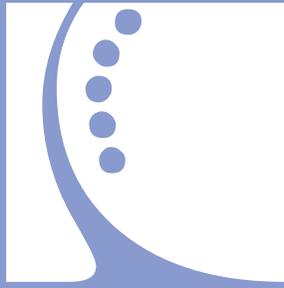




United States
Renal Data System

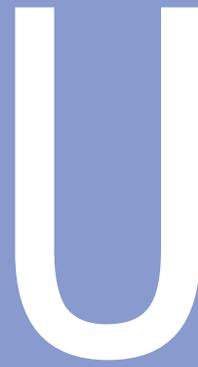
A decorative graphic in the top right corner of the blue vertical bar. It consists of a white circle with a blue arc on its left side and five blue dots arranged vertically inside the circle.

2001 ANNUAL DATA REPORT

ATLAS
OF END-STAGE
RENAL DISEASE
IN THE
UNITED STATES

National Institutes of Health
National Institute of Diabetes
and Digestive and Kidney Diseases
Division of Kidney, Urologic,
and Hematologic Diseases

This 13th 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.

A large, white, serif capital letter 'U' is centered in the upper portion of a solid blue vertical bar.

Undoubtedly we have no questions to ask which are unanswerable. We must trust the perfection of the creation so far, as to believe that whatever curiosity the order of things has awakened in our minds, the order of things can satisfy.

RALPH WALDO EMERSON, *Nature*

CONTENTS

vii	Acknowledgements
ix	Introduction
17	Précis · A summary of the U.S. ESRD program
37	One · Incidence & prevalence
53	Two · Patient characteristics
69	Three · Treatment modalities
79	Four · Clinical indicators of care
91	Five · Morbidity & hospitalization
107	Six · Pediatric ESRD
117	Seven · Transplantation
135	Eight · Survival, mortality, & causes of death
147	Nine · Cardiovascular special studies
159	Ten · Preventive health care measures
169	Eleven · Provider characteristics
181	Twelve · Economic costs of ESRD
195	Thirteen · International comparisons
	Appendices
204	A · Analytical methods
231	B · ESRD Network definitions
232	C · Glossary
236	D · USRDS staff & co-investigators
238	E · USRDS products & services · data requests
249	Reference Tables

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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.



With gratitude and respect we acknowledge the contribution of patients and caregivers in the day-to-day challenges of living with and providing care for end-stage renal disease. Providers—whether in laboratories, hospitals, or at a patient’s side in a dialysis unit—seek to advance the health and welfare of their patients. And it is through contact with our patients that we are constantly reminded of the purpose of our work; they teach us what is important and true. The USRDS was created with the purpose of improving outcomes in this vulnerable population, and our work will continue to center on this goal.



INTRODUCTION

THE UNITED STATES
RENAL DATA SYSTEM

WHAT'S NEW

In the 2001 USRDS Annual Data Report we have continued to expand our application of an atlas format to the presentation of data on end-stage renal disease. This year's book contains a new chapter with data from the Cardiovascular Special Studies Center, directed by Charles Herzog, MD, as well as an expanded transplant section created by Bertram Kasiske, MD, USRDS Deputy Director. Sections on clinical components of care and on preventive health care measures have been significantly expanded to provide a more complete understanding of care delivered to the ESRD population.

The Economic Special Studies Center, directed by Lawrence Hunsicker, MD, was created in 2000, and will be contributing to the 2002 Annual Data Report. The Nutrition and Rehabilitation Special Studies Centers have yet to be awarded at the time of printing.

The volume and complexity of the Reference Tables have continued to pose challenges in creating the printed version of the Annual Data Report. To accommodate the growing output of data we have moved standard errors to the USRDS website (www.usrds.org), including them in Excel files along with the related tables. These files also contain supplemental tables, which are noted in footnotes in the printed book.

We have continued to refine the analytical methods used in creating this book. We have spent considerable time this year, for instance, revising the methodology used to estimate prevalent mortality and hospitalization rates for the calculation of standardized mortality and hospitalization ratios (SMRs/SHRs). While multiple models were previously used to estimate death rates, the USRDS biostatistical group is now using a single model for all interactions of age, gender, race, dis-

ease, and modality, and computing the standard errors for these individual cells using the bootstrapping method. Methods for estimating the first-, second-, and third-year patient survival and death rates have also been modified. Average coefficients were previously entered into the Cox proportional hazards model for these estimations, but a careful examination suggested that the average output from the model would give a more accurate representation of survival estimates and subsequent death rates. These modifications are detailed in Appendix A.

Most of the 2001 Annual Data Report contains data through December 31, 1999, with certain sections (those with data on patient characteristics from the Medical Evidence Form) complete through November 2000.

USRDS WEBSITE: WWW.USRDS.ORG

The USRDS website provides users with access to PDF files of the printed Annual Data Report, Excel files of the Reference Tables and the data underlying the graphs and state maps, and PowerPoint slides of USRDS presentations. (Because of the size and complexity of the ADR files, downloading time for large portions of the book may be substantial; estimated times using a 56 kbs modem are provided next to the file names.) The USRDS has also created an online data query system for routine demographic information that includes incident and prevalent counts and percentages. Tables can be generated online that give distributions of age, gender, race, renal diagnosis, ethnicity, and geographic location. To follow USRDS confidentiality policies, all data is aggregated, and data for cells with fewer than ten patients or five providers are not provided.

THE USRDS DATABASE

Most data sets used by the USRDS are provided by HCFA. In addition to the complete data of

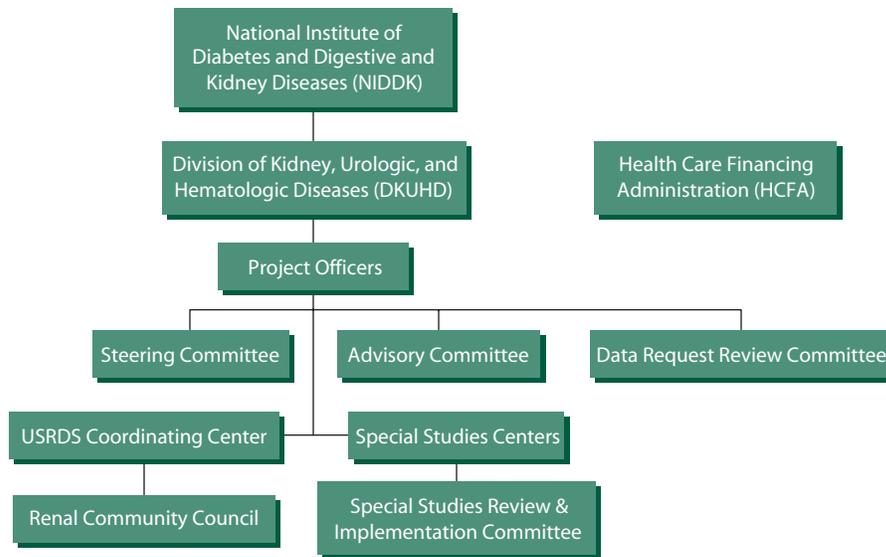


Figure i.1
Administrative oversight of the USRDS

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	Economic SSC Director Lawrence Hunsicker, MD lawrence-hunsicker@uiowa.edu	CC data requests & publication orders 612.347.7776 or 1.888.99USRDS usrds@usrds.org

Table i.1
USRDS contacts
A complete list of USRDS staff and their affiliations is presented in Appendix D.

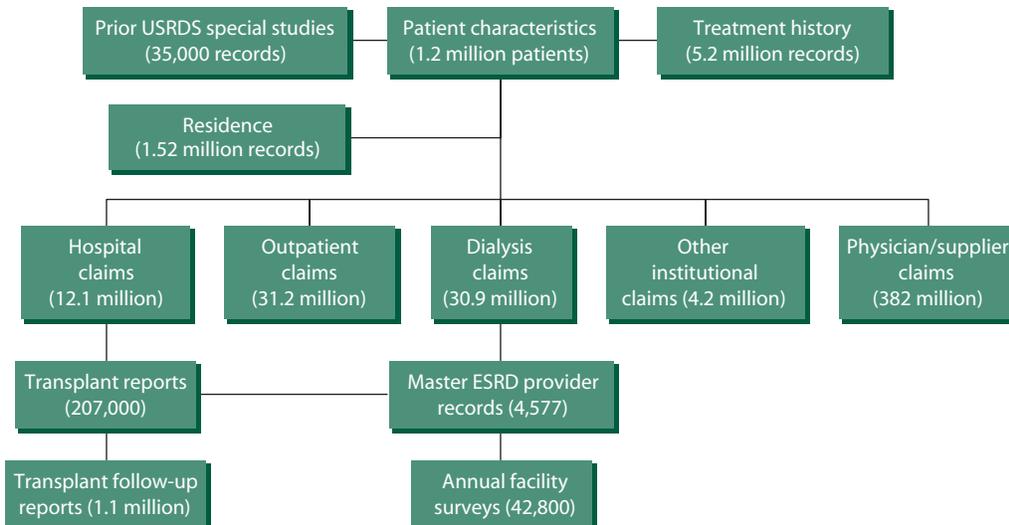


Figure i.2
Structure of the USRDS database
with counts of patient & facility records as of January 2000
More information on this database, as well as a detailed description of analytical methods, is provided in Appendix A.

Figure i.3
**Departmental organization of
 the Coordinating Center**

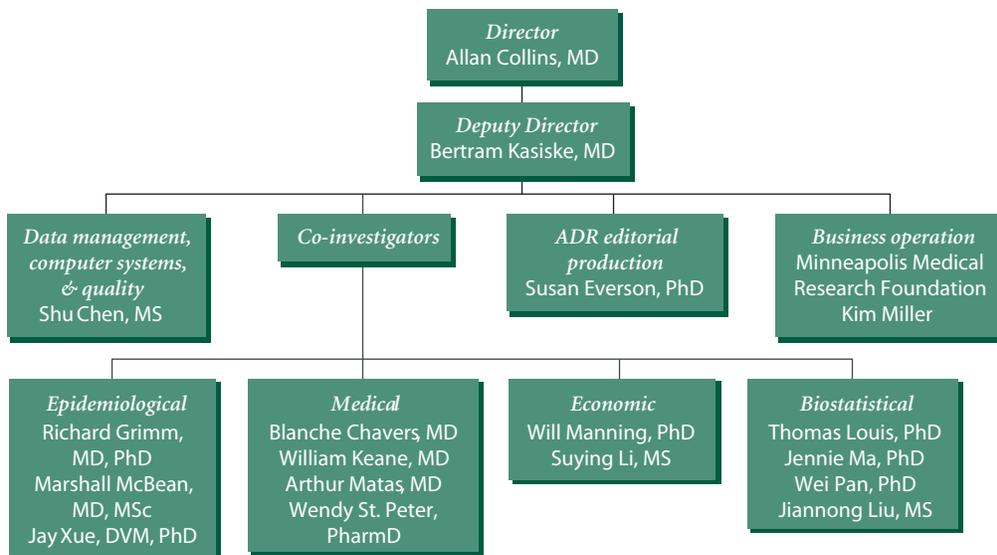


Figure i.4
**Departmental organization of
 the Cardiovascular Special
 Studies Center**

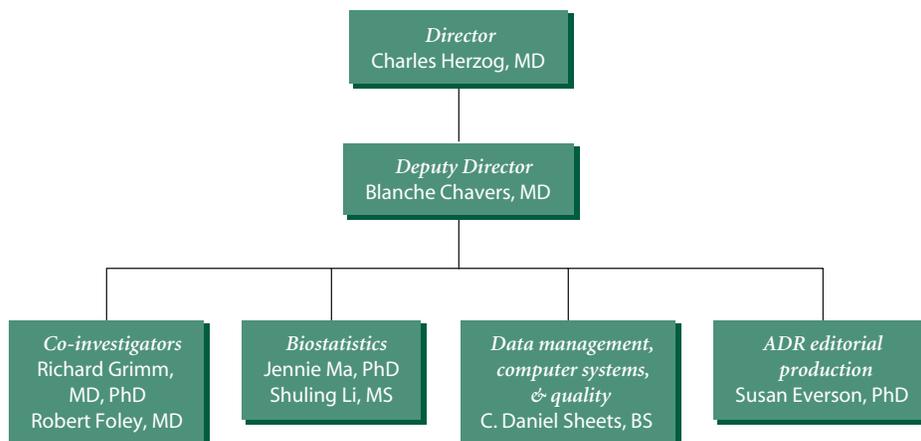


Figure i.5
**Departmental organization of
 the Economic Special Studies
 Center**

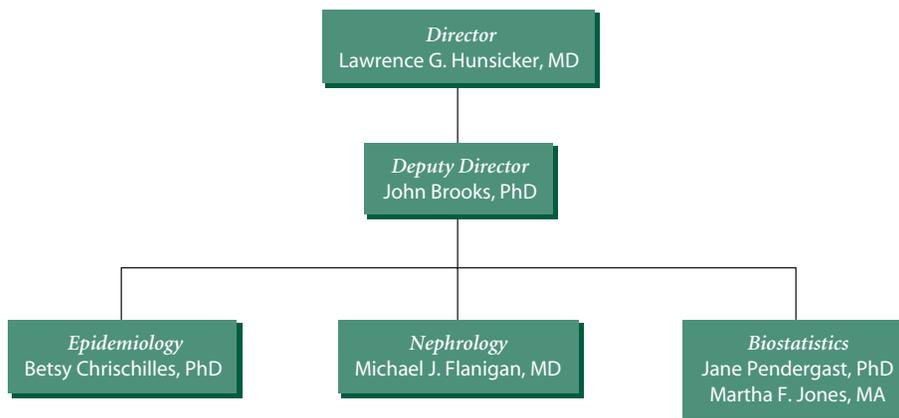


Table i.2
Key personnel of the USRDS

<p>National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Josephine Briggs, MD Director, Division of Kidney, Urologic, and Hematologic Diseases (DKUHD)</p> <p>Lawrence Y.C. Agodoa, MD Co-Project Officer, USRDS; Director, End-Stage Renal Disease Program, DKUHD</p> <p>Paul W. Eggers, PhD Co-Project Officer, USRDS; Program Director, Kidney and Urology Epidemiology, NIDDK</p> <p>Robert Coonley Contract Officer, Coordinating Center</p> <p>Marlene Mireles Contract Specialist, Cardiovascular Special Studies Center</p> <p>Health Care Financing Administration (HCFA) Pamela R. Frederick, MSB HCFA Project Coordinator, USRDS; Technical Advisor for the ESRD Program, Quality Measurement and Health Assessment Group, Office of Clinical Standards and Quality (OCSQ)</p> <p>Joel W. Greer, PhD Social Science Research Analyst, Office of Strategic Planning</p> <p>Jeffrey L. Kang, MD, MPH Director, OCSQ</p> <p>Roger Milam Computer Specialist, Division of ESRD Systems and Contract Management, Information System Group, OCSQ</p> <p>Ida Sarsitis Director, Division of Contract Policy and Performance, Quality Improvement Group, OCSQ</p> <p>Dennis Stricker Acting Director, Information System Group, OCSQ</p>	<p>USRDS Coordinating Center, Minneapolis Medical Research Foundation Allan J. Collins, MD, FACP Coordinating Center Director University of Minnesota, Hennepin County Medical Center</p> <p>Bertram Kasiske, MD Coordinating Center Deputy Director University of Minnesota, Hennepin County Medical Center</p> <p>USRDS Special Studies Centers Charles Herzog, MD Cardiovascular Special Studies Center Director University of Minnesota, Hennepin County Medical Center</p> <p>Lawrence Hunsicker, MD Economic Special Studies Center Director University of Iowa</p> <p>USRDS Coordinating Center Co-Investigators Blanche Chavers, MD University of Minnesota</p> <p>Richard Grimm, MD, PhD University of Minnesota, Hennepin County Medical Center</p> <p>Charles Herzog, MD University of Minnesota, Hennepin County Medical Center</p> <p>William Keane, MD University of Minnesota, Hennepin County Medical Center</p> <p>Thomas Louis, PhD Rand Corporation</p> <p>Jennie Ma, PhD University of Tennessee</p> <p>Willard Manning, PhD University of Chicago</p> <p>Arthur Matas, MD University of Minnesota</p> <p>Marshall McBean, MD, MSc University of Minnesota</p> <p>Wei Pan, PhD University of Minnesota</p> <p>Wendy St. Peter, PharmD University of Minnesota</p>
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the ESRD Renal Beneficiary Utilization System/ Program Management and Medical Information System (REBUS/PMMIS) and the Annual Facility Survey, HCFA supplies data from the ESRD networks, data on Medicare beneficiaries, and Medicare Part A and B claims data. The USRDS also obtains data from the United Network for Organ Sharing (UNOS) and from the National Surveillance of Dialysis-Associated Diseases in the United States, compiled by the Centers for Disease Control and Prevention (CDC). The structure of the USRDS database is illustrated in Figure i.2, and detailed descriptions of the database

itself and of the methods used to create the files and analyze the data are provided in Appendix A. In 2000 the USRDS converted a relational Oracle database to a database that uses a SAS-only data warehousing methodology. This allowed for more consistency in the programs used to generate the database output, as well as in the structure of the analyses done for the ADR.

MEDICARE & NON-MEDICARE PATIENTS

In the 2000 ADR we discussed the difficulties inherent in dealing with the combination of Medicare and non-Medicare (“ZZ”) patients in the

USRDS database. The revised version of the Medical Evidence Form, introduced in April 1995, requires that all ESRD patients be reported to the ESRD Networks, and data on the increased numbers of non-Medicare patients reported continues to differ considerably from that available on traditional Medicare patients. While deaths of Medicare patients, for example, are reported both on the Death Notification Form (2746) and in the enrollment database, deaths of non-Medicare patients are reported on only the 2746 form, leading often to incomplete mortality data for these patients. The Coordinating Center continues to advance its efforts to more fully identify non-Medicare patients, particularly in analyses of causes of death.

TYPES OF ESRD TREATMENT

The Coordinating Center and the Health Care Financing Administration's REBUS group have worked extensively on methods to categorize patients by different ESRD treatment modalities. The primary source of information on patient modality at the initiation of treatment is the Medical Evidence Form 2728. The modality indicated here may, however, be temporary, as patients often change to a new modality within the first 90 days. Methods used to determine modality within this time are significantly influenced by the availability of data. Patients 65 and older have Medicare claims in the first 90 days; these claims contain revenue codes which designate modality. Patients younger than 65 who are in employer group health plans or Medicare risk programs, however, have no claims in this time 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 those patients who are found to have an unstable modality (<60 days on a modality) 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 adequately identified and appropriately assigned to individual 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 actual mortality and hospitalization events with the least biasing of the data.

The Coordinating Center and HCFA continue to work on methods to reduce the number of patients classified as having unknown or unstable dialysis modalities by reconciling the claims data with the direct ESRD Network census data.

HEALTHY PEOPLE 2010

The Healthy People program, developed by the Department of Health and Human Services, focuses on the improvement of public health. The first set of objectives was promoted in Healthy People 2000, and a revised set has been released as Healthy People 2010 (www.health.gov/healthypeople). The program is "designed to identify the most significant preventable threats to health and to establish national goals to reduce these threats." Objectives focused on kidney disease were added to the HP2010 program, with goals including reduction of the disease's incidence, prevalence, and cardiovascular complications.

Kidney disease affects certain racial groups at different rates, and programs targeted towards prevention and treatment need to take these realities into consideration. African Americans, American Indians, and Hispanics, for example,

have higher rates of kidney disease, particularly that caused by diabetes. Racial disparities also occur in access to renal replacement therapy. To provide a deeper understanding of these disparities, we have provided data by race and ethnicity wherever possible. We have also added a special section before Reference Section A, addressing each of the kidney disease objectives through data culled from throughout the atlas and table sections of the 2001 ADR.

ADMINISTRATIVE OVERSIGHT OF THE USRDS

Paul Eggers, PhD, Program Director for the Kidney and Urology Epidemiology Division of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), joined the USRDS as Co-Project Officer in 2000. The remaining organizational structures of the Coordinating Center, Cardiovascular SSC, and Economic SSC are unchanged.

Because of the complexity of the ADR's layout and design, the CC has worked to advance the editorial production of the book, and staff members in the editorial office work with their counterparts at the National Institutes of Health and the Government Printing Office to ensure that the book meets appropriate standards.

Lawrence Agodoa, MD and Paul Eggers, PhD provide direct oversight of the CC and SSCs, and members of HCFA, the renal 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 HCFA, 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 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.

The Data Management Advisory Committee (DMAC) includes members from HCFA, 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 CC, and works to ensure the timely fulfillment of data requests made to the USRDS.

The Annual Data Report Committee (ADRC) reviews the data sections of previous ADRs, proposals for additions to future ADRs, and ideas for expanded data availability on the USRDS website.

The Information Systems Committee (ISC) reviews planned hardware requirements, systems configuration, documentation, and performance, and evaluates new technologies that may enhance the structure, function, and management of the database.

The Medical Advisory Board suggests topics for possible investigation, and discusses appropriate analytical methods.

The Scientific Review Group (SRG) provides initial evaluation of studies proposed by the CC and the SSCs.

The Special Studies Review & Implementation Committee (SSRIC) serves as the operations committee for SSC proposals and for support of CC projects. It is a collaboration of members from HCFA, the ESRD networks, and the providers.

The Data Request Review Committee (DRRC) reviews data requests that require more than two hours of staff time at the CC or SSCs to fulfill, and makes recommendations to the Project Officers based on the types of data sets requested by researchers 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 interested in ESRD, serves as a significant liaison between the USRDS and the ESRD community.

NOTE

In all map legends, mean values of the highest and lowest quintiles are indicated in parentheses.

The following materials could not have been produced without the extraordinary work of members of the ESRD community and the dedicated efforts of the USRDS staff and investigators. Feedback on the ADR and on other work of the USRDS is welcomed, and all comments and requests are reviewed by the Director, Deputy Director, and staff in order to provide the best possible responses, improve future materials, and ensure a strong working relationship between the USRDS and clinicians, researchers, patients, and others involved in ESRD care.