# Chapter II

# Incidence and Prevalence of ESRD

*Key Words:*
ESRD incidence
ESRD prevalence
Dialysis patient counts
HCFA data
ESRD growth rates
Diabetic ESRD
ESRD Medical Evidence Form 2728
ESRD Medicare
Cause of ESRD
Race
Gender

This chapter presents basic information about the incidence and prevalence of treated end-stage renal Disease (ESRD). Incidence refers to the new cases of ESRD during a given year and is a key population measure of kidney disease and access to renal replacement therapy. Prevalence refers to all cases of ESRD during a given year and is a population measure of disease burden and resource requirements. Prevalence is determined by incidence and patient life expectancy.

Like most data reported in the ADR, incidence and prevalence figures are primarily derived from Medicare billing records. The process and problems of data collection are described in Chapter XIII. This ADR continues the practice, first adopted in the 1997 ADR, of reporting data updated within 2 years of the ADR year (i.e. this 1998 ADR contains data through 1996). The report lag for prior ADRs was 3 years. A 2-year lag time (actually 1.25 years when the report is prepared) represents the limits of current reporting cycles and technology. Even so, counts take even longer to stabilize as Medicare records are continuously updated. Although a 2-year reporting lag may seem long, the reality is that records are relatively incomplete even after 2 years. Recent experience has shown that incidence counts increase by approximately 5 percent between the 2-year and 3-year updates. In other words, this ADR reports that the 1995 ESRD incident patient count was 5 percent higher than was reported in the 1997 ADR. There are many reasons for delayed case reporting but these are particular to the Medicare reimbursement system rather than the USRDS or other users of the billing data.

Due to the long lag time until ESRD counts can be considered stable, the data in this ADR must be considered preliminary for 1996. It appears that counts for prior years are relatively stable. In addition to reporting lags, a number of other factors contribute to uncertainty about the counts, as described in Chapter XIII. Foremost, the USRDS learns about potential ESRD patients through many sources including the Medical Evidence Form (Form 2728), Medicare billing records, UNOS transplant records, ESRD Network Census reports, and ESRD death notification reports. The degree of certainty that any individual (as indicated by a unique social security number) is truly an ESRD patient is determined by the quantity of corroborating data. At one extreme, there is little question about the ESRD status of an individual for whom the database includes a Medical Evidence Form, billing records, and a Network Census entry. At the other extreme, ESRD status is uncertain for patients with only a death notification form. For reporting purposes, ESRD is defined by a person who has a Medical Evidence Form filed or has a Medicare claim for outpatient dialysis or a kidney transplant. The 1997 ADR contains an extensive discussion of issues related to accurately counting ESRD patients.

**Treated Medicare ESRD Point Prevalence and Incidence Counts and Rates[1] by Age, Sex, Race, and Primary Diagnosis, 1996**

| | Prevalence on 12/31/96 | | | Incidence during 1996 | | |
|---|---|---|---|---|---|---|
| Characteristic[2] | Count[3] (n) | Percent of Total | Rate per Million[3] | Count[3] (n) | Percent of Total | Rate per Million[3] |
| Age 0-19 | 5,180 | 1.8 | 64 | 1,129 | 1.5 | 13 |
| Age 20-44 | 73,734 | 26.0 | 692 | 12,622 | 17.3 | 117 |
| Age 45-64 | 109,834 | 38.7 | 2,280 | 25,417 | 34.8 | 542 |
| Age 65-74 | 58,549 | 20.6 | 3,518 | 19,456 | 26.6 | 1144 |
| Age 75+ | 36,635 | 12.9 | 2,715 | 14,467 | 19.8 | 1079 |
| Female | 130,551 | 46.0 | 883 | 33,835 | 46.3 | 225 |
| Male | 153,381 | 54.0 | 1,233 | 39,256 | 53.7 | 325 |
| Asian/Pacific Islander | 9,863 | 3.5 | 1,291 | 2,408 | 3.3 | 354 |
| Black | 91,580 | 32.3 | 3,404 | 21,808 | 29.8 | 829 |
| Native American | 4,504 | 1.6 | 2,761 | 1,279 | 1.7 | 817 |
| White | 173,443 | 61.1 | 754 | 46,102 | 63.1 | 199 |
| Other/Unknown | 4,542 | 1.6 | n.a. | 1,494 | 2.0 | n.a. |
| Diabetes | 92,211 | 32.5 | 339 | 30,933 | 42.3 | 113 |
| Hypertension | 69,538 | 24.5 | 256 | 18,844 | 25.8 | 70 |
| Glomerulonephritis | 50,378 | 17.7 | 185 | 7,882 | 10.8 | 29 |
| Cystic Kidney Dis | 13,454 | 4.7 | 50 | 1,796 | 2.5 | 7 |
| Total | 283,932 | 100.0 | 1,041 | 73,091 | 100.0 | 268 |

*[1]Rates are adjusted for age, sex and race. Rates are computed relative to the corresponding population for age, sex, and race results. Preliminary.*

*[2]Patients with other or unknown race are excluded from rate analyses. Other urologic, other, unknown, and missing cause of ESRD are included in the total but are not shown.*

*[3]Counts and rates do not include patients from Puerto Rico or U.S. Territories.*

*Source: Reference Tables B.1 and A.1 for the counts and B.8 and A.6 for the rates.*

***USRDS 1998***

**Table II-1**

## Measuring Incidence and Prevalence of ESRD

ESRD is defined by treatment with any form of chronic dialysis or renal transplantation, using the criteria described above. Patients who die of renal failure without first receiving dialysis or a transplant are not considered ESRD patients. Dialysis for acute renal failure is not considered ESRD unless renal function fails to recover. As a practical matter, the degree of renal failure or the reason for initiation of dialysis does not impact the ESRD classification.

A patient is considered incident at the time of first regular dialysis for chronic renal failure or transplantation. Center dialysis patients who were not receiving Medicare benefits at the start of dialysis must wait 60 to 90 days for Medicare eligibility to begin. For purposes of incidence and prevalence, the true ESRD start date is used.

A patient is considered prevalent if he/she is known to be receiving dialysis treatment or to have a working kidney transplant (regardless of when the transplant was performed). Point prevalence refers to the number (or population normalized fraction) of ESRD patients at a particular point in time (e.g., on 12/31/96). Period prevalence refers to the number of patients with ESRD (as defined above) during an interval of time, usually a year. Period prevalence is somewhat higher than point prevalence due to deaths during the period. Most prevalence statistics reported by the USRDS refer to a point prevalence.

**Reported ESRD Period and Point Prevalence, Incidence, Death and Lost-to-Followup Counts, 1987-96**

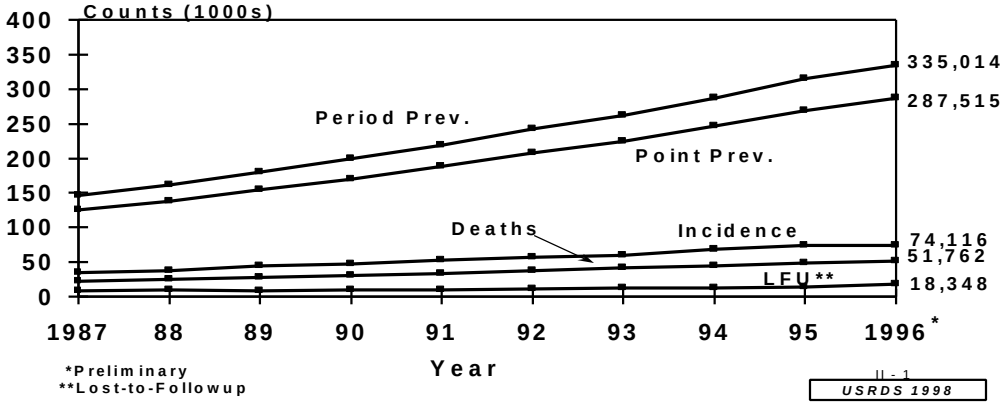


**Figure II-1**

*Reported ESRD period prevalence counts (patients alive at any time during the year), point prevalence counts (patients alive on 12/31 of the year), incidence counts, patient deaths, and patients lost to followup by year from 1987-96. Point prevalence counts exclude patients lost to followup (LFU). Patients in Puerto Rico and U.S. Territories are included in all estimates except period prevalence counts. Source: Reference Tables A.1, A.2, B.1, B.3, D.1*

Prevalence is a direct function of incidence and survival. Prevalence rates are 3 to 4 times higher than incidence rates because the average survival time is 3 to 4 years. Changes in prevalence are attributable to changes in either incidence, average survival time, or both.

Patients who return to dialysis after a failed transplant are not counted as incident ESRD patients; this situation is viewed as a modality change. Similarly, patients who stop chronic dialysis and then restart are counted as prevalent, not incident patients. Patients are maintained in the ESRD database until death. Patients who lack any evidence of payment activity in the Medicare database for 1 year are classified as lost-to-followup and are no longer counted as prevalent since they may have recovered renal function. If such a patient reappears in the Medicare payment records, they are again counted as prevalent. It is important to note the dynamic quality of the USRDS registry as the status of some patients becomes clarified over time. This is one reason why the prevalence or incidence counts for a given year may change at a later date.

Incidence and prevalence are expressed in terms of absolute counts as well as rates (i.e., number per million population). Technically, incidence is expressed as a rate (number/million population/year) while prevalence is expressed as a proportion (number/million population). For simplicity, we will refer to both incidence and prevalence as rates.

The incidence and prevalence rates are adjusted to a reference population using the direct method (described in Chapter XIII). Use of an adjusted rate accounts for growth and aging of the general population and permits meaningful comparisons across years. In other words, the adjusted rate assumes a constant reference population. The reference population for the 1998 ADR, which covers detailed data through 1996, comes from the U.S. Census estimates for 1996. The adjusted rates change slightly with each ADR because the reference population is updated (in addition to the yearly count update described above). When rates are given for specific subgroups (e.g., by age, sex, or race), they are adjusted for remaining characteristics. Growth trends over time should be evaluated on the basis of adjusted rates. Trends in counts reflect growth and aging of the general population as well as ESRD trends.

## Overall Incidence and Prevalence

Table II-1 summarizes the prevalence and incidence counts and rates for 1996. During the year, 283,932 patients were treated for ESRD and 73,091 new patients started ESRD treatment. Incidence and prevalence rates tend to increase with age and then fall off for the oldest age group. The largest group of

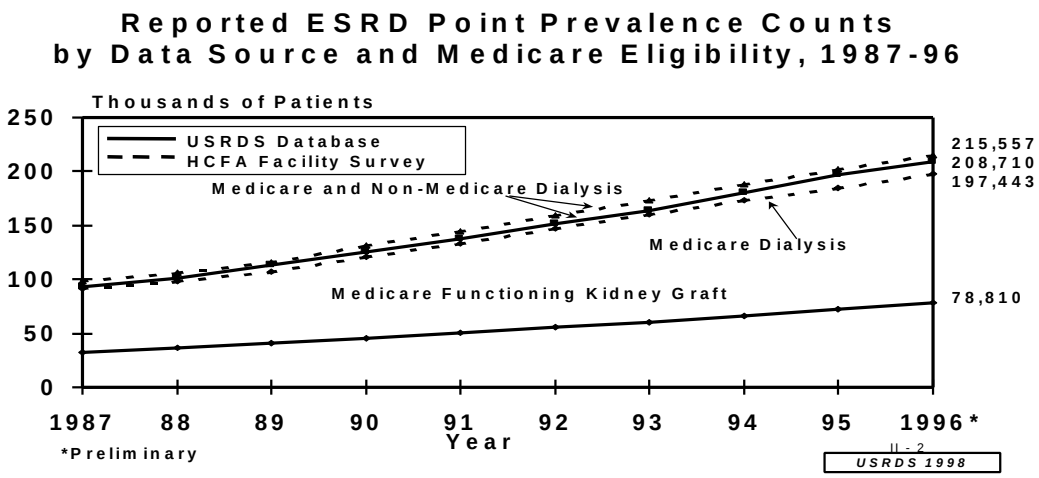


**Figure II-2**

*Reported point prevalent counts on December 31 of each year from 1987-96 for: Medicare and non-Medicare dialysis patients, including patients whose Medicare eligibility is current or pending (from HCFA Annual Facility Survey (AFS) and the USRDS database (DB)); Medicare patients with a functioning kidney transplant (from USRDS DB); and dialysis patients not insured by Medicare (from AFS). Counts of Medicare dialysis patients from the USRDS DB do not include patients lost to followup. All prevalence counts include patients in Puerto Rico and U.S. Territories. Source: Reference Tables C.2, I.10*

patients falls in the 45-64-year age group. The disease was more common in men than women. Individuals classified as Black race constituted 30-32 percent of treated ESRD patients as contrasted with 12.6 percent of the U.S. population. As in the past, diabetes was the most common reported cause of ESRD, at 43 percent of new patients in 1996.

Figure II-1 displays ESRD trends over 10 years. The figure shows total ESRD patients including both dialysis and transplant patients. The figure shows that ESRD continued to grow, as discussed further below.

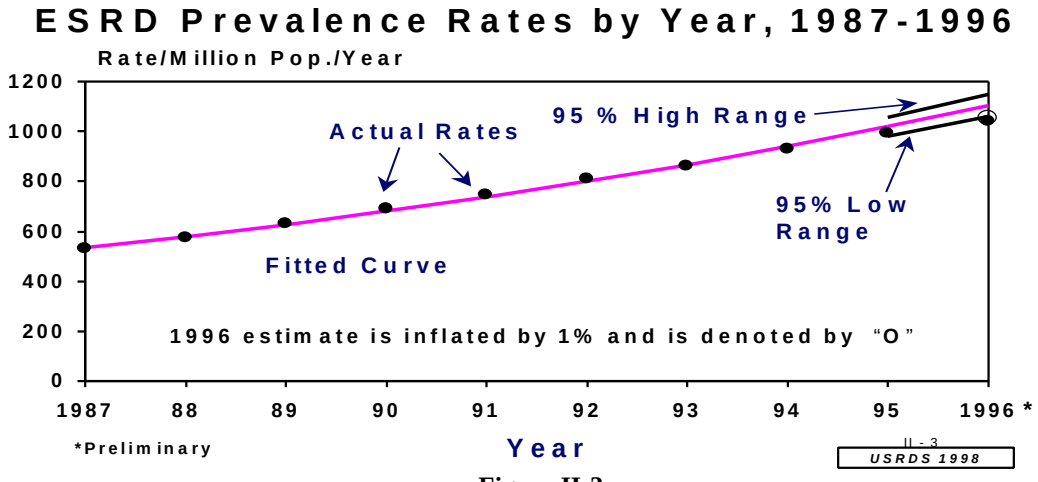


**Figure II-3**

*Observed and fitted prevalence rates of treated ESRD per million population, 1987-96. Rates are adjusted for sex, age, and race. Rates do not include patients from Puerto Rico or U.S. Territories. Source: Reference Table B.8, Special Analysis*

The period prevalence exceeded the end-of-year point prevalence, largely due to deaths during the year. The number of prevalent patients was approximately 4 times higher than the number of incident patients, in accordance with a life span of approximately 4 years for the typical ESRD patient (see Table V-4). The USRDS database records a small but substantial number of patients who are lost-to-followup (LFU). These patients were registered as ESRD patients in the HCFA system at some point but are classified as LFU when there is a lapse in billing or other records for a period of 1 year.

Figure II-2 displays prevalence counts for dialysis and transplant patients. The number of Medicare patients with a functioning kidney graft continued to grow steadily, limited primarily by the number of organs available for transplantation. The figure shows ESRD counts from two separate data sources: the USRDS database and the HCFA Annual Facility Survey. The HCFA Annual Facility Survey captures prevalent dialysis patients as of 12/31/96 and classifies them according to whether dialysis services are covered by the Medicare program. As in past years, Medicare covered approximately 92 percent of dialysis patients. The USRDS database is derived from a variety of HCFA records (see Chapter XIII) and includes all Medicare and an increasing number of non-Medicare patients. As expected, the USRDS estimate of prevalent patients falls between the Medicare and total counts reported in the annual Facility Survey. The USRDS database has, in recent years, attempted to capture enrollment information on non-Medicare patients, accounting for the narrowing gap between the Facility Survey total and the USRDS total in recent years.

Figure II-3 shows the trend in ESRD prevalence over 10 years. ESRD prevalence increased steadily at a rate of 8 percent per year through most of the period. In the last several years, there has been some suggestion that the growth rate is slowing but this conclusion has been confounded by year-to-year uncertainty in the actual counts and rates for reasons described above. In the 1997 ADR, the 1995 prevalence was lower than expected but this was the first ADR with a 1.25- year reporting lag (previous ADRs had a 2.25-year reporting lag). The HCFA reporting system accrued additional patients between the earlier and later updates, resulting in an approximate 1 percent increase in prevalence counts and rates. Thus, the reported growth in prevalence from 1994 to 1995 was 8 percent in the 1997 ADR as compared to 9 percent in the current 1998 ADR.

Figure II-3 displays a fitted exponential curve for the years 1987 through 1994, the years for which data are most stable. An exponential model was used because it provided the best fit of the data in prior years. The fitted curve has been extrapolated, with 95 percent prediction intervals, through 1996. The prevalence rate falls within the 95 percent interval for the expected rate while the current 1996 rate falls below the lower prediction bound. However, past

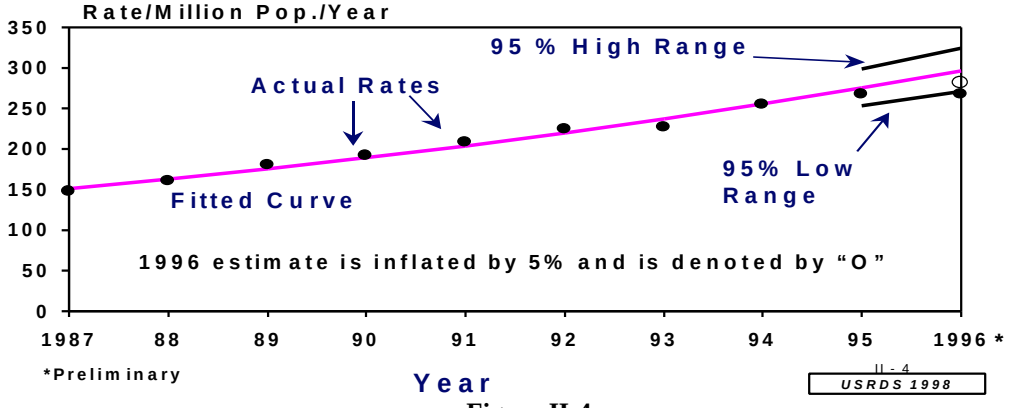


**Figure II-4**

*Observed and fitted incidence rates of treated ESRD per million population, 1987-96. Rates are adjusted for sex, age, and race. Rates do not include patients from Puerto Rico or U.S. Territories. Source: Reference Table A.6, Special Analysis*

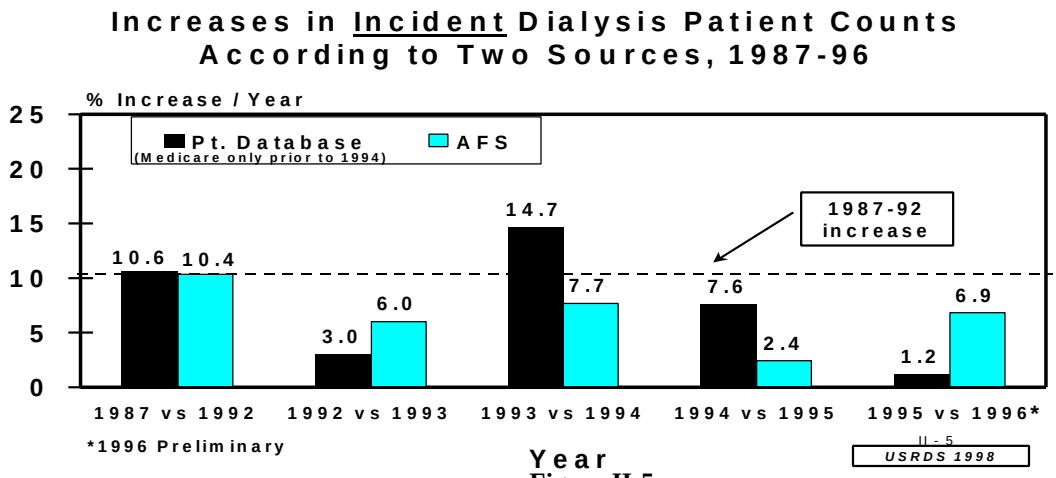


**Figure II-5**

*Increases in incident dialysis patient counts according to the USRDS patient database and the Annual Facility Survey (AFS), 1987-96. 1996 data are preliminary. Source: Reference Tables A.1, I.15*

experience suggests that the 1996 prevalence rate will increase by 1 percent at the next update in 1999 so the projected final prevalence rate will fall within the 95 percent prediction band. Thus, the suggestion for a somewhat slower rate of growth of ESRD is not supported by statistical significance. The incidence growth rates are a major determinant of future ESRD impact (Lippert; Port).

Figure II-4 shows ESRD incidence by year. Most of the changes in prevalence are due to changes in incidence because death rates have been relatively more constant over the years (see Chapter V). Figure II-4 shows a dip in incidence in 1993 followed by the rebound in 1994, suggesting a reporting artifact (see the 1997 ADR for further discussion). As for the prevalence analysis, the fitted curve for 1987 through 1994 has been extrapolated through 1996. The

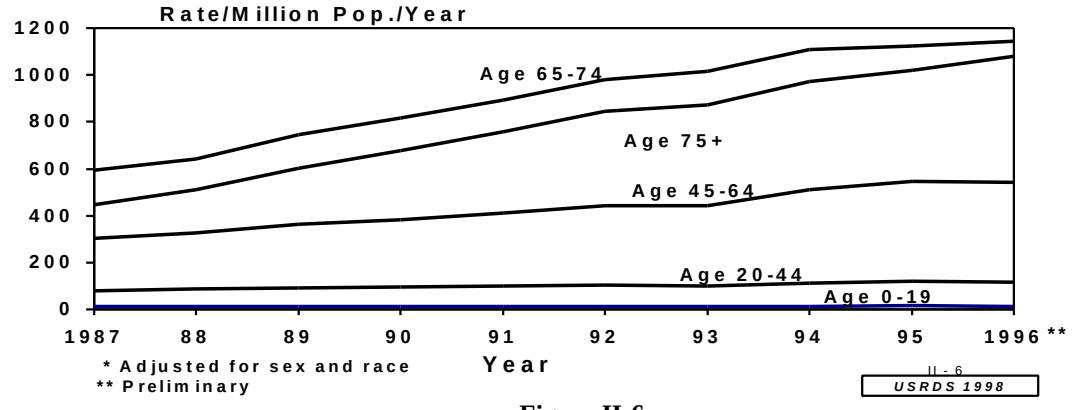


**Figure II-6**

*Reported ESRD incidence rates per million U.S. resident population by age group, 1987-96. Rates by age adjusted for sex and race. Rates do not include patients from Puerto Rico or the U.S. Territories. Source: Reference Table A.6*

current estimate of incidence for 1995 falls within the 95 percent prediction interval whereas the 1996 rate falls below the lower bound. However, as noted above, it is expected that the 1996 rate will increase by 5 percent, as reporting becomes more complete by 1999. This "adjusted" estimate of the 1996 incidence rate falls within the 95 percent prediction band.

ESRD incidence trends are further explored in Figure II-5 which shows yearly growth rates based on the USRDS database and the HCFA Annual Facility Survey. The USRDS database indicates only a 1.2 percent growth rate in 1996 (compared with 1995) but reporting is known to be incomplete at this time. In contrast, the AFS indicates a 6.9 percent growth rate, which is closer to the 10.6 percent annual growth rate from 1987 through 1992. At this time, the best estimate is that ESRD incidence is growing by approximately 6 to 7 percent per year and there is insufficient evidence to confidently conclude that the rate of growth is declining.

## Characteristics of ESRD Patients

### Age

The age distribution for prevalent and incident ESRD patients in 1996 is shown in Table II-1. The prevalence and incidence rates increased steadily with age and then reached a peak at age 65-69 and age 70-74 years, respectively. ESRD incidence trends by age group are shown in Figure II-6 which also illustrates the rising incidence rates through age 74 and then a somewhat lower incidence rate for the oldest age group. However, new ESRD grew fastest among the oldest (75+) age group. Most of the growth in ESRD occurred among patients above the age of 65 years whereas growth was relatively flat for younger age groups. In 1996, there was no growth in the 45-64-year age group, unlike prior years in which small growth was observed for this group. However, this estimate could be altered when the 1996 figures are updated.

The mean age of new ESRD patients has increased over time (Figure II-7). Furthermore, there were large racial differences in the mean age at onset of ESRD. On average, Black patients were youngest at onset of ESRD followed by Native Americans, Asians, and Whites. At onset of ESRD, Black patients were in recent years 6.4 years younger than White patients, on average.

### Sex

The distribution of ESRD by sex is shown in Table II-1. As in the past, the incidence of treated ESRD is higher for males than for females. This applies for most causes of ESRD with some exceptions as described below.

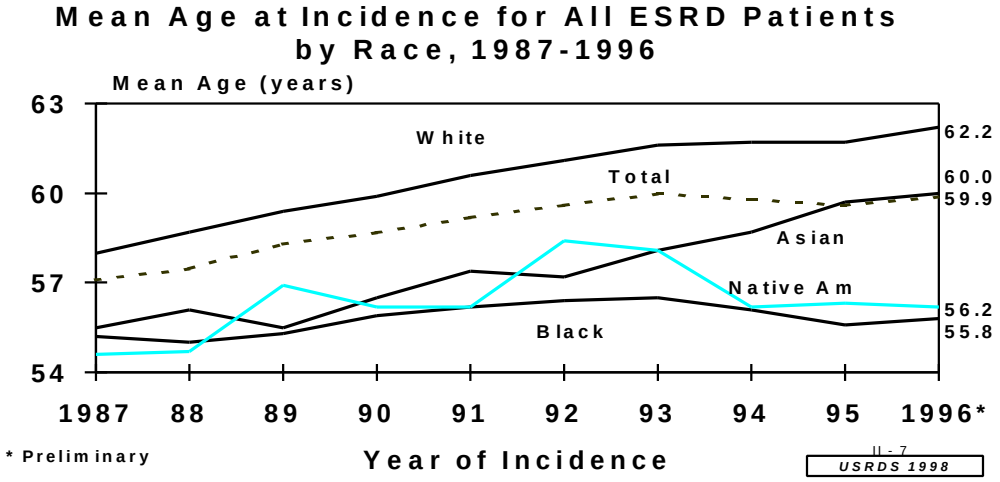


**Figure II-7**

*Mean age at incidence of ESRD by year, 1987-1996. Includes patients from Puerto Rico and U.S. Territories. Source: Reference Table A.14*

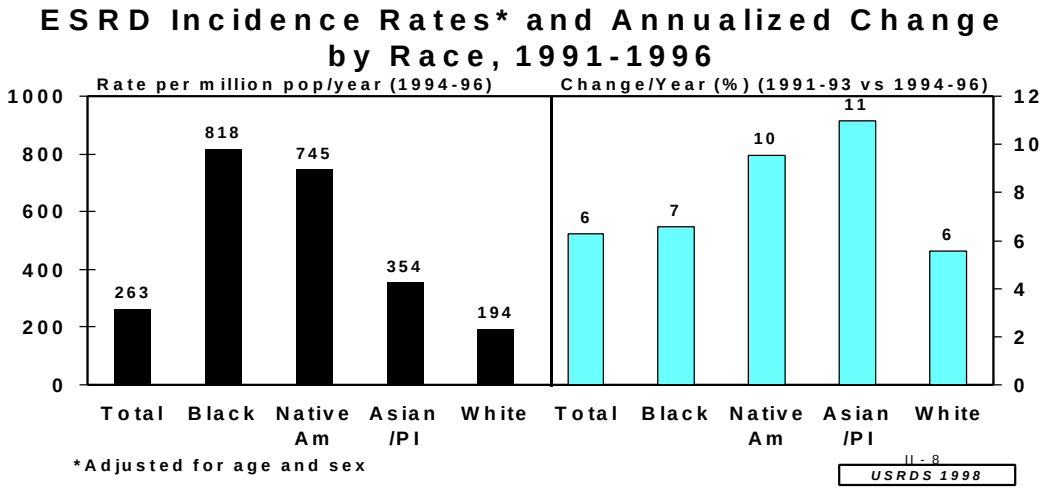


**Figure II-8**

*Treated ESRD incidence rates per year by race, 1994-96, and annualized change in treated ESRD incidence rates by race, 1991-93 to 1994-96. Rates by race adjusted for sex and age. Overall rates adjusted by age, race, and sex. Rates do not include patients from Puerto Rico or the U.S. Territories. Source: Reference Table A.8*

## Race

The racial distribution of ESRD patients in 1996 is shown in Table II-1 and continues to show disproportionately high rates of treated ESRD incidence in Blacks and Native Americans. In 1996, Blacks constituted 29.8 percent of ESRD patients as compared to 12.6 percent of the U.S. population and Native Americans constituted 1.7 percent of ESRD patients as compared to 0.9 percent of the U.S. population. The incidence rates and growth in incidence over a longer period of time are shown in Figure II-8. The adjusted incidence of ESRD grew by

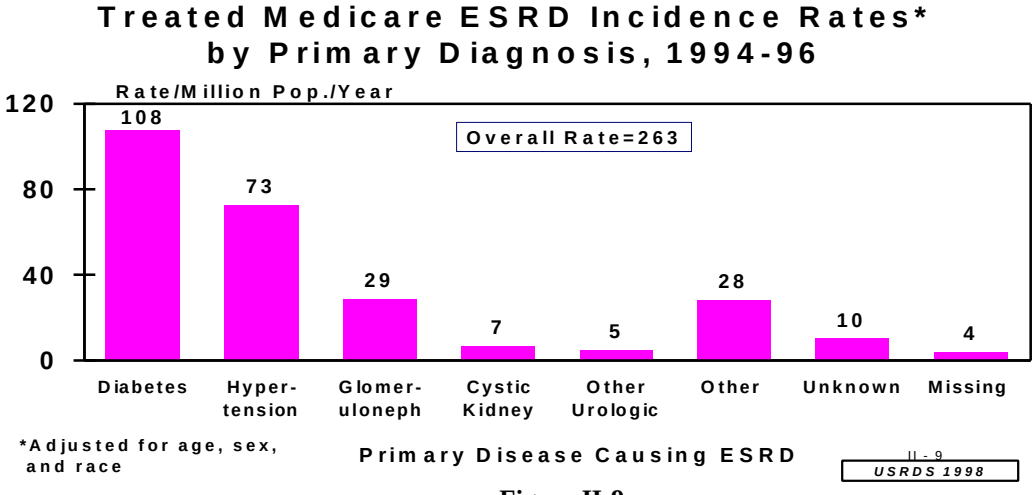


**Figure II-9**

*Treated ESRD incidence rates per year by primary diagnoses, 1994-96. Rates by diagnoses adjusted for age, sex, and race. Rates do not include patients from Puerto Rico or the U.S. Territories. Source: References Tables A.8, A.34*

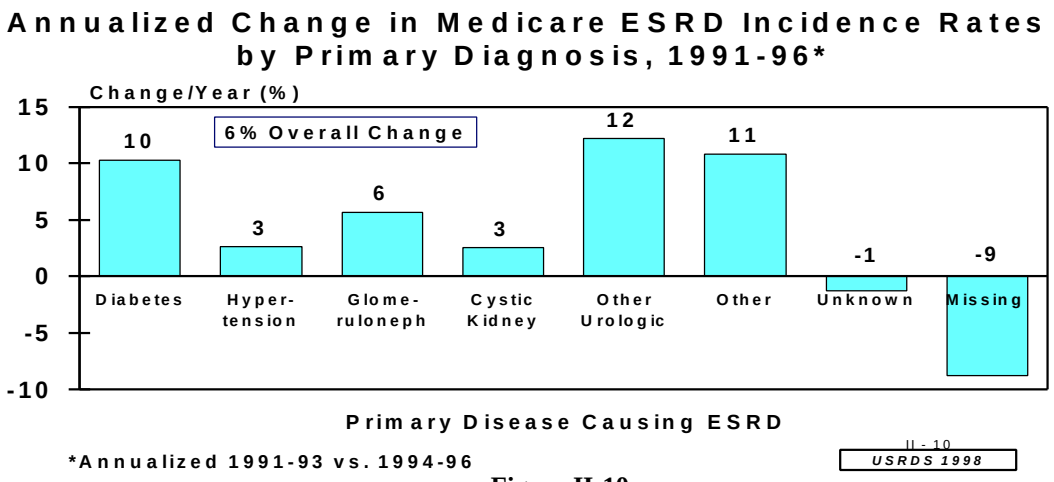


**Figure II-10**

*Annualized change in treated ESRD incidence rates by primary diagnoses, 1991-93 to 1994-96. Rates do not include patients from Puerto Rico or the U.S. Territories. Source: Reference Tables A.8, A.34*

6-7 percent/year overall and was similar for Blacks and Whites for the period from 1994 to 1996 as compared to the prior 3-year period. In contrast, the growth rate was nearly twice as fast for Native Americans and Asian/Pacific Islanders.

## Diagnosis

The attributed cause of ESRD is subject to a certain amount of uncertainty (Young). The attribution of ESRD to diseases such as polycystic kidney disease and diabetes (Brancati) is reasonably secure. On the other hand, there may be more uncertainty about ascribing ESRD to hypertension in any individual patient although the association between blood pressure and ESRD has been established in recent epidemiological studies (Klag; Iseki).

The distribution of new ESRD cases by attributed major diagnosis is shown in Table II-1 for 1992-1996 and in Figure II-9 for the period from 1994-1996. Diabetes was the most common attributed cause of ESRD followed by hypertension, glomerulonephritis, other, unknown, cystic diseases, and urologic diseases. Other lesser causes combined to make up 28 percent of new ESRD and missing reports account for 4 percent of incident cases. The growth in new ESRD cases was highest for diabetes, urologic, and other renal diseases (Figure II-10). There has been a notable decrease in ESRD cases classified as unknown or missing.

Detailed listing of ESRD diagnoses, broken down by demographic subgroups, is provided in Table II-2 and II-3. Table II-2 shows column percentages, which are useful for understanding the distribution of ESRD diagnoses within a particular demographic group. It can be seen that the attributed cause of ESRD varies by age. In the youngest age group (<20 years), the most common diagnoses are glomerulonephritis (31.7 percent) and cystic/hereditary/congenital diseases (24.4 percent) whereas diabetes is rare (1.6 percent). For the oldest age group (>64 years) the most common attributed causes of ESRD are hypertension (36.8 percent) and diabetes (35.9 percent). Diabetes is, overall, the most common attributed causes in both men and women. However, diabetes is relatively more common in women and hypertension is relatively more common in men. Important interactions are also seen for race and diagnosis. Diabetes is especially common among Native Americans (63.2 percent) and, to a lesser extent, Asians/Pacific Islanders (41.6 percent). Hypertension is notably high among Blacks (35.9 percent) and glomerulonephritis is disproportionately high for Asians/Pacific Islanders (17.8 percent).

Table II-3 shows row percentages that are useful for understanding the demographic distribution for any given diagnosis. Diabetes, glomerulonephritis, secondary GN/vasculitis, and cystic/hereditary/ congenital diseases were disproportionately represented in the 20-64-year age group. Hypertension and neoplasms were disproportionately represented in the >64 age group. Interstitial

**Column Percents for Incidence of Treated ESRD by Detailed Primary Disease, Age, Sex, and Race for all Patients, 1992-1996**[1]

| | | | Age Group | | | Sex | | Race | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | Total | % of | (% Age) | | | (%) | | (%) | | | |
| Primary Disease | 1992-96 | Total[2] | <20 | 20 - 64 | >64 | Male | Female | White | Black | Asian | Nat Am |
| **All ESRD (reference)** | **332459** | **100.0** | **5155** | **171774** | **155530** | **176868** | **155591** | **212461** | **97753** | **10324** | **5044** |
| **Diabetes** | **130473** | **39.2** | **1.6** | **43.4** | **35.9** | **35.0** | **44.1** | **39.4** | **38.0** | **41.6** | **63.2** |
| . Type 1, juvenile type | 46100 | 13.9 | 0.8 | 18.3 | 9.4 | 12.8 | 15.0 | 15.2 | 11.7 | 10.5 | 14.6 |
| . Type 2, adult-onset or unspec. type | 84373 | 25.4 | 0.8 | 25.1 | 26.5 | 22.1 | 29.1 | 24.2 | 26.3 | 31.1 | 48.7 |
| **Glomerulonephritis** | **36499** | **11.0** | **31.7** | **13.1** | **7.9** | **12.5** | **9.2** | **11.7** | **9.0** | **17.8** | **9.0** |
| . Focal glomerulosclerosis, focal GN | 6497 | 2.0 | 10.0 | 2.7 | 0.9 | 2.3 | 1.6 | 1.8 | 2.5 | 1.7 | 1.2 |
| . Membranous nephropathy | 1554 | 0.5 | 0.4 | 0.6 | 0.3 | 0.6 | 0.3 | 0.5 | 0.4 | 0.3 | 0.3 |
| . Membranoproliferative GN, types 1&2 | 1284 | 0.4 | 2.5 | 0.5 | 0.2 | 0.4 | 0.3 | 0.4 | 0.2 | 0.7 | 0.4 |
| . IgA nephropathy, Berger's disease | 1080 | 0.3 | 1.3 | 0.5 | 0.1 | 0.4 | 0.2 | 0.4 | 0.1 | 1.3 | 0.4 |
| . IgM nephropathy | 121 | 0.0 | 0.1 | 0.1 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.2 | 0.0 |
| . Rapidly progressive GN | 1336 | 0.4 | 2.1 | 0.4 | 0.4 | 0.4 | 0.4 | 0.5 | 0.2 | 0.5 | 0.4 |
| . Goodpasture's Syndrome | 780 | 0.2 | 0.7 | 0.2 | 0.2 | 0.2 | 0.3 | 0.3 | 0.1 | 0.1 | 0.2 |
| . Post infectious GN, SBE | 214 | 0.1 | 0.1 | 0.1 | 0.0 | 0.1 | 0.1 | 0.1 | 0.0 | 0.0 | 0.1 |
| . Glomerulonephritis (GN) | 22749 | 6.8 | 13.2 | 7.8 | 5.5 | 7.8 | 5.8 | 7.3 | 5.4 | 12.5 | 5.7 |
| . Other proliferative GN | 884 | 0.3 | 1.3 | 0.3 | 0.2 | 0.3 | 0.2 | 0.3 | 0.2 | 0.5 | 0.2 |
| **Secondary GN/Vasculitis** | **8122** | **2.4** | **9.1** | **3.4** | **1.2** | **1.5** | **3.5** | **2.4** | **2.5** | **2.7** | **2.0** |
| . Lupus erythematosus, (SLE nephritis) | 4177 | 1.3 | 5.0 | 2.1 | 0.2 | 0.5 | 2.2 | 0.9 | 1.9 | 2.0 | 0.9 |
| . Polyarteritis | 173 | 0.1 | 0.1 | 0.1 | 0.1 | 0.0 | 0.1 | 0.1 | 0.0 | 0.1 | 0.0 |
| . Wegener's granulomatosis | 890 | 0.3 | 0.5 | 0.3 | 0.3 | 0.3 | 0.2 | 0.4 | 0.0 | 0.1 | 0.2 |
| . Henoch-Schonlein syndrome | 153 | 0.0 | 1.0 | 0.1 | 0.0 | 0.0 | 0.0 | 0.1 | 0.0 | 0.1 | 0.1 |
| . Vasculitis and its derivatives | 467 | 0.1 | 0.1 | 0.1 | 0.2 | 0.1 | 0.2 | 0.2 | 0.0 | 0.1 | 0.1 |
| . Scleroderma | 740 | 0.2 | 0.0 | 0.3 | 0.1 | 0.1 | 0.4 | 0.3 | 0.1 | 0.1 | 0.2 |
| . Hemolytic uremic syndrome | 695 | 0.2 | 1.9 | 0.2 | 0.1 | 0.1 | 0.3 | 0.3 | 0.1 | 0.1 | 0.1 |
| . Nephropathy from heroin/related abuse | 661 | 0.2 | 0.3 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.2 | 0.3 |
| . Secondary GN, other | 166 | 0.0 | 0.1 | 0.1 | 0.0 | 0.1 | 0.0 | 0.0 | 0.1 | 0.0 | 0.1 |
| **Interstitial Nephritis/Pyelonephritis** | **14577** | **4.4** | **10.8** | **4.0** | **4.6** | **4.7** | **4.1** | **5.4** | **2.4** | **4.0** | **2.8** |
| . Chronic pyelonephritis, reflux neph. | 1805 | 0.5 | 2.3 | 0.6 | 0.4 | 0.4 | 0.7 | 0.7 | 0.2 | 0.6 | 0.4 |
| . Analgesic abuse | 416 | 0.1 | 0.0 | 0.1 | 0.1 | 0.1 | 0.2 | 0.2 | 0.1 | 0.1 | 0.1 |
| . Nephropathy caused by other agents | 1865 | 0.6 | 1.4 | 0.5 | 0.7 | 0.7 | 0.4 | 0.7 | 0.4 | 0.4 | 0.3 |
| . Nephrolithiasis, Obstruction, Gouty | 4078 | 1.2 | 4.5 | 0.9 | 1.5 | 1.7 | 0.7 | 1.5 | 0.7 | 1.2 | 0.6 |
| . Nephrocalcinosis | 121 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| . Chronic interstitial nephritis | 5946 | 1.8 | 2.4 | 1.7 | 1.8 | 1.6 | 1.9 | 2.2 | 1.0 | 1.6 | 1.4 |
| . Acute interstitial nephritis | 346 | 0.1 | 0.2 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.0 |
| **Hypertensive/Large Vessel Disease** | **93651** | **28.2** | **5.0** | **21.0** | **36.8** | **30.3** | **25.8** | **25.7** | **35.9** | **23.6** | **14.4** |
| . Hypertension (no primary renal dis.) | 86403 | 26.0 | 4.6 | 20.3 | 33.0 | 27.8 | 23.9 | 22.5 | 35.5 | 22.7 | 13.6 |
| . Renal artery stenosis or occlusion | 5894 | 1.8 | 0.4 | 0.6 | 3.1 | 2.0 | 1.5 | 2.6 | 0.4 | 0.7 | 0.7 |
| . Cholesterol emboli, renal emboli | 1354 | 0.4 | 0.0 | 0.1 | 0.7 | 0.5 | 0.3 | 0.6 | 0.1 | 0.2 | 0.2 |
| **Cystic/Hereditary/Congenital Dis.** | **11618** | **3.5** | **24.4** | **4.5** | **1.7** | **3.7** | **3.3** | **4.5** | **1.6** | **2.6** | **1.9** |
| . Polycystic kidneys, adult (dominant) | 8724 | 2.6 | 2.5 | 3.7 | 1.4 | 2.6 | 2.7 | 3.4 | 1.1 | 2.0 | 1.2 |
| . Other cystic | 155 | 0.0 | 1.4 | 0.0 | 0.0 | 0.0 | 0.0 | 0.1 | 0.0 | 0.0 | 0.0 |
| . Alports, other hereditary/familial dis | 720 | 0.2 | 2.9 | 0.3 | 0.0 | 0.3 | 0.1 | 0.3 | 0.1 | 0.1 | 0.2 |
| . Other congenital hereditary | 2019 | 0.6 | 17.7 | 0.5 | 0.2 | 0.8 | 0.4 | 0.7 | 0.4 | 0.4 | 0.5 |
| **Neoplasms/Tumors** | **5428** | **1.6** | **0.6** | **1.2** | **2.1** | **1.9** | **1.3** | **2.0** | **1.0** | **0.8** | **1.0** |
| . Renal or urological neoplasms | 1457 | 0.4 | 0.6 | 0.3 | 0.6 | 0.6 | 0.3 | 0.6 | 0.2 | 0.2 | 0.3 |
| . Multiple myeloma | 2809 | 0.8 | 0.0 | 0.6 | 1.2 | 0.9 | 0.7 | 1.0 | 0.6 | 0.4 | 0.5 |
| . Light chain nephropathy | 158 | 0.0 | 0.0 | 0.0 | 0.1 | 0.1 | 0.0 | 0.1 | 0.0 | 0.0 | 0.0 |
| . Amyloidosis | 1004 | 0.3 | 0.0 | 0.3 | 0.4 | 0.3 | 0.3 | 0.4 | 0.1 | 0.1 | 0.2 |
| **Miscellaneous Conditions** | **8765** | **2.6** | **2.8** | **3.4** | **1.8** | **3.3** | **1.9** | **2.2** | **4.0** | **0.9** | **1.5** |
| . Complication post bone marr/other txp | 111 | 0.0 | 0.0 | 0.1 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| . Sickle cell disease/anemia or trait | 345 | 0.1 | 0.3 | 0.2 | 0.0 | 0.1 | 0.1 | 0.0 | 0.3 | 0.0 | 0.1 |
| . AIDS nephropathy | 3264 | 1.0 | 0.3 | 1.9 | 0.0 | 1.4 | 0.5 | 0.1 | 2.9 | 0.1 | 0.3 |
| . Traumatic/surgical loss of kidney(s) | 175 | 0.1 | 0.1 | 0.0 | 0.1 | 0.1 | 0.0 | 0.1 | 0.0 | 0.0 | 0.0 |
| . Hepatorenal syndrome | 329 | 0.1 | 0.0 | 0.1 | 0.1 | 0.1 | 0.1 | 0.1 | 0.0 | 0.0 | 0.2 |
| . Tubular necrosis (no recovery) | 3188 | 1.0 | 1.0 | 0.7 | 1.2 | 1.1 | 0.8 | 1.3 | 0.4 | 0.4 | 0.5 |
| . Other Renal Disorders | 1353 | 0.4 | 1.1 | 0.3 | 0.5 | 0.5 | 0.3 | 0.5 | 0.2 | 0.3 | 0.3 |
| **Etiology Uncertain** | **14151** | **4.3** | **8.1** | **3.8** | **4.7** | **4.6** | **3.9** | **4.7** | **3.4** | **4.9** | **3.3** |
| **Missing** | **9175** | **2.8** | **5.7** | **2.2** | **3.3** | **2.6** | **2.9** | **2.0** | **2.2** | **1.2** | **1.0** |

[1]Column percentages in any category should be compared with the "overall percent of total" (Column 2) as well as with neighboring categories. Source: Reference Tables A.15, A.16, A.18, A.20, A.22

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**Table II-2**

**Row Percents for Incidence of Treated ESRD by Detailed Primary Disease, Age, Sex and Race for all Patients, 1992-1996** [1]

| | | Age Group | | | Sex | Race | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Total | (% Age) | | | (%) | (%) | | | |
| Primary Disease | 1992-96 | <20 | 20 - 64 | >64 | Male | White | Black | Asian | Nat Am |
| **All ESRD, (reference)** | **332459** | **5155** | **171774** | **155530** | **176868** | **212461** | **97753** | **10324** | **5044** |
| **% of Total ESRD** | **100.0** | **1.6** | **51.7** | **46.8** | **53.2** | **63.9** | **29.4** | **3.1** | **1.5** |
| **Diabetes** | **130473** | **0.1** | **57.2** | **42.8** | **47.4** | **64.2** | **28.5** | **3.3** | **2.4** |
| . Type 1, juvenile type | 46100 | 0.1 | 68.3 | 31.6 | 49.3 | 70.2 | 24.9 | 2.4 | 1.6 |
| . Type 2, adult-onset or unspec. type | 84373 | 0.0 | 51.1 | 48.9 | 46.3 | 60.9 | 30.5 | 3.8 | 2.9 |
| **Glomerulonephritis** | **36499** | **4.5** | **61.9** | **33.6** | **60.8** | **68.0** | **24.1** | **5.0** | **1.2** |
| . Focal glomerulosclerosis, focal GN | 6497 | 7.9 | 70.6 | 21.5 | 62.8 | 57.7 | 37.4 | 2.7 | 1.0 |
| . Membranous nephropathy | 1554 | 1.5 | 64.2 | 34.3 | 66.5 | 71.4 | 24.2 | 2.3 | 1.1 |
| . Membranoproliferative GN, types 1&2 | 1284 | 10.1 | 69.3 | 20.6 | 60.4 | 74.2 | 16.7 | 5.5 | 1.7 |
| . IgA nephropathy, Berger's disease | 1080 | 6.1 | 80.2 | 13.7 | 69.6 | 74.0 | 8.5 | 12.4 | 1.9 |
| . IgM nephropathy | 121 | 5.0 | 80.2 | 14.9 | 66.1 | 71.1 | 10.7 | 13.2 | 0.8 |
| . Rapidly progressive GN | 1336 | 7.9 | 48.9 | 43.2 | 52.0 | 80.2 | 12.9 | 4.0 | 1.5 |
| . Goodpasture's Syndrome | 780 | 4.4 | 47.4 | 48.2 | 47.2 | 89.4 | 7.1 | 1.8 | 1.2 |
| . Post infectious GN, SBE | 214 | 3.3 | 64.0 | 32.7 | 61.7 | 75.2 | 19.2 | 2.3 | 1.9 |
| . Glomerulonephritis (GN) | 22749 | 3.0 | 59.1 | 37.9 | 60.6 | 68.4 | 23.0 | 5.7 | 1.3 |
| . Other proliferative GN | 884 | 7.4 | 62.2 | 30.4 | 56.8 | 74.0 | 18.7 | 5.4 | 1.1 |
| **Secondary GN/Vasculitis** | **8122** | **5.8** | **71.3** | **22.9** | **32.9** | **63.3** | **30.6** | **3.4** | **1.2** |
| . Lupus erythematosus, (SLE nephritis) | 4177 | 6.2 | 85.3 | 8.5 | 19.4 | 47.9 | 44.0 | 4.8 | 1.1 |
| . Polyarteritis | 173 | 4.0 | 50.3 | 45.7 | 49.1 | 82.1 | 11.6 | 4.6 | 1.2 |
| . Wegener's granulomatosis | 890 | 3.1 | 48.3 | 48.5 | 60.0 | 91.6 | 5.4 | 1.1 | 1.3 |
| . Henoch-Schonlein syndrome | 153 | 32.7 | 58.2 | 9.2 | 56.2 | 81.7 | 7.2 | 6.5 | 3.3 |
| . Vasculitis and its derivatives | 467 | 1.5 | 39.6 | 58.9 | 48.4 | 88.2 | 8.1 | 1.3 | 1.3 |
| . Scleroderma | 740 | 0.1 | 70.3 | 29.6 | 23.4 | 80.1 | 17.4 | 1.1 | 1.1 |
| . Hemolytic uremic syndrome | 695 | 14.2 | 61.0 | 24.7 | 36.5 | 82.4 | 15.3 | 1.3 | 0.7 |
| . Nephropathy from heroin/related abuse | 661 | 2.6 | 57.5 | 39.9 | 62.3 | 58.7 | 35.4 | 2.7 | 2.0 |
| . Secondary GN, other | 166 | 2.4 | 67.5 | 30.1 | 55.4 | 58.4 | 34.9 | 1.8 | 2.4 |
| **Interstitial Nephritis/Pyelonephritis** | **14577** | **3.8** | **46.6** | **49.5** | **56.7** | **79.2** | **15.9** | **2.8** | **1.0** |
| . Chronic pyelonephritis, reflux neph. | 1805 | 6.6 | 61.6 | 31.7 | 38.0 | 84.2 | 9.9 | 3.5 | 1.1 |
| . Analgesic abuse | 416 | 0.5 | 46.4 | 53.1 | 35.3 | 77.4 | 18.0 | 2.4 | 0.7 |
| . Nephropathy caused by other agents | 1865 | 3.8 | 41.6 | 54.6 | 70.6 | 77.3 | 18.8 | 2.1 | 0.8 |
| . Nephrolithiasis, Obstruction, Gouty | 4078 | 5.7 | 38.1 | 56.3 | 72.7 | 78.6 | 16.3 | 3.0 | 0.8 |
| . Nephrocalcinosis | 121 | 0.8 | 46.3 | 52.9 | 51.2 | 77.7 | 14.0 | 4.1 | 0.8 |
| . Chronic interstitial nephritis | 5946 | 2.1 | 50.0 | 47.9 | 49.0 | 78.6 | 16.5 | 2.7 | 1.2 |
| . Acute interstitial nephritis | 346 | 2.9 | 39.3 | 57.8 | 49.4 | 81.5 | 15.3 | 2.0 | 0.3 |
| **Hypertensive/large vessel disease** | **93651** | **0.3** | **38.5** | **61.2** | **57.2** | **58.2** | **37.5** | **2.6** | **0.8** |
| . Hypertension (no primary renal dis.) | 86403 | 0.3 | 40.3 | 59.4 | 56.9 | 55.4 | 40.2 | 2.7 | 0.8 |
| . Renal artery stenosis or occlusion | 5894 | 0.4 | 18.0 | 81.7 | 59.4 | 92.0 | 5.9 | 1.2 | 0.6 |
| . Cholesterol emboli, renal emboli | 1354 | 0.0 | 17.1 | 82.9 | 66.3 | 94.0 | 3.6 | 1.3 | 0.6 |
| **Cystic/Hereditary/Congenital Diseases** | **11618** | **10.8** | **66.8** | **22.3** | **55.9** | **82.2** | **13.3** | **2.3** | **0.8** |
| . Polycystic kidneys, adult (dominant) | 8724 | 1.5 | 72.8 | 25.7 | 52.3 | 83.2 | 12.6 | 2.4 | 0.7 |
| . Other cystic | 155 | 45.8 | 41.9 | 12.3 | 55.5 | 80.0 | 16.8 | 1.9 | 0.6 |
| . Alports, other hereditary/familial dis | 720 | 20.7 | 72.6 | 6.7 | 72.1 | 84.4 | 10.6 | 1.8 | 1.4 |
| . Other congenital hereditary | 2019 | 45.1 | 40.8 | 14.1 | 65.7 | 76.8 | 17.0 | 2.3 | 1.2 |
| **Neoplasms/Tumors** | **5428** | **0.6** | **37.9** | **61.6** | **61.8** | **79.0** | **18.0** | **1.5** | **0.9** |
| . Renal or urological neoplasms | 1457 | 2.1 | 37.7 | 60.2 | 70.7 | 80.6 | 16.5 | 1.2 | 1.0 |
| . Multiple myeloma | 2809 | 0.0 | 35.2 | 64.8 | 59.7 | 76.5 | 20.4 | 1.6 | 0.9 |
| . Light chain nephropathy | 158 | 0.0 | 36.7 | 63.3 | 59.5 | 75.9 | 18.4 | 3.2 | 0.6 |
| . Amyloidosis | 1004 | 0.1 | 45.6 | 54.3 | 55.4 | 83.8 | 13.4 | 1.5 | 0.8 |
| **Miscellaneous Conditions** | **8765** | **1.7** | **66.0** | **32.4** | **66.5** | **52.2** | **44.3** | **1.0** | **0.8** |
| . Complication post bone marr/other txp | 111 | 0.9 | 81.1 | 18.0 | 61.3 | 84.7 | 11.7 | 0.9 | 1.8 |
| . Sickle cell disease/anemia or trait | 345 | 4.3 | 90.4 | 5.2 | 52.2 | 5.2 | 92.2 | 0.0 | 1.4 |
| . AIDS nephropathy | 3264 | 0.6 | 98.4 | 1.1 | 76.9 | 9.3 | 87.7 | 0.2 | 0.5 |
| . Traumatic/surgical loss of kidney(s) | 175 | 2.9 | 48.0 | 49.1 | 69.1 | 82.3 | 12.6 | 1.7 | 1.1 |
| . Hepatorenal syndrome | 329 | 0.6 | 74.2 | 25.2 | 68.1 | 85.4 | 9.1 | 0.9 | 2.7 |
| . Tubular necrosis (no recovery) | 3188 | 1.6 | 39.5 | 59.0 | 60.0 | 84.2 | 12.9 | 1.3 | 0.7 |
| . Other Renal Disorders | 1353 | 4.1 | 43.2 | 52.8 | 60.2 | 78.0 | 16.8 | 2.6 | 1.2 |
| **Etiology Uncertain** | **14151** | **3.0** | **45.8** | **51.2** | **57.4** | **70.6** | **23.2** | **3.6** | **1.2** |
| **Missing** | **9175** | **3.2** | **41.7** | **55.1** | **50.7** | **46.6** | **23.4** | **1.3** | **0.6** |

[1]Row percentages in any category should be compared with the "overall percent of total" ESRD (Row 2).

Source: Reference Tables A.15, A.16, A.18, A.20, A.22

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**Table II-3**

**Treated Medicare ESRD Incidence and Prevalence by ESRD Network, 1996**

| Network | Location of Network Office[1] | States and Territories | Network Name | Point Prevalence Rates[2] 1996 | Incidence Rates[2] 1996 |
|---|---|---|---|---|---|
| 1 | CT | CT, MA, ME, NH, RI, VT | ESRD Network of New England | 909 | 263 |
| 2 | NY | NY | ESRD Network of New York, Inc. | 1102 | 263 |
| 3 | NJ | NJ, PR[3], VI[3] | TransAtlantic Renal Council | 1161 | 303 |
| 4 | PA | DE, PA | ESRD Network Organization No. 4 | 1160 | 293 |
| 5 | VA | DC, MD, VA, WV | Mid-Atlantic Renal Coalition | 1247 | 281 |
| 6 | NC | GA, NC, SC | Southeastern Kidney Council, Inc. | 1316 | 324 |
| 7 | FL | FL | ESRD Network of Florida, Inc. | 1095 | 266 |
| 8 | MS | AL, MS, TN | Network 8, Inc. | 1287 | 266 |
| 9 | IN | IN, KY, OH | Tri State Renal Network, Inc. | 1011 | 290 |
| 10 | IL[4] | IL | Renal Network of Illinois | 1137 | 290 |
| 11 | MN | MI, MN, ND, SD, WI | Renal Network of the Upper Mid-West, Inc. | 1022 | 281 |
| 12 | MO | IA, KS, MO, NE | ESRD Network Organization No. 12 | 957 | 283 |
| 13 | OK | AR, LA, OK | ESRD Network Organization No. 13 | 1172 | 266 |
| 14 | TX | TX | ESRD Network of Texas, Inc. | 1100 | 313 |
| 15 | CO | AZ, CO, NM, NV, UT, WY | Intermountain ESRD Network, Inc. | 829 | 254 |
| 16 | WA | AK, ID, MT, OR, WA | Northwest Renal Network | 768 | 223 |
| 17 | N-CA | AS[3], CA (N), CM[3], HI, GU[3] | TransPacific ESRD Network and | 1016 | 268 |
| 18 | S-CA | CA(S) | ESRD Network Organization No. 18 | 920 | 269 |

*[1] The state location of the Network Office is frequently used to identify ESRD Networks in figures throughout this report.*

*[2] Adjusted for age, race and sex. Per million population per year. Preliminary. Source: Reference Talbes B.20, A.28.*

*[3] PR=Puerto Rico, VI=Virgin Islands, AS=American Samoa, CM=Marianna Islands, GU=Guam.*

*[4] Location of network office is now Indianapolis, IN*

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**Table II-4**

nephritis/pyelonephritis was over-represented among the youngest and oldest patients. Glomerulonephritis, secondary glomerulonephritis/vasculitis, and cystic/hereditary/congenital diseases were also especially common in the <20-year age group. Primary glomerulonephritis, hypertension, and neoplasms were especially frequent in males while secondary glomerulonephritis/vasculitis and diabetes were over-represented in females.

## Geographic Patterns

Geographic variation in the prevalence and incidence of ESRD in 1996 is shown in Table II-4. Incidence rates varied from 223 to 324 per million across the 18 ESRD Networks. Since these rates were adjusted for age, race, and sex, these factors are not likely to influence these large variations. There is no clear explanation for this large range in incidence but possibilities include variation in reporting, access to care, and the incidence of underlying kidney diseases. Prevalence rates varied from 768 to 1,316 per million and could be explained by variation in incidence as well as mortality rates. The sometimes dramatic geographic variation in ESRD treatment require further analysis.

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