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 time period and is a key population measure of kidney disease and access to renal replacement therapy. Prevalence refers to all patients receiving ESRD treatment at a particular time (point prevalence) or during a given time period (period prevalence) and is a population measure of disease burden and resource requirements. Prevalence is determined by incidence and patient life expectancy.

The incidence and prevalence results reported here are derived primarily from the ESRD Medical Evidence Form and Medicare billing records (Chapter XIII documents the complexity of this process). This 1999 ADR reports incidence and prevalence counts through 1997. This lag time, actually 1.25 years when the report is prepared, represents the limits of current reporting cycles. Even with this lag, the incidence counts for 1997 are only 96.5 percent complete, based on prior experience. For example, this 1999 ADR reports a more complete 1996 ESRD incident patient count that is 3.5 percent higher than was reported in the 1998 ADR. Similar experience indicates that the current incidence reports for 1998 are less than 80 percent complete and consequently are not reported here.

Due to the known lag time until ESRD counts are completely reported, the data in this ADR should be considered preliminary for 1997. Experience indicates that counts in this report for years prior to 1997 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 (HCFA 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 this report, we count persons who have a submitted Medical Evidence Form or a Medicare claim for outpatient dialysis or a record of a kidney transplant as an ESRD patient. Chapter XIII and the 1997 ADR contain extensive discussions of issues related to accurately counting ESRD patients.

Treated Medicare ESRD Point Prevalence Counts, Rates, and Average Rate Change by Age, Sex, Race, and Primary Diagnosis

Characteristic[2]	1997[1] Count (n)	Percent of Total	Rate per Million[3]	Average % Rate Change[3] 1988-92	1992-96
Age 0-19	5,480	1.8	66	3%	3%
Age 20-44	76,018	25.0	708	6%	4%
Age 45-64	117,865	38.8	2,360	9%	7%
Age 65-74	63,197	20.8	3,840	12%	8%
Age 75+	41,523	13.7	3,027	15%	10%
Female	138,907	45.7	931	9%	7%
Male	165,176	54.3	1,314	9%	7%
Asian/Pacific Islander	10,795	3.6	1,369	6%	9%
Black	97,503	32.1	3,579	10%	7%
Native American	4,614	1.5	2,773	14%	10%
White	186,341	61.3	803	9%	6%
Other/Unknown	4,830	1.6	n.a.	n.a.	n.a.
Diabetes	100,892	33.2	366	15%	11%
Hypertension	72,961	24.0	266	11%	5%
Glomerulonephritis	52,229	17.2	190	6%	5%
Cystic Kidney Disease	13,992	4.6	51	6%	4%
Total	304,083	100.0	1,105	9%	7%

[1] *Data are preliminary for 1997.*

[2] *Patients from Puerto Rico or U.S. Territories are not included. 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] *Rates are adjusted for age, sex and race. Rates are computed relative to the corresponding population for age, sex, and race results.*

Source: Reference Table B.1 for the counts and B.8 for the rates.

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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 transplantation or first regular dialysis for chronic renal failure. It is possible that incidence is not fully reported, especially for patients who die before chronic treatment is fully established (see Chapter V for mortality reporting methods).

A patient is considered prevalent if he/she is known to be receiving dialysis treatment or to have a functioning 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 December 31, 1997). Period prevalence refers to the number of patients with treated ESRD during a period

Treated Medicare ESRD Incidence Counts, Rates, and Average Rate Change by Age, Sex, Race, and Primary Diagnosis

	1997[1]			Average % Rate Change[3]	
Characteristic[2]	Count (n)	Percent of Total	Rate per Million[3]	1988-92	1992-96
Age 0-19	1,069	1.4	13	2%	4%
Age 20-44	11,800	14.9	109	5%	4%
Age 45-64	26,253	33.2	545	8%	6%
Age 65-74	22,056	27.9	1296	11%	5%
Age 75+	17,924	22.7	1292	14%	8%
Female	36,973	46.7	242	10%	5%
Male	42,129	53.3	348	9%	6%
Asian/Pacific Islander	2,383	3.0	344	2%	11%
Black	22,926	29.0	873	10%	6%
Native American	928	1.2	586	13%	8%
White	51,171	64.7	218	9%	5%
Other/Unknown	1,694	2.1	n.a.	n.a.	n.a.
Diabetes	33,096	41.8	120	14%	9%
Hypertension	20,066	25.4	73	11%	1%
Glomerulonephritis	7,390	9.3	27	3%	3%
Cystic Kidney Disease	1,772	2.2	6	4%	1%
Total	79,102	100.0	287	9%	5%

[1] *Data are preliminary for 1997.*

[2] *Patients from Puerto Rico or U.S. Territories are not included. 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] *Rates are adjusted for age, sex and race. Rates are computed relative to the corresponding population for age, sex, and race results.*

Source: Reference Table A.1 for the counts and A.6 for the rates.

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Table II-2

of time, usually a year, and includes patients point prevalent at the end of the period as well as those who die during the period. Most prevalence statistics reported by the USRDS refer to point prevalence. Prevalence is a direct function of incidence and survival. Prevalence rates are on average 4 to 5 times higher than incidence rates because the average survival time is 4 to 5 years for ESRD patients. Changes in prevalence are attributable to changes in 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, for example. 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.

Reported ESRD Period and Point Prevalence, Incidence, Death and Lost-to-Followup Counts, 1988-97

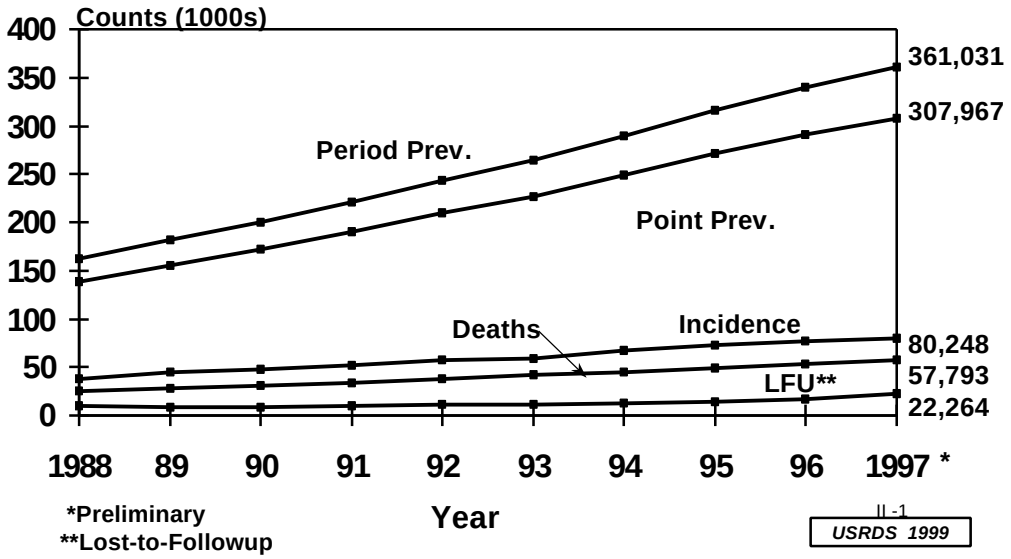

Figure II-1

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 1988-97. 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, and D.1.

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 1997, comes from the U.S. Census estimates for 1997. 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.

Growth trends are of major interest for public health surveillance and resource planning. To summarize the growth trends in incidence, we report both the incidence rate and the percent annual change in the incidence rates. The adjusted incidence rate of treated ESRD has grown steadily since the inception of the Medicare entitlement for ESRD in 1973. The determination of the most recent ESRD growth rate is complicated by uncertainty about the completeness of incident counts at the time the ADR is prepared. Through 1990, incidence rates exhibited nearly exponential growth from year to year, corresponding to a constant percentage increase in the incidence rates each year. Recently, the annual percent increase in the incidence rates has declined, resulting in continued growth, but with a linear pattern rather than an exponential pattern from year to year. The growth in incidence rates could be due to a combination of

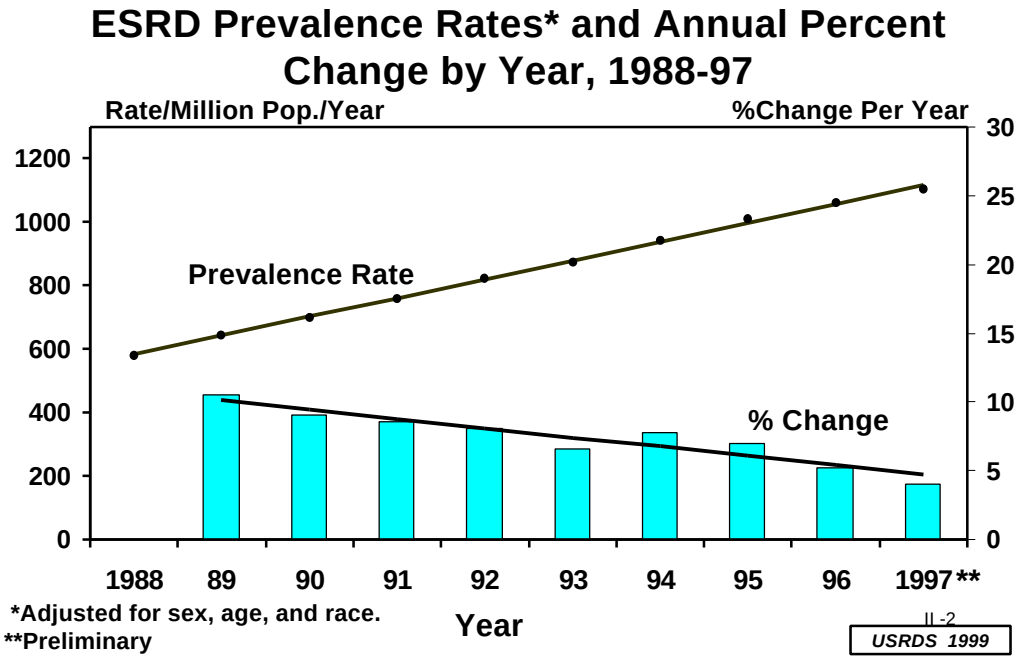

Figure II-2

ESRD prevalence rates and percent change by year, 1988-97. 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

improved referral and initiation of treatment for ESRD and to an increase in the underlying incidence of disease. A trend for decreased growth generally requires several years to confirm.

Overall Incidence and Prevalence

Table II-1 summarizes ESRD prevalence counts and rates for 1997 for the United States (excluding Puerto Rico and U.S. Territories). At the end of 1997 there were 304,083 patients being treated for ESRD. Just over 1 in a thousand U.S. citizens were receiving treatment for ESRD (the prevalence rate was 1105 per million population). Table II-2 has similar summaries related to incidence. During the year, 79,102 new patients started ESRD treatment. The incidence rate was 287 per million (2.87 per thousand). However, both prevalence and incidence rates have increased during the last ten years, as described next.

The top two lines of Figure II-1 display ESRD prevalence count trends (both dialysis and transplant patients) for 1988 to 1997. At the end of 1997, over 307,000 patients were receiving treatment for ESRD (point prevalence) while over 360,000 patients received ESRD treatment sometime during 1997 (period prevalence includes ESRD patients who died in 1997). The prevalence counts have more than doubled during this decade. The number of prevalent patients was approximately 4.5 times higher than the number of incident patients, the third line from the bottom of Figure II-1, which is expected since the average lifetime for ESRD dialysis patients 55 to 60 years old is approximately 4.5 years (see Table V-4). The USRDS database records a small 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-1 reports the number LFU and dead by year for the U.S. (including Puerto Rico and Territories).

The data points in the top line of Figure II-2 show the trend in the adjusted reported ESRD prevalence rate (cases per million population, adjusted for age, race, and sex) for the 9 years since 1988. The prevalence rate has risen every year, almost doubling during the decade. Most of the changes in prevalence rates are due to changes in incidence, because death

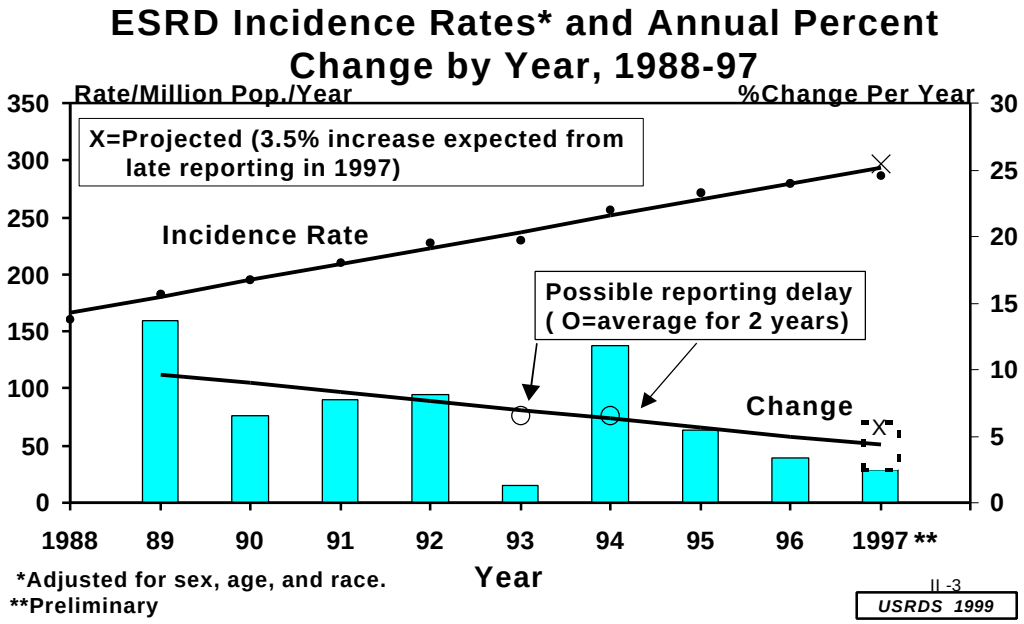

Figure II-3

ESRD incidence rates and percent change by year, 1988-97. 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.

rates have been comparatively stable (see Chapter V). The bars in Figure II-2 show the percent changes (right hand axis) in the prevalence rate relative to the prior year. The annual percent increase was near 10 percent at the start of the decade and has fallen to less than a 5 percent increase in 1997. With this drop in the annual percentage rate, the prevalent rates have grown linearly during the decade rather than exhibiting the exponential growth that would result if the annual percent increase had been consistent during the decade. Note that it would take 14 years for the rate to double with a 5 percent increase per year, while it would take only 7 years for it to double with 10 percent increases per year. The average growth rates for 1992-96 were 7 percent for all ESRD, 5 percent for nondiabetic ESRD, and 11 percent for diabetic ESRD (Table II-1). Prevalence growth rates are a major determinant of future ESRD resource needs (Lippert; Port).

The data points in the top line of Figure II-3 show the trend in the adjusted reported ESRD incidence rate (cases per million population, adjusted for age, race, and sex) for the 9 years since 1988. The incidence rate has risen every year, nearly doubling during the decade. The straight line fitted to these reported incidence rates, which has an r-square of 98.7 percent indicting a very close agreement with the observed values, is also shown. Not shown is an exponential curve fitted to these same observed incidence values, which has an r-square of 97.4 percent, indicating a slightly poorer agreement with the observed values. The bars in Figure II-3 show the percent changes (right hand axis) in the incidence rate relative to the prior year. We also inflated the 1997 rate by 3.5 percent and denote the rate with an "X" symbol. We denote the percent change of the inflated value with a dashed bar. The annual percent increases vary substantially from year to year, especially for the years 1993 and 1994. We suspect that the low growth rate for 1993 and the higher growth rate for 1994 were a result of delayed reporting of ESRD treatment start for patients who actually started in 1993. The figure also shows the average growth rate for these two years with the symbol "O" to correspond to the possibility of late reporting. In spite of the variability from year to year, it appears that the overall increases in incidence were larger at the start of the last 9 years and are smaller at the end. This is also clear from Table II-2, which shows the average annual increase in incidence rates to be 9 percent and 5 percent for the first and second halves of the decade, respectively. Note that

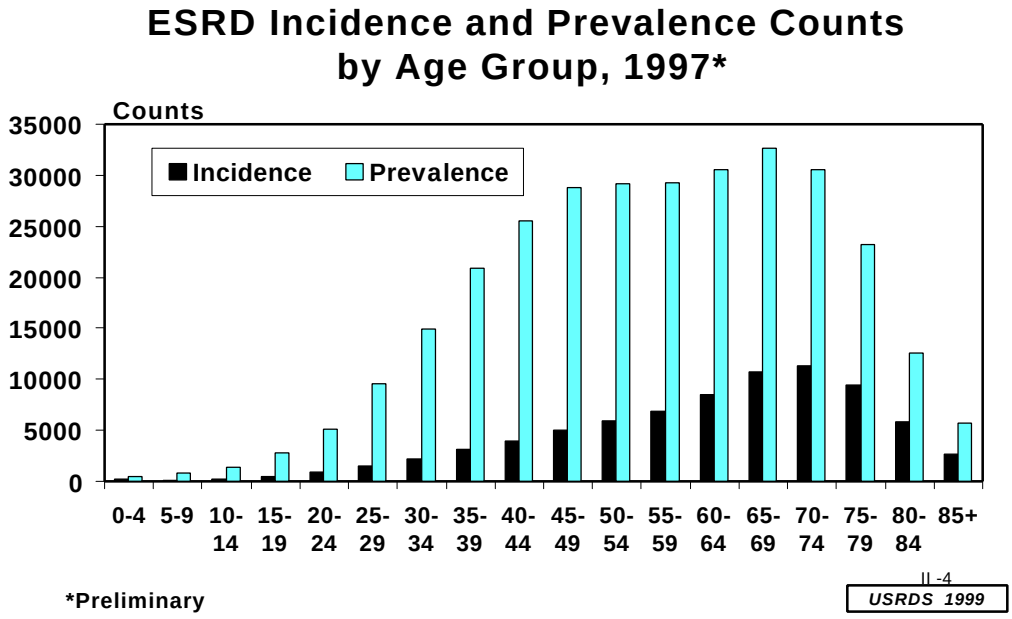

Figure II-4

ESRD incidence and prevalence counts by age group, 1997. Counts do not include patients from Puerto Rico or the U.S. Territories. Source: Reference Tables A.1, B.1.

it would take 14 years for the rate to double with a 5 percent increase per year, while it would take only 8 years for it to double with 9 percent increases per year. The increases in incidence rates differ among patient subgroups. For example, the average growth rates for 1992-96 were 5 percent overall, 3 percent for nondiabetic ESRD, and 9 percent for diabetic ESRD (Table II-2). Part of the decrease in the rate of ESRD growth could be due to incomplete reporting of patients in managed care plans. The magnitude of this phenomenon is unknown and is being explored.

ESRD incidence trends are further explored in Chapter XIII, which shows yearly counts, based on the USRDS database and the HCFA Annual Facility Survey.

Characteristics of the ESRD Patient Population

The characteristics of incident patients are described more fully in Chapter IV of this report. Here, we describe the incident and prevalent populations as they relate to age, sex, race, and cause of ESRD (diagnosis).

Entry into the ESRD patient population is described by incidence rates and exit from that population is described by death rates. The size of the prevalent ESRD population (those receiving treatment) results from the combined effects of incidence and mortality. Just as some population subgroups are over-represented among incident ESRD patients, compared to the general population, due to higher incidence rates; some groups are over-represented in the prevalent ESRD population, relative to their representation in the incident ESRD population, due to their lower death rates as ESRD patients.

Age

In 1997, the average age was 56 for prevalent patients. The age distribution of prevalent patients on December 31, 1997, is shown in Figure II-4 by 5-year age ranges and in Table II-1 in broader age ranges. The prevalence counts per 5-year age range increase with age up to more than 30,000 patients receiving ESRD therapy in the age range 65-69 and then fall to fewer than 10,000 patients age 85+ receiving ESRD treatment (Figure II-4). Table II-1 shows that the prevalence rate per million ranged between 66 and 3,027 for ages 0-19 and 75+, respectively. Between 1988 and 1992, the prevalence rate per million

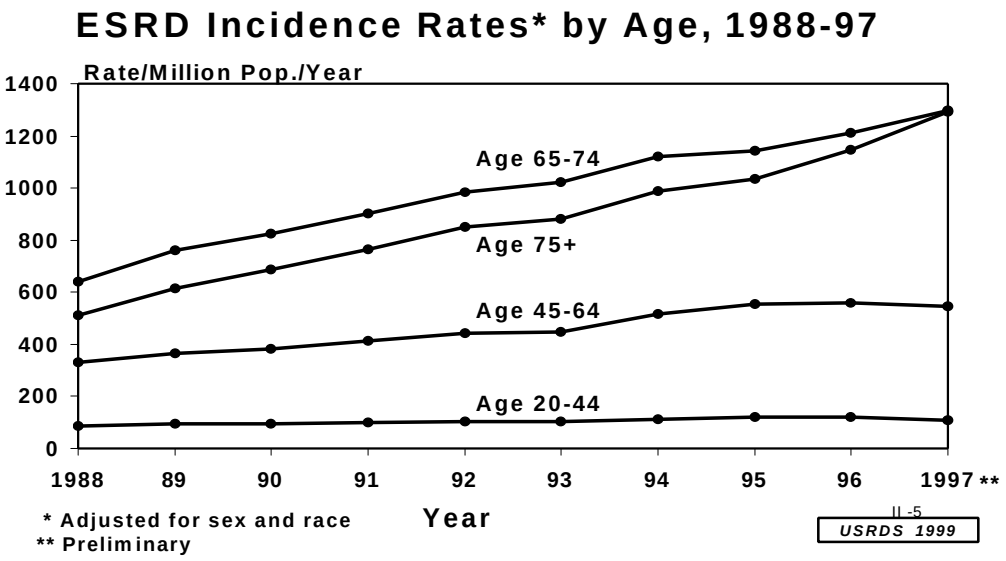

Figure II-5

Reported ESRD incidence rates per million U.S. resident population by age group, 1988-97. 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

population increased annually by between 3 percent and 15 percent for the age ranges 0-19 and 75+, respectively. The prevalence rates per million population increased more slowly from 1992-1996 than from 1988-1992 for every age range except less than 20 years.

In 1997, the average age was 61 for incident

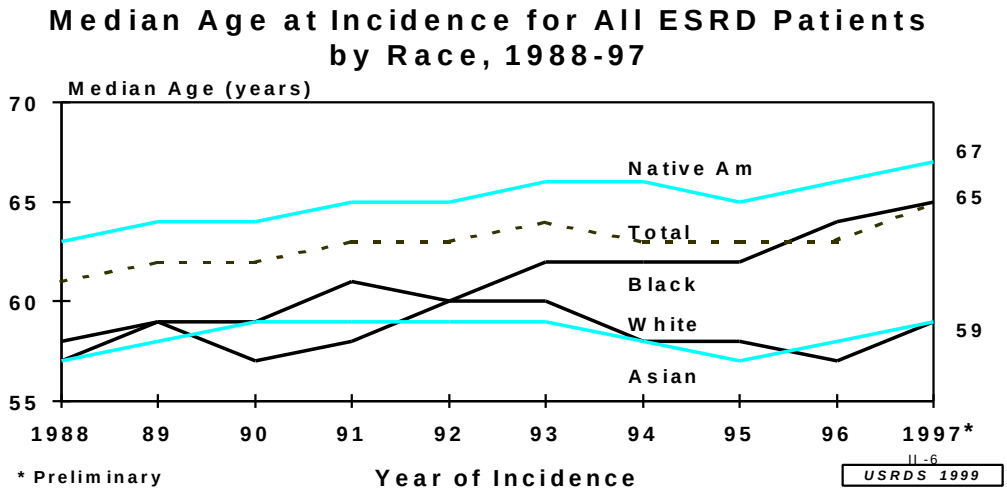

Figure II-6

Median age at incidence of ESRD by race, 1988-1997. Includes patients from Puerto Rico and U.S. Territories. Source: Reference Table A.13.

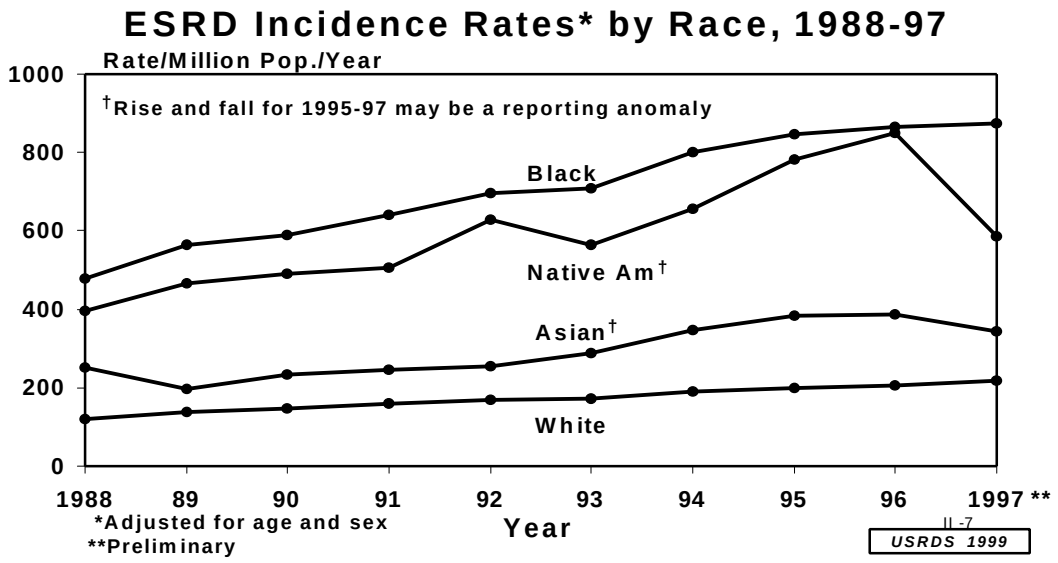

Figure II-7

ESRD incidence rates per year by race, 1988-97. Rates adjusted by sex and age. Rates do not include patients from Puerto Rico or the U.S. Territories. Source: Reference Table A.6

patients. The distribution of incident patient ages for 1997 is shown in Figure II-4. The incidence counts per 5-year age range increased steadily up to ages 70-74 and then fall steadily through age 85+. The incidence rates (Table II-2) increased steadily with age, ranging from 13 per million for ages less than 20 to a peak of 1,296 per million for ages 65-74 and then falling to 1,292 per million for ages 75+.

ESRD incidence rate trends for the last decade are shown by age group in Figure II-5. Over the first 4 years of the decade, the average rate of change in ESRD incidence was 5 percent for age 20-44, 8 percent for age 45-64, 11 percent for age 65-74, and 14 percent for age 75 and above. In the last 5 years, the average rate change in ESRD incidence was 4 percent for age 20-44, 6 percent for age 45-64, 5 percent for age 65-74, and 8 percent for age 75 and above. ESRD incidence rates grew more quickly at the end of the decade than at the start for all age groups 20 years and older. Incidence increased fastest and most consistently with prior trends in the oldest (75+) age group.

The median age of incident ESRD patients in 1997 is 65 years (Figure II-6). The median age for Native American patients is higher than White and Asian patients, while the median age for Black patients is intermediate between them. The median age appears to be rising overall and especially for Blacks and Native Americans. The pattern for White and Asian patients is less clear. The 1998 ADR showed similar trends for the mean (as opposed to median) age. The median age is approximately 5 years higher than the mean age, reflecting the skewed distribution of ages seen in Figure II-5.

Sex

The distribution of incident ESRD by sex is shown in Table II-2. In 1997, the ESRD age-race-adjusted incidence rate was 43 percent higher among males than among females with incidence rates of 348 and 242 per million population, respectively. Males represented 53 percent of the incident patients in 1997. The annual percent increase in incidence rates was similar for males and females (6 and 5 percent per year since 1993). Males represent more than half of the ESRD incident population for most causes of ESRD with some exceptions as described below.

Race

The racial distribution of incident ESRD patients in 1997 is shown in Table II-2 and continues to show disproportionately high rates of treated ESRD incidence in Blacks and Native Americans. In 1997, Blacks constituted 29.0 percent of new ESRD

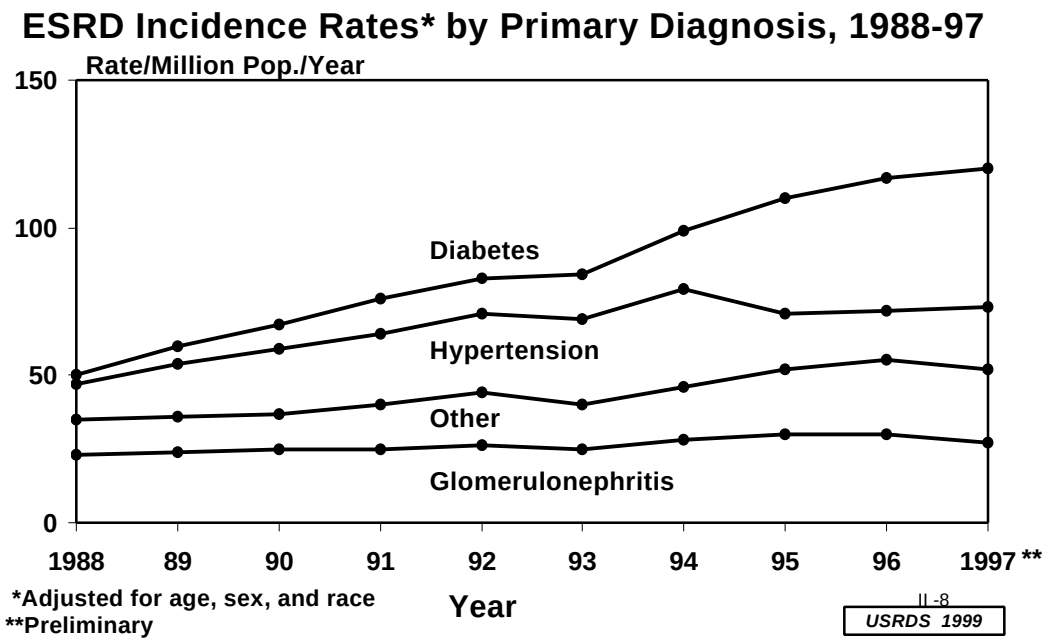

Figure II-8

ESRD incidence rates per year by primary diagnoses, 1988-97. 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.6.

patients as compared to 12.6 percent of the U.S. population and Native Americans constituted 1.2 percent of ESRD patients as compared to 0.8 percent of the U.S. population. The age-sex adjusted ESRD incidence rates were much higher for the Black (873 per million) and Native American (586 per million) populations than for the Asian/Pacific Islander (344 per million) and White (218 per million) populations.

Figure II-7 shows the age-sex adjusted incidence rates for 1988 through 1997 and Table II-2 shows the average percentage rate change from 1988-1992 and 1992-1996. For Blacks, the historical growth rate declined from 10 percent per year between 1988-1992 to 6 percent per year for 1992-1996. The rates shown in Figure II-7 for Native Americans and Asian Americans appear to have increased for the years 1995 and 1996 and then declined for 1997. This rise and subsequent decline may be a reporting anomaly. For Native Americans, the reported growth rate declined from 13 percent/year (1988-1992) to 8 percent per year (1992-1996). The decline in incidence is visually dramatic. For Asians, the growth rate increased from 2 percent per year (1988-1992) to 11 percent per year (1992-1996). Chapter IV gives more details for race groups based on a new medical evidence form that has been in use since 1995. Growth trends by race may be obscured by the race code changes for several years. Important race differences have been described for treatment rate and outcomes of ESRD. Nonetheless, it is useful to consider the scientific and cultural limitations of race classification (Witzig).

Diagnosis

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

Distribution (Column %) of Primary Disease Demographics by Demographic Subgroup (Age, Sex, Race) of Incident ESRD Patients, 1993-1997[1]

			Age Group			Sex		Race			
	Total	% of	(% Age)			(%)		(%)			
Primary Disease	1993-97	Total[2]	<20	20 - 64	>64	Male	Female	White	Black	Asian	Nat Am
All ESRD, (reference)	**357,051**	**100.0**	**5431**	**181493**	**170127**	**189951**	**167100**	**228332**	**105177**	**11654**	**5182**
Diabetes	**143,854**	**40.3**	**1.6**	**44.2**	**37.3**	**36.1**	**45.0**	**40.1**	**39.0**	**42.6**	**65.1**
. Type I, juvenile type, ketosis prone	41,521	11.6	0.8	16.0	7.3	10.9	12.4	12.8	9.7	8.4	12.0
. Type II, adult-onset or unspec. type	102,333	28.7	0.8	28.2	30.0	25.2	32.6	27.3	29.3	34.2	53.0
Glomerulonephritis	**37,642**	**10.5**	**30.1**	**12.7**	**7.6**	**12.0**	**8.8**	**11.1**	**8.6**	**17.1**	**9.0**
. Focal glomerulosclerosis, focal GN	7,333	2.1	10.3	2.8	1.0	2.4	1.7	1.9	2.5	1.6	1.3
. Membranous nephropathy	1,711	0.5	0.5	0.6	0.4	0.6	0.4	0.5	0.4	0.3	0.3
. Membranoproliferative GN, types 1&2	1,388	0.4	2.5	0.5	0.2	0.4	0.3	0.5	0.2	0.6	0.5
. IgA nephropathy, Bergers disease	1,619	0.5	1.6	0.7	0.1	0.6	0.3	0.5	0.1	1.6	0.5
. IgM nephropathy	175	0.0	0.0	0.1	0.0	0.1	0.0	0.1	0.0	0.2	0.0
. Rapidly progressive GN	1,479	0.4	2.2	0.4	0.4	0.4	0.4	0.5	0.2	0.5	0.5
. Goodpastures Syndrome	664	0.2	0.7	0.2	0.2	0.2	0.2	0.3	0.0	0.1	0.2
. Post infectious GN, SBE	258	0.1	0.2	0.1	0.0	0.1	0.1	0.1	0.0	0.1	0.0
. Glomerulonephritis (GN)	21,902	6.1	10.4	7.0	5.1	7.0	5.2	6.4	4.8	11.6	5.3
. Other proliferative GN	1,113	0.3	1.5	0.4	0.2	0.3	0.3	0.4	0.2	0.5	0.3
Secondary GN/Vasculitis	**8,552**	**2.4**	**8.9**	**3.3**	**1.2**	**1.5**	**3.5**	**2.4**	**2.5**	**2.5**	**2.0**
. Lupus erythematosus, (SLE nephritis)	4,317	1.2	4.6	2.0	0.2	0.4	2.1	0.9	1.8	1.8	0.9
. Polyarteritis	188	0.1	0.2	0.0	0.1	0.0	0.1	0.1	0.0	0.1	0.0
. Wegeners granulomatosis	949	0.3	0.7	0.2	0.3	0.3	0.2	0.4	0.0	0.1	0.2
. Henoch-Schonlein syndrome	145	0.0	0.8	0.0	0.0	0.0	0.0	0.1	0.0	0.1	0.0
. Vasculitis and its derivatives	695	0.2	0.2	0.2	0.2	0.2	0.2	0.3	0.1	0.1	0.3
. Scleroderma	761	0.2	0.0	0.3	0.1	0.1	0.4	0.3	0.1	0.1	0.2
. Hemolytic uremic syndrome	719	0.2	2.0	0.2	0.1	0.1	0.3	0.3	0.1	0.1	0.1
. Nephropathy from heroin /related abuse	531	0.1	0.2	0.2	0.1	0.2	0.1	0.1	0.2	0.1	0.2
. Secondary GN, other	247	0.1	0.0	0.1	0.0	0.1	0.1	0.1	0.1	0.0	0.0
Interstitial Nephritis/Pyelonephritis	**14,836**	**4.2**	**9.2**	**3.8**	**4.4**	**4.4**	**3.9**	**5.1**	**2.3**	**3.6**	**2.5**
. Chronic pyelonephritis, reflux neph.	1,979	0.6	2.7	0.7	0.3	0.4	0.7	0.7	0.2	0.6	0.4
. Analgesic abuse	567	0.2	0.0	0.1	0.2	0.1	0.2	0.2	0.1	0.1	0.0
. Nephropathy caused by other agents	1,768	0.5	0.9	0.5	0.5	0.6	0.4	0.6	0.3	0.3	0.2
. Nephrolithiasis, Obstruction, Gouty	4,457	1.2	3.3	0.9	1.6	1.7	0.7	1.5	0.7	1.2	0.6
. Nephrocalcinosis	180	0.1	0.0	0.0	0.1	0.1	0.1	0.1	0.0	0.1	0.0
. Chronic interstitial nephritis	5,442	1.5	2.0	1.5	1.5	1.4	1.7	1.9	0.9	1.3	1.1
. Acute interstitial nephritis	443	0.1	0.2	0.1	0.2	0.1	0.1	0.2	0.1	0.1	0.0
Hypertensive/large vessel disease	**96,796**	**27.1**	**4.9**	**20.0**	**35.4**	**29.0**	**24.9**	**24.7**	**34.2**	**23.1**	**13.0**
. Hypertension, (no primary ren. dis.)	87,817	24.6	4.5	19.2	31.0	26.2	22.8	21.0	33.8	22.2	12.2
. Renal artery stenosis or occlusion	6,701	1.9	0.3	0.6	3.3	2.0	1.7	2.7	0.4	0.7	0.6
. Cholesterol emboli, renal emboli	2,278	0.6	0.0	0.2	1.1	0.8	0.5	0.9	0.1	0.2	0.2
Cystic/Heriditary/Congenital Diseases	**12,094**	**3.4**	**26.2**	**4.4**	**1.6**	**3.6**	**3.2**	**4.3**	**1.6**	**2.7**	**1.8**
. Polycystic kidneys, adult (dominant)	8,833	2.5	2.0	3.5	1.4	2.4	2.5	3.2	1.1	2.0	1.0
. Other cystic	240	0.1	2.1	0.1	0.0	0.1	0.1	0.1	0.0	0.0	0.0
. Alports, other hereditary/familial dis	786	0.2	2.7	0.3	0.0	0.3	0.1	0.3	0.1	0.1	0.2
. Other congenital hereditary	2,235	0.6	19.3	0.5	0.2	0.8	0.4	0.7	0.4	0.6	0.5
Neoplasms/Tumors	**5,979**	**1.7**	**0.7**	**1.2**	**2.2**	**2.0**	**1.4**	**2.0**	**1.1**	**0.8**	**1.0**
. Renal or Urological Neoplasms	1,665	0.5	0.7	0.3	0.6	0.6	0.3	0.6	0.3	0.2	0.3
. Multiple myeloma	2,996	0.8	0.0	0.6	1.1	0.9	0.7	1.0	0.6	0.4	0.5
. Light chain nephropathy	252	0.1	0.0	0.0	0.1	0.1	0.1	0.1	0.0	0.1	0.0
. Amyloidosis	1,066	0.3	0.0	0.3	0.3	0.3	0.3	0.4	0.2	0.1	0.2
Miscellaneous Conditions	**10,828**	**3.0**	**3.8**	**3.7**	**2.3**	**3.7**	**2.2**	**2.6**	**4.3**	**1.0**	**1.4**
. Complication post bone marr/other txp	196	0.1	0.2	0.1	0.0	0.1	0.0	0.1	0.0	0.0	0.0
. Sickle cell disease/anemia or trait	375	0.1	0.3	0.2	0.0	0.1	0.1	0.0	0.3	0.0	0.0
. AIDS nephropathy	3,629	1.0	0.4	2.0	0.0	1.4	0.5	0.1	3.0	0.1	0.4
. Traumatic/surgical loss of kidney(s)	247	0.1	0.0	0.1	0.1	0.1	0.0	0.1	0.0	0.0	0.0
. Hepatorenal syndrome	424	0.1	0.0	0.2	0.1	0.2	0.1	0.2	0.0	0.1	0.2
. Tubular necrosis (no recovery)	3,802	1.1	1.0	0.8	1.4	1.2	0.9	1.4	0.5	0.4	0.3
. Post-Partum Fail, Oth Renal Disorders	2,155	0.6	1.7	0.5	0.7	0.7	0.5	0.7	0.3	0.4	0.3
Etiology Uncertain	**14,133**	**4.0**	**7.2**	**3.4**	**4.5**	**4.3**	**3.6**	**4.3**	**3.1**	**4.6**	**2.7**
Missing	**12,337**	**3.5**	**7.4**	**3.2**	**3.6**	**3.5**	**3.4**	**3.3**	**3.5**	**2.1**	**1.6**

[1]Column percentages in any demographic can be compared with the "overall percent of total" (Column 2)

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

0.0 indicates less than 10 patients

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Table II-3

Total Count, Median Age and Distribution (Row %) of Demographic Characteristics (Age, Sex, Race) for Each Primary Disease of Incident ESRD Patients, 1993-97[1]

		Age	Age Group			Sex	Race			
	Total	(yrs)	(% Age)			(%)	(%)			
Primary Disease	1993-97	Median	<20	20 - 64	>64	Male	White	Black	Asian	Nat Am
All ESRD, (reference)	**357051**	**64**	**5431**	**181493**	**170127**	**189951**	**228332**	**105177**	**11654**	**5182**
% of Total ESRD	**100.0**		**1.5**	**50.8**	**47.6**	**53.2**	**63.9**	**29.5**	**3.3**	**1.5**
Diabetes	**143854**	**63**	**0.1**	**55.6**	**44.1**	**47.7**	**63.6**	**28.5**	**3.5**	**2.3**
. Type 1, juvenile type	41521	56	0.1	69.5	30.0	50.0	70.2	24.7	2.4	1.5
. Type 2, adult-onset or unspec. type	102333	64	0.0	49.9	49.8	46.8	60.9	30.1	3.9	2.7
Glomerulonephritis	**37642**	**54**	**4.3**	**60.7**	**34.5**	**60.8**	**67.4**	**24.0**	**5.3**	**1.2**
. Focal glomerulosclerosis, focal GN	7333	46	7.6	68.0	23.9	62.3	58.5	36.5	2.6	0.9
. Membranous nephropathy	1711	59	1.7	60.8	37.3	65.8	70.6	24.9	2.3	0.9
. Membranoproliferative GN, types 1&2	1388	46	9.9	67.7	21.8	59.0	74.4	16.5	5.2	2.0
. IgA nephropathy, Berger's disease	1619	41	5.3	80.4	14.2	68.3	75.7	7.4	11.3	1.7
. IgM nephropathy	175	43	4.0	80.6	15.4	68.4	77.7	8.0	10.3	0.6
. Rapidly progressive GN	1479	62	7.6	46.0	44.4	50.8	80.0	12.6	3.9	1.8
. Goodpasture's Syndrome	664	62	5.6	47.9	45.8	46.7	88.9	7.1	2.1	1.2
. Post infectious GN, SBE	258	55	4.7	63.2	32.2	61.6	77.5	16.3	3.1	1.6
. Glomerulonephritis (GN)	21902	58	2.6	57.6	39.4	60.6	67.1	23.2	6.2	1.3
. Other proliferative GN	1113	52	7.3	61.9	30.7	58.2	73.9	18.1	5.4	1.4
Secondary GN/Vasculitis	**8552**	**46**	**5.7**	**70.3**	**23.7**	**32.4**	**63.1**	**30.5**	**3.3**	**1.2**
. Lupus erythematosus, (SLE nephritis)	4317	38	5.8	85.0	8.8	18.5	47.2	44.2	4.8	1.1
. Polyarteritis	188	64	4.8	46.8	48.4	47.8	83.5	10.6	5.3	0.5
. Wegener's granulomatosis	949	64	4.2	46.3	49.1	58.8	91.9	5.2	1.3	0.9
. Henoch-Schonlein syndrome	145	26	31.0	58.6	8.3	57.1	81.4	8.3	6.2	2.8
. Vasculitis and its derivatives	695	68	1.9	40.1	58.0	47.6	87.5	7.6	1.6	2.0
. Scleroderma	761	57	0.1	67.1	32.1	22.5	77.8	18.8	1.4	1.1
. Hemolytic uremic syndrome	719	49	14.7	61.3	23.8	35.4	80.1	17.4	1.3	0.7
. Nephropathy from heroin/related abuse	531	53	2.3	62.7	34.8	62.8	54.4	40.3	2.3	1.9
. Secondary GN, other	247	52	2.8	65.2	32.0	58.7	58.7	34.8	2.0	2.0
Interstitial Nephritis/Pyelonephritis	**14836**	**65**	**3.3**	**46.2**	**50.1**	**56.4**	**78.8**	**16.1**	**2.8**	**0.9**
. Chronic pyelonephritis, reflux neph.	1979	49	7.4	62.6	29.8	39.4	84.0	10.4	3.3	1.1
. Analgesic abuse	567	66	0.5	43.4	56.1	36.1	76.9	18.7	2.5	0.7
. Nephropathy caused by other agents	1768	65	2.7	46.2	50.9	66.2	77.4	18.2	2.2	0.6
. Nephrolithiasis, Obstruction, Gouty	4457	68	3.9	36.5	59.2	73.3	78.3	16.1	3.1	0.7
. Nephrocalcinosis	180	68	0.6	46.1	53.3	53.0	76.7	16.7	3.9	0.6
. Chronic interstitial nephritis	5442	64	1.9	49.3	48.3	48.5	77.7	17.3	2.7	1.0
. Acute interstitial nephritis	443	68	2.9	37.2	58.2	48.7	81.9	14.7	2.0	0.2
Hypertensive/large vessel disease	**96796**	**69**	**0.3**	**37.3**	**62.2**	**57.0**	**58.3**	**37.2**	**2.8**	**0.7**
. Hypertension (no primary renal dis.)	87817	68	0.3	39.4	60.0	56.7	54.7	40.4	2.9	0.7
. Renal artery stenosis or occlusion	6701	73	0.3	16.8	82.8	57.7	92.3	5.6	1.2	0.5
. Cholesterol emboli, renal emboli	2278	72	0.0	16.1	83.9	65.9	94.9	3.3	1.1	0.4
Cystic/Hereditary/Congenital Diseases	**12094**	**50**	**11.7**	**65.1**	**22.7**	**56.2**	**81.3**	**13.7**	**2.6**	**0.8**
. Polycystic kidneys, adult (dominant)	8833	54	1.2	71.6	26.7	52.6	82.4	13.1	2.6	0.6
. Other cystic	240	22	46.7	42.5	10.8	50.0	81.7	14.2	1.3	1.3
. Alports, other hereditary/familial dis	786	24	18.8	72.4	8.1	69.8	84.2	11.1	1.9	1.3
. Other congenital hereditary	2235	33	46.5	39.1	13.6	66.4	75.7	17.1	2.9	1.2
Neoplasms/Tumors	**5979**	**60**	**0.6**	**36.8**	**62.4**	**62.0**	**78.1**	**18.6**	**1.5**	**0.9**
. Renal or urological neoplasms	1665	15	2.2	35.5	62.1	72.5	79.8	17.1	1.3	1.1
. Multiple myeloma	2996	53	0.0	35.2	64.7	59.2	75.8	20.8	1.7	0.9
. Light chain nephropathy	252	41	0.0	34.1	65.9	61.8	77.0	18.3	3.2	0.4
. Amyloidosis	1066	21	0.1	44.2	55.5	53.8	82.4	15.0	1.0	0.8
Miscellaneous Conditions	**10828**	**35**	**1.9**	**62.6**	**35.4**	**65.4**	**55.2**	**41.4**	**1.1**	**0.7**
. Complication post bone marr/other txp	196	26	5.1	77.6	17.3	62.8	86.2	10.7	1.0	1.0
. Sickle cell disease/anemia or trait	375	14	4.5	89.6	5.6	52.7	5.1	93.1	0.3	1.1
. AIDS nephropathy	3629	12	0.6	98.1	1.1	74.9	9.0	87.6	0.2	0.6
. Traumatic/surgical loss of kidney(s)	247	68	2.4	44.1	53.4	70.3	81.8	13.0	2.0	1.2
. Hepatorenal syndrome	424	68	0.5	73.1	26.4	69.1	82.5	10.8	1.7	2.6
. Tubular necrosis (no recovery)	3802	69	1.4	36.7	61.7	59.9	84.1	13.2	1.3	0.4
. Other Renal Disorders	2155	71	4.2	42.4	53.4	59.9	79.3	16.4	2.3	0.7
Etiology Uncertain	**14133**	**66**	**2.7**	**43.3**	**53.5**	**57.4**	**70.2**	**23.2**	**3.8**	**1.0**
Missing	**12337**	**53**	**3.6**	**55.1**	**50.1**	**53.7**	**61.4**	**29.5**	**1.9**	**0.7**

[1]Row percentages in any primary disease group can be compared with the "overall percent of total" ESRD (Row 2).
Source: Reference Tables A.15, A.16, A.18, A.20, A.22
0.0 indicates less than 10 patients

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Table II-4

Mean Age and Diabetes among Prevalent Patients, ESRD Incidence by ESRD Network, 1997

Net-work	Location of Network Office[1]	States and Territories	Network Name	Prevalence		Point Prevalence		Incidence	
				Mean Age[2]	Cause Diabetes	Counts	Rates[3]	Counts	Rates[3]
1	CT	CT, MA, ME, NH, RI, VT	ESRD Network of New England	57.8	28%	12,844	909	3,199	263
2	NY	NY	ESRD Net. of New York, Inc.	56.6	29%	21,206	1,102	5,707	263
3	NJ	NJ, PR[4], VI[4]	TransAtlantic Renal Council	57.0	32%	13,337	1,161	3,776	303
4	PA	DE, PA	ESRD Net. Org. No. 4	57.6	30%	15,592	1,160	4,181	293
5	VA	DC, MD, VA, WV	Mid-Atlantic Renal Coalition	56.1	30%	18,879	1,247	4,910	281
6	NC	GA, NC, SC	Southeastern Kidney Council, Inc	55.8	31%	25,877	1,316	6,143	324
7	FL	FL	ESRD Net. of Florida, Inc.	58.0	29%	16,725	1,095	4,758	266
8	MS	AL, MS, TN	Net. 8, Inc.	55.6	30%	16,918	1,287	4,228	266
9	IN	IN, KY, OH	Tri State Renal Net., Inc.	55.8	32%	22,446	1,011	5,708	290
10	IL[5]	IL	Renal Net. of Illinois	55.7	29%	14,123	1,137	3,632	290
11	MN	MI, MN, ND, SD, WI	Renal Net. of the Upper Mid-Wes	55.6	33%	22,505	1,022	5,307	281
12	MO	IA, KS, MO, NE	ESRD Net. Org. No. 12	56.0	32%	12,631	957	3,174	283
13	OK	AR, LA, OK	ESRD Net. Org. No. 13	55.4	33%	12,743	1,172	3,474	266
14	TX	TX	ESRD Net. of Texas, Inc.	55.3	37%	22,621	1,100	5,490	313
15	CO	AZ, CO, NM, NV, UT, WY	Intermountain ESRD Net., Inc.	54.9	40%	12,557	829	3,140	254
16	WA	AK, ID, MT, OR, WA	Northwest Renal Net.	54.2	32%	8,982	768	2,076	223
17	N-CA	AS[4], CA (N), CM[4], HI, GU[4]	TransPacific ESRD Net.	56.2	33%	14,156	1,016	3,677	268
18	S-CA	CA(S)	ESRD Net. Org. No. 18	55.9	33%	19,786	920	5,533	269
Total[6]				**56.0**	**32%**	**304,083**	**1,041**	**77,248**	**268**

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

[2] Age on December 31, 1997

[3] Adjusted for age, race and sex. Per million population per year. Preliminary.

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

[5] Location of network office is now Indianapolis, IN

[6] Includes patients where network is unknown.

Source: Reference Tables A.1, A.6, A.26, A.28, B.1, B.8, B.18, B. 20, Special Analysis .

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Table II-5

The distribution of new ESRD cases by attributed major diagnosis is shown in Table II-2 for 1997 and in Figure II-8 for the period from 1988-1997. Diabetes was the most common attributed cause of ESRD followed by hypertension, glomerulonephritis, and cystic diseases. Other causes combined to make up 16 percent of new ESRD and missing reports account for 5 percent of incident cases. The growth in new ESRD cases was highest for diabetes. The incidence rate of diabetes grew by 9 percent annually since 1992 while incidence rates for other major causes grew by 3 percent, or less, per year.

Detailed listing of ESRD diagnoses, broken down by demographic subgroups, is provided in Table II-3 and II-4. Table II-3 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 (30.1 percent) and cystic/hereditary/congenital diseases (26.2 percent) whereas diabetes is rare (1.6 percent). For the oldest age group (>64 years) the most common attributed causes of ESRD are hypertension (35.4 percent) and diabetes (37.3 percent). Diabetes is, overall, the most common attributed cause 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 (65.1 percent) and, to a lesser extent, Asians/Pacific Islanders (42.6 percent). Hypertension is notably high among Blacks (34.2 percent) and glomerulonephritis is disproportionately high for Asians/Pacific Islanders (17.1 percent).

Table II-4 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 nephritis/pyelonephritis was over-represented among the youngest 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 diagnoses were over-represented in females.

Geographic Patterns

Geographic variation in the prevalence and incidence of ESRD in 1997 is shown in Table II-5. 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. Mean age varied from 54.2 to 58.0, while percent diabetic ranged from 28 to 40 percent among the 18 ESRD Networks.

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