Information map: by audience
Of particular interest to...

Patients
- Transplantation
- Access to care (preventive care, insurance)
- Healthy People 2010
- Rehabilitation & quality of life
- Survival
- Anemia treatment
- Clinical indicators (hemoglobin, URR, Kt/V)
- Chapter Ten
- Appendix B

Policy makers
- Transplantation
- Costs of ESRD care
- Anemia treatment
- Preventive care
- Patient outcomes
- Chapter Eleven
- Appendix A

Researchers
- Chronic kidney disease, pre-ESRD care
- Analytical methods, data sources
- USRDS products (data requests, data files)
- Chapter One
- Appendix A

Clinicians
- Transplantation
- Cardiovascular special study
- Chapter Nine
- Patient outcomes
- NINAMES
- Patient outcomes
- Chapter Seven, Six & Nine
- Patient outcomes
- Chapter Seventeen, Six & Nine
- Patient outcomes
- Chapter Seven
- Patient outcomes
- Chapter Seven
- Patient outcomes
- Chapter Seventeen

For additional ways to navigate this Annual Data Report, please see the Table of Contents (pages iv-v) & the Index (pages 224-226)
This 15th annual report of the United States Renal Data System is produced by the USRDS Coordinating Center, operated under NIH contract N01-DK-9-2343 by the Minneapolis Medical Research Foundation.

2003 Annual Data Report
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
In memoriam  
Belding H. Scribner, 1921–2003

A dialysis pioneer, Dr. Scribner created a device that made it possible for patients who have lost kidney function to stay alive on dialysis, and to receive their therapy in an outpatient setting. He trained more of the original nephrologists than any other physician, created the first bioethics committee, and was instrumental in shepherding the initial ESRD program legislation through Congress. A mentor to many, and a truly nice guy, he will be sorely missed.

In memoriam  
Rupert Vance Hartke, 1919–2003

In 1972, Senator Hartke (D-Indiana) introduced an addition to the Social Security Amendments, granting Medicare coverage to patients with end-stage renal disease. His passionate belief that all citizens—regardless of income—should have access to proper medical treatment led to the creation of the ESRD program and the provision of care to millions of citizens.

It is with awe and admiration that we acknowledge the members of the renal community and the patients they serve, recognizing their perseverance, dedication, and the promise of hope which they demonstrate each day in the pursuit of improved health and wellness. We reaffirm our commitment to their efforts, and we will continue to devote our energies and skills to helping assure that their endeavors result in positive strides toward a better quality of life.


Publications based upon USRDS data reported here or supplied upon request must include this citation and the following notice: The data reported here have been supplied by the United States Renal Data System (USRDS). The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy or interpretation of the U.S. government.
It is what we imagine knowledge to be:
dark, salt, clear, moving, utterly free,
drawn from the cold hard mouth
of the world, derived from the rocky breasts
forever, flowing and drawn, and since
our knowledge is historical, flowing, and flown.

Elizabeth Bishop, "At the Fishhouses"
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Introduction
THE UNITED STATES RENAL DATA SYSTEM

In this year’s Annual Data Report we have consolidated several topics to create space for a new chapter on chronic kidney disease, and another by the Rehabilitation/Quality of Life Special Studies Center. The Nutrition SSC will contribute a chapter to the 2004 edition, examining the interrelations between nutrition and inflammation.

In our ongoing effort to make the ADR more accessible to its varied readers, we have this year placed on the book’s frontispiece two information maps—one organized by broad topics of interest, and the second by some of the book’s different audiences. We hope that with these maps, along with the table of contents and index, readers can more easily navigate the large amounts of information presented here.

This year we have also worked extensively with the Centers for Medicare and Medicaid Services (CMS) and the ESRD networks to address the ESRD patient census. The revised Medical Evidence form (2728), introduced in 1995, requires the reporting of both Medicare and non-Medicare patients. As discussed in earlier ADRs, difficulties in tracking non-Medicare patients and their transition to Medicare have resulted in some patients being counted twice. To address this problem we have used the SIMS event file from the ESRD networks, which allows us to obtain a more accurate patient treatment history. Use of this file has also enabled us to reconcile almost 15,000 patients previously defined as lost-to-followup. The patient census reported by the USRDS is now very close to that of the ESRD Facility Survey, with prevalent counts now showing more patients under treatment than previously reported, and incident counts adjusted downward.

Chapter overview

In the Précis we provide a broad overview of the ESRD program, showing patient counts, Medicare expenditures, hospitalization and mortality rates by patient vintage, and trends in the provider community. We also look at data from the National Health and Nutrition Examination Survey (NHANES).

The next chapter presents information related to Healthy People 2010, a program sponsored by the Department of Health and Human Services. HP2010 objectives related to kidney disease include reducing the incidence of ESRD overall and of kidney disease caused by diabetes. To address progress toward these objectives we have included data from the Medicare 5 percent sample, which provides information on the general Medicare population, and which we use later in the book to analyze hospitalizations and preventive healthcare services.

Chapter One consolidates information on chronic kidney disease, previously presented throughout the ADR. Data include cardiovascular and infectious hospitalization rates of the CKD, non-CKD, and dialysis populations, and mortality rates associated with cardiovascular disease and infection. We look as well at mortality by the location in which patients die, and present results of a study on the probability of developing cardiovascular comorbidity, comparing patients who progress toward...
1.2 Structure of the USRDS database

<table>
<thead>
<tr>
<th>CMS PMMIS/REBUS</th>
<th>CMS Part A SAF claims: OP, IP, SNF, HH, hospice</th>
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<th>UNOS transplant data</th>
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<tr>
<td>USRDS database (1.4 million patients)</td>
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Common Standard Re-usable Working Set Library

<table>
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<th>ESRD cohort finder files</th>
<th>Patient profile</th>
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In Chapter Three we examine patient characteristics at the start of ESRD therapy, looking in particular at the relation of estimated glomerular filtration rates at initiation to subsequent hospitalization and survival. We also examine the insurance coverage of patients beginning therapy, an important issue in access to care and the ability of providers to deliver needed treatment.

Chapter Four provides demographic data by modality for both incident and prevalent populations, as well as information on the changing landscape of dialysis care, showing recent growth in the number of patients receiving treatment in units owned by large corporations. And in Chapter Five we have combined information previously presented in separate chapters, looking at clinical indicators such as anemia, dialysis therapy, and access services, as well as at preventive care in both the CKD and ESRD populations.

We have also chosen this year to juxtapose hospitalization and mortality data in one chapter, allowing readers to more directly compare these major outcomes. In Chapter Six we present trends in hospitalization over the last decade, and in mortality since 1980, emphasizing the relation of patient vintage—time on a modality—to outcomes. These data make it clear that prevalent death rates that do not take patient vintage into account can be quite misleading. Chapter Six also includes new data on septic complications and the associated risk of death.

Renal transplantation data in Chapter Seven include trends in the number of transplants, patient demographics, information on wait-listed patients, and donation rates by state and population. Information on risk factors for graft and patient survival has now been divided into two tables, one for transplants from deceased donors and one for living donor transplants. Also new this year are several spreads on complications following transplant, including fractures, diabetes, infections, and malignancy.

In Chapter Eight we explore long-term trends in the pediatric ESRD population, including patient counts, anemia treatment, L-carnitine use, and hospitalization and mortality—particularly for cardiovascular disease and infection. The chapter also includes data on patient characteristics at the start of ESRD therapy and on the relatively low rates of preventive care received by children with ESRD, and we introduce data on complications following transplant.

For its contribution to this year’s ADR, the Cardiovascular Special Studies Center focuses in Chapter Nine on two at-risk portions of the ESRD population: dialysis patients who have had an acute myocardial infarction, and patients who have received a first renal transplant. The chapter includes data on hemoglobin levels and mortality after AMI, on car-

ESRD or death with those who survive the study period.

Chapter Two, on the incidence and prevalence of ESRD, illustrates long-term trends in the ESRD population. We have now developed a more complete model for projecting the ESRD population over the next several decades, showing the impact of the World War II baby boomers and of the growing minority populations. The Markov model used here incorporates changes in the baseline population of the United States, as well as in rates of ESRD incidence, prevalence, and mortality.

In this chapter, as well as in Chapter Five, we again present data on some of the less common diseases that cause ESRD: IgA and IgM nephropathy, Wegener’s granulomatosis, systemic lupus erythematosus, secondary glomerulonephritis, polycystic kidney disease, Alport’s syndrome, multiple myeloma, and AIDS. We hope that this information will continue to prompt new awareness of patients affected by these less frequent causes of ESRD.

In Chapter Three we examine patient characteristics at the start of ESRD therapy, looking in particular at the relation of estimated glomerular filtration rates at initiation to subsequent hospitalization and survival. We also examine the insurance coverage of patients beginning therapy, an important issue in access to care and the ability of providers to deliver needed treatment.
diovascular event rates after transplantation, and on testing for cardiac disease in the three years prior to and three years following a transplant.

The Rehabilitation and Quality of Life Special Studies Center makes its first contribution to the ADR this year, in Chapter Ten presenting data from the Dialysis Morbidity and Mortality (Wave 2) study conducted by the USRDS. The Center focuses here on how patients perceive their own health and well-being, on their ability to work, and on the physical therapy and cardiac rehabilitation they receive.

Our chapter on the economic costs of ESRD again explores the costs of the program and how they are distributed by payor, type of therapy, and patient group; changes in these costs are presented in total and on a per patient basis.

As in previous editions of the ADR, we conclude the chapters with information from the international renal community. More than 35 countries responded to our survey this year, compiling data on incidence, prevalence, ESRD related to diabetes, dialysis therapy, and transplantation. We are very grateful to the renal registries in these countries, and for the broad perspectives their information provides.

Most of the 2003 ADR contains data through December 31, 2001, with data on patient characteristics from the Medical Evidence form complete through April 2002.

Reference tables & RenDER

This year we have extended many of the reference tables—including those on incidence and prevalence, hospitalization, and survival—to present data from as far back as 1978. The 2004 edition of the ADR will include additional trend information on costs of the ESRD program, components of care, and preventive care services.

Supplemental tables are again included on our website; these consist of standard errors for all rates, as well as tables for subgroups of patients. A complete list of these tables is provided on the first page of the Excel file of each reference section.

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.

We continue to improve our real-time online query system, which allows users to build data tables and maps based on query specifications. The Renal Data Extraction and Referencing System (RenDER) can be accessed on the USRDS website.

www.usrds.org

On our website users can download PDF files of the printed ADR, Excel files of the Reference Tables and the data underlying the graphs, and PowerPoint slides of ADR figures and USRDS presentations. (Due to the size of the ADR files,
new to this edition of the annual data report
  a chapter on chronic kidney disease
  a chapter by the rehabilitation & quality of life special studies center
  expanded information on trends in the ESRD program
  projected populations to 2030
  data on hospitalizations & mortality related to sepsis
  new information on cardiac disease & other complications in renal transplant patients
  in the reference tables, expanded information on hospitalization & mortality rates

downloading time may be substantial; we provide estimated times for a 56 kbs modem.) All data are aggregated in order to comply with USRDS confidentiality policies, and data for cells with fewer than ten patients or five providers are omitted.

Researcher’s Guide
To assist users of the USRDS data, the Coordinating Center has again updated and revised 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, and a hard copy will be sent to researchers upon request.

The USRDS database
The Coordinating Center frequently responds to concerns about changes in reported counts of incident and prevalent patients and in counts by modality. The USRDS dataset is a living record of ESRD care in the United States, and is continually updated with new information on the ESRD population. Delays in the reporting of data are unavoidable, and we add late information to the database as soon as it becomes available. This information includes data from the Medical Evidence form, claims for hospital and physician services, and updates of the Medicare Enrollment Database that are received after the ADR has gone to press.

Throughout this ADR we have applied a newly adopted payor history file to identify Medicare eligibility status and other insurance payors; see Appendix A for more details. And to close some of the gaps noted in past ADRs we have continued this year to collaborate with the Centers for Medicare and Medicaid Services (formerly HCFA) and the ESRD networks. Information obtained from the Medical Evidence form, the Facility Survey form, and the Standard Informa-
We have extensively revised the process by which we reconcile patients in the database, working to account for duplicate patients and resolve data on those lost-to-followup. Use of the SIMS census and event files, compiled by the ESRD networks, has helped us resolve 2,000 duplicate incident patients from the year 2000, and almost 15,000 lost-to-followup patients. Because we cannot track non-Medicare patients over time, this latter group has posed particular problems. We will continue to refine our patient reconciliation system through use of the SIMS database, and for the transplant population, will focus as well on tracking patient events and followup.

CMS and the USRDS are also sharing additional datasets that will be used to advance research on the ESRD population. Since 1994 CMS has collected information on a random sample of dialysis patients through the Clinical Performance Measures Project (CPM, formerly the Core Indicator Project). The data include information on dialysis adequacy, anemia treatment, vascular access, and, more recently, pediatric patients.

The USRDS and CMS have created a joint steering committee to guide this collaborative research, and have developed datasets in a format similar to that of the Special Studies data files, using universal identifiers to link the CPM data to the main USRDS data files.

### U.S. population estimates

The USRDS uses U.S. census data to calculate incident and prevalent rates, as well as rates of organ donation. For the 2002 ADR, which included data on incident and prevalent ESRD patients in 2000, we used the Census Bureau’s projected U.S. population for 2000, which was based on the 1990 census. The actual 2000 population reported by the Census Bureau, however, contains almost 10 million people more than estimated in prior years. Directly applying these figures to the 2000 ESRD data would result in a drop in incident and prevalent rates of about 4 percent, creating a discontinuity in the data.
During the past year we have discussed with the Census Bureau the re-estimation of 1991–1999 populations based on actual data from 2000. These revised estimates will not be complete until late in the fall of 2003, after the printing of the 2003 ADR. Following consultation with the USRDS Project Officers and the biostatistical group, the Coordinating Center has developed projection models for the 2000 and 2001 U.S. populations; these models have been validated against the U.S. Census Bureau estimates, and found to have an excellent fit. We have used these estimates, then, for this edition of the ADR.

- **Types of ESRD treatment**

The CC and the REBUS group at CMS have worked extensively on methods of categorizing patients by their ESRD treatment modalities. While the Medical Evidence form is the primary source of data on modality at the initiation of treatment, the modality it indicates may be temporary, as patients often change to a new one within the first 90 days. It can be difficult to determine modality during this time. Patients 65 and older have Medicare claims in the first 90 days; these claims contain revenue codes that designate modality. Patients younger than 65 who are in employer group health plans or Medicare risk programs, however, have no claims in this period. A patient’s modality may therefore not be determined until Medicare becomes the primary payor at day 91 or, for patients in employer group health plans, at 30–33 months after the first ESRD service date. These limitations influence the CC’s ability to determine a patient’s exact modality at any one point in time.

Of particular concern are patients categorized as having an unstable modality (i.e. they are treated on that modality for fewer than 60 consecutive days) in the first 90 days, and who are therefore not recognized as being hemodialysis, peritoneal dialysis, or transplant patients. These patients tend to have higher death and hospitalization rates, and unless they are identified and assigned to modalities, interpretations of modality-specific outcomes should be viewed with caution. These patients are included in the “all ESRD” category, which provides a more complete view of mortality and hospitalization with the least biasing of the data.

The Coordinating Center and CMS will continue working to reconcile the claims and ESRD network census data, reducing the number of patients classified as having unknown or unstable dialysis modalities.

- **Administrative oversight of the USRDS**

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 functions as the governing body of the USRDS, and 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 the 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 1.c.

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 the data provided to the USRDS, and works to ensure timely fulfillment of data requests.

The Annual Data Report Committee (ADRC) reviews the data sections of previous ADRs, proposals for future editions, and ideas for expanded availability of data 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) serves as the operations committee for SSC proposals and support of CC projects. It 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 data sets requested and the ways in which the CC can improve the availability of data.

The Renal Community Council (RCC), with 30 professional, scientific, and advocacy groups, serves as a significant liaison between the USRDS and the ESRD community.

To facilitate comparisons of maps that present data for several different years or time periods, we have applied a single legend to each of the maps in a series, e.g., rates of diabetes in 1990 and 2000. 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 the colors or ranges listed in the legend.

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

On the summary page at the end of each chapter we have included several numbers to help you interpret the maps and their relation to other data presented in the ADR. The map-specific mean is calculated using only the population whose data are included in the map itself—i.e., the mean for a state map excludes all patients whose state of residency is unknown. 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 is 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.

Notes

In an effort to be more sensitive to transplant donors, recipients, and their families, we are beginning to employ the term “deceased donor” rather than “cadaveric donor.” This change will be completed by the 2004 ADR.

The Annual Data Report could not be produced without the extraordinary work of members of the ESRD community—including the staff of CMS and the ESRD networks—and the dedicated efforts of the USRDS staff and investigators. The efforts of providers are crucial in the collection of data used by the USRDS, and their dedication in collecting data is greatly appreciated.

Feedback on the ADR and on other USRDS work is welcome, and all comments are reviewed by the Director, Deputy Director, and staff 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.

analytical methods are described briefly in figure & table captions, & are detailed in Appendix A