

# **Chapter II**

## **Prevalence of ESRD Therapy**

The most frequent data request received by the USRDS CC is a basic question: "How many people have end-stage renal disease (ESRD)?" This question frames the way the renal community approaches ESRD in a variety of ways. The prevalence counts indicate how pervasive ESRD is within the U.S. population, and are therefore critical for those who have an interest in public health, budget planning issues, provision of care, product development and prevention of ESRD. These data also indicate to the medical community what the future may hold in terms of treatment needs.

Each year the USRDS reports an increase in both the count- that is, the number of people with ESRD, and the rate- or the fraction of the overall population affected by the disease. Previous reports have discussed some of the reasons for growth in prevalence. Heightened awareness has probably led to a reduction in the number of people with untreated chronic uremia. The changes in U.S. demographics, specifically the growing elderly population, contribute to the increase in patients requiring renal replacement therapy. In addition, there has also been a steady decline in the mortality of ESRD patients, extending the average lifetime during which patients require therapy. This combination of factors has led to an exponential rate of growth in the ESRD population. In addition, preliminary results from the Casemix Adequacy Study indicate that the data received from HCFA's ESRD Program Medical Management and Information System (PMMIS), may undercount the Medicare patients by as much as five percent.

This chapter presents an overview of the number of people receiving ESRD therapy in the United States and describes overall demographic trends in the treated ESRD population over the last decade. For the first time there is an inclusion of basic demographic characteristics for a sample of the Hispanic ESRD population from the Casemix

Adequacy Study. In an attempt to accurately depict what the future ESRD population will look like, percent increases experienced by various subgroups in the recent past are reported.

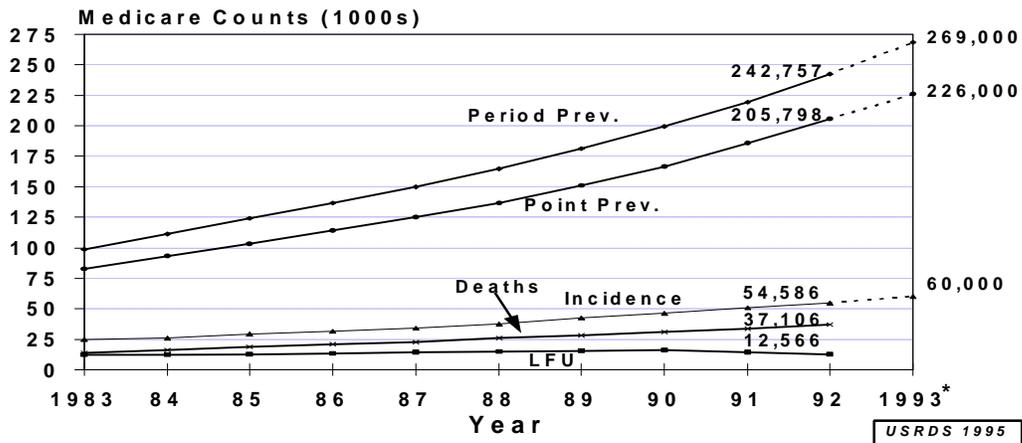
---

### **The Medicare ESRD Program**

Recent evidence suggests improved success with both major forms of ESRD therapy, maintenance dialysis and kidney transplantation (see Chapters VI and VIII). Despite these improvements, kidney failure is often associated with devastating medical, social and economic costs. The U.S. government has implemented several programs designed to improve access to quality treatment for ESRD and to alleviate the financial impact of ESRD on patients and their families. The most immediate and timely help comes through the provision and regulation of medical care to the patient and through financing much of the cost of this care. As part of the 1972 Amendments to the Social Security Act, Congress extended coverage under Medicare, the public insurance program funded by the Federal Government, to people with end-stage kidney failure (Fox, Rettig, HCFA 1993). Several legislative changes have occurred since 1973, including the 1978 Social Security Amendments, that have sought to encourage reduction in treatment costs through shifts toward home dialysis and changes in payment methods (HCFA 1982, HCFA 1993).

Medicare coverage for the ESRD program has been expanded to include immunosuppressive drugs administered to kidney transplant recipients for up to 3 years and for erythropoietin therapy in dialysis patients (Erslev, HCFA 1993). Both of these programs provide coverage for outpatient drugs, and are exceptions to the general rules governing Medicare insurance.

**Treated Medicare ESRD Period and Point Prevalence, Incidence, Death and Lost-to-Follow-up Counts, 1983-93\***



**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 follow-up (see Chapter XIV for details). Point prevalence counts exclude patients lost to follow-up (LFU). Patients in Puerto Rico and U.S. Territories are included in all estimates. Medicare patients only. \*1993 projections are based on geometric growth calculations. Source: Reference Tables B.1, B.3, A.1, D.1.

Medicare now insures the vast majority of Americans treated for ESRD, providing coverage to over 92 percent of dialysis patients and 90 percent of kidney transplant recipients in 1991 (see discussion later in this chapter). The ESRD population represents a growing fraction of total Medicare beneficiaries, largely due to growth in the incidence of treated ESRD (see Chapter IV). Between 1976 and 1991, the ESRD portion of the total Medicare population increased five-fold, from 0.1 to 0.5 percent (MADRS).

### How Many Americans Have ESRD?

During 1992 Figure II-1 shows that over 242,000 people in the 50 states and the District of Columbia were treated for end-stage renal disease under the Medicare program. This figure includes patients with current or past Medicare eligibility, including those with a functioning kidney transplant who have lost eligibility, but does not include those ESRD patients not in the USRDS data system. (Chapter I for details). When including patients not in the Medicare program, the 1992 ESRD period prevalence count, defined as the number of people receiving treatment for ESRD sometime during the year, approached 255,000. Using a geometric growth calculation we

have estimated what the period, point and incidence counts will be for 1993.

The constant increase in Medicare ESRD enrollees from 1983 to 1992 is illustrated in Figure II-1. Estimated period prevalence counts and point prevalence counts (patients treated on 12/31 of the year) increased 11 and 12 percent, respectively, between 1991 and 1992. This continues a trend that has yielded a 9 to 13 percent increase in prevalence counts each year since 1984. Figure II-1 also illustrates trends in counts of patients who are incident (i.e., new to ESRD), patients who have died and patients who are lost to follow-up. As shown in Figure II-1, there were 205,798 Medicare patients under treatment with all modalities on December 31, 1992. During 1992, there were 54,586 incident (i.e., new to ESRD) patients, 37,106 deaths among ESRD patients and 12,566 patients previously in the data files who were classified as lost to follow-up (LFU).

As described in the last two Annual Data Reports (USRDS 1994, USRDS 1993) and also in Chapter XIV of this report, USRDS point prevalence estimates do not include dialysis patients who are lost to follow-up. Patients are considered lost to follow-up if there is no information in the USRDS patient

### Reported ESRD Prevalence Counts by Data Source and Medicare Eligibility, 1984-92

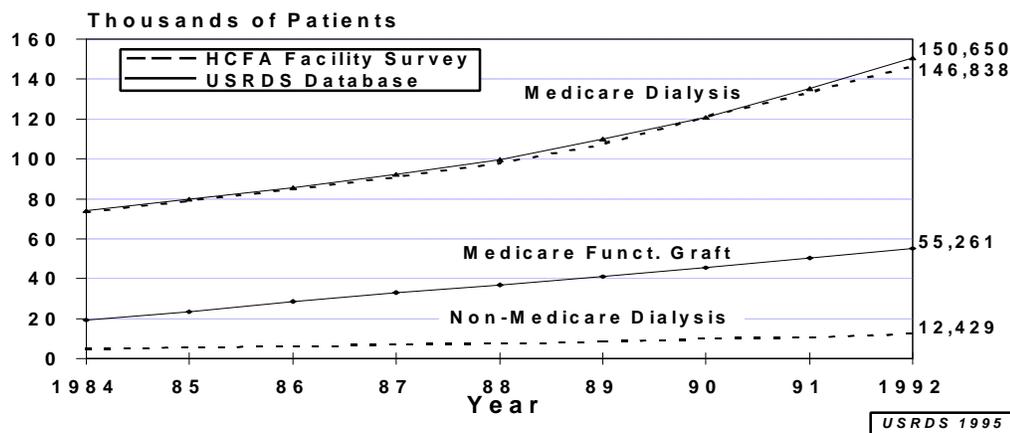


Figure II-2

Reported point prevalent counts on December 31 of each year from 1984-92 for: Medicare dialysis patients, including patients whose Medicare eligibility is current or pending (from HCFA 1993 Facility Survey, 1993 FS, and the USRDS database, DB); Medicare patients with a functioning kidney transplant (from USRDS DB); and dialysis patients not insured by Medicare (from 1993 FS). Prevalence counts also do not include approximately 1500 Department of Veteran Affairs (DVA) patients who are not counted by the FS. Counts of Medicare dialysis patients from the USRDS DB do not include patients lost to follow-up. All prevalence counts include patients in Puerto Rico and U.S. territories. Source: Reference Tables C.2, I.10.

database regarding dialysis, transplant, or death status for a period of one year or more as of 12/31 of the year. An exception is made during the first year following the reported date of first ESRD service, since many patients who have private insurance are not yet eligible for Medicare or have other primary insurance coverage during the first year of ESRD (and up to 21 months from start of ESRD). Analyses of HCFA reimbursement data for patients identified as lost-to-follow-up suggest that less than ten percent of these patients had sufficient Medicare spending to be receiving regular dialysis (USRDS 1992).

The exclusion of Medicare patients lost to follow-up reduces the effective 1992 ESRD point prevalence by over 12,566 patients. The number of patients classified as lost to follow-up fluctuated between 12,000 and 15,000 for most of the 1980s, but as a percentage of the total point prevalence has dropped from 10 percent to 5.2 percent since 1988. Further details regarding the lost-to-follow-up classification can be found in Chapter XIV of this report and in Chapter XI of the 1992 ADR (USRDS 1992).

The point prevalence of treated ESRD (the number of people receiving renal replacement therapy, RRT, on December 31) from 1983-92 is reported separately for dialysis patients with and without Medicare eligibility and for kidney transplant recipients in Figure II-2. Data are provided from two sources, the USRDS patient database and the HCFA Annual Facility Survey (AFS). The AFS is focused on dialysis facilities, and as such does not provide a count of prevalent kidney transplant recipients. The USRDS point prevalence count of dialysis patients who are (or will be) insured by Medicare was 150,650 after excluding patients lost to follow-up. This estimate is only slightly different from the count of Medicare dialysis patients from the AFS, varying by two percent or less of the AFS count for most of the 83-92 period. These counts do not include dialysis patients who were not insured by Medicare (and are not included in the USRDS database), who numbered 12,566 patients in 1991.

<b>Treated Medicare ESRD Point Prevalence Counts and Rates<sup>1</sup></b>			
<b>By Age, Sex, Race, and Primary Diagnosis</b>			
<b>December 31, 1992</b>			
<b>Characteristic<sup>2</sup></b>	<b>Count (N)</b>	<b>Percent of Total</b>	<b>Prevalence Rate per Million<sup>3</sup> in Each Group</b>
Age 0-19	4,201	2.0	57
Age 20-44	60,167	29.2	584
Age 45-64	76,545	37.2	1,732
Age 65-74	42,168	20.5	2,560
Age 75+	22,717	11.0	1,859
Female	94,142	45.7	669
Male	111,656	54.3	940
Asian/Pacific Islander	4,932	2.4	754
Black	63,286	30.8	2,509
Native American	2,792	1.4	1,871
White	132,588	64.4	598
Other/Unkown	2,200	1.1	n.a.
Diabetes	56,059	27.2	216
Hypertension	49,438	24.0	191
Glomerulonephritis	36,973	18.0	142
Cystic Kidney	9,984	4.9	39
Total	205,798	100.0	791

<sup>1</sup>Rates are adjusted for age, sex and race. Rates are computed relative to the corresponding population for age, sex, and race results.

<sup>2</sup>Patients with other or unknown race are excluded from rate analyses. Other urologic, other, unknown and missing diagnoses are included in the total but are not shown.

<sup>3</sup>Counts and rates do not include patients from Puerto Rico or U.S. Territories.

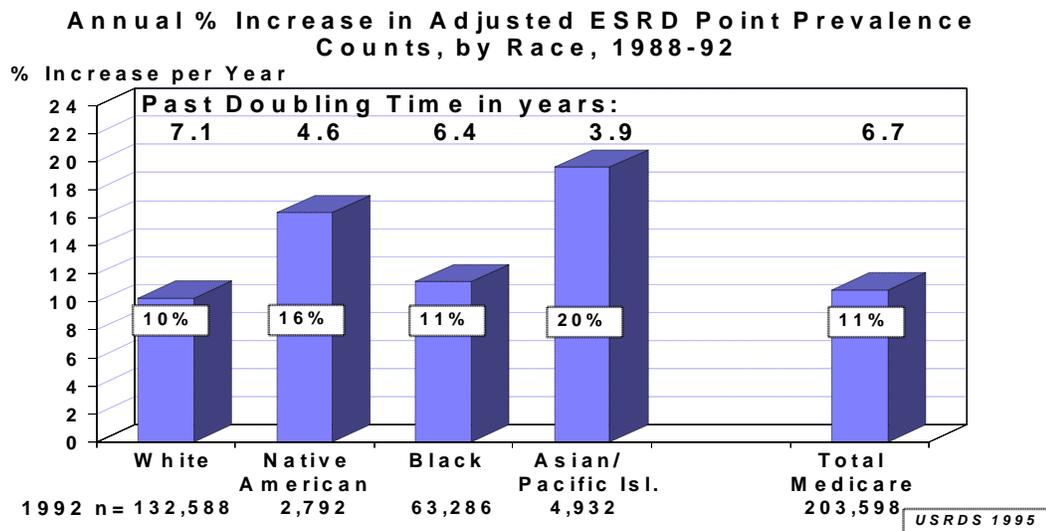
Source: B.1 for the counts and B.8 for the rates.

**Table II-1**

An additional 55,261 people with a functioning kidney transplant were reported alive according to the Medicare ESRD program in 1992. This estimate includes transplant recipients whose Medicare eligibility has been terminated. An analysis of patients who received a kidney transplant during 1983-86 and were Medicare eligible at time of transplant (USRDS 1993) shows that one third of recipients were no longer Medicare eligible at 3.5 years following transplant (Reference Table F.62). Kidney transplant recipients who lose Medicare eligibility are included in all USRDS prevalence estimates throughout this report.

## Characteristics of the Prevalent ESRD Population

Table II-1 shows some basic demographic characteristics of the Medicare ESRD patient population on December 31, 1992. These breakdowns indicate that the 45-64 age group continues to represent the majority of the ESRD



**Figure II-3**

Annual percent increases in adjusted point prevalence counts by race 1988-92. Total counts by subgroup for 1992. The number of years it has taken for that subgroup to double in total counts. Excludes patients in Puerto Rico, U.S. territories, and patients lost to follow-up. Medicare patients only. Source Reference Table B.6.

population. In comparison with the 1994 Annual Report the younger age groups now represent a smaller percent of the total ESRD population, with age 0-19 now declining from 2.2 to 2.0 percent of total, and 20-44 experiencing a drop from 30.2 to 29.2 percent. Both of these changes are due to the growth among the elderly ESRD population since the actual prevalence count grew in all age groups.

The distribution of prevalent patients by sex shows that females still make up 46 percent of the population. Examining the table by race shows that while 64 percent of the patients are white, this is a decline of 1.4 percentage points from 1991. Blacks continue to be 31 percent of the total ESRD population, and the Asian/Pacific Isl. and Native American groups which have increased slightly from 2.1 to 2.4 percent and 1.2 to 1.4 percent, respectively. The three primary diagnose of diabetes (27 percent), hypertension (24 percent), and glomerulonephritis (19 percent) continue to account for 69 percent of the cause of renal failure, though among those groups diabetes increased from 26.1 to 27.2 from 1991 to 1992.

The 1992 Medicare ESRD point prevalence rate was 791 per million U.S. resident population, or one patient per 1264 U.S. residents. Rates by age show that ESRD is more common with increasing age; it was four times as common among people 65 to 74

years of age compared to people 20 to 44 years of age. Treated ESRD is also more common in males (940 patients per million, or PPM) than in females (669 PPM). Point prevalence rates adjusted for age and race (Reference Table B.16) show an almost two-fold higher rate of renal failure caused by hypertension or glomerulonephritis in males compared to females. Prevalence rates by race indicate that Blacks are overrepresented among patients with ESRD. Among Black Americans there is 1 ESRD patient per 399 U.S. residents. In contrast, there is 1 patient per 1,672 White U.S. residents. Further details on these characteristics for incident patients are reported in Chapter III.

As shown in Figure II-4, the number of Medicare ESRD patients treated on December 31, 1992 (205,798), represents a doubling in the point prevalence count since the end of 1985 (101,799). These estimates do not include patients in Puerto Rico and the U.S. Territories, for whom information about race in the resident population was not available. Point prevalent counts have at least doubled in the last eight years for all four race groups as shown in Figure II-3. Counts for Native Americans and Asian/Pacific Islanders have doubled

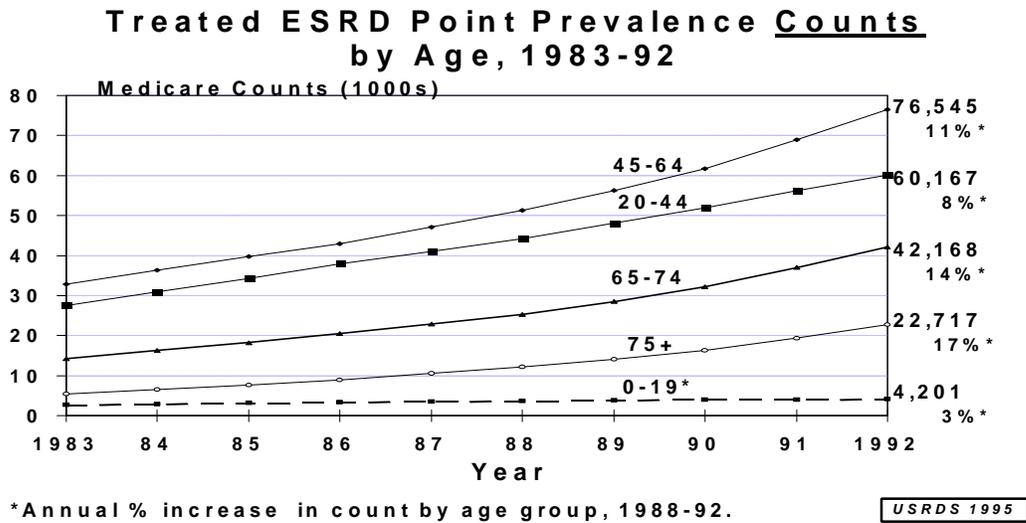


Figure II-4

Reported ESRD point prevalence counts (patients alive on December 31) by age at onset of ESRD and year, 1983-92. No adjustments have been made for changes in demographic characteristics. Excludes patients in Puerto Rico, U.S. territories, and patients lost to follow-up. Medicare patients only. Source Reference Table B.1.

since 1986 and 1988, respectively. Results from the USRDS Data Validation Special Study (USRDS 1992) indicated that Native Americans were often miscoded as white patients. Thus, the estimates in

Figure II-3 may understate the true count of Native Americans in the Medicare ESRD population. Note that these trends in point prevalence counts reflect both growth in the rate of treated Medicare ESRD patients per population, changes in average lifetimes

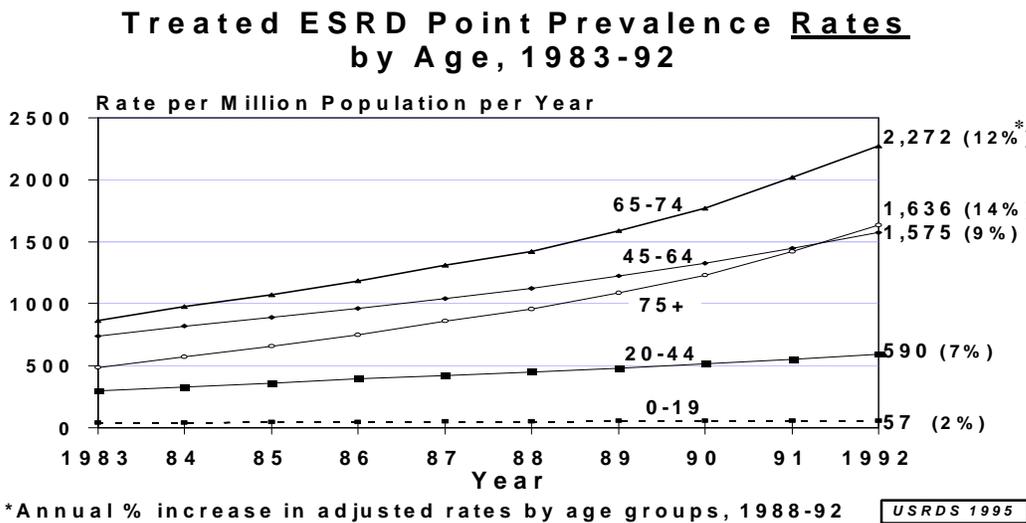


Figure II-5

Reported ESRD point prevalence rates prevalence rate per million U.S. resident population between 1988 and 1992, by age at onset of ESRD and year, 1983-92. No adjustments have been made for changes in demographic characteristics. Prevalence rates are adjusted for race, primary diagnosis and sex using the 1991 U.S. resident population. Excludes patients in Puerto Rico, U.S. territories, and patients lost to follow-up. Medicare patients only. Source Reference Table B.1.

**Descriptive Statistics From the Casemix Adequacy Study,  
By Ethnicity 1990-91**

<b>Patient Characteristics</b>	<b>non-Hispanic</b>	<b>Hispanic</b>
<b>Patient Demographics</b>		
Age at Study Start Date (mean in years)	58.7	56.7
<b>Race</b>		
White (%)	55.4	86.9
Black (%)	40.0	5.8
Other Race (%)	4.7	7.3
<b>Sex</b>		
Male (%)	50.7	49.7
Female (%)	49.3	50.3
<b>Anthropometric Characteristics (mean)</b>		
Weight (kg)	69.0	64.2
Height (cm)	168.4	162.6
Body mass index (Kg/m <sup>2</sup> )	24.3	24.3
<b>Primary Cause of ESRD</b>		
Diabetic	27.0	40.5
Hypertension	29.6	16.0
Glomerulonephritis	14.8	15.1
Other, includes missing	28.3	28.3
<b>Sample Size</b>		
Prevalent > 1 year	4181	556
Incident	1481	207
<b>Total</b>	<b>5662</b>	<b>763</b>

**Table II-2**

after the start of ESRD therapy and growth in the underlying U.S. resident population.

Comparisons of adjusted point prevalence rates per million U.S. resident population (Reference Table B.8) reveal a more than doubling in the overall rate of treated Medicare ESRD between 1983 (437 patients per million) and 1992 (791 PPM).

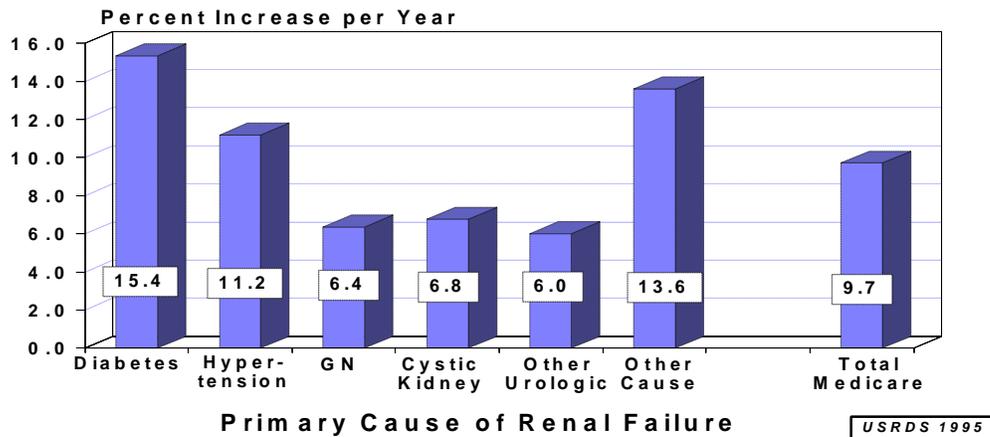
Figure II-3 shows the annual percent increase in point prevalence counts by race for the more recent time period of 1988-92. The figure also includes the number of years it has taken the subgroup to double in total counts. The Asian/Pacific Island ESRD population is increasing an average of 20% per year and if the current rate of increase continues, the count will double in less than 4 years. Native Americans are also increasing rapidly at an average of 16% per year and will double in less than 5 years if that rate remains steady.

Table II-2 presents some descriptive statistics from the Casemix Adequacy Study (CMA) comparing

characteristics of Hispanic and Non-Hispanic patients in basic categories. Hispanics represent just under 12 percent of both the incident and prevalent sample. Hispanics are slightly younger with a mean age of 57 at study start date compared to 59 for non-Hispanics and are overwhelmingly White (87% compared to 55% for this non-Hispanic population). Diabetes is the most common cause of renal failure for Hispanics, 41% compared to 27% of non-Hispanics.

The increase in point prevalence counts is shown by age at start of ESRD therapy in Figure II-5. Patients between 20 and 64 years of age continue to represent the majority of patients treated for ESRD in the U.S. However, prevalence rates have increased at a greater than average rate for patients in the 65-74 and 75 years and older age groups, a result of a growing incidence of treated ESRD among people 65 years and older (see Chapter III). Between 1988 and 1992, ESRD patients in the 65-74 age groups increased an average of 14% annually, while the 75 and older group increased an average of 17% annually. These trends demonstrate that the future

**Annual % Increase in Adjusted ESRD Point Prevalence Rate, by Diagnosis, 1988-92**



**Figure II-6**

*Percent increases per year in reported ESRD point prevalence rate per million U.S. resident population between 1988 and 1992, by primary diagnosis. Other urologic is defined as interstitial nephritis or collagen vascular disease. Prevalence rates are adjusted for age, race and sex using the 1991 U.S. resident population. Excludes patients in Puerto Rico, U.S. territories, and patients lost to follow-up. Medicare patients only. Source Reference Table B.1.*

ESRD population will be an increasingly older population.

Figure II-5 illustrates the growth in prevalence rates (per million population, per year), by age for the last ten years. It clearly illustrates slower rates of increase for younger U.S. residents (2% for the 0-19 age group and 7% for the 20-44) from 1988-92 than for people over 45. While the 65-74 age group has the highest rate at 2,272 PPM, the 75 and older group has seen a 14% increase in the average rate PPM from 1988-92, and in 1992 passed the 45-64 age group for second highest rate PPM.

The growth in point prevalence rates for each cause of ESRD during the 1988-92 time interval, expressed as the number of patients per million U.S. resident population and adjusted for age, sex and race, are shown in Figure II-6. Diabetes, "other" cause and hypertension continue to increase at a rate higher than the average. While the average annual growth in the adjusted ESRD prevalence rate was 9.7 percent per year between 1988-92, the rate of increase for diabetes, hypertension and "other" diagnoses was 15.4, 11.2, and 13.6 percent per year, respectively. The other urologic causes are interstitial nephritis and obstructive nephropathy. Greater than average growth among 1988-92 incident patients was also observed for "other causes", which includes the following diagnoses in order of decreasing

importance: interstitial nephritis, obstructive nephropathy, collagen vascular diseases, malignancies and congenital or other hereditary diseases. Further detail for these diagnoses for 1988-92 incident patients is shown in Table II-3. Missing cause, not shown, increased at less than one percent.

As indicated above, estimated prevalence counts from the USRDS patient database represent an undercount of the total number of Americans with treated ESRD because they include only those patients who are currently or previously Medicare eligible. The Annual Facility Survey, conducted by HCFA through the 18 ESRD Networks, provides an indication of the proportion of dialysis patients not covered by Medicare. (As reported in Chapter XIV, over 95% patient-based data are believed to be generally complete through 1992, and over 90% complete for 1993 while the HCFA Annual Facility Survey, which reports on facility-based data, is current through 1993).

In 1993, non-Medicare dialysis patients were estimated to be 7.6 percent of total dialysis patients in the United States, as shown in Figure II-2. This estimate is slightly lower than the 7.8 percent estimate for the previous year of 1990 (USRDS 1993).

Comparable prevalence estimates for non-Medicare patients with a functioning kidney

transplant are not available. However, of 10,411 patients receiving a transplant in the U.S. in 1993 10.1 percent were not insured by Medicare (Reference Table I.10), these estimates which

suggests that non-Medicare patients may represent a slightly greater percentage of the prevalent population with a functioning transplant. This percentage is approximately the same as in 1992.

However, when excluding transplant recipients who were not U.S. residents (accounting for 13 percent of non-Medicare kidney transplants during 1993), the percentage of total kidney transplants performed among non-Medicare patients is reduced to 8.9 percent, which is similar to the corresponding figure (7.6 percent) for non-Medicare dialysis patients in 1993.

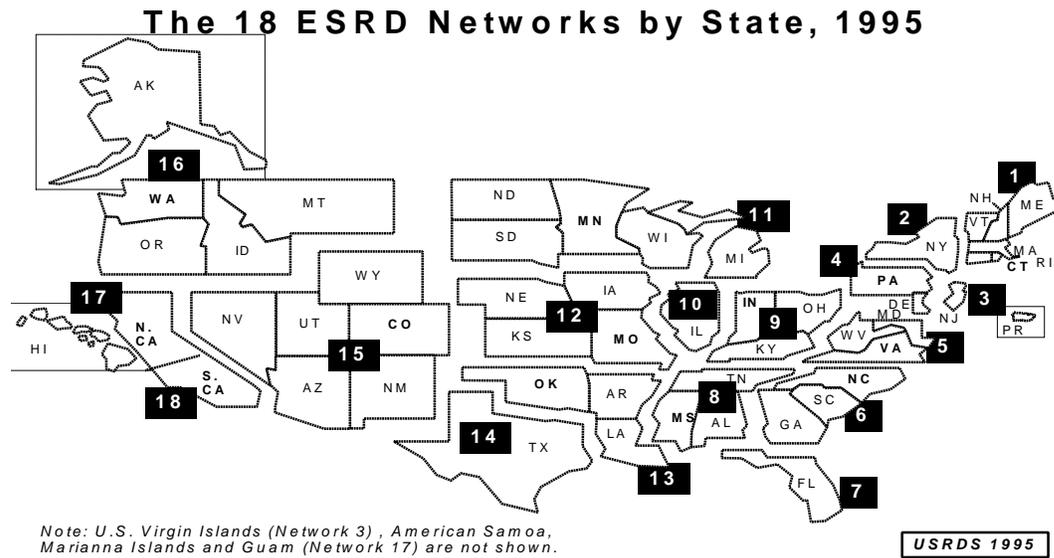
As shown in Figure II-7, the percent of non-Medicare dialysis patients varies by region in the United States. In 1993 there was a greater than five-fold difference in the proportion of dialysis patients not insured by Medicare between the Southern California Network (16 percent) and the Missouri Network (3 percent).

Several analyses in this report, including the percent non-Medicare in Figure II-8, compare results by geographic region, represented by the 18 ESRD Networks under contract with HCFA. The Networks are responsible for dialysis quality assurance, data collection for HCFA and for a

National Renal Registry and for adjudication of patient grievances. For figures and tables reporting data by ESRD Network, the state in which the 'Network Office' is located is used to refer to a particular ESRD Network.

Figure II-8 identifies the location of the states and other territories included in each of the 18 ESRD Networks, while Table II-3 includes the location of the Network Office and a list of the states and territories in each Network.

ESRD Network Key, 1995				
Network Key <sup>1</sup> to	Point Prevalence			
Number	Figures	States in the Network	Network Name	Rate <sup>2</sup>
1	CT	CT, MA, ME, NH, RI, VT	ESRD Network of New England	684
2	NY	NY	ESRD Network of New York, Inc.	819

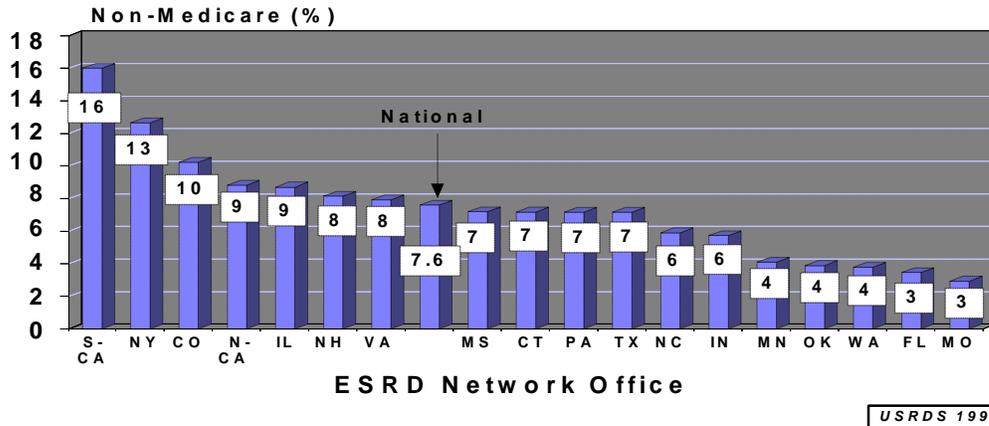


<sup>1</sup>Location of Network Office, frequently used to identify ESRD Networks in Figures throughout this report.

<sup>2</sup>Adjusted for age, race and sex. Per million population per year.

**Figure II-8**  
**Table II-3**  
 Geographic location of the 18 ESRD Networks under contract with the Health Care Financing Administration of the U.S. Department of Health and Human Services. The Networks are frequently identified throughout this report by the location of each Network Office, as shown in Table II-2. A map of the 9 census geographic regions used for the Hospitalization Chapter is located in chapter IX.

**Non-Medicare Dialysis Patients as a Percent of Total Dialysis Patients, by Network, 1993**



**Figure II-7**

Percent of the total December 31, 1993, ESRD point prevalent dialysis patient population not insured by Medicare, by ESRD Network. These estimates include patients in Puerto Rico (NJ Network) and U.S. Territories (NJ or N-CA Networks). Source: 1993 HCFA Facility Survey.

Figure II-8 and Table II-3 will be referred to frequently throughout this report. A map of the Census Geographic Regions used for hospitalization and mortality analyses in Chapter XII is located at the end of Chapter XII.

**References**

Erslev A. Erythropoietin coming of age. *N Engl J Med* 1987; 316:101-123.

Fox RC, Swazey JP. *The Courage to Fail: A Social View of Organ Transplants and Dialysis*. 2d rev. ed. Chicago: University of Chicago Press, 1979.

Health Care Financing Administration (HCFA). *Health Care Financing Research Report, End Stage Renal Disease, 1991*. Department of Health and Human Services, HCFA, Bureau of Data Management and Strategy, Office of Research and Demonstrations, Baltimore, MD, May 1993.

Health Care Financing Administration. Proposed rule: prospective reimbursement for dialysis services. *Fed Reg* 1982; 42:6556-6575.

Medicare Automated Data Retrieval System (MADRS) of the Bureau of Data Management and Strategy (BDMS), Health Care Financing Administration (HCFA). Personal communication from Paul Eggers, United States Department of Health and Human Services, HCFA, BDMS,

Office of Research and Demonstrations, Baltimore, MD, March 15, 1994, and May 4, 1994.

Miller BA, Ries LAG, Hankey BF, Kosary CL, Hurray A, Devesa SS, Edwards BK (eds). *SEER Cancer Statistics Review: 1973-90*, National Cancer Institute. NIH Pub. No. 93-2789, 1993, pp. VI.13, XV.13 and XXII.8.

Rettig RA. The Federal government and social planning for end-stage renal disease: past, present and future. *Semin Nephrol* 1982; 2:111-133.

United States Bureau of the Census, *Statistical Abstract of the United States: 1992* (112th edition), Washington, DC., 1992.

United States Renal Data System, *USRDS 1993 Annual Data Report*, the National Institute of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, March 1993 and *Am J Kidney Dis* 22 (Suppl 2), 1993.

United States Renal Data System, *USRDS 1992 Annual Data Report*, the National Institute of

Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, August 1992 and Am J Kidney Dis 20 (Suppl 2), 1992.

United States Renal Data System, USRDS 1991 Annual Data Report, National Institutes of Health, National Institutes of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 1991, and Am J Kidney Dis 18 (Suppl 2), 1991.

