Volume Two: Atlas of End-Stage Renal Disease in the United States
Finding what you need
in the Annual Data Report

**table of contents** an overview of the volume, listing all chapters, the main topics covered within them, & the appendices & reference sections; found on page vi

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**chapter tables of contents** listings of all two-page spreads, as well as the detailed topics covered within them; found on the third page of each chapter

**chapter highlights** key points; found on the third page of each chapter

**chapter summaries** central points from each two-page spread; found on the last page of each chapter

**CD-ROM** all volumes of the ADR, plus slides of all figures, Excel files of all data, & supplemental reference tables; found inside the back cover of Volume Two

**glossary** with a list of acronyms; page 238 of this volume

**index** a comprehensive guide to all figures & tables in Volume Two; page 259

**reference tables** detailed data tables; titles & subtitles listed on the second page of each reference section; Volume Three
United States
Renal Data System
2008 Annual Data Report

Volume Two: Atlas of End-Stage Renal Disease in the United States

National Institutes of Health
National Institute of Diabetes & Digestive & Kidney Diseases
Division of Kidney, Urologic, & Hematologic Diseases
Funding & chapter contributors

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Listed below are those who contributed to this volume of the ADR and to the Reference Tables. Unless otherwise noted in parentheses, the contributor’s employer was MMRF or its parent organization, Hennepin Faculty Associates.

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Disclosures for potential conflicts of interest


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The doors of the year open, like the doors of language, onto the unknown. Last night you said:

  tomorrow we must draw signs, sketch a landscape, hatch a plot on the unfolded page of paper and the day. Tomorrow we must invent, anew, the reality of this world.

Octavio Paz, "January First," translated by Eliot Weinberger
A new volume, examining chronic kidney disease in the United States. An Emerging Issues chapter that looks this year at first-year mortality, hospitalization, & vascular access. Expanded data on achieved hemoglobin levels. A Special Studies chapter that includes data from the Cardiovascular Special Studies Center & the Rehabilitation/Quality of Life & Nutrition Special Studies Centers. Reformatted reference tables, using 2005 as the reference year.

PDF files of the 2008 Annual Data Report & the Researcher’s Guide. PowerPoint slide files of all figures in the ADR, & Excel files of the data underlying the graphs. Excel files of the Reference Tables, including supplemental hospitalization & mortality tables with calculations per 1,000 patients, & Medicare-only tables. ReNDER, our online query application for accessing USRDS data. An online application for requesting data from the USRDS. A fully navigable index of figures & tables in Volume Two of the ADR.

on our website, www.usrds.org
frequently requested data in the reference tables Volume Three
35 years of the ESRD program

20 years of the United States Renal Data System

Total Medicare spending on ESRD in 2006: $23 billion
Percentage of Medicare program spent on ESRD in 2006: 6.4%
Total outpatient expenditures for ESRD: $7.8 billion

Total Medicare spending on ESAs in 2006: $1.9 billion
Medicare expenditures per patient year, 2006: $70k
Per patient per month inpatient/outpatient costs for Medicare ESRD pts, 2006: $17k

Change in total costs for ESRD patients, 1996 to 2006:
- Dialysis: 103% increase
- ESRD: 146% increase
- ESRD + diabetes: 131% increase

Number of U.S. adults age 75 & older with ESRD: 1 in 200

Rate per million population of patients receiving ESRD therapy, by race, 2006:
- African American: 5004
- Native American: 2691
- Asian: 1831
- White: 1194

Rate per million population of new patients with ESRD, by diagnosis:
- Hypertension: 1980
- Diabetes: 2006
- Heart failure: 2006

Rate per million population of all patients receiving ESRD therapy for ESRD, by diagnosis:
- Hypertension: 894
- Diabetes: 4.4
- Heart failure: 84

Rate per million population of new patients beginning ESRD therapy:
- Hemodialysis: 101,306
- Transplant: 330
- Peritoneal dialysis: 6725

Rate per million population of new patients beginning ESRD therapy & wait-listed for a transplant:
- Hemodialysis: 327,754
- Transplant: 151,502
- Peritoneal dialysis: 229

Total patients receiving ESRD therapy & wait-listed for a transplant:
- Hemodialysis: 46,191
- Transplant: 10,128
- Peritoneal dialysis: 229
681 days
Median time to receive a kidney-only transplant (pts transplanted in 2006)

3014
Units owned by large dialysis organizations in 2006

307 ESRD
Deaths per 1,000 patient years among patients age 65 & older, 2006

51 General population
Expected remaining lifetimes (years) of ESRD patients & of the general population

25.3 General population

16.1 Transplant

5.8 Dialysis

3 of 4
Transplant patients surviving five years after their first transplant, 1997–2001

1 of 3
Dialysis patients surviving five years after starting ESRD therapy, 1997–2001

22.4 Non-white
Percentage of patients still waiting for a transplant five years after listing, 2001

11.5 White

533,800 transplant 250,813
Projected number of ESRD patients in 2020

1978 Congress authorizes creation of ESRD networks
Omnibus Budget Reconciliation Act (OMBA) includes Medicare Secondary Payor provision
Composite rate payment system for dialysis becomes effective; cyclosporine introduced

1980 Congress authorizes creation of ESRD networks

1981 Thomas Graham uses term “dialysis” to describe solute transfer through a semipermeable membrane

1940s Dr. Willem Kolff develops & uses first successful artificial kidney

1950 June Ruth Tucker receives first kidney transplant

1960 Dr. Belding Scribner & Wayne Quinton develop Teflon shunt, introducing the first permanent vascular access & making it possible for patients to survive on maintenance dialysis

1960 March Dr. Scribner leads team that inserts the shunt in Clyde Shields, who survives 11 years on intermittent dialysis

1972 October U.S. Congress passes legislation authorizing the end-stage renal disease program, & extending Medicare coverage to Americans with ESRD

1973 July ESRD program launched

1 April 2008 CMS adopts 26 new Clinical Performance Measures to monitor the quality of care received by ESRD patients

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1 April 2008 CMS adopts 26 new Clinical Performance Measures to monitor the quality of care received by ESRD patients
This is the twentieth annual report on the end-stage renal disease (ESRD) program in the United States, and the ninth in our atlas series, which provides an in-depth, graphic presentation of data spanning the last quarter century. Based on data developed in our previous Annual Data Reports (ADRs), chronic kidney disease (CKD) has been given a designated scope of work under the new USRDS contract. In the past several books we have devoted a chapter to CKD; this year, however, we have developed an entire volume focusing on the disease. With Volume One now addressing CKD, Volume Two focuses on issues related to ESRD, and on the historical surveillance data that first started the USRDS reports.

At its inception, the ESRD program was expected to plateau at 40,000 prevalent patients—a number passed more than 20 years ago. ESRD was at first considered a rare disease, as defined by the Orphan Drug Act of 1983 and its subsequent amendments, but that definition also became outdated when the prevalent population exceeded 200,000—the threshold defined by the act—in 1990. At the end of 2006 the ESRD program was treating 506,256 dialysis and transplant patients—a new milestone.

For 2006 we document a large increase in the number of new cases—3.4 percent, to a total of 110,854, and growth not seen since 2001. The population returning to dialysis after a failed kidney transplant also grew, reaching 5,578—an increase of 34 percent since 2000. Growth in the incident population should be viewed with caution, as it may take several years to determine if these findings will be sustained or are just a one-time observation. The number of baby boomers entering their sixties will certainly lead to higher numbers of patients—especially given that deaths from cardiovascular disease are declining—but may not affect the rates.

In this year’s Précis, we again provide an overview of ESRD patients in the United States, their care, and their expenditures, and present data on the populations with diabetes, congestive heart failure, CKD, and ESRD, along with their related costs. The size of the recognized CKD population has grown since 1996, possibly reflecting the implementation of new diagnosis codes that include CKD stage. We look at the pre-ESRD care documented on the new Medical Evidence form, modality use, the transplant wait list, and indicators of quality of care, and illustrate recent changes in hospitalization rates, mortality rates, and five-year survival in the dialysis population. While prevalent death rates have been falling for a number of years, even death rates in the first year of dialysis appear to have declined. Figures on ESRD expenditures show per person and total costs in the program, and compare costs for Medicare and employer group health plan patients during the transition from CKD to ESRD.

We have reported data related to Healthy People 2010 objectives for a number of years, tracking progress in basic public health goals for the kidney disease population. Several targets have been not only met but exceeded, including fistula use among relatively new dialysis patients and evaluations of those with diabetes. Cardiovascular death rates are down, and are approaching the target set almost a decade ago. We also present new data for Objective 4.3, on pre-ESRD care, and update our analyses for Objective 4.8, addressing the medical evaluation and treatment given to patients with both CKD and diabetes.

In 2007, a number of policy, surveillance, and safety issues related to ESRD received considerable public attention. The USRDS added the Emerging Issues chapter to the ADR that same year to address such issues, and this year we continue to focus on the high mortality and morbidity in the first year on hemodialysis. This chapter—now Chapter One—addresses cause-specific death and hospitalization rates, and illustrates their considerable impact in the first three months of hemodialysis. Growth in the rate of infectious hospitalizations and the high placement rates for dialysis catheters are both major issues.

Incident and prevalent counts are reported in Chapter Two, along with projected counts to 2020. We again look at rates of ESRD in major metropolitan areas, which have been a concern for many years. Interestingly, the highest incidence is reported in Riverside-San Bernardino, California, for whites, and in Pittsburgh, Pennsylvania, for African Americans. Rates of prevalent ESRD are highest in Los Angeles for whites, in Pittsburgh for African Americans, and in St. Louis, Missouri, for Hispanics. These findings may help direct public health programs in high-burden areas of the country.
In Chapter Three we present information from added data fields on the newly revised Medical Evidence form, introduced in the spring of 2005. Information on vascular access, for example, shows the high rate of catheter use, with 82 percent of incident patients using a catheter at the first outpatient dialysis treatment. This high rate may contribute to higher mortality in the first year on dialysis, an area discussed in Chapters One and Six. Data on anemia treatment prior to initiation of ESRD therapy show that fewer patients are now being treated with erythropoiesis stimulating agents (ESAs), but this may reflect a change in the related question on the Medical Evidence form, which now specifically asks about ESA use prior to the first ESRD service date (rather than prior to a single dialysis treatment). The chapter concludes with new information on glycosylated hemoglobin levels among incident ESRD patients with either a primary or secondary diagnosis of diabetes.

Chapter Four presents information on trends in modality use. Peritoneal dialysis is now used by just 7.4 percent of the dialysis population, down from 15–17 percent in the mid-1990s. New guidelines on peritoneal dialysis treatment, along with the emergence of daily home hemodialysis as a new modality, may change perceptions about the use of home therapies. Insurance coverage in the incident and prevalent populations appears to be changing, with a larger percentage of patients covered by Medicare Advantage. This may reflect new adjustments to the payment rates based on the inclusion of more chronic disease adjustors.

Chapter Five, on clinical indicators of care, assesses dialysis adequacy, vascular access, anemia treatment, hemoglobin levels exceeding 12 g/dl and falling below 10 g/dl, transfusion rates over time, and preventive care in the diabetic and general ESRD populations. We show, for instance, that while influenza vaccination rates have grown, they have been under 60 percent for the last five years, despite a target of 90 percent. We also look at the marked differences in vascular access complication rates associated with the use of fistulas, catheters, and grafts.

Mortality data in Chapter Six show continued gains across most time periods in both the incident and prevalent populations. Even first-year mortality rates declined in the 2005 cohort, a new finding compared to the last decade. New data address the use of hospice care in the ESRD population — including rates of withdrawal from dialysis and associated hospice care and costs — as well as the burden of walking disability.

As we illustrate in Chapter Seven, transplant counts continue to rise. This year we show an increase in the number of transplants from deceased donors, but a slight decline in the number from living donors. Waiting times continue to grow, due to the continued shortage of donated kidneys. Patterns of immunosuppressive drug use show marked changes, with MMF and tacrolimus now the most common combination. And death with a functioning graft is an area of concern, with cardiovascular disease accounting for 38 percent of these deaths once unknown cause of death is removed. This year we have added new data on pediatric transplant patients, including information on listings, wait times, common immunosuppressive medications, and causes of graft failure.

Striking in the data on pediatric patients is the lack of progress in their survival. As shown in Chapter Eight, there has been no change in mortality among young dialysis or transplant patients. Both incident and prevalent rates in the adult population, in contrast, have fallen. The chapter includes analyses of anemia treatment similar to those in Chapter Five, addressing the likelihood of exceeding hemoglobin levels of 12 g/dl and of falling below 10 g/dl.

In Chapter Nine, each Special Studies Center addresses aspects of care related to its target areas. The Cardiovascular Special Studies Center presents data on the use of diagnostic tests and interventions, while the Rehabilitation/Quality of Life and Nutrition Special Studies Centers present preliminary data on the Comprehensive Dialysis Study (CDS) of incident dialysis patients, describing the CDS sampling method and showing degrees of disability and physical function along with basic nutritional parameters.

Over the past twenty years the landscape of dialysis providers has altered dramatically, with the consolidation of smaller providers into large dialysis chains. In 2005 and 2006 it changed even further, with the acquisition of Renal Care Group by Fresenius Medical Care, and the purchase of Gambro Healthcare by DaVita. These transitions create new challenges for the USRDS in assessing care. In Chapter Ten this year we provide data on the duration of unit
ownership among both the consolidated and remaining providers. Since anemia treatment has received considerable attention during these past two years, we present provider-level data on hemoglobin levels above 12 g/dl and under 10 g/dl. We also address iron dosing practices and transfusion use, and assess provider-specific billing for additional tests beyond those reimbursed in the composite rate, including calcium/phosphorus and complete blood counts. Mortality and hospitalization comparisons have been presented in the ADR for many years, but this year we provide a new perspective with data on regional comparisons of large and small dialysis organizations as well as those that are hospital-based.

Chapter Eleven, on expenditures related to ESRD, begins with data on the overall costs of both the Medicare ESRD and employer group health plan (Medstat) programs, along with the costs in both programs of ESA treatment. We again present information on costs during the transition from CKD to ESRD in the Medicare and EGHP populations, and illustrate expenditures for clinical services, injectables, preventive care, and vascular access by the various dialysis provider groups. The chapter concludes with data on Medicare Advantage patients. For 2006, it appears that predictions using the hierarchical payment method are generally closer to the actual payments, improving the ratio of predicted to actual costs and allowing health plans to incur less risk from adverse patient selection.

In Chapter Twelve we summarize data from the international community, illustrating differences in incidence, prevalence, diabetic ESRD, dialysis, and transplantation. We are again grateful to the registries which provide this information and thus allow us to see the U.S. ESRD community through a wider lens.

Overall, surveillance data show improvement in survival in both the incident and prevalent ESRD populations. The provision of care has improved, with an increase in cardiovascular services and diabetic preventive care, though in areas such as vaccination rates there is still much progress to be made.

Mortality and morbidity among hemodialysis patients in the first year of ESRD therapy — particularly the increasing rate of hospitalizations due to infections — continue to be major concerns. Placement rates for dialysis catheters are down, but this may reflect the use of cuffed catheters, which remain in place longer and thus continue to expose patients to infectious risks. Hemoglobin levels in the incident population frequently exceed 12 g/dl, and commonly do so for more than three months during a year. And the disappointing lack of progress in pediatric patient survival needs to be addressed. The USRDS will continue to investigate and report on patterns of care and associated morbidity and mortality to identify areas for improvement in the care of patients with ESRD.

Most of the 2008 ADR contains data through December 31, 2006; data on patient characteristics, obtained from the Medical Evidence form, are complete through June, 2007.

www.usrds.org
On our website users can download PDF files of the ADR, Excel files of the tables and the data underlying the graphs, and PowerPoint slides of ADR figures and USRDS presentations. Supplemental tables are also included, with standard errors for rates as well as tables for patient subgroups.

Also available on the website are supplemental tables on ESRD patients covered by Medicare. These tables parallel tables in the printed ADR, and include information on incidence and prevalence, modalities, hospitalization, transplant, mortality, survival, and the costs of ESRD.

RenDER & the Researcher’s Guide
Our real-time online query system allows users to build data tables and maps. The Renal Data Extraction and Referencing System (RenDER) can be accessed on our website.

To assist users of USRDS data, the Coordinating Center annually updates and revises the Researcher’s Guide, which provides information on all analytical methods used by the CC, along with a detailed index of files and variables in the USRDS researcher datasets. It is available on our website in PDF format.

USRDS database
The USRDS dataset is a living record of patient care in the U.S., continually updated with new data. Delays in data reporting are
unavoidable, and we add late information as soon as it becomes available. This includes data from the Medical Evidence form, claims for hospital and physician services, and updates of the Medicare Enrollment Database received after the ADR has gone to press.

**Administrative oversight**

Lawrence Agodoa, MD, and Paul Eggers, PhD, provide direct oversight of the Coordinating Center and Special Studies Centers, and members of CMS, the ESRD networks, and the renal community provide crucial input and feedback through their committee participation.

The Steering Committee, the governing body of the USRDS, is responsible for the operations of the CC and SSCs. It works under the direction of the Project Officers, and includes representatives from CMS, the NIH, the CC, and each of the SSCs. Its responsibilities include coordination among the centers, study design, project tracking, data management and validation, assurance of data availability for researchers and government officials, and oversight of Annual Data Report production.

The USRDS External Advisory Committee plays a major role in advising Project Officers on appropriate and necessary special studies, data studies, and analyses. This committee is also responsible for reviewing manuscripts and Annual Data Reports. Members are listed in Table I.d.

The Data Management Advisory Committee (DMAC) includes CMS members, Network Forum representatives, database technical staff, and others appointed by the Project Officers. DMAC addresses the accuracy and completeness of data provided to the USRDS, and works to ensure timely fulfillment of data requests. The Annual Data Report Committee (ADRC) reviews the data in previous ADRs, proposals for future editions, and ideas for expanded data availability on the USRDS website. The Information Systems Committee (ISC) reviews hardware requirements, systems configuration, documentation, and performance, and evaluates technologies that may enhance database structure, function, and management.

The Special Studies Review and Implementation Committee (SSRIC), the operations committee for SSC proposals and CC project support, is a collaboration of CMS, the ESRD networks, and the providers. The Data Request Review Committee (DRRC) reviews data requests requiring more than two hours of staff time to fulfill, and makes recommendations to the Project Officers based on the types of datasets requested and the ways in which the CC can improve the availability of data.

**Reading the maps**

The majority of mapping in the ADR is by Health Service Area (HSA), a group of counties described by authors of the CDC Atlas of United States Mortality as “an area that is relatively self-contained with respect to hospital care.”

Maps present data divided into quintiles. Each range in a legend contains approximately one-fifth of the data points. In the sample map on page xviii, for example, one-fifth of all data points displayed have a value of 10.8 or above. Ranges include the number at the lower end of the range, and exclude that at the upper end (i.e., the second range in the sample map is 8.2–9.2). To facilitate comparisons of maps showing data for different periods, we commonly apply a single legend to each map in a series. Because such a legend applies to multiple maps, the data in each individual map are not evenly distributed in quintiles, and a map for a single year may not contain all colors or ranges listed in the legend.

Numbers in gray indicate the mean values of data points in the highest and lowest quintiles. These can be used to calculate the percent variation between quintiles. For maps with shared legends we have provided these values by repeating the legends and inserting the unique quintile values.

On the Excel page for each map (found on our website and the CD-ROM in the back of this book) we include several numbers to help you interpret the maps and their relation to other data in the ADR. The map-specific mean is calculated using only the population whose data are included in the map itself. This mean will usually not match data presented in tables elsewhere in the ADR, and should be quoted with caution. The overall mean includes all patients for whom data are available, whether or not their residency is known. We also include the number of patients excluded in the map-specific mean, and the total number of patients used for the overall calculation.
### 11.3 Structure of the USRDS database

Common Standard Re-usable Working Set Library

- USRDS database (1.9 million patients)
- ESRD cohort finder files
- Patient profile
- Modality/payer sequence
- Comorbidity profile
- Tx profile
- CMS ESRD & 5% general Medicare claims data: Part A, Part B, & EPO
- USRDS Annual Data Report
- USRDS researcher SAF CDs
- Data analyses
- USRDS custom data files
- USRDS web-based applications
- UNOS tx data
- Ingenix™ & Medstat® enrollment & claims data
- CMS EPO data
- CMS ESRD facility data
- CDC survey data
- NHANES
- Network SIMS
- CMS ESRD Part B SAF claims: Physician/Supplier, DME
- CMS PMMS/REBUS/REMIS
- CMS ESRD Part A SAF claims: OP, IP, SNF, HH, hospice
- 5% general Medicare SAF claims: OP, IP, SNF, HH, hospice, Physician/Supplier, DME
- USRDS Special Studies data
- Disease-specific cohort finder files (CKD, CHF, DM)
- EGHP claims data: Parts A & B
- CMS PMMS/REBUS/REMIS
- CMS ESRD Part B SAF claims: Physician/Supplier, DME
- CMS ESRD Part A SAF claims: OP, IP, SNF, HH, hospice
- 5% general Medicare SAF claims: OP, IP, SNF, HH, hospice, Physician/Supplier, DME
- UNOS tx data
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- CDC survey data
- NHANES
- Network SIMS
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- CMS PMMS/REBUS/REMIS
- CMS ESRD Part A SAF claims: OP, IP, SNF, HH, hospice
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- CDC survey data
- NHANES
- Network SIMS
- CMS ESRD Part B SAF claims: Physician/Supplier, DME
- CMS PMMS/REBUS/REMIS
- CMS ESRD Part A SAF claims: OP, IP, SNF, HH, hospice
- 5% general Medicare SAF claims: OP, IP, SNF, HH, hospice, Physician/Supplier, DME
- UNOS tx data
- Ingenix™ & Medstat® enrollment & claims data
- CMS EPO data
- CMS ESRD facility data
- CDC survey data
- NHANES
- Network SIMS

### 11.4 USRDS members

**National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK)**
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- **Lawrence Y.C. Agodoa, MD**
  - Co-Project Officer, USRDS; Director, End-Stage Renal Disease Program
- **Paul W. Eggers, PhD**
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- **Richard Bailey**
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**Centers for Medicare & Medicaid Services (CMS)**
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- **Penny Mohr**
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- **Samanta Richardson**
  - Manager, ESRD Network Program, & Director, DSIFPCAC, Quality Improvement Group, OCSQ
- **Barry Straube, MD**
  - CMS Chief Medical Officer & Director, OCSQ
- **Richard McNaney**
  - Acting Director, Information System Group, OCSQ
- **USRDS Coordinating Center (CC) & Special Studies Centers (SSCs)**
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  - Associate Professor, U of MN College of Pharmacy; Department of Medicine, HCMC
- **Jon Snyder, PhD**
  - Epidemiology, USRDS
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We welcome feedback on all elements of USRDS work, and all comments are reviewed by the Director, Deputy Director, and staff of the USRDS in order to improve future materials and ensure a strong working relationship between the USRDS and clinicians, researchers, patients, and others involved in ESRD care across the United States and throughout the world.