRD patients in 2009 were Hispanic. The incident rate in this population continues to fall — 1.5 percent in 2009, to 501 per million population — yet remains 1.5 times greater than that seen among non-Hispanics.

With the exception of an uptick in 2006, the rate of new ESRD cases caused by diabetes has remained quite stable since 2000, and was 154 per million population in 2009. The rate of ESRD due to hypertension, in contrast, has grown 8.7 percent since 2000, to 101, while that of ESRD due to glomerulonephritis has fallen 23 percent, to 23.8. >> Figures 1.5–8; see page 379 for analytical methods: Incident ESRD patients. Adj: gender/race (1.5); age/gender (1.6–7), age/gender/race (1.8); ref: 2005 ESRD patients.
The adjusted rate of prevalent cases of end-stage renal disease rose 2.1 percent in 2009 — up slightly from the 1.9 percent growth in 2008 — to 1,738 per million population. This rate is nearly 23 percent higher than that seen in 2000. The annual rate of increase has remained between 1.9 and 2.4 percent since 2003. >> Figure 1.9; see page 379 for analytical methods.


In 2009, the rate of prevalent ESRD was 1,738 per million population. Geographic patterns generally follow those found in the incident population, with rates in the upper quintile averaging 2,278. (Rates are not adjusted for ethnicity.) >> Figure I.10; see page 379 for analytical methods.

Reaching 6,066 per million population in 2009, the adjusted rate of prevalent ESRD for patients age 65–74 has increased 28 percent since 2000, while the rate among those age 75 and older has grown 37 percent, to 5,545. Among those age 20–44 and 45–64, in contrast, growth has been 13 and 20 percent, respectively.

By race, rates of prevalent ESRD remain greatest in the African American and Native American populations, at 5,284 and 2,735 per million population in 2009, compared to 1,279 and 2,101 among whites and Asians. The rate among Hispanics reached 2,538 in 2009, 1.5 times greater than that in the non-Hispanic population.

Rates of ESRD due to diabetes and hypertension rose 2.2 and 2.7 percent, respectively, in 2009, to 647 and 429 per million population. ESRD caused by cystic kidney disease rose 2.4 percent, to 83, and ESRD due to glomerulonephritis remained stable, at 263. » Figures 1.11–14; see page 379 for analytical methods. December 31 point prevalent ESRD patients. Adj: gender/race (1.11); age/gender (1.12–13); age/gender/race (1.14); ref: 2005 ESRD patients.
In 2009, 104,252 new patients began ESRD therapy on hemo-
dialysis, 6,966 were placed on peritoneal dialysis, and 2,500
received a preemptive transplant (these data exclude patients
with missing demographic information). The rate per million
population reached 325 for hemodialysis, 21.9 for peritoneal
dialysis, and 7.9 for transplant.

Dramatic differences by race persist, with the rate for Afri-
can American patients initiating on hemodialysis at 928 per
million population — 3.7 times greater than the rate of 251
among whites. The rate for patients who receive a preemptive
transplant, in contrast, is 32 among Asians, compared to 6–7
among whites and African Americans and 22 among
Native Americans.

Past studies have suggested high mortality and significant
movement between modalities in the first 90 days after ESRD
initiation. The total number of patients with a known modality
fell 12 percent between initiation and day 90. The hemodialysis
population at day 90 was 14 percent smaller than at initiation;
the peritoneal dialysis and transplant populations, in contrast,
gained 1.4 and 21 percent, respectively.

Between initiation and day 90, the rate per million popula-
tion for hemodialysis fell from 325 to 280, while the rate for
transplant rose from 7.9 to 9.5, and that for peritoneal dialysis
remained relatively steady, rising from 21.9 to 22.2. > Table 1.6; see
page 379 for analytical methods. Incident ESRD patients, 2009; unknowns
dropped. Ref: 2005 patients.

| Incident counts & adjusted rates of ESRD at initiation & day 90, by
| modality, age, gender, race, ethnicity, & primary diagnosis, 2009 |
|---|---|---|
| At initiation | Rate per million population | At day 90 |
| Number of patients | HD | PD | Tx | HD | PD | Tx | HD | PD | Tx |
| 0-19 | 684 | 402 | 214 | 8.0 | 4.8 | 2.5 | 583 | 392 | 262 | 6.8 | 4.7 | 3.1 |
| 20-44 | 11,958 | 1,251 | 646 | 113 | 11.9 | 5.9 | 10,245 | 1,106 | 382 | 101.5 | 124.8 | 7.3 |
| 45-64 | 39,337 | 2,987 | 1,238 | 552 | 40.6 | 16.1 | 35,045 | 3,012 | 1,493 | 493.1 | 40.9 | 19.5 |
| 65-74 | 24,688 | 1,377 | 360 | 1,318 | 69.6 | 17.2 | 20,957 | 1,426 | 440 | 1,123.1 | 72.2 | 21.1 |
| 75+ | 27,585 | 949 | 42 | 1,704 | 53.9 | 2.1 | 22,422 | 929 | 44 | 1,381.2 | 52.2 | 2.1 |
| Male | 59,081 | 3,884 | 1,462 | 415 | 26.3 | 9.5 | 50,535 | 3,988 | 1,781 | 353.4 | 26.9 | 11.5 |
| Female | 45,171 | 3,082 | 1,038 | 256 | 18.4 | 6.4 | 39,217 | 3,077 | 1,240 | 222.8 | 18.4 | 7.7 |
| White | 68,173 | 5,043 | 1,722 | 251 | 19.1 | 6.6 | 56,912 | 5,098 | 2,182 | 209.8 | 19.3 | 8.4 |
| African American | 30,818 | 1,662 | 209 | 918 | 41.2 | 5.7 | 27,580 | 1,469 | 263 | 181.0 | 41.7 | 7.2 |
| Native American | 1,255 | 73 | 71 | 473 | 25.4 | 21.7 | 1,129 | 94 | 69 | 435.9 | 32.5 | 21.0 |
| Asian | 4,406 | 388 | 498 | 341 | 27.8 | 32.4 | 4,031 | 404 | 507 | 309.9 | 28.9 | 33.1 |
| Hispanic | 13,704 | 822 | 227 | 470 | 23.7 | 5.8 | 12,475 | 849 | 287 | 426.0 | 24.3 | 7.3 |
| Non-Hispanic | 90,548 | 6,144 | 2,273 | 314 | 21.9 | 8.3 | 77,277 | 6,216 | 2,734 | 268.5 | 22.2 | 10.0 |
| Diabetes | 46,500 | 2,791 | 453 | 143 | 8.7 | 1.4 | 41,911 | 2,833 | 603 | 139.6 | 8.8 | 1.9 |
| Hypertension | 30,338 | 1,662 | 345 | 94.7 | 5.2 | 1.1 | 26,211 | 1,684 | 412 | 81.9 | 5.3 | 1.3 |
| Glomerulonephritis | 6,107 | 901 | 476 | 19.3 | 2.9 | 1.5 | 5,480 | 925 | 575 | 173.3 | 3.0 | 1.8 |
| Cystic kidney | 1,760 | 448 | 413 | 5.6 | 1.4 | 1.3 | 1,666 | 403 | 488 | 53.3 | 1.3 | 1.5 |
| Other urologic | 1,397 | 93 | 61 | 4.4 | 0.3 | 0.2 | 1,263 | 97 | 71 | 4.0 | 0.3 | 0.2 |
| Other cause | 13,322 | 803 | 494 | 42.0 | 2.6 | 1.6 | 9,473 | 839 | 604 | 29.9 | 2.7 | 1.9 |
| Unknown/missing | 4,828 | 268 | 258 | 15.2 | 0.9 | 0.8 | 3,748 | 284 | 268 | 11.8 | 0.9 | 0.8 |
| All | 104,252 | 6,966 | 2,500 | 325.0 | 21.9 | 7.9 | 89,752 | 7,065 | 3,021 | 279.7 | 22.2 | 9.5 |

Forty-five percent of new hemodialysis patients are covered solely by Medicare, 13.5 percent have dual Medicare/Medicaid
coverage, and 15.3 percent are covered by a Medicare HMO provider. Medicare cov-
ers 41 and 22 percent of new peritoneal
dialysis and transplant patients, while 9.8 and 4.2 percent are dually-enrolled, and
9.8 and 3.5 percent have HMO coverage. Coverage by non-Medicare insurers has increased for hemodialysis patients from
5.4 percent in 1978 to nearly 17 percent in
2009. > Figure 1.5; see page 379 for analytical methods. Incident ESRD patients.
On December 31, 2009, more than 362,000 ESRD patients were receiving hemodialysis therapy, 27,015 were being treated with peritoneal dialysis, and 167,589 had a functioning graft. Rates of ESRD in the prevalent population continue to be highest among African Americans, at 4,166 per million population for hemodialysis, 192 for peritoneal dialysis, and 918 for transplant. Rates for peritoneal dialysis and transplant are similar in the Native American and Asian populations; at 1,992, however, the rate of Native Americans receiving hemodialysis is 54 percent greater than that found in the Asian population and more than double that found in whites. Table 1.e; see page 379 for analytical methods.

Nine in ten prevalent hemodialysis patients had some type of Medicare coverage in 2009, with 40 percent covered solely by Medicare, and 32 percent under Medicare/Medicaid. In the transplant population, in contrast, just 32 percent are covered solely by Medicare. Transplant patients younger than 65 and not disabled lose their entitlement after three years with a functioning graft. Coverage by non-Medicare insurers continues to increase in the dialysis population, in 2009 reaching 10.8 and 10.2 percent for hemodialysis and peritoneal dialysis patients, respectively. Figure 1.16; see page 379 for analytical methods. December 31 point prevalent ESRD patients, 2009; unknowns dropped. Ref: 2005 patients.
Among patients receiving more than 12 months of nephrologist care prior to starting ESRD therapy in 2009, half of those with a primary diagnosis of cystic kidney disease had a fistula as their first access, compared to 29–34 percent of those with ESRD due to diabetes, hypertension, or glomerulonephritis. » Figure 1.18; see page 379 for analytical methods. Incident hemodialysis patients, 2009.

Among patients beginning ESRD therapy in 2009, 45 percent of those with a primary diagnosis of hypertension had received no pre-ESRD nephrologist care, compared to 16 percent of those with cystic kidney disease. One in two patients with cystic kidney disease had received more than 12 months of nephrologist care, compared to 23 and 26 percent of those with hypertension or diabetes. » Figure 1.17; see page 379 for analytical methods. Incident ESRD patients, 2009.

More than 43 percent of patients starting ESRD therapy in 2009 had not seen a nephrologist prior to initiation. Of these patients, 89 percent initiated with a catheter and only 3 percent with a fistula; 12.4 percent had a maturing internal access. Patients with more than one year of pre-ESRD nephrologist care, in contrast, were far more likely to initiate treatment with a fistula, at 25.4 percent. » Table 1.f; see page 379 for analytical methods. Incident ESRD patients, 2009.

Among hemodialysis patients who have seen a nephrologist for more than a year prior to starting ESRD therapy, less than half initiate treatment using a catheter; these patients have the greatest likelihood at initiation of having an arteriovenous fistula (AV) or maturing fistula, at 30 and 19.2 percent, respectively. Patients with no pre-ESRD nephrology care most frequently start treatment with a cather, at 82 percent, while only 17.3 percent initiate with either a mature or maturing AV fistula or graft. » Figure 1.19; see page 379 for analytical methods. Incident hemodialysis patients, 2009.
In the incident ESRD population, the mean hemoglobin at initiation has continued to fall from its peak in 2006, reaching 9.85 g/dl overall, 9.94 for patients receiving pre-ESRD treatment with an erythropoiesis stimulating agent (ESA), and 9.81 for patients without ESA treatment; 22 percent of new patients at the end of 2009 had received a pre-ESRD ESA.

The percentage initiating dialysis with a hemoglobin less than 10 g/dl is highest in parts of Texas and states along the Gulf Coast and Atlantic Seaboard, averaging 56 percent in the upper quintile.

The likelihood of starting dialysis with laboratory values outside the test’s normal limit is, with few exceptions, similar across demographic and disease categories. Overall, 57 percent of patients start treatment with a serum albumin below the test’s lower limit, and 52 percent have a hemoglobin less than 10 g/dl. Sixteen percent initiate with a total cholesterol greater than 200 mg/dl, 70 percent have low density lipid (LDL) measurements less than 100 mg/dl, and 58 percent have high density lipid (HDL) levels below the Adult Treatment Panel (ATP) III target of 40 mg/dl. Triglyceride levels above 150 mg/dl occur in 38 percent of incident patients, and 28 percent have a glycosylated hemoglobin (A1c) level above the recommended maximum of 7 percent.

Comparisons of estimated glomerular filtration rates (eGFRs) at the initiation of ESRD therapy indicate that patients are starting treatment sooner than in the past. In 2009, using the MDRD and CKD-EPI formulas to estimate GFR, 34 and 29 percent, respectively, initiated treatment with eGFRs of 10–15 ml/min/1.73 m², compared to 23 and 17.7 percent in 2000. And 19.8 and 15.5 percent started with eGFRs of 15 or greater, in contrast to 9.8 and 7.4 percent in 2000. *Figures 1.20–23 & Table 1.g; see page 379 for analytical methods. Incident ESRD patients (1.20–23); incident ESRD patients, 2009 (1.g).
### Summary

#### Number of New ESRD Patients, 2009

- **White**: 75,077
- **African American**: 32,416
- **Native American**: 1,404
- **Asian**: 5,311
- **Hispanic**: 14,766
- **Non-Hispanic**: 99,142
- **Diabetes**: 49,786
- **Hypertension**: 32,373
- **Glomerulonephritis**: 7,505
- **Cystic Kidney Disease**: 2,634

#### Adjusted Rate of Incident ESRD Patients, 2009

**Per Million Population**

- **Overall**: 355
- **White**: 277
- **African American**: 976
- **Native American**: 523
- **Asian**: 403
- **Hispanic**: 501
- **Non-Hispanic**: 345
- **Diabetes**: 154
- **Hypertension**: 101
- **Glomerulonephritis**: 23.8
- **Cystic Kidney Disease**: 8.4

#### Number of Prevalent ESRD Patients, 2009

- **White**: 341,701
- **African American**: 179,718
- **Native American**: 7,583
- **Asian**: 29,237
- **Hispanic**: 79,730
- **Non-Hispanic**: 478,509
- **Diabetes**: 210,475
- **Hypertension**: 138,498
- **Glomerulonephritis**: 82,914
- **Cystic Kidney Disease**: 26,872

#### Adjusted Rate of Prevalent ESRD Patients, 2009

**Per Million Population**

- **Overall**: 1,738
- **White**: 1,279
- **African American**: 5,284
- **Native American**: 2,735
- **Asian**: 2,101
- **Hispanic**: 2,538
- **Non-Hispanic**: 1,685
- **Diabetes**: 647
- **Hypertension**: 429
- **Glomerulonephritis**: 263
- **Cystic Kidney Disease**: 83

#### Adjusted Rates of ESRD at Initiation and at Day 90, 2009

**Rate Per Million Population**

- **At Initiation**: 325
- **Peritoneal Dialysis**: 21.9
- **Transplant**: 7.9
- **At Day 90**: 280
- **Peritoneal Dialysis**: 22.2
- **Transplant**: 9.5

#### Patients with More Than 12 Months of Pre-ESRD Nephrologist Care, 2009

- **Overall**: 24.5%
- **Diabetes**: 26%
- **Hypertension**: 23%
- **Glomerulonephritis**: 34%
- **Cystic Kidney Disease**: 50%

#### Patients using an Erythropoiesis Stimulating Agent at Initiation, 2009

**By Pre-ESRD Nephrologist Care**

- **No Care**: 2.3%
- **0-12 Months**: 35%
- **More Than 12 Months**: 47%

#### Patients with Hemoglobin Less Than 10 g/dL at Initiation, 2009

- **Overall**: 52.4%
- **White**: 50%
- **African American**: 60%
- **Native American**: 55%
- **Asian**: 47%
- **Hispanic**: 55%