

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

# Incidence

- The number of incident (newly reported) ESRD cases in 2013 was 117,162; the unadjusted incidence rate was 363 per million/year.
- The adjusted incidence rate of ESRD in the United States rose sharply in the 1980s and 1990s, leveled off in the early 2000s, and has declined slightly since its peak in 2006.
- In 2013, the adjusted ESRD incidence rate ratios for Black/African Americans, Native Americans, and Asians/Pacific Islanders, compared with Whites, were 3.0, 1.1 and 1.2; the rate ratio for Hispanics versus Non-Hispanics was 1.4.

# **Prevalence**

- On December 31, 2013, there were 661,648 prevalent cases of ESRD; the unadjusted prevalence (proportion) was 2,034 per million in the U.S. population.
- While the number of ESRD incident cases plateaued in 2010, the number of ESRD prevalent cases continues to rise by about 21,000 cases per year.
- Compared to Whites, ESRD prevalence is about 3.7 times greater in Blacks, 1.4 times greater in Native Americans, and 1.5 times greater in Asians.

# Characteristics of Incident ESRD Cases

- Up to 38% of incident ESRD cases in 2013 received little or no pre-ESRD nephrology care.
- Mean eGFR at initiation of dialysis in 2013 increased steadily from 1996 until 2009, but has been stable or decreased slightly from 2010 to 2013

# **Treatment Modalities**

- In 2013, 88.2% of all incident cases began renal replacement therapy with hemodialysis, 9.0% started with peritoneal dialysis, and 2.6% received a preemptive kidney transplant.
- On December 31, 2013, 63.7% of all prevalent ESRD cases were receiving hemodialysis therapy, 6.8% were being treated with peritoneal dialysis, and 29.2% had a functioning kidney transplant.

# Introduction

The focus of this chapter is the incidence and prevalence of end-stage renal disease (ESRD) in the U.S. population. Incidence refers to the occurrence or detection of new (incident) cases of ESRD during a given period. Incidence is expressed in this chapter as a count (number of incident cases) and as a rate (number of new cases in one year, divided by the amount of person-years at risk, which is approximated by the mid-year census for the population in that year). Rates are then expressed

as per million population per year. For example, if 3,000 incident ESRD cases occurred in 2013 in a population of 10,000,000 adults, the incidence rate would be 0.000300 per year or 300 per million per year. Incidence rates are used to describe the occurrence of disease in populations, to identify risk factors for ESRD in etiologic studies, and to evaluate the impact of interventions for reducing ESRD risk in primary-prevention studies.

Prevalence refers to the presence of existing ESRD cases at a point in time (point prevalence) or during a specific

period (period prevalence; not used in this chapter); it is expressed in this chapter as a count (number of prevalent cases) and as a proportion (number of prevalent cases, divided by the size of the population from which those cases were identified); prevalence at the end of each year is then expressed as per million population. Note that prevalence is not a rate; it is a proportion. Prevalence is used to describe the existing burden of disease in populations, to quantify the need for and to allocate health care resources.

Although prevalence is easier to estimate than incidence, prevalence findings are more difficult to interpret because the prevalence of a condition depends on both the incidence rate of that condition and how long ESRD patients live with the condition before recovering or dying. For example, if something favorable is done to improve survival among ESRD patients without changing the incidence rate, the prevalence of ESRD will increase. On the other hand, if something favorable is done to reduce the ESRD incidence rate without changing the survival of ESRD patients, the prevalence of ESRD will decrease.

This chapter examines trends in ESRD incidence and prevalence, patient characteristics, and treatment modalities from 1996 through 2013. While the prevalence of ESRD continues to rise, the trend over the past decade indicates that ESRD incidence has plateaued after increasing for many years. If these incidence and prevalence trends continue in the coming years, this would be good news indeed, as it implies likely improvements in prevention of ESRD as well as longer survival among patients who have reached ESRD.

# PRIMARY CAUSE OF ESRD: A CAUTIONARY NOTE

The "primary cause of renal failure," as assessed by individual physicians and reported on Form CMS-2728, has been used for many years in nephrology to compare populations and assess temporal trends. In the ADR, it allows us to estimate the ESRD incidence rate and prevalence for different disease subtypes, i.e., those with the primary cause listed as diabetes, hypertension, glomerulonephritis, or cystic kidney disease. It should be noted, however, that this approach is not the same as stratifying on comorbidity status, e.g., in this chapter we are not estimating adjusted incidence rates of ESRD among diabetics or non-diabetics in the U.S. population. Furthermore, the reliability of clinician assigned "primary-cause" of ESRD has not been well established; and because causation cannot be definitively established for all patients on the basis of clinical judgment or testing, and also because many patients arrive at ESRD without benefit of prior nephrology care, the validity of these etiologic subtypes of ESRD remains a challenge.

# ADJUSTMENT OF INCIDENCE RATES AND PREVALENCE

When comparing the incidence rate or prevalence of ESRD between different groups or years, the magnitude of the difference might be distorted (biased) if the groups or years differ in the distribution of one or more risk factors for ESRD. To control for those risk factors (potential confounders or covariates) in this chapter, we stratify on them in each group or year and calculate a weighted average of the stratum-specific rate or prevalence estimates, where the weights are the numbers of persons in each stratum of a standard population. This method is called standardization or "direct adjustment." To control for the potential confounders when comparing groups or years, we standardize all sets of rates or prevalences to the same standard population. In the 2015 ADR, standardization is used to adjust for age, sex, and race or ethnicity; and the standard population is the total U.S. population in 2011 (the same as in the 2014 ADR). Each standardized rate or prevalence for any specific group or year is interpreted as the rate or prevalence expected if that group or year had exhibited the covariate distribution of the standard population.

The major limitation of this adjustment method is that we are controlling for only a few demographic variables in this chapter. We are not controlling for other major ESRD risk factors such as CKD stage, diabetes status, hypertension status, or cardiovascular burden. Therefore, interpreting comparisons of incidence rates or prevalences between groups or years should be done with caution.

# **ANALYTICAL METHODS**

See the ESRD Analytical Methods chapter for an explanation of analytical methods used to generate the figures and tables in this chapter.

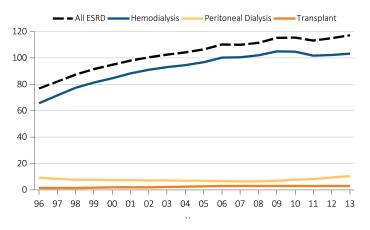
# Incidence of ESRD: Counts, Rates, and Trends

# **OVERALL INCIDENCE RATE**

The number of incident (newly reported) ESRD cases in 2013 was 117,162 (Figure 1.1). The unadjusted incidence rate in 2013 was 363 per million/year. After a year-by-year rise in ESRD incidence over two decades from 1980 through 2000, it has been roughly stable from 2000 to 2013. The size of the incident dialysis

population (hemodialysis and peritoneal dialysis) increased 1.9% from 2012 to 2013, reaching 113,944, and is now 24% larger than in 2000. The size of the pre-emptive transplant population rose 2.6% in 2013 to 3046 patients and is now 59.2% larger than in 2000.

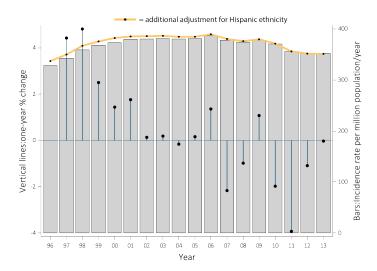
vol 2 Figure 1.1 Trends in the annual number of ESRD incident cases (in thousands) by modality, in the U.S. population, 1996-2013



Data Source: Reference Table D1. Abbreviation: ESRD, end-stage renal disease.

The incidence rate of ESRD virtually plateaued beginning in 2001, declined in all but one year between 2007 and 2012, and was essentially unchanged in 2013 (Figure 1.2). The adjusted incidence rate of 352 per million/year in 2013 was the lowest since 1997. These findings provide further indication that the sustained rise in ESRD incidence rate through the 1980s and 1990s has not continued.

vol 2 Figure 1.2 Trends in the adjusted\* incidence rate (per million/year) of ESRD (bars; scale on right), and annual change (%) in the adjusted\* incidence rate of ESRD (lines; scale on left) in the U.S. population, 1996-2013



Data Source: Reference Table A.2(2) and special analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

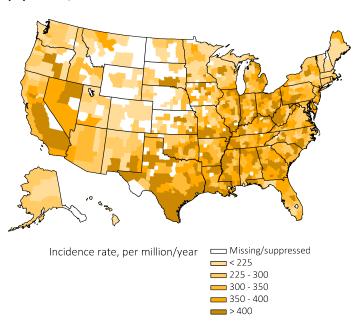
# **INCIDENCE RATE: BY REGION**

Variation in ESRD incidence rates among the 18 ESRD Networks remains substantial (Table 1.1). Adjusting for differences in age, sex, and race, the lowest rate was 244 per million/year in Network 1 (CT, MA, ME, NH, RI, VT), while the rate in Network 18 (S. CA) was 80% higher at 438 per million/year.

Among incident ESRD cases, mean age varied by over 4 years from 60.3 years in Network 6 to 64.7 years in Network 4. The distribution of race among incident cases continues to vary widely across networks. Black/African Americans constitute fewer than 10% of all incident cases in Networks 15 and 16, but nearly 50% in Networks 5 and 8 and 52% in Network 6. Hispanics constitute fewer than 5% of patients in eight networks, but approximately 40% in Networks 3, 14, and 18.

The adjusted incidence rate of ESRD in 2013 ranged across 677 Health Service Areas from a low of 48 per million/year to a high of 3,751 per million/year (interquartile range: 262 to 405 per million/year) (Figure 1.3). The rates were generally highest in parts of the Ohio and Mississippi River valleys, the Southeast, Texas, and California, and lowest in New England, the Northwest, and certain Upper Midwest and Rocky Mountain states.

vol 2 Figure 1.3 Map of the adjusted\* incidence rate (per million/year) of ESRD, by Health Service Area, in the U.S. population, 2013



Data Source: Special analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

vol 2 Table 1.1 Adjusted\* incidence rate (per million/year) of ESRD in the U.S. population, and distribution (%) of age, diabetes, sex, race, and ethnicity among incident ESRD cases by ESRD Network, 2013

|         |                        | Rate per          | Total no.         | % of              | Mean | %              | %         |            | Race               |           |            | Ethnicity |
|---------|------------------------|-------------------|-------------------|-------------------|------|----------------|-----------|------------|--------------------|-----------|------------|-----------|
| Network | States in network      | million /<br>year | incident<br>cases | incident<br>cases | age  | 76<br>Diabetic | %<br>Male | %<br>White | % Black /<br>Af Am | % N<br>Am | %<br>Asian | % Hisp    |
| 1       | CT, MA, ME, NH, RI, VT | 244               | 3,600             | 3.1               | 64.3 | 41.6           | 61.1      | 83.4       | 13.3               | 0.1       | 3.1        | 8.8       |
| 16      | AK, ID, MT, OR, WA     | 270               | 3,461             | 3.0               | 61.8 | 43.8           | 59.1      | 83.5       | 6.1                | 2.9       | 7.2        | 7.7       |
| 15      | AZ, CO, NV, NM, UT, WY | 294               | 5,519             | 4.7               | 61.3 | 47.0           | 58.3      | 81.5       | 6.8                | 7.5       | 3.8        | 24.5      |
| 7       | FL                     | 317               | 7,523             | 6.4               | 63.8 | 39.9           | 59.4      | 68.1       | 29.2               | 0.2       | 2.3        | 16.8      |
| 2       | NY                     | 323               | 7,005             | 6.0               | 64.0 | 43.9           | 60.0      | 63.5       | 29.5               | 0.2       | 6.4        | 14.5      |
| 5       | MD, DC, VA, WV         | 326               | 6,508             | 5.6               | 62.7 | 37.6           | 57.3      | 52.5       | 43.9               | 0.0       | 3.3        | 2.8       |
| 6       | NC, SC, GA             | 327               | 10,103            | 8.6               | 60.3 | 40.0           | 55.3      | 46.1       | 52.0               | 0.4       | 1.3        | 2.7       |
| 11      | MI, MN, ND, SD, WI     | 335               | 7,329             | 6.3               | 63.5 | 39.2           | 58.4      | 73.4       | 21.5               | 2.5       | 2.4        | 3.3       |
| 12      | IA, KS, MO, NE         | 336               | 4,358             | 3.7               | 63.3 | 41.2           | 56.9      | 77.7       | 20.4               | 0.4       | 1.4        | 4.3       |
| 17      | N. CA, HI, GUAM, AS    | 344               | 5,665             | 4.8               | 62.4 | 50.6           | 57.7      | 56.8       | 11.5               | 0.4       | 30.9       | 20.4      |
| 4       | DE, PA                 | 353               | 5,403             | 4.6               | 64.7 | 41.8           | 58.5      | 74.2       | 24.3               | 0.0       | 1.3        | 3.9       |
| 8       | AL, MS, TN             | 363               | 6,387             | 5.5               | 60.7 | 41.6           | 55.9      | 53.3       | 45.5               | 0.2       | 0.8        | 1.3       |
| 3       | NJ, PR                 | 374               | 5,091             | 4.3               | 64.1 | 48.4           | 59.6      | 72.4       | 23.7               | 0.0       | 3.6        | 36.1      |
| 13      | AR, LA, OK             | 376               | 4,796             | 4.1               | 60.8 | 43.6           | 55.2      | 56.4       | 39.0               | 3.1       | 1.2        | 3.2       |
| 10      | IL                     | 389               | 5,211             | 4.4               | 63.8 | 40.2           | 56.6      | 68.6       | 28.3               | 0.0       | 2.6        | 10.4      |
| 9       | IN, KY, OH             | 390               | 9,119             | 7.8               | 63.5 | 43.8           | 57.9      | 78.6       | 20.5               | 0.0       | 0.8        | 2.2       |
| 14      | TX                     | 436               | 10,336            | 8.8               | 60.4 | 53.3           | 57.0      | 74.5       | 22.8               | 0.1       | 2.4        | 39.9      |
| 18      | S. CA                  | 438               | 9,310             | 7.9               | 63.2 | 48.8           | 58.0      | 74.6       | 11.9               | 0.2       | 13.1       | 41.0      |
|         | All                    | 352               | 117,162           | 100.0             | 62.5 | 43.9           | 57.8      | 67.7       | 26.2               | 0.9       | 4.9        | 14.8      |

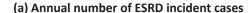
Data Source: Reference Table A.10 and special analyses, USRDS ESRD Database. \*Adjusted for age, sex, race, and ethnicity. The standard population was the U.S. population in 2011. Listed from lowest to highest rate per million/year. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; Hisp, Hispanic; N Am, Native American.

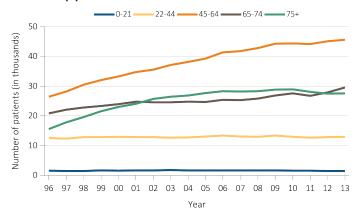
# **INCIDENCE RATE: BY AGE**

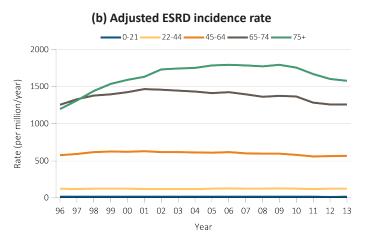
The number of incident ESRD cases per year among those aged o-21 and 22-44 years old has been generally stable for the past two decades (Figure 1.4.a.). By contrast, for ages 45 to 74, the number of incident ESRD cases per year has been rising for the past two decades, and continues to do so. For ages 75 and over, the number of incident ESRD cases had been rising steeply 10 to 20 years ago, but has been generally stable for the past decade.

Across age groups, adjusted ESRD incidence rates have been generally stable or fallen for a decade or more (Figure 1.4.b). Pronounced declines have been seen recently among ages 65 and over: among ages 65-74, the ESRD incidence rate is the lowest since 1996; and among ages 75 and over, the rate is the lowest since 1999.

vol 2 Figure 1.4 Trends in (a) annual number of ESRD incident cases (in thousands), and (b) adjusted\* ESRD incidence rate (per million/year), by age group, in the U.S. population, 1996-2013







Data Source: Reference Table A.1 and special analyses, USRDS ESRD Database. \*Adjusted for sex and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

# **INCIDENCE RATE: BY RACE AND ETHNICITY**

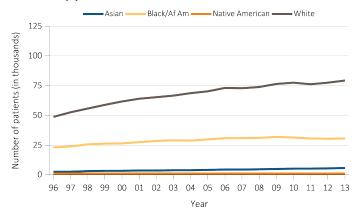
The number of incident ESRD cases per year continues to rise slowly among Whites, although it appears to have plateaued among Blacks and Native Americans (Figure 1.5.a). The number of incident ESRD cases per year had been rising since 1996 across racial groups, but it has plateaued over the past two-to-five years among Whites, Blacks, and Native Americans (Figure 1.5.a). Among Asians, the number of incident ESRD cases appears still to be rising.

The ESRD incidence rates for Blacks, Native Americans, and Asians have declined over the nearly 20-year period shown in Figure 1.5.b. The decline has been greatest (over 2-fold) among Native Americans. Over the same period, the rate initially rose among Whites but has been generally stable since around 2000. The ratio of incidence rates for Blacks versus

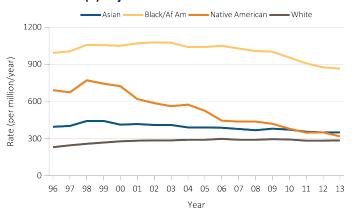
Whites decreased from 3.8 in 2000 to 3.0 in 2013. Similarly, the ratio of incidence rates for Asians versus Whites decreased from 1.5 to 1.2 during the same period; and the ratio of incidence rates for Native Americans versus Whites decreased from 2.6 to 1.1.

vol 2 Figure 1.5 Trends in (a) annual number of ESRD incident cases (in thousands), and (b) adjusted\* ESRD incidence rate (per million/year), by *race*, in the U.S. population, 1996-2013

## (a) Annual number of ESRD incident cases



### (b) Adjusted ESRD incidence rate

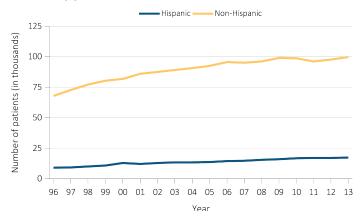


Data Source: Reference Table A.1 and special analyses, USRDS ESRD Database. \*Adjusted for age and sex. The standard population was the U.S. population in 2011. Abbreviations: Af Am, African American; ESRD, end-stage renal disease.

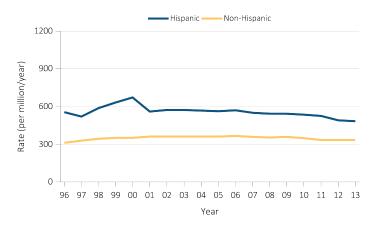
Among both Hispanic and non-Hispanic populations, the number of incident ESRD cases per year had been rising since data were first available in 1996, but this rise has been less evident over the past three to five years (Figure 1.6.a). For both groups, ESRD incidence rates have been stable or somewhat declining since 2001 (Figure 1.6.b). However, the ESRD incidence rate remains nearly 50% higher among Hispanics than non-Hispanics.

vol 2 Figure 1.6 Trends in (a) annual number of ESRD incident cases (in thousands), and (b) adjusted\* ESRD incidence rate (per million/year), by Hispanic ethnicity, in the U.S. population, 1996-2013

# (a) Annual number of ESRD incident cases



# (b) Adjusted ESRD incidence rate



Data Source: Reference Tables A.1, A.2(2). \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

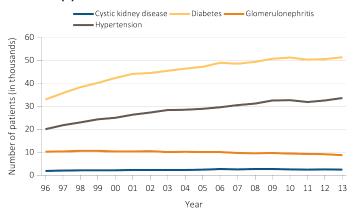
### INCIDENCE RATE: BY PRIMARY CAUSE OF ESRD

The number of incident ESRD cases per year with diabetes or hypertension listed as the primary cause had been rising rapidly, but they have been generally stable over the past five years (Figure 1.7.a). The number with glomerulonephritis listed as the primary cause of ESRD has declined since the 1990s, while the number with cystic kidney disease listed as the primary cause has been generally stable over this period.

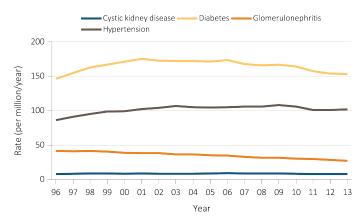
Since 1997, the rate of new ESRD cases with diabetes listed as the primary cause plateaued in 2001 and has declined in most subsequent years, with the lowest rate in 2013 (Figure 1.7.b). The rate with ESRD due to hypertension plateaued in 2003 and has been quite stable since then. The rate due to glomerulonephritis has fallen steadily since the 1990s, while the rate due to cystic disease has remained stable.

vol 2 Figure 1.7 Trends in (a) annual number of ESRD incident cases (in thousands), and (b) adjusted\* ESRD incidence rate (per million/year), by primary cause of ESRD, in the U.S. population, 1996-2013

## (a) Annual number of ESRD incident cases



# (b) Adjusted ESRD incidence rate



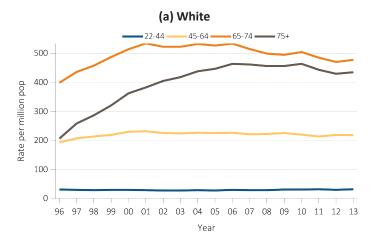
Data Source: Reference Table A.1 and special analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

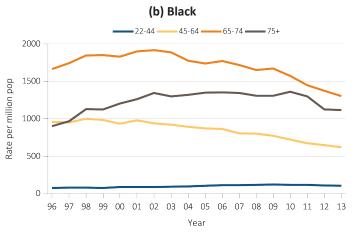
# DIABETES AS PRIMARY CAUSE OF ESRD, BY PATIENT CHARACTERISTICS

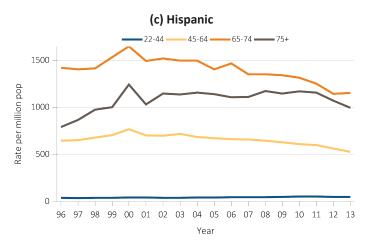
The incidence rate of ESRD due to diabetes as the primary cause is, as expected, higher for ages 65 and older than for younger age groups among Whites (Figure 1.8.a) and Blacks (Figure 1.8.b) and among Hispanics (Figure 1.8.c). Among individuals aged 20-44 years, these rates have been generally stable or slightly increased. In older individuals, rates have declined among White, Black, and Hispanic groups.

Incidence rates of ESRD due to diabetes were severalfold higher in Blacks, compared to Whites, within each age category. These racial differences in the incidence rate of ESRD due to diabetes are generally similar to those seen for overall ESRD incidence rates. Among Hispanics, the incidence rates of ESRD due to diabetes are comparable to Whites aged 22-44 years, but much higher than for Whites aged 44 and over. Across age categories, incidence rates in Hispanics are lower than the rates in Blacks.

vol 2 Figure 1.8 Trends in the sex-adjusted incidence rate (per million/year) of ESRD due to diabetes as the primary cause, by age and race (a & b), and by age and ethnicity (c), in the U.S. population, 1996-2013







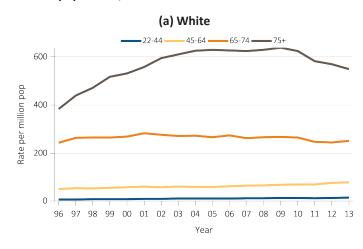
Data Source: Special analyses, USRDS ESRD Database. \*Adjusted for sex. The standard population was the U.S. population in 2011. Abbreviations: ESRD, end-stage renal disease.

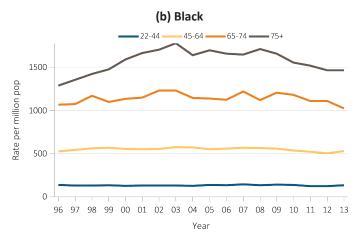
# HYPERTENSION AS PRIMARY CAUSE OF ESRD, BY PATIENT CHARACTERISTICS

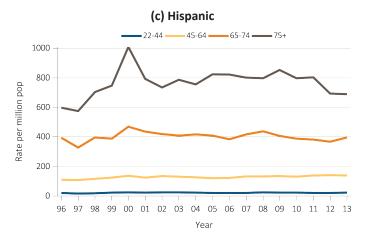
The incidence rate of ESRD with hypertension listed as the primary cause increases with age among White and Black racial groups and among Hispanics (Figure 1.9). In contrast to incidence rates of ESRD with diabetes listed as the primary cause, these rates are substantially higher at age 75 and older than at 65-74 years of age. Rates have been quite stable over the past two decades, with some decline in recent years in older age groups.

Within each age category, the incidence rate of ESRD with hypertension listed as the primary cause is dramatically higher among Blacks than among other racial/ethnic groups. Compared to Whites, incident rates among Blacks in 2013 were over 10-fold higher in younger age categories, 4-fold higher at ages 65-74, and nearly 3-fold higher at age 75 and over.

vol 2 Figure 1.9 Trends in the sex-adjusted incidence rate (per million/year) of ESRD due to hypertension as the primary cause, by (a & b) age and race, and by (c) age and ethnicity, in the U.S. population, 1996-2013







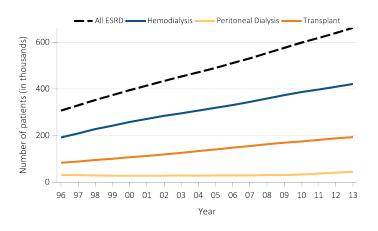
Data Source: Special analyses, USRDS ESRD Database. \*Adjusted for sex. The standard population was the U.S. population in 2011. Abbreviations: ESRD, end-stage renal disease.

# PREVALENCE OF ESRD: COUNTS, PREVALENCE, AND TRENDS

### **Overall Prevalence**

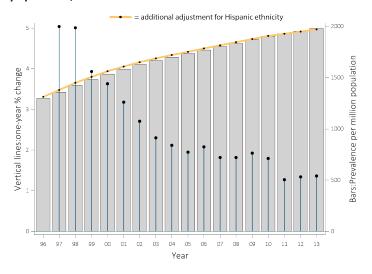
On December 31, 2013, there were 661,648 prevalent cases of ESRD in the United States, an increase of 3.5% since 2012 and an increase of 68% since 2000 (Figure 1.10). The ESRD prevalence reached 1,981 per million (~0.20%), an increase of 1.4% since 2012 and an increase of 29% since 2000 (Figure 1.11). The size of the prevalent dialysis population (hemodialysis and peritoneal dialysis) increased 4% in 2013, reaching 466,607, and is now 63.2% larger than in 2000. The size of the transplant population rose 3.1% in 2013 to 193,262 patients and is now 81.0% larger than in 2000.

vol 2 Figure 1.10 Trends in the number of ESRD prevalent cases (in thousands) by modality, in the U.S. population, 1996-2013



Data Source: Reference Table D.1. Abbreviation: ESRD, end-stage renal disease.

vol 2 Figure 1.11 Trends in the adjusted\* ESRD prevalence (per million) (bars; scale on left), and annual change (%) in adjusted\* prevalence of ESRD (lines; scale on right), in the U.S. population, 1996-2013



Data Source: Reference Table B.2(2) and special analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

# PREVALENCE: BY REGION

There was a 2-fold variation in dialysis prevalence among the 18 ESRD Networks, from a low of 944 per million in Network 16 to a high of 1,855 per million in Network 8 (Table 1.2). Among prevalent dialysis cases, mean age varied by nearly 5 years, from 54.8 years in Network 6 to 59.2 years in Network 1. The distribution of patients by race continues to vary widely across Networks. Blacks/African Americans, for example, constitute just 8.4% percent of the prevalent dialysis population in Network 16 but 65.7% of patients in Network 6. This variability probably reflects, to some extent but not entirely, the racial/ethnic distributions of the network populations.

vol 2 Table 1.2 Adjusted\* prevalence (per million) of dialysis in the U.S. population, and distribution (%) of age, diabetes, sex, race, and ethnicity among prevalent dialysis patients, by ESRD Network, 2013

|         |                        |                              | Total no.                      | % of                           |             |               |           |            | Race               | е      | -          | Ethnicity |
|---------|------------------------|------------------------------|--------------------------------|--------------------------------|-------------|---------------|-----------|------------|--------------------|--------|------------|-----------|
| Network | States in network      | Prevalence<br>per<br>million | prevalent<br>dialysis<br>cases | prevalent<br>dialysis<br>cases | Mean<br>age | %<br>Diabetic | %<br>Male | %<br>White | % Black /<br>Af Am | % N Am | %<br>Asian | %<br>Hisp |
| 16      | AK, ID, MT, OR, WA     | 944                          | 13,373                         | 2.9                            | 56.5        | 43.1          | 57.1      | 79.1       | 8.4                | 3.2    | 9.1        | 11.2      |
| 1       | CT, MA, ME, NH, RI VT  | 982                          | 14,042                         | 3.0                            | 59.2        | 39.9          | 58.2      | 75.3       | 20.6               | 0.2    | 3.5        | 12.0      |
| 15      | AZ, CO, NV, NM, UT, WY | 1,095                        | 22,233                         | 4.7                            | 56.6        | 50.6          | 57.3      | 73.8       | 10.1               | 11.5   | 4.5        | 31.0      |
| 12      | IA, KS, MO, NE         | 1,128                        | 15,683                         | 3.3                            | 57.7        | 40.7          | 56.4      | 68.7       | 29.0               | 0.6    | 1.6        | 5.8       |
| 11      | MI, MN, ND, SD, WI     | 1,188                        | 27,191                         | 5.8                            | 58.0        | 40.9          | 56.7      | 63.0       | 31.0               | 2.8    | 3.1        | 4.7       |
| 9       | IN, KY, OH             | 1,415                        | 32,196                         | 6.9                            | 57.6        | 43.7          | 56.2      | 66.3       | 32.6               | 0.1    | 0.9        | 2.9       |
| 4       | DE, PA                 | 1,420                        | 19,325                         | 4.1                            | 58.6        | 40.5          | 57.7      | 63.4       | 34.7               | 0.1    | 1.7        | 5.2       |
| 7       | FL                     | 1,434                        | 28,218                         | 6.0                            | 57.9        | 39.8          | 57.6      | 57.3       | 40.1               | 0.2    | 2.2        | 17.6      |
| 2       | NY                     | 1,485                        | 29,272                         | 6.2                            | 58.1        | 40.7          | 57.5      | 53.4       | 38.1               | 0.4    | 7.1        | 16.4      |
| 10      | IL                     | 1,555                        | 19,987                         | 4.3                            | 57.5        | 38.8          | 56.2      | 56.9       | 39.3               | 0.0    | 3.5        | 14.8      |
| 5       | MD, DC, VA, WV         | 1,588                        | 26,760                         | 5.7                            | 56.6        | 38.1          | 56.0      | 39.2       | 57.3               | 0.1    | 3.3        | 4.1       |
| 17      | N. CA, HI, GUAM, AS    | 1,607                        | 26,043                         | 5.6                            | 57.0        | 49.3          | 55.6      | 51.7       | 14.1               | 0.6    | 33.1       | 25.0      |
| 13      | AR, LA, OK             | 1,620                        | 18,543                         | 4.0                            | 55.0        | 42.3          | 53.8      | 43.4       | 51.4               | 3.8    | 1.3        | 3.9       |
| 14      | TX                     | 1,656                        | 44,189                         | 9.4                            | 55.2        | 52.8          | 54.8      | 68.9       | 28.5               | 0.1    | 2.4        | 45.2      |
| 18      | S. CA                  | 1,672                        | 40,522                         | 8.7                            | 57.0        | 48.8          | 57.9      | 70.9       | 14.7               | 0.3    | 13.8       | 48.1      |
| 3       | NJ, PR                 | 1,674                        | 19,203                         | 4.1                            | 58.7        | 46.7          | 59.2      | 64.3       | 30.9               | 0.0    | 3.6        | 38.2      |
| 6       | NC, SC, GA             | 1,780                        | 44,475                         | 9.5                            | 54.8        | 39.3          | 54.5      | 32.5       | 65.7               | 0.5    | 1.3        | 3.0       |
| 8       | AL, MS, TN             | 1,855                        | 26,114                         | 5.6                            | 55.1        | 40.5          | 54.2      | 38.2       | 60.6               | 0.3    | 0.8        | 1.3       |
|         | All                    | 1,425                        | 468,386                        | 100.0                          | 56.9        | 43.6          | 56.3      | 57.8       | 35.2               | 1.2    | 5.5        | 17.9      |

Data Source: Special analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Listed from lowest to highest prevalence per million. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; Hisp, Hispanic; N Am, Native American.

The adjusted prevalence of kidney transplant patients varied by nearly 45% among the ESRD Networks, from 512 per million in Network 13 and 14 to 737 per million in Network 11 (Table 1.3) Differences in the racial/ethnic distribution between transplant and dialysis patients by ESRD Network raise the possibility of disparities in access to kidney transplants or transplant care. For example, Blacks account for 65.7% of prevalent dialysis patients, but only 41.2% of prevalent transplant patients in Network 6.

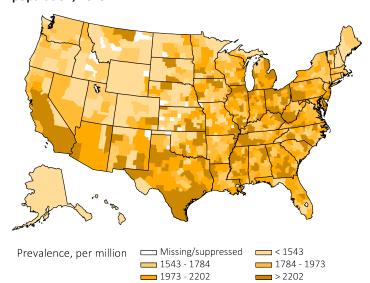
vol 2 Table 1.3 Adjusted\* prevalence (per million) of kidney transplant patients in the U.S. population, and distribution (%) of age, diabetes, sex, race, and ethnicity among prevalent transplant patients, by ESRD Network, 2013

|         |                        |                           | Total no.                                  | % of                                       |             |               |           |            | Race               |           |            | Ethnicity |
|---------|------------------------|---------------------------|--|--|-------------|---------------|-----------|------------|--------------------|-----------|------------|-----------|
| Network | States in network      | Prevalence<br>per million | prevalent<br>kidney<br>transplant<br>cases | prevalent<br>kidney<br>transplant<br>cases | Mean<br>age | %<br>Diabetic | %<br>Male | %<br>White | % Black /<br>Af Am | % N<br>Am | %<br>Asian | % Hisp    |
| 13      | AR, LA, OK             | 512                       | 5,779                                      | 3.0  | 41.4        | 23.6          | 60.2      | 65.5       | 30.1               | 2.2       | 2.0        | 3.6       |
| 14      | TX                     | 512                       | 13,553                                     | 7.0  | 40.7        | 25.4          | 58.3      | 77.7       | 18.0               | 0.2       | 3.7        | 37.8      |
| 18      | S. CA                  | 521                       | 12,319                                     | 6.4  | 40.3        | 20.8          | 59.0      | 75.7       | 10.4               | 0.3       | 13.0       | 41.1      |
| 6       | NC, SC, GA             | 522                       | 13,061                                     | 6.8  | 41.8        | 21.8          | 58.4      | 55.2       | 41.2               | 0.7       | 2.2        | 3.2       |
| 7       | FL                     | 535                       | 10,578                                     | 5.5  | 43.9        | 21.3          | 59.1      | 72.1       | 23.1               | 0.3       | 3.6        | 19.5      |
| 16      | AK, ID, MT, OR, WA     | 539                       | 7,664                                      | 4.0  | 42.1        | 23.0          | 58.9      | 83.8       | 5.3                | 1.6       | 8.7        | 7.5       |
| 15      | AZ, CO, NV, NM, UT, WY | 552                       | 11,101                                     | 5.7  | 42.5        | 28.4          | 58.8      | 84.4       | 5.7                | 5.1       | 4.4        | 23.6      |
| 8       | AL, MS, TN             | 571                       | 8,099                                      | 4.2  | 40.7        | 20.8          | 59.8      | 60.5       | 37.8               | 0.1       | 1.3        | 1.6       |
| 9       | IN, KY, OH             | 579                       | 13,151                                     | 6.8  | 41.9        | 24.0          | 60.5      | 80.2       | 17.7               | 0.1       | 1.4        | 2.6       |
| 1       | CT, MA, ME, NH, RI VT  | 599                       | 8,737                                      | 4.5  | 42.6        | 20.2          | 61.1      | 83.4       | 11.5               | 0.3       | 3.6        | 8.5       |
| 2       | NY                     | 618                       | 12,519                                     | 6.5  | 42.7        | 21.1          | 59.5      | 65.8       | 23.5               | 0.7       | 7.0        | 18.5      |
| 12      | IA, KS, MO, NE         | 618                       | 8,547                                      | 4.4  | 42.0        | 23.0          | 60.6      | 83.2       | 13.9               | 0.4       | 2.1        | 5.2       |
| 17      | N. CA, HI, GUAM, AS    | 652                       | 10,489                                     | 5.4  | 41.8        | 22.1          | 58.9      | 63.5       | 9.2                | 0.6       | 24.6       | 24.9      |
| 4       | DE, PA                 | 662                       | 9,049                                      | 4.7  | 43.3        | 22.6          | 60.2      | 75.4       | 21.1               | 0.2       | 2.5        | 4.3       |
| 3       | NJ, PR                 | 666                       | 7,527                                      | 3.9  | 43.1        | 23.7          | 62.0      | 65.3       | 20.4               | 0.2       | 5.6        | 29.7      |
| 5       | MD, DC, VA, WV         | 667                       | 11,098                                     | 5.7  | 43.1        | 21.9          | 59.4      | 55.6       | 38.6               | 0.2       | 4.9        | 4.7       |
| 10      | IL                     | 725                       | 9,317                                      | 4.8  | 42.0        | 23.2          | 59.5      | 71.0       | 23.0               | 0.3       | 4.3        | 14.9      |
| 11      | MI, MN, ND, SD, WI     | 737                       | 16,706                                     | 8.6  | 42.5        | 25.6          | 60.6      | 80.2       | 14.2               | 1.8       | 3.5        | 3.4       |
|         | All                    | 582                       | 193,262                                    | 100.0                                      | 42.0        | 22.6          | 59.7      | 71.3       | 19.8               | 0.9       | 5.8        | 14.5      |

Data Source: Special analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Listed from lowest to highest prevalence per million. Abbreviations: Af Am, African American; ESRD, end-stage renal disease; Hisp, Hispanic; N Am, Native American.

The adjusted prevalence of ESRD in 2013 ranged across 786 Health Service Areas from a low of 533 per million to a high of 7,717 per million (interquartile range: 1,640 to 2,217 per million) (Figure 1.12). ESRD prevalence in 2013 was generally highest in parts of the Ohio and Mississippi River valleys, the Southeast, Texas, and California, and was lowest in New England, the Northwest, and certain Upper Midwest and Rocky Mountain regions. These patterns were roughly similar to patterns of ESRD incidence shown earlier in this chapter in Figure 1.3.

vol 2 Figure 1.12 Map of the adjusted\* prevalence (per million) of ESRD, by Health Service Area, in the U.S. population, 2013\*\*



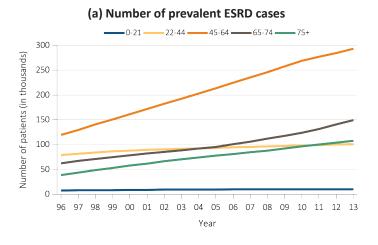
Data Source: Special analyses, USRDS ESRD Database. \*Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. \*\*Three Health Service Areas were suppressed because the ratio of unadjusted rate to adjusted rate or adjusted rate to unadjusted rate was greater than 3. Abbreviation: ESRD, end-stage renal disease.

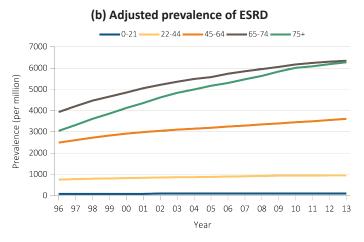
# PREVALENCE: BY AGE

The number of prevalent ESRD cases continues to increase in all age groups, except among patients aged o-21 years, with a steeper increase among patients aged 45-64 years (Figure 1.13.a). With the recent leveling off of the number of incident ESRD cases, the continuing rise in ESRD prevalence is due largely to longer survival among ESRD patients in recent years.

In 2013, the adjusted prevalence of ESRD per million was 104 for ages 0-21, 959 for ages 22-44, 3,624 for ages 45-64, 6,347 for ages 65-74, and 6,275 for ages 75 and over (Figure 1.13.b).

vol 2 Figure 1.13 Trends in (a) number of prevalent ESRD cases (in thousands) and (b) the adjusted\* prevalence (per million) of ESRD, by age group, in the U.S. population, 1996-2013



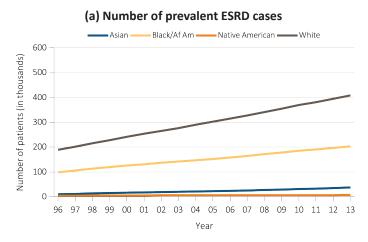


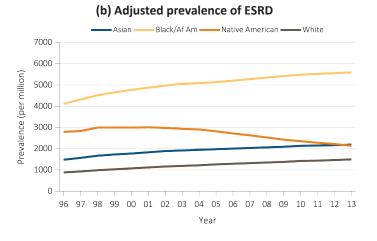
Data Source: Reference Table B.1 and special analyses, USRDS ESRD Database. \*Point prevalence on December 31 of each year. Adjusted for sex and race. The standard population was the U.S. population in 2011. Abbreviations: ESRD, end-stage renal disease.

# PREVALENCE: BY RACE AND ETHNICITY

The number of prevalent ESRD cases, as well as adjusted prevalence, continues to rise among Whites, Blacks, and Asian Americans (Figure 1.14.a and b). However, the remarkable decline in incidence rates among Native Americans has resulted in a 29% decline in the prevalence of ESRD in this population since 2000. This represents the only instance, since the beginning of ESRD care in 1973, of a decline in adjusted prevalence for a major racial group. In 2013, the prevalence per million was 5,584 among Black/African Americans, 2,133 among Native Americans, 2,196 among Asians, and 1,499 among Whites (Figure 1.14.b). The prevalence per million remains much higher in Blacks than in other racial groups, at nearly 2.6-fold higher than Native Americans and Asians, and nearly 4-fold higher than Whites.

vol 2 Figure 1.14 Trends in (a) number of prevalent ESRD cases (in thousands) and (b) the adjusted\* prevalence (per million) of ESRD, by race, in the U.S. population, 1996-2013

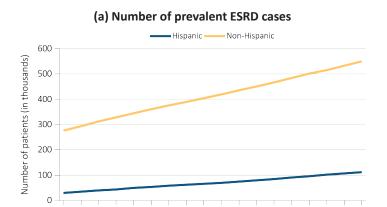




Data Source: Reference Table B.1 and special analyses, USRDS ESRD Database. \*Point prevalence on December 31 of each year. Adjusted for age and sex. The standard population was the U.S. population in 2011. Abbreviations: Af Am, African American; ESRD, end-stage renal disease.

The number of prevalent ESRD cases, as well as adjusted prevalence, has continued to rise for both non-Hispanics and Hispanics (Figure 1.15). In 2013, the adjusted prevalence was 1,838 per million among non-Hispanics and nearly 62% higher, at 2,970 per million, among Hispanics.

vol 2 Figure 1.15 Trends in (a) number of prevalent ESRD cases (in thousands) and (b) the adjusted\* prevalence (per million) of ESRD, by Hispanic ethnicity, in the U.S. population, 1996-2013



98 99 00 01 02 03 04 05 06 07 08 09 10 11 12 13

# (b) Adjusted prevalence of ESRD Hispanic Non-Hispanic 7000 4000 2000 1000 96 97 98 99 00 01 02 03 04 05 06 07 08 09 10 11 12 13 Year

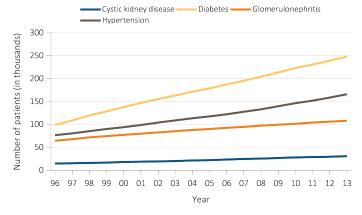
Data Source: Reference Tables B.1, B.2(2). \*Point prevalence on December 31 of each year. Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

# **PREVALENCE: BY PRIMARY CAUSE OF ESRD**

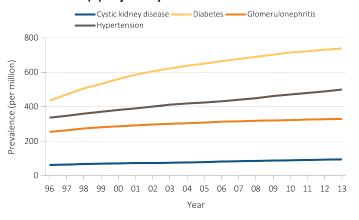
The number of prevalent ESRD cases with diabetes, hypertension, glomerulonephritis, or cystic kidney disease listed as the primary cause has continued to rise since 1996 (Figure 1.16.a), despite the recent stabilization of incidence rates. The prevalence also continues to rise for these causes of ESRD (Figure 1.16.b). For diabetes as the primary cause, the increase in prevalence was slower over approximately the last decade than it had been previously.

vol 2 Figure 1.16 Trends in (a) number of prevalent ESRD cases (in thousands) and (b) adjusted\* prevalence (per million) of ESRD, by primary cause of ESRD, in the U.S. population, 1996-2013





## (b) Adjusted prevalence of ESRD



Data Source: Reference Table B.1 and special analyses, USRDS ESRD Database. \*Point prevalence on December 31 of each year. Adjusted for age, sex, and race. The standard population was the U.S. population in 2011. Abbreviation: ESRD, end-stage renal disease.

# Patient and Treatment Characteristics at ESRD Onset

# **PRE-ESRD CARE**

Twenty-five (25) percent of patients starting ESRD therapy in 2013 were reported on CMS Form 2728 as not having received nephrology care prior to ESRD start (Table 1.4). This reflects little decline from 26% in 2012. An additional 13% had unknown duration of pre-ESRD nephrology care. Because treatment characteristics (e.g., ESA use and dietary care) for this group were similar to those for no pre-ESRD nephrology care, one may assume that up to 38% of new ESRD cases received little or no pre-ESRD nephrology care (Table 1.4.a).

Several differences are notable in the distributions of

pre-ESRD nephrology care by patient characteristics. Young patients (0-21) were most likely (43%), and adults aged 22-64 years were least likely (27%), to have had longer duration (12 months or more) of pre-ESRD nephrology care. African Americans were somewhat less likely to have had pre-ESRD care than were other racial groups, and Hispanics were less likely to have had pre-ESRD care than were non-Hispanics.

ESRD patients with a primary etiologic diagnosis of glomerulonephritis or cystic kidney disease were more likely to have had pre-ESRD nephrology care than were patients with a diagnosis of diabetes or hypertension. Having no nephrology care was most common for patients with hypertension as the primary cause of ESRD; one could surmise that some patients initially presenting at, or near, ESRD might be assigned this diagnosis in the absence of evidence of other possible etiologies.

Patients receiving longer pre-ESRD nephrology care were relatively more likely to use an ESA before ESRD, receive dietary care before ESRD, and start dialysis with an arteriovenous fistula (AV) fistula rather than a central venous catheter (Table 1.4.b). Patients receiving longer pre-ESRD nephrology care were less likely to start dialysis at either very low eGFR levels (<5 ml/min/1.73 m²) or very high (≥15 ml/min/1.73 m²)eGFR levels.

vol 2 Table 1.4 Distribution (%) of the reported duration of pre-ESRD nephrology care, by (a) demographic and (b) clinical characteristics, among incident ESRD cases in the U.S. population, 2013

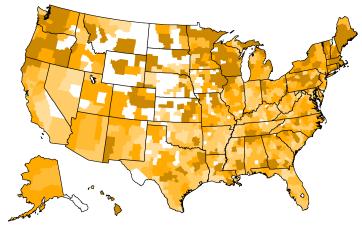
|                    | (a) Demogr | aphic charact | eristics (% wit | hin row) |      |         |
|--------------------|------------|---------------|-----------------|----------|------|---------|
|                    | n          | >12 mo.       | 6-12 mo.        | 0-6 mo.  | None | Unknown |
| Total              | 114,417    | 30.0          | 18.6            | 13.2     | 25.3 | 12.6    |
| Age                |            |               |                 |          |      |         |
| 0-21               | 1,550      | 42.8          | 14.6            | 14.2     | 21.9 | 6.3     |
| 22-44              | 12,946     | 26.7          | 16.9            | 13.6     | 31.1 | 11.5    |
| 45-64              | 44,268     | 27.9          | 18.6            | 13.5     | 27.3 | 12.4    |
| 65-74              | 28,554     | 31.8          | 19.5            | 13.1     | 22.5 | 12.7    |
| 75+                | 27,099     | 32.4          | 18.6            | 12.7     | 22.3 | 13.7    |
| Sex                |            |               |                 |          |      |         |
| Female             | 48,833     | 30.1          | 18.8            | 13.3     | 24.6 | 12.9    |
| Male               | 65,584     | 30.0          | 18.5            | 13.2     | 25.7 | 12.4    |
| Race               |            |               |                 |          |      |         |
| Native American    | 1,147      | 28.2          | 20.3            | 17.0     | 26.1 | 8.4     |
| Asian              | 5,785      | 30.1          | 19.9            | 13.8     | 22.7 | 13.2    |
| Black              | 31,202     | 25.9          | 18.5            | 12.9     | 28.0 | 14.5    |
| White              | 76,271     | 31.8          | 18.6            | 13.3     | 24.3 | 11.9    |
| Other/Unknown      | 12         | *             | *               | *        | *    | *       |
| Ethnicity          |            |               |                 |          |      |         |
| Non-Hispanic       | 98,367     | 31.2          | 18.7            | 13.2     | 24.4 | 12.2    |
| Hispanic           | 16,050     | 23.1          | 17.9            | 13.8     | 30.2 | 14.9    |
| Primary Diagnosis  |            |               |                 |          |      |         |
| Diabetes           | 52,354     | 30.9          | 20.7            | 13.7     | 22.2 | 12.3    |
| Hypertension       | 34,104     | 26.6          | 18.2            | 13.1     | 26.8 | 15.2    |
| Glomerulonephritis | 9,016      | 39.8          | 17.5            | 12.7     | 22.5 | 7.4     |
| Cystic kidney      | 2,557      | 57.9          | 16.5            | 9.8      | 9.5  | 6.0     |
| Other/Unknown      | 16,386     | 24.5          | 13.6            | 12.8     | 35.8 | 12.3    |

| (b                              | ) Clinical cha | racteristics ( | % within col | umn)    |       |         |
|---------------------------------|----------------|----------------|--------------|---------|-------|---------|
|                                 | n              | >12 mo.        | 6-12 mo.     | 0-6 mo. | None  | Unknown |
| Total                           | 114,417        | 100.0          | 100.0        | 100.0   | 100.0 | 100.0   |
| Dietary care                    |                |                |              |         |       |         |
| No                              | 105,311        | 85.7           | 89.2         | 88.3    | 99.7  | 99.8    |
| Yes                             | 9,106          | 14.3           | 10.8         | 11.7    | 0.3   | 0.2     |
| ESA use                         |                |                |              |         |       |         |
| No                              | 96,661         | 72.0           | 78.9         | 80.6    | 98.2  | 98.9    |
| Yes                             | 17,756         | 28.0           | 21.1         | 19.4    | 1.8   | 1.1     |
| eGFR at RRT start               |                |                |              |         |       |         |
| <5                              | 15,660         | 11.1           | 11.5         | 12.4    | 19.0  | 13.7    |
| 5-<10                           | 52,610         | 48.8           | 47.6         | 45.8    | 43.2  | 42.9    |
| 10-<15                          | 31,548         | 29.2           | 29.4         | 29.1    | 24.0  | 26.7    |
| ≥15                             | 14,436         | 10.8           | 11.5         | 12.7    | 13.6  | 16.5    |
| Vascular Access                 |                |                |              |         |       |         |
| AV fistula                      | 17,115         | 26.9           | 20.1         | 11.2    | 2.5   | 8.1     |
| AV graft                        | 2,884          | 3.7            | 3.2          | 2.4     | 1.0   | 1.8     |
| CV Catheter only                | 60,908         | 32.2           | 41.6         | 55.4    | 77.4  | 70.3    |
| CVC with maturing fistula/graft | 20,233         | 18.1           | 20.7         | 19.3    | 15.2  | 15.6    |
| Other/Unknown                   | 13,277         | 19.1           | 14.4         | 11.7    | 3.8   | 4.2     |

Data Source: Special analyses, USRDS ESRD Database. Population only includes incident cases with CMS form 2728. \*Count  $\leq$ 10. eGFR calculated using the CKD-EPI equation (CKD-EPI eGFR ( $ml/min/1.73 m^2$ ) for those aged  $\geq$ 18 years and the Schwartz equation for those aged <18 years. Abbreviations: CKD-EPI, chronic kidney disease epidemiology calculation; eGFR, estimated glomerular filtration rate; ESA, erythropoiesis-stimulating agents; RRT, renal replacement therapy.

The proportion of incident ESRD cases in 2013 with >12 months of pre-ESRD nephrology care was 30% in the US; it varied substantially across 677 Health Services Areas, ranging from a low of 0% to a high of 75% (interquartile range: 24 to 42%) (Figure 1.17). Health Service Areas with the greatest proportions of patients with >12 months of pre-ESRD care were clustered in the Northeast, Upper Midwest, and Northwest, where over 40 percent of patients were under a nephrologists care for more than one year prior to ESRD.

vol 2 Figure 1.17 Percent of incident cases who had received >12 months of pre-ESRD nephrology care, by Health Service Area, 2013

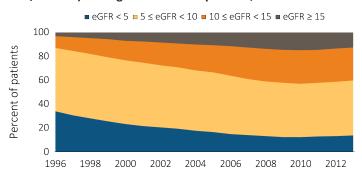


Data Source: Special analyses, USRDS ESRD Database. Population only includes incident cases with CMS form 2728. Abbreviations: ESRD, endstage renal disease; Neph., nephrology.

# **EGFR AT ESRD ONSET**

Figure 1.18 shows that the percentage of incident ESRD cases who were initiated on renal replacement therapy at higher eGFR levels increased steadily from 1996 until 2009, but has been stable or decreased slightly from 2010 to 2013. For example, the percent of incident ESRD cases who started with eGFR at ≥10 ml/min/1.73 m² rose from 12.9% in 1996 to 43.0% in 2010, but decreased to 40.2% in 2013. In parallel, the percent of incident ESRD cases who started therapy at eGFR <5 ml/min/1.73 m² decreased from 33.9% in 1996 to 12.4% in 2010, then increased to 13.7% in 2013.

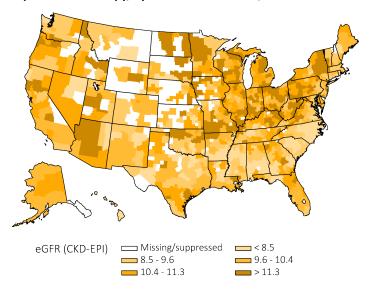
vol 2 Figure 1.18 Trends in the distribution (%) of eGFR (ml/min/1.73 m²) among incident ESRD patients, 1996-2013



Data Source: Special analyses, USRDS ESRD Database. Population only includes incident cases with CMS form 2728. eGFR calculated using the CKD-EPI equation (CKD-EPI eGFR ( $ml/min/1.73\ m^2$ ) for those aged  $\geq 18$  and the Schwartz equation for those aged < 18. Abbreviations: CKD-EPI; chronic kidney disease epidemiology calculation; eGFR, estimated glomerular filtration rate; ESRD, end-stage renal disease.

Mean eGFR at ESRD start was higher among young patients (o-21), males, White, non-Hispanic, or with diabetes as the primary cause of ESRD (Table 1.5). Mean eGFR at ESRD start in 2013 varied substantially by Health Service Area (Figure 1.19). Perhaps the most striking geographic patterns are the prominence of Health Service Areas with higher average eGFRs at initiation of ESRD in the North and Midwest regions and Health Service Areas with lower average eGFRs at ESRD start in the South. Regional variation in eGFR at initiation does not seem to be related to length of time with pre-ESRD nephrology care (Table 1.6).

vol 2 Figure 1.19 Map of average eGFR at initiation of renal replacement therapy, by Health Service Area, 2013



Data Source: Special analyses, USRDS ESRD Database. Population only includes incident cases with CMS form 2728. eGFR calculated using the CKD-EPI equation (CKD-EPI eGFR (ml/min/1.73  $m^2$ ) for those aged  $\geq$ 18 and the Schwartz equation for those aged <18. Abbreviations: eGFR, estimated glomerular filtration rate; CKD-EPI, chronic kidney disease epidemiology calculation.

# **ANEMIA AT ESRD ONSET**

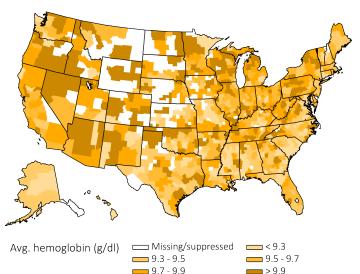
The overall mean hemoglobin level at ESRD onset in 2013 was 9.6 g/dL. Incident ESRD cases with cystic kidney disease as the primary cause had higher mean hemoglobin levels at ESRD onset than did other ESRD cases (Table 1.5). Figure 1.20 shows the distribution of mean hemoglobin levels by Health Service Area across the United States. There appears to be large Health Service Areas with higher average hemoglobin levels in the western half of the U.S., especially in the Rocky Mountain areas, with smaller areas of the higher hemoglobin at start of ESRD across the rest of the country.

vol 2 Table 1.5 Distributions of laboratory values (mean) and treatment characteristics (%), by age, sex, race, ethnicity, and primary cause of ESRD, among incident ESRD cases, 2013

|                       | •CED                          | Α                          | nemia               | Nutrit               | ion            | Lipids                       |                | Diabetes  |
|-----------------------|-------------------------------|----------------------------|---------------------|----------------------|----------------|------------------------------|----------------|-----------|
|                       | eGFR<br>(ml/min /<br>1.73 m²) | Serum<br>albumin<br>(g/dL) | Dietary Care<br>(%) | Hemoglobin<br>(g/dL) | ESA Use<br>(%) | Total Cholesterol<br>(mg/dL) | LDL<br>(mg/dL) | HbA1c (%) |
| Age                   |                               |                            |                     |                      |                |                              |                |           |
| 0-21                  | 13.15                         | 3.4                        | 36.4                | 9.7                  | 27.6           | 184                          | 107.1          | 5.35      |
| 22-44                 | 9.48                          | 3.2                        | 7.2                 | 9.5                  | 10.9           | 173                          | 102.1          | 6.95      |
| 45-64                 | 10.12                         | 3.2                        | 7.8                 | 9.6                  | 12.7           | 161                          | 93.0           | 6.85      |
| 65-74                 | 10.44                         | 3.3                        | 7.8                 | 9.7                  | 15.9           | 147                          | 81.8           | 6.68      |
| 75+                   | 10.54                         | 3.3                        | 6.9                 | 9.7                  | 17.4           | 142                          | 77.9           | 6.46      |
| Sex                   |                               |                            |                     |                      |                |                              |                |           |
| Male                  | 10.59                         | 3.3                        | 8.1                 | 9.7                  | 13.4           | 149                          | 85.0           | 6.69      |
| Female                | 9.84                          | 3.2                        | 7.5                 | 9.5                  | 16.3           | 165                          | 92.9           | 6.79      |
| Race                  |                               |                            |                     |                      |                |                              |                |           |
| White                 | 10.53                         | 3.3                        | 8.2                 | 9.7                  | 14.9           | 152                          | 85.9           | 6.76      |
| Black                 | 9.84                          | 3.2                        | 6.5                 | 9.3                  | 13.1           | 162                          | 94.5           | 6.67      |
| Native American       | 9.77                          | 2.8                        | 7.7                 | 9.5                  | 15.1           | 152                          | 81.8           | 6.83      |
| Asian                 | 8.95                          | 3.4                        | 10.7                | 9.6                  | 19.7           | 160                          | 88.7           | 6.68      |
| Ethnicity             |                               |                            |                     |                      |                |                              |                |           |
| Hispanic              | 9.75                          | 3.2                        | 7.3                 | 9.5                  | 12.6           | 157                          | 88.2           | 6.83      |
| Non-Hispanic          | 10.35                         | 3.3                        | 7.9                 | 9.7                  | 15.0           | 155                          | 88.2           | 6.71      |
| Primary Cause of ESRD |                               |                            |                     |                      |                |                              |                |           |
| Diabetes              | 10.47                         | 3.2                        | 7.6                 | 9.6                  | 16.6           | 153                          | 86.7           | 7.05      |
| Hypertension          | 9.80                          | 3.3                        | 6.0                 | 9.6                  | 12.8           | 153                          | 87.8           | 6.20      |
| Glomerulonephritis    | 9.37                          | 3.3                        | 12.3                | 9.6                  | 19.5           | 176                          | 101.3          | 5.76      |
| Cystic kidney         | 9.48                          | 3.8                        | 15.8                | 11.1                 | 16.1           | 164                          | 94.0           | 5.72      |
| All                   | 10.27                         | 3.3                        | 7.9                 | 9.6                  | 14.6           | 155                          | 88.2           | 6.73      |

Data Source: Special analyses, USRDS ESRD Database. Population only includes incident cases with CMS form 2728. eGFR calculated using the CKD-EPI equation (CKD-EPI eGFR ( $mI/min/1.73 \text{ m}^2$ ) for those aged  $\geq 18$  years and the Schwartz equation for those aged < 18 years. Abbreviations: CKD-EPI; chronic kidney disease epidemiology calculation; eGFR, estimated glomerular filtration rate; ESA, erythropoiesisstimulating agents; ESRD, end-stage renal disease; HbA1c, glycosylated hemoglobin; Hgb, hemoglobin; LDL, low-density lipoprotein.

vol 2 Figure 1.20 Map of average hemoglobin level at initiation of renal replacement therapy, by Health Service Area, 2013



Data Source: Special analyses, USRDS ESRD Database. Population only includes incident cases with CMS form 2728. Abbreviation: ESRD, endstage renal disease.

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# **VARIATION IN TREATMENT CHARACTERISTICS BY ESRD NETWORK**

Geographic variation in pre-ESRD care is also evident by ESRD Network. Most pronounced was over 2-fold variation in the percentage of incident ESRD cases with pre-ESRD nephrology care >12 months, ranging from 19% in Network 18 to 45% in Network 1. Mean eGFR at ESRD start ranged from 9.0 ml/min/1.73 m<sup>2</sup> in Network 6 to 10.8 ml/min/1.73 m<sup>2</sup> in Networks 9. Mean Hgb at dialysis start was 9.4 to 9.9 g/dL in 16 of 18 Networks, but >10 g/dL in Networks 15 and 16, which include states at higher elevations (Table 1.6).

vol 2 Table 1.6 Distribution (%) of mean duration of pre-ESRD nephrology care, mean hemoglobin level, eGFR, by ESRD Network, among incident ESRD cases, 2013

|         |                        |               |                | duration of one of the control of th |      |         | eGFR                              | Hgb    |
|---------|------------------------|---------------|----------------|--|------|---------|-----------------------------------|--------|
| Network | States in network      | >12<br>months | 6-12<br>months | 0-6<br>months  | None | Unknown | (ml/min/<br>1.73 m <sup>2</sup> ) | (g/dL) |
| 18      | S. CA                  | 18.7          | 16.0           | 17.2   | 25.2 | 22.9    | 10.4                              | 9.8    |
| 10      | IL                     | 24.1          | 17.2           | 13.1   | 22.7 | 22.8    | 10.3                              | 9.7    |
| 14      | TX                     | 25.2          | 18.5           | 13.3   | 30.5 | 12.5    | 9.5                               | 9.4    |
| 13      | AR, LA, OK             | 25.6          | 20.1           | 11.9   | 28.4 | 14.0    | 9.7                               | 9.6    |
| 5       | MD, DC, VA, WV         | 25.8          | 21.7           | 13.3   | 26.7 | 12.4    | 9.7                               | 9.4    |
| 7       | FL                     | 26.8          | 17.7           | 12.7   | 29.0 | 13.8    | 10.1                              | 9.6    |
| 3       | NJ, PR                 | 28.6          | 19.2           | 9.4  | 35.6 | 7.2     | 9.8                               | 9.7    |
| 9       | IN, KY, OH             | 29.4          | 21.1           | 11.9   | 21.9 | 15.7    | 10.8                              | 9.6    |
| 17      | N. CA, HI, GUAM, AS    | 29.6          | 19.6           | 15.7   | 21.9 | 13.2    | 10.0                              | 9.6    |
| 8       | AL, MS, TN             | 29.9          | 18.6           | 13.4   | 27.8 | 10.3    | 9.2                               | 9.5    |
| 2       | NY                     | 32.4          | 17.3           | 12.1   | 24.7 | 13.4    | 9.5                               | 9.5    |
| 15      | AZ, CO, NV, NM, UT, WY | 32.8          | 19.0           | 15.7   | 22.1 | 10.4    | 10.5                              | 10.2   |
| 6       | NC, SC, GA             | 33.2          | 19.2           | 13.5   | 23.8 | 10.3    | 9.0                               | 9.5    |
| 12      | IA, KS, MO, NE         | 35.8          | 18.3           | 12.2   | 24.8 | 8.9     | 10.7                              | 9.6    |
| 4       | DE, PA                 | 36.1          | 18.7           | 14.1   | 21.7 | 9.4     | 10.5                              | 9.7    |
| 11      | MI, MN, ND, SD, WI     | 38.6          | 16.1           | 12.2   | 24.6 | 8.5     | 10.7                              | 9.6    |
| 16      | AK, ID, MT, OR, WA     | 41.4          | 18.4           | 14.7   | 21.8 | 3.8     | 10.1                              | 10.1   |
| 1       | CT, MA, ME, NH, RI VT  | 45.3          | 20.5           | 10.3   | 15.9 | 8.0     | 9.4                               | 9.5    |
| All     |                        | 30.1          | 18.7           | 13.3   | 25.3 | 12.6    | 10.0                              | 9.6    |

Data Source: Special analyses, USRDS ESRD Database. Population only includes incident cases with CMS form 2728. eGFR calculated using the CKD-EPI equation (CKD-EPI eGFR (ml/min/1.73 m²) for those aged ≥18 and the Schwartz equation for those aged <18. Abbreviations: ESRD, end-stage renal disease; eGFR, estimated glomerular filtration rate; CKD-EPI, chronic kidney disease epidemiology calculation; Hqb, hemoglobin.

# Modality of Renal Replacement Therapy: Distributions, Geographic Variation, and Trends

# **AMONG INCIDENT CASES OF ESRD IN 2013**

In 2013, 88.4% of all incident cases began renal replacement therapy with hemodialysis, 9.0% with peritoneal dialysis, and 2.6% received a preemptive kidney transplant (Table 1.7). Use of peritoneal dialysis and pre-emptive kidney transplant were relatively more common in younger groups and relatively less common among Black or Hispanic patients. Use of peritoneal dialysis and pre-emptive kidney transplant were more common among patients with glomerular or cystic kidney disease, versus diabetes or hypertension, as the primary cause of ESRD. This difference may be attributed in part to age, as both glomerular and cystic kidney disease are more common in younger patients.

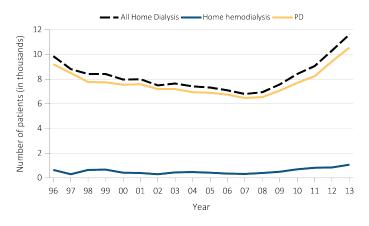
vol 2 Table 1.7 Number and percentage of incident cases of hemodialysis, peritoneal dialysis, and transplantation by age, sex, race, ethnicity, and primary cause of ESRD, in the U.S. population, 2013

|                          | Takal   | HD      |      | PE     | )    | Transplant |      |  |
|--------------------------|---------|---------|------|--------|------|------------|------|--|
|                          | Total   | n       | %    | n      | %    | n          | %    |  |
| Age                      |         |         |      |        |      |            |      |  |
| 0-21                     | 1,470   | 832     | 56.6 | 371    | 25.2 | 267        | 18.2 |  |
| 22-44                    | 12,977  | 10,472  | 80.7 | 1,793  | 13.8 | 712        | 5.5  |  |
| 45-64                    | 45,566  | 39,593  | 86.9 | 4,515  | 9.9  | 1,458      | 3.2  |  |
| 65-74                    | 29,453  | 26,598  | 90.3 | 2,296  | 7.8  | 559        | 1.9  |  |
| 75+                      | 27,524  | 25,887  | 94.1 | 1,587  | 5.8  | 50         | 0.2  |  |
| Sex                      |         |         |      |        |      |            |      |  |
| Male                     | 67,580  | 59,865  | 88.6 | 5,992  | 8.9  | 1,723      | 2.5  |  |
| Female                   | 49,410  | 43,517  | 88.1 | 4,570  | 9.2  | 1,323      | 2.7  |  |
| Race                     |         |         |      |        |      |            |      |  |
| White                    | 79,244  | 69,447  | 87.6 | 7,479  | 9.4  | 2,318      | 2.9  |  |
| Black / African American | 30,664  | 28,038  | 91.4 | 2,292  | 7.5  | 334        | 1.1  |  |
| Native American          | 1,040   | 932     | 89.6 | 71     | 6.8  | 37         | 3.6  |  |
| Asian                    | 5,714   | 4,721   | 82.6 | 698    | 12.2 | 295        | 5.2  |  |
| Other/Unknown            | 328     | 244     | 74.4 | 22     | 6.7  | 62         | 18.9 |  |
| Ethnicity                |         |         |      |        |      |            |      |  |
| Hispanic                 | 17,276  | 15,527  | 89.9 | 1,460  | 8.5  | 289        | 1.7  |  |
| Non-Hispanic             | 99,714  | 87,855  | 88.1 | 9,102  | 9.1  | 2,757      | 2.8  |  |
| Primary cause of ESRD    |         |         |      |        |      |            |      |  |
| Diabetes                 | 51,339  | 46,502  | 90.6 | 4,392  | 8.6  | 445        | 0.9  |  |
| Hypertension             | 33,585  | 30,459  | 90.7 | 2,850  | 8.5  | 276        | 0.8  |  |
| Glomerulonephritis       | 8,802   | 6,801   | 77.3 | 1,444  | 16.4 | 557        | 6.3  |  |
| Cystic kidney            | 2,482   | 1,547   | 62.3 | 485    | 19.5 | 450        | 18.1 |  |
| Other/Unknown            | 20,782  | 18,073  | 87.0 | 1,391  | 6.7  | 1,318      | 6.3  |  |
| All                      | 116,990 | 103,382 | 88.4 | 10,562 | 9.0  | 3,046      | 2.6  |  |

Data Source: Special analyses, USRDS ESRD Database. The numbers in this table exclude "Other PD" and "Uncertain Dialysis." Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis.

Use of home dialysis among incident ESRD patients has increased notably in recent years (Figure 1.21). Home dialysis use overall in 2013 was 52% higher than a decade ago in 2003 and 71% higher than at its nadir in 2007. Use of peritoneal dialysis and home hemodialysis in 2013 are 63% and 222% higher, respectively, than in 2007. Despite the large relative rise in home hemodialysis, its overall use among incident ESRD patients is low, as only 9.1% of home dialysis patients were treated with home hemodialysis in 2013.

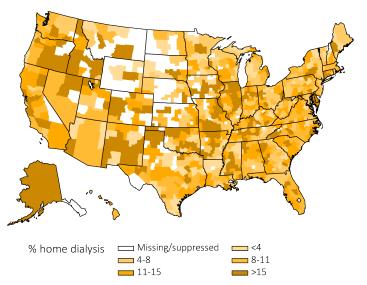
vol 2 Figure 1.21 Trends in the number of incident ESRD cases (in thousands) using home dialysis, by type of therapy, in the U.S. population, 1996-2013



Data Source: Reference Table D.1. Abbreviations: ESRD, end-stage renal disease; PD, peritoneal dialysis.

The proportion of incident dialysis cases using home dialysis was 10.2% in the US; it varied substantially across 677 Health Services Areas, ranging from a low of 0% to a high of 58% (interquartile range: 6.3 to 14.2%) (Figure 1.22). Geographic patterns are less apparent, supporting the likelihood that differences in home dialysis use are largely driven by differences among individual dialysis centers or groups of centers, rather than by large-scale regional effects.

vol 2 Figure 1.22 Map of the percentage of incident dialysis cases using home dialysis, by Health Service Area, 2013



Data Source: Special analyses, USRDS ESRD Database.

# **AMONG PREVALENT CASES OF ESRD IN 2013**

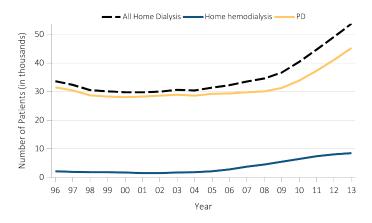
On December 31, 2013, 63.9% of all prevalent ESRD cases were receiving hemodialysis therapy, 6.9% were being treated with peritoneal dialysis, and 29.3% had a functioning kidney transplant (Table 1.8).

Distributions of modality use by patient characteristics generally mirror those for incident patients. Peritoneal dialysis and kidney transplant were more commonly used among patients who were younger and more likely White, non-Hispanic, and with glomerular disease or cystic kidney disease as the primary cause of ESRD.

The use of home dialysis (peritoneal dialysis or home hemodialysis, Figure 1.23) has increased appreciably in recent years. Home dialysis accounted for 11.5 percent of all prevalent dialysis patients in 2013, up from a low of 8.9 percent in 2008. Among home dialysis cases, the proportion using home hemodialysis was over 3-fold higher in 2013 (15.8%) than in 2001 (5.2%).

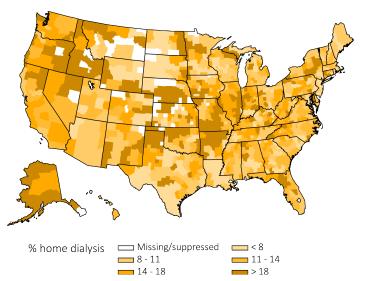
As observed for incident dialysis patients, there was substantial variation in home dialysis use by Health Service Area among prevalent dialysis cases in 2013. The percent of prevalent dialysis cases using home dialysis ranged across 763 Health Service Areas from a low of 0% to a high of 77% (interquartile range: 8.8 to 16.9%) (Figure 1.24). Scattered geographic patterns are apparent as in the case of incident utilization of home dialysis, further supporting the likelihood that differences in home dialysis use are largely being driven by preferences and availability of home dialysis at individual dialysis centers or groups of centers, rather than by large-scale regional influences, though this phenomenon requires further investigation.

vol 2 Figure 1.23 Trends in number of prevalent ESRD cases (in thousands) using home dialysis, by type of therapy, in the U.S. population, 1996-2013



Data Source: Reference Table D.1. December 31 prevalent ESRD patients; PD consists of CAPD and CCPD only. Abbreviations: CAPD, continuous ambulatory peritoneal dialysis; CCPD, continuous cycler peritoneal dialysis; ESRD, end-stage renal disease; PD, peritoneal dialysis.

vol 2 Figure 1.24 Map of the percentage of prevalent dialysis cases using home dialysis, by Health Service Area, 2013



Data Source: Special analyses, USRDS ESRD Database.

vol 2 Table 1.8 Number and percentage of prevalent cases of hemodialysis, peritoneal dialysis, and transplantation by age, sex, race, ethnicity, and primary ESRD diagnosis, in the U.S. population, 2013

|                          |         | HD      |      | PD     |      | Transp  | lant |
|--------------------------|---------|---------|------|--------|------|---------|------|
|                          | Total   | n       | %    | n      | %    | n       | %    |
| Age                      |         |         |      |        |      |         |      |
| 0-21                     | 9,979   | 1,993   | 20.0 | 1,206  | 12.1 | 6,780   | 67.9 |
| 22-44                    | 100,836 | 50,973  | 50.6 | 8,751  | 8.7  | 41,112  | 40.8 |
| 45-64                    | 292,344 | 174,610 | 59.7 | 20,051 | 6.9  | 97,683  | 33.4 |
| 65-74                    | 149,225 | 102,609 | 68.8 | 9,368  | 6.3  | 37,248  | 25.0 |
| 75+                      | 107,485 | 91,164  | 84.8 | 5,882  | 5.5  | 10,439  | 9.7  |
| Sex                      |         |         |      |        |      |         |      |
| Male                     | 378,185 | 238,277 | 63.0 | 24,602 | 6.5  | 115,306 | 30.5 |
| Female                   | 281,604 | 183,009 | 65.0 | 20,651 | 7.3  | 77,944  | 27.7 |
| Race                     |         |         |      |        |      |         |      |
| White                    | 407,377 | 239,192 | 58.7 | 30,323 | 7.4  | 137,862 | 33.8 |
| Black / African American | 202,843 | 153,406 | 75.6 | 11,169 | 5.5  | 38,268  | 18.9 |
| Native American          | 7,188   | 5,000   | 69.6 | 438    | 6.1  | 1,750   | 24.3 |
| Asian                    | 36,882  | 22,548  | 61.1 | 3,195  | 8.7  | 11,139  | 30.2 |
| Other/Unknown            | 5,579   | 1,203   | 21.6 | 133    | 2.4  | 4,243   | 76.1 |
| Ethnicity                |         |         |      |        |      |         |      |
| Hispanic                 | 111,622 | 76,790  | 68.8 | 6,901  | 6.2  | 27,931  | 25.0 |
| Non-Hispanic             | 548,247 | 344,559 | 62.8 | 38,357 | 7.0  | 165,331 | 30.2 |
| Primary cause of ESRD    |         |         |      |        |      |         |      |
| Diabetes                 | 247,257 | 187,520 | 75.8 | 16,060 | 6.5  | 43,677  | 17.7 |
| Hypertension             | 165,634 | 122,624 | 74.0 | 11,962 | 7.2  | 31,048  | 18.7 |
| Glomerulonephritis       | 107,853 | 45,012  | 41.7 | 8,557  | 7.9  | 54,284  | 50.3 |
| Cystic kidney            | 30,977  | 9,810   | 31.7 | 1,990  | 6.4  | 19,177  | 61.9 |
| Other/Unknown            | 108,148 | 56,383  | 52.1 | 6,689  | 6.2  | 45,076  | 41.7 |
| All                      | 659,869 | 421,349 | 63.9 | 45,258 | 6.9  | 193,262 | 29.3 |

Data Source: Special analyses, USRDS ESRD Database. The numbers in this table exclude "Other PD" and "Uncertain Dialysis." Abbreviation: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis.