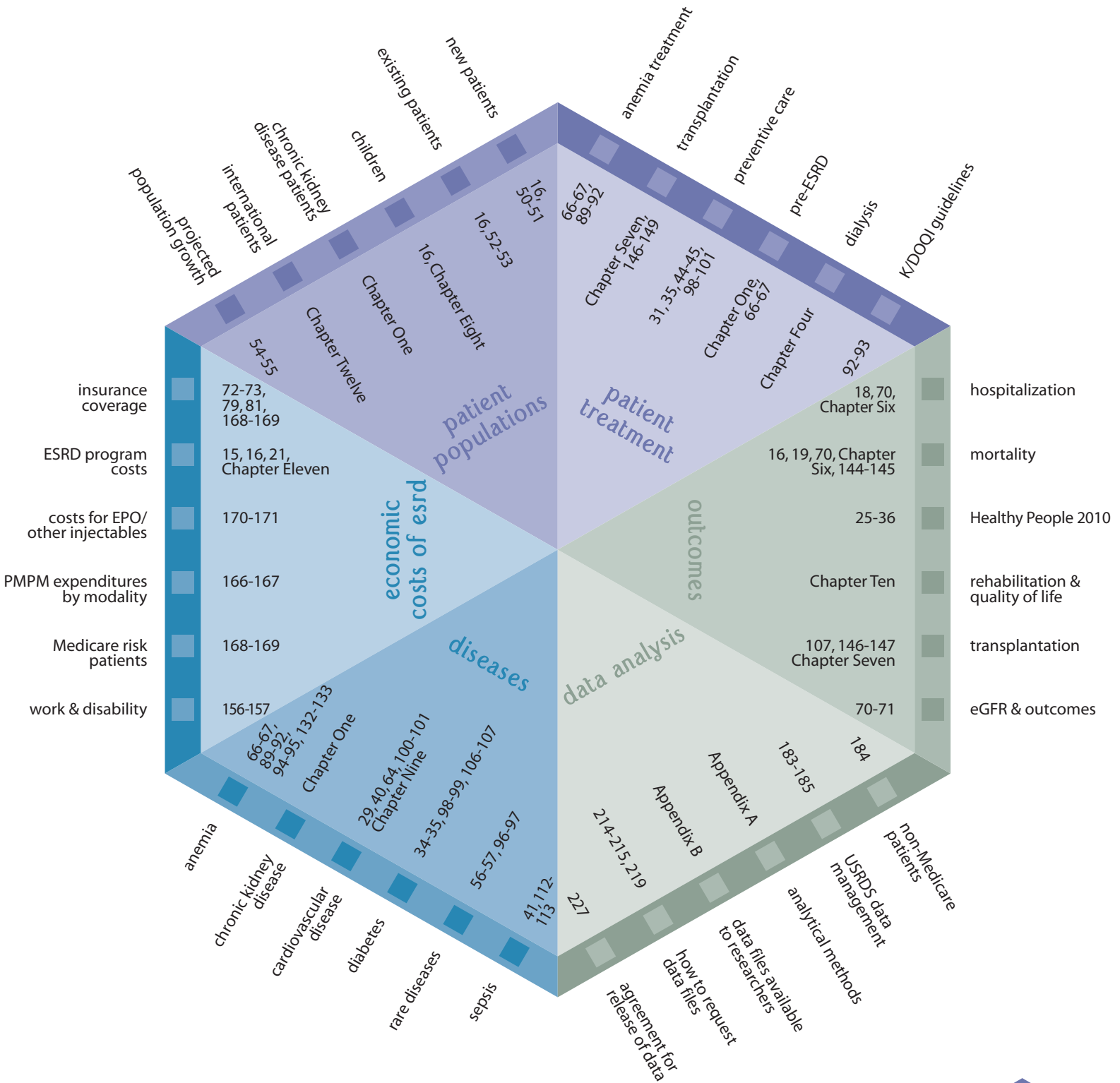




Information map: by topic

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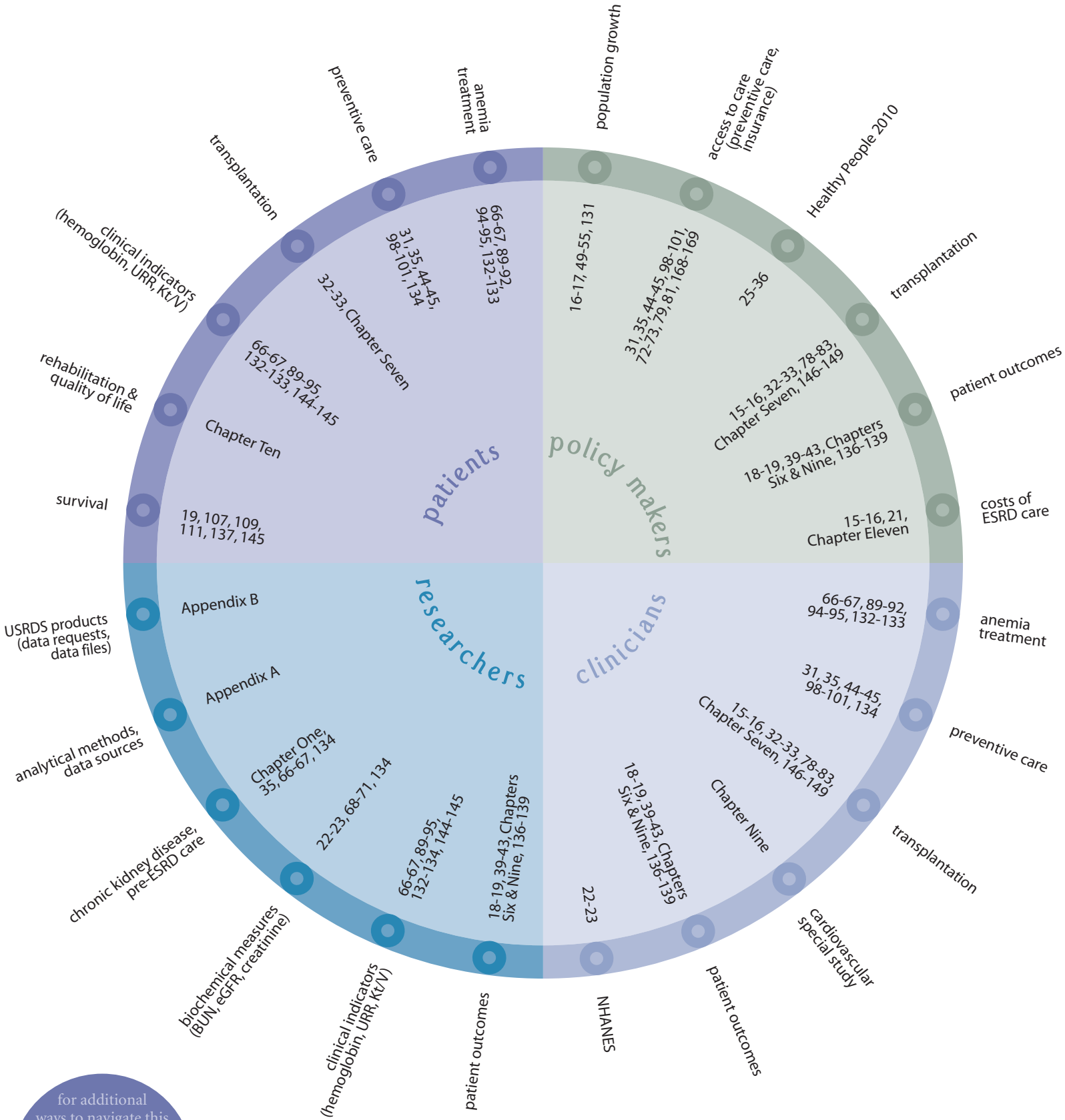


for additional ways to navigate this Annual Data Report, please see the *Table of Contents* (pages iv-v) & the *Index* (pages 224-226)



Information map: by audience

Of particular interest to...



for additional ways to navigate this Annual Data Report, please see the *Table of Contents* (pages iv-v) & the *Index* (pages 224-226)



USRDS

United States
Renal Data System

*This 15th annual report of the
United States Renal Data
System is produced by the
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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.

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.

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.



Suggested citation for this report: U.S. Renal Data System, *USRDS 2003 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, Bethesda, MD, 2003.

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

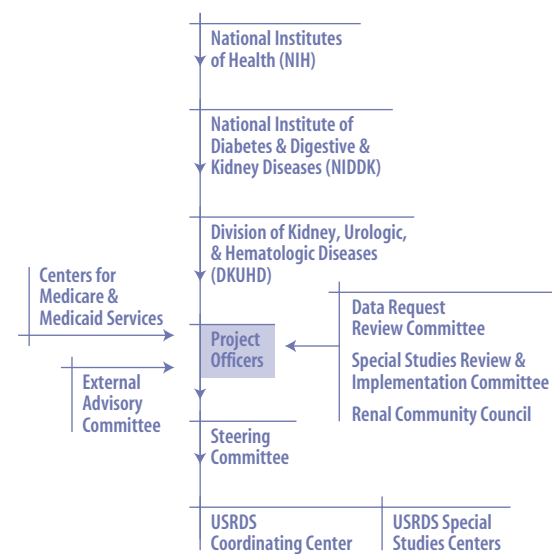
In the Précis we provide a broad overview of the ESRD program, showing patient counts, Medicare expenditures, hospitalization and mortality rates by patient vintage, and trends in the provider community. We also look at data from the National Health and Nutrition Examination Survey (NHANES).

The next chapter presents information related to Healthy People 2010, a program sponsored by the Department of

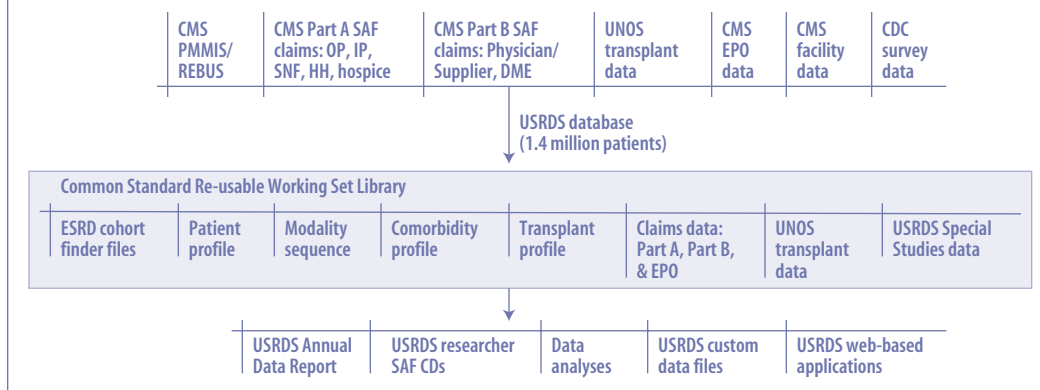
Health and Human Services. HP2010 objectives related to kidney disease include reducing the incidence of ESRD overall and of kidney disease caused by diabetes. To address progress toward these objectives we have included data from the Medicare 5 percent sample, which provides information on the general 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

i.1 • Administrative oversight of the USRDS



i.2 • Structure of the USRDS database



on our website, www.usrds.org

PDF files of the 2003 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

information on requesting data from the USRDS is provided in Appendix B, starting on page 214

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 im-

portant 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 re-

cent 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-

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,

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i.3 • Departmental organization of the Coordinating Center



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 confi-
dentiality 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 up-
dated 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 con-
tinually updated with new information on the ESRD popu-
lation. Delays in the reporting of data are unavoidable, and
we add late information to the database as soon as it be-

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comes 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 contin-
ued this year to collaborate with the Centers for Medicare
and Medicaid Services (formerly HCFA) and the ESRD net-
works. Information obtained from the Medical Evidence
form, the Facility Survey form, and the Standard Informa-

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tion Management System (SIMS) database has been reviewed to identify discrepancies.

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. population; 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

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