



A man sets out to draw the world. As the years go by, he peoples a space with images of provinces, kingdoms, mountains, bays, ships, islands, fishes, rooms, instruments, stars, horses, and individuals. A short time before he dies, he discovers that the patient labyrinth of lines traces the lineaments of his own face.

Jorge Luis Borges  
DREAMTIGERS





2013 USRDS  
ANNUAL DATA REPORT  
VOLUME TWO

*Atlas of End-Stage  
Renal Disease in the  
United States*

# volume one

## ATLAS OF CHRONIC KIDNEY DISEASE IN THE UNITED STATES

guide to topics in the ADR + 8

list of CKD figures & tables  
appearing each year + 10

Volume One highlights + 12

overview of CKD in the u.s. + 14

introduction + 18

chapters + 23

reference tables: CKD + 119

analytical methods + 137

*Precis* AN INTRODUCTION TO CKD IN THE US. + 23

*One* CKD IN THE GENERAL POPULATION + 41  
prevalence of CKD; comorbidity; awareness, treatment, & control; life expectancy

*Two* IDENTIFICATION & CARE OF PATIENTS WITH CKD + 51  
prevalence of recognized CKD; laboratory testing of patients  
at risk for CKD; probability & odds of a CKD diagnosis code;  
probability & odds of seeing a physician after diagnosis

*Three* MORBIDITY & MORTALITY IN PATIENTS WITH CKD + 63  
hospitalization rates; rehospitalization; mortality rates

*Four* CARDIOVASCULAR DISEASE IN PATIENTS WITH CKD + 73  
cardiovascular disease, intervention, & survival; medication use; heart failure

*Five* PART D PRESCRIPTION DRUG COVERAGE IN PATIENTS WITH CKD + 83  
part D enrollment patterns in patients with CKD; part D coverage plans; costs of part D  
enrollment; coverage phase analyses; prescription drug therapy in CKD & ESRD patients

*Six* ACUTE KIDNEY INJURY + 95  
characteristics of patients with AKI; hospitalization for AKI; patient  
care & outcomes; changes in CKD status following AKI

*Seven* COSTS OF CKD + 107  
trends in costs of CKD; part D costs; drug utilization;  
expenditures during the transition to ESRD

2013  
USRDS  
ANNUAL  
DATA  
REPORT

volume two  
*esrd*

154

# Volume Two

## ATLAS OF END-STAGE RENAL DISEASE IN THE UNITED STATES

- list of ESRD figures & tables appearing each year + 156
- ESRD program highlights + 158
- overview of ESRD in the U.S. + 160
- hospitalization & Part D use in the ESRD population + 162
- introduction + 164
- chapters + 169
- reference tables: ESRD + 345
- analytical methods + 421
- USRDS products & services + 454
- glossary + 461
- CMS forms + 469
- data requests + 454
- agreement for release of data + 465
- merged dataset agreement for release of data + 467
- Precis* AN INTRODUCTION TO ESRD IN THE U.S. + 169
- Healthy People 2020* + 193  
recommended care among patients with AKI, diabetes, & CKD; ACEI/ARB treatment; ESRD incidence; kidney failure due to diabetes; nephrologist care; vascular access; transplantation; mortality
- One* INCIDENCE, PREVALENCE, PATIENT CHARACTERISTICS, & TREATMENT MODALITIES + 215  
incident counts & rates; incident rates & racial differences; prevalent counts & rates; incident & prevalent modality; patient characteristics
- Two* CLINICAL INDICATORS & PREVENTIVE CARE + 229  
anemia treatment by modality; preventive care; vascular access
- Three* HOSPITALIZATION + 237  
admission rates & hospital days; hospital admissions: infection; hospital admissions: cardiovascular; rehospitalization
- Four* CARDIOVASCULAR DISEASE + 249  
diagnosis of cardiovascular disease; cardiac events & rates of sudden cardiac death; pharmacological interventions; body mass index & cardiac death; bariatric surgery; heart failure
- Five* MORTALITY + 263  
mortality & survival; mortality in the general & ESRD populations
- Six* PART D PRESCRIPTION DRUG COVERAGE IN ESRD PATIENTS + 271  
part D enrollment patterns; part D coverage plans; overall costs of part D enrollment; coverage analysis & antibiotic use; bone & mineral medication use pre- & post-bundle
- Seven* TRANSPLANTATION + 283  
wait list; donation; transplant; outcomes; follow-up care; part D medications in kidney transplant recipients
- Eight* PEDIATRIC ESRD + 295  
ESRD diagnosis in the pediatric population; incidence of ESRD; vaccinations; hospitalization; mortality; mean hemoglobin; medication use
- Nine* REHABILITATION/QUALITY OF LIFE & NUTRITION SPECIAL STUDIES + 307  
ACTIVE/ADIPOSE study; frailty index
- Ten* ESRD PROVIDERS + 315  
provider growth; preventive care; treatment under the dialysis composite rate; standardized hospitalization & mortality ratios
- Eleven* COSTS OF ESRD + 325  
overall & per person per year costs of ESRD; Part D costs by low income subsidy & provider
- Twelve* INTERNATIONAL COMPARISONS + 333  
worldwide view of the incidence of ESRD; incidence of ESRD; prevalence of ESRD; dialysis; transplantation

# data on end-stage renal disease

APPEARING EACH YEAR IN THE ANNUAL DATA REPORT

## précis

- p.1 distribution of general Medicare patients & costs for CKD, CHF, diabetes, & ESRD
- p.a summary statistics on reported ESRD therapy in the U.S.
- p.2 counts of new & returning dialysis patients
- p.3 patient counts, by modality

## chapter one

- 1.1 incident & prevalent patient counts, by modality
- 1.2, 1.10 adjusted rates of ESRD & annual percent change
- 1.3, 1.11 geographic variations in adjusted rates of ESRD
- 1.4–7 incident counts & adjusted rates of ESRD, by age, race, ethnicity, & primary diagnosis
- 1.12–15 prevalent counts & adjusted rates of ESRD, by age, race, ethnicity, & primary diagnosis
- 1.17, 1.19 patient distribution, by modality & payer
- 1.22 access use at first outpatient hemodialysis, by pre-ESRD nephrology care
- 1.23 mean hemoglobin at initiation, by pre-ESRD ESA treatment
- 1.24 variations in mean hemoglobin by HSA, 2011
- 1.25 patient distribution at initiation, by eGFR
- 1.a–c patient demographics & adjusted rates, by ESRD network
- 1.d–e counts & adjusted rates of ESRD, by modality, age, gender, race, ethnicity, & primary diagnosis
- 1.f pre-ESRD nephrologist care
- 1.g patients initiating dialysis with laboratory values outside the normal limit

## chapter two

- 2.2, 2.8 patient distribution, by mean monthly hemoglobin
- 2.3, 2.9 mean monthly hemoglobin & mean EPO dose per week
- 2.4, 2.10 mean monthly hemoglobin after initiation
- 2.5, 2.11 mean EPO dose per week after initiation
- 2.6, 2.12 IV iron in the first six months of dialysis
- 2.7, 2.13 transfusions
- 2.14–17 preventive care in ESRD patients with diabetes
- 2.a vaccination rates
- 2.18–20 access use at initiation

## chapter three

- 3.1 change in adjusted all-cause & cause-specific hospitalization rates, by modality
- 3.2 adjusted admission rates & days, by modality
- 3.a all-cause & cause-specific hospitalization rates in hemodialysis patients
- 3.14–20 all-cause and cause-specific rehospitalization rates 30 days after live hospital discharge

## chapter five

- 5.1 adjusted mortality (from day 90), by modality & year of treatment
- 5.3 adjusted mortality (from day one) in the first year of hemodialysis
- 5.4 adjusted mortality in prevalent hemodialysis patients, by vintage
- 5.b adjusted five-year survival probabilities, from day one, in the incident ESRD population
- 5.c mortality rates in the ESRD & general Medicare populations
- 5.5–6 adjusted mortality in the ESRD & general populations

## chapter six

- 6.2–4 sources of prescription drug coverage in Medicare enrollees
- 6.7 Part D non-LIS enrollees with gap coverage or no deductible, by modality
- 6.9 total estimated net Part D payment for enrollees
- 6.10 PDP Medicare & out-of-pocket Part D costs for enrollees
- 6.e twelve-month probability of reaching the coverage gap in Part D non-LIS enrollees
- 6.13 Part D non-LIS enrollees who reach each coverage phase
- 6.18 top 15 drugs used by Part D-enrolled dialysis patients, by net costs & drug class

### chapter seven

- 7.1 trends in transplantation
- 7.2 patients wait-listed or receiving a deceased donor transplant within one year of initiation
- 7.8 likelihood of dying while awaiting transplant
- 7.9 cumulative incidence of transfusion in wait-listed patients, by PRA
- 7.10 donation rates
- 7.12, 7.14 deceased & living donor transplants
- 7.13, 7.15 adjusted transplant rates
- 7.17–18 transplant outcomes
- 7.19 acute rejection within the first year post-transplant
- 7.22 primary diagnoses of cardiac & infectious hospitalizations post-transplant
- 7.23–24 cumulative incidence of PTLD & diabetes
- 7.25 adjusted rate of outcomes after transplant
- 7.26 causes of death with function
- 7.27 immunosuppression use
- 7.28 follow-up care & screening in the first 12 months post-transplant, by age
- 7.33–35 medication use in the first six months post-transplant

### chapter eight

- 8.a distribution of incident ESRD pediatric patients, by primary diagnosis
- 8.5–6 vaccination rates in pediatric patients
- 8.10 adjusted all-cause mortality rates in pediatric patients (from day one), by age & modality
- 8.13 adjusted five-year survival in pediatric patients

### chapter ten

- 10.1 distribution of patients, by unit affiliation
- 10.3 dialysis unit & patient counts, by unit affiliation
- 10.4–6 preventive care in diabetic dialysis patients, by unit affiliation & number of tests
- 10.9–12 all-cause standardized hospitalization & mortality ratios

### chapter eleven

- 11.1 ESRD spending, by payer
- 11.2 costs of the Medicare & ESRD programs
- 11.3 estimated numbers of point prevalent ESRD patients
- 11.4 annual percent change in Medicare ESRD spending
- 11.5 total Medicare dollars spent on ESRD, by type of service
- 11.6–7 total Medicare ESRD expenditures overall & PPPY, by modality

### chapter twelve

- 12.1 comparison of unadjusted ESRD incidence & prevalence worldwide
- 12.2 geographic variations in the incidence of ESRD
- 12.3, 12.a incidence of ESRD
- 12.4–5 incident patients with ESRD due to diabetes
- 12.6, 12.b prevalence of ESRD
- 12.7, 12.c percent distribution of prevalent dialysis patients, by modality
- 12.8, 12.d prevalent rates of functioning grafts
- 12.9, 12.e transplant rates

# highlights OF VOLUME TWO

## patients

115,643

number of new ESRD patients, 2011 (Table p.a)

357

adjusted rate of incident ESRD, 2011 (per million population; Table p.a)  
white: 280 • black/African American: 940  
• Native American: 453 • Asian: 399

15.6

adjusted rate of incident ESRD in pediatric patients, 2011 (per million population; Table p.a)

615,899

number of prevalent ESRD patients, 2011 (Table p.a)

1,901

adjusted rate of prevalent ESRD, 2011 (per million population; Table p.a)  
white: 1,395 • black/African American: 5,583  
• Native American: 2,701 • Asian: 2,265

89

adjusted rate of prevalent ESRD in pediatric patients, 2011 (per million population; Table p.a)

75%

prevalent hemodialysis patients enrolled in Medicare Part D, 2011 (Table 6.c)

58%

prevalent transplant patients enrolled in Medicare Part D, 2011 (Table 6.c)

## patient care

9.7

mean hemoglobin (g/dl) for patients initiating ESRD therapy (Table 1.g)

70%

diabetic patients receiving two or more A1c tests, 2010–2011 (Figure 2.14)

51%

diabetic patients receiving two or more lipid tests, 2010–2011 (Figure 2.15)

21%

diabetic patients receiving two or more eye examinations, 2010–2011 (Figure 2.16)

16%

patients using a fistula at first outpatient dialysis, 2011 (Figure 2.18)

## outcomes

1.88

adjusted all-cause admission rate among hemodialysis patients, 2010–2011 (admissions per patient year; Table 3.a)  
white: 1.91 • black/African American: 1.91  
• other race: 1.5

0.51

adjusted cardiovascular admission rate among hemodialysis patients, 2010–2011 (admissions per patient year; Table 3.a)  
white: 0.51 • black/African American: 0.52  
• other race: 0.4

0.47

adjusted rate of admission for infection (overall) among hemodialysis patients, 2010–2011 (admissions per patient year; Table 3.a)  
white: 0.49 • black/African American: 0.45  
• other race: 0.4



The Southern Hemisphere

TABLE of the Places of the SUN in the Equinoctial Declination

254 adjusted all-cause first-year mortality among 2010 incident patients (deaths per 1,000 patient years at risk, from day one; Figure 5.1)  
*hemodialysis: 269 + peritoneal dialysis: 121 + transplant (from date of transplant): 54*

2.5 adjusted rate of deceased donor kidney transplants, 2011 (per 100 dialysis patient years; Figure 7.13)  
*white: 2.7 + black/African American: 2.0 + Asian: 3.6 + other race: 2.4*

229 adjusted all-cause fifth-year mortality among 2006 incident patients (deaths per 1,000 patient years at risk, from day one; Figure 5.1)  
*hemodialysis: 238 + peritoneal dialysis: 257 + transplant (from date of transplant): 62*

1.2 adjusted rate of living donor kidney transplants, 2011 (per 100 dialysis patient years; Figure 7.15)  
*white: 1.8 + black/African American: 0.4 + Asian: 2.1 + other race: 1.0*

0.34 adjusted five-year survival probability among white ESRD patients incident in 2006 (Table 5.b)

0.42 adjusted five-year survival probability among black/African American ESRD patients incident in 2006 (Table 5.b)

expenditures

\$34.4 billion total Medicare ESRD expenditures, 2011 (Table p.a)

\$14.9 billion total non-Medicare ESRD expenditures, 2011 (Table p.a)

\$49.3 billion total ESRD expenditures, 2011 (Table p.a)

\$87,945 total Medicare expenditures per person per year for hemodialysis patients, 2011 (Table p.a)

\$71,630 total Medicare expenditures per person per year for peritoneal dialysis patients, 2011 (Table p.a)

\$32,922 total Medicare expenditures per person per year for transplant patients, 2011 (Table p.a)

\$2.1 billion total estimated net Part D payment for ESRD patients, 2011 (Figure 6.9)  
*hemodialysis: \$1.6 billion + peritoneal dialysis: \$102 million + transplant: \$315 million*

transplantation

17,671 total kidney transplants, 2011 (Table p.a)  
*deceased donor: 11,835 + living donor: 5,772*

22.4 rate of deceased donor kidney donation, 2011 (per million population; Figure 7.10)  
*white: 22.3 + black/African American: 27.2 + Native American: 9.3 + Asian: 8.4*

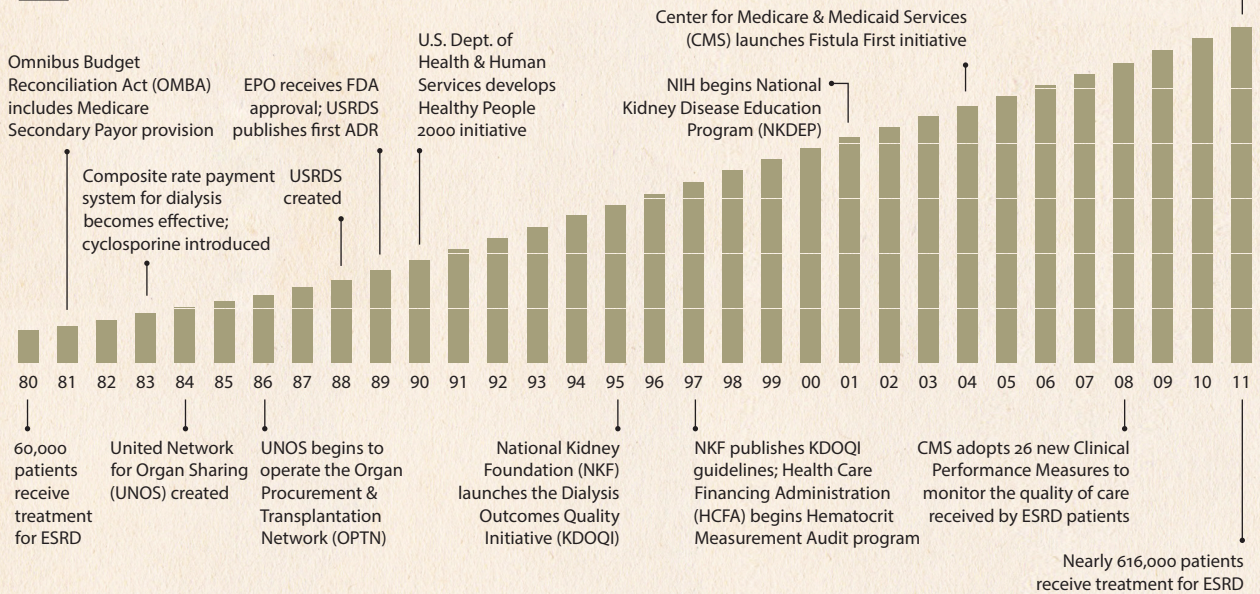
20.3 rate of living donor kidney donation, 2011 (per million population; Figure 7.10)  
*white: 20.7 + black/African American: 19.6 + Native American: 5.5 + Asian: 11.5*

# end-stage renal disease

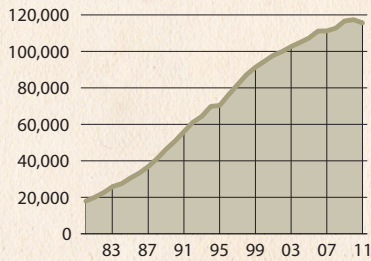
## IN THE UNITED STATES

1972 Congress authorizes medical coverage of ESRD  
 1978 Congress authorizes creation of ESRD networks

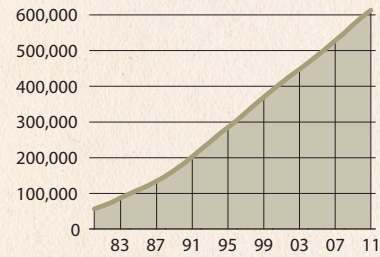
New bundled Prospective Payment System for dialysis patients implemented in January, 2011



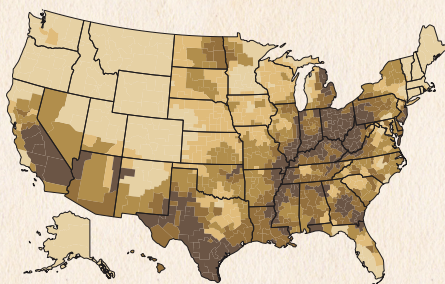
**New patients** Nearly 116,000 people began treatment for end-stage renal disease (ESRD) in 2011.



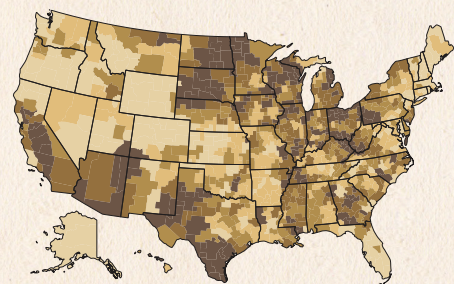
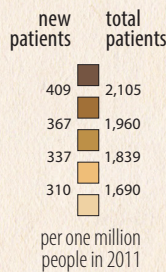
**Total patients** Nearly eleven times more patients are now being treated for ESRD than in 1980.



1980 U.S. patients newly diagnosed with ESRD 1 in 11,000  
 2011 1 in 2,800



1980 U.S. patients being treated for ESRD 1 in 3,400  
 2011 1 in 526

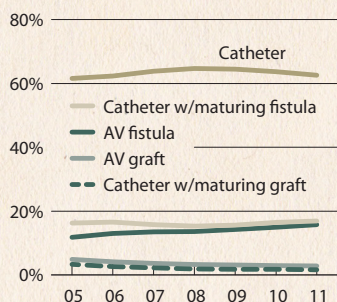


Graphs: Figure 1.1  
 Rates of new & existing patients: Figures 1.5 & 1.13  
 Maps: Figures 1.3 & 1.11

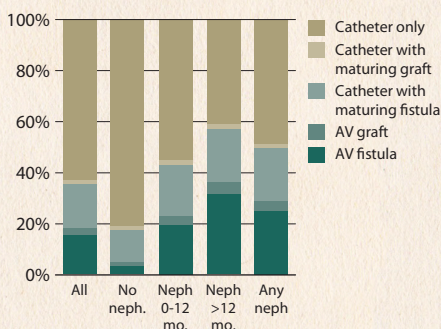
44% of new ESRD cases have a primary diagnosis of **DIABETES**;  
28% have a primary diagnosis of **HYPERTENSION**

The rate of new ESRD cases is **3.4 TIMES HIGHER**  
among **BLACKS/AFRICAN AMERICANS**  
than among whites

**Access** Most patients use a catheter at their first outpatient dialysis run.



But patients who receive pre-ESRD care from a nephrologist are more likely to start dialysis with a fistula—an access associated with lower risks of complications.



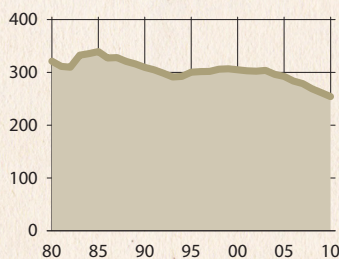
**24,000**  
number of adult patients waiting for a kidney transplant in 1995

**90,000**  
number waiting in 2011

**2.6 years**  
median time on transplant wait list (adults)

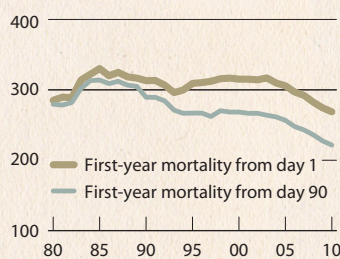
**Mortality** All-cause mortality rates in the ESRD population, calculated from the first day of treatment, continue to fall.

Deaths per 1,000 patient years at risk, from day 1: **ESRD**

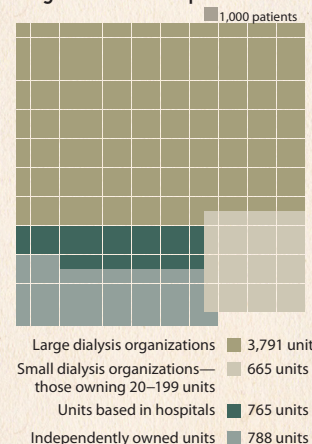


But in the hemodialysis population, rates calculated day 1 of therapy are considerably higher than those using the traditional calculation from day 90.

Deaths per 1,000 patient years at risk: **hemodialysis**



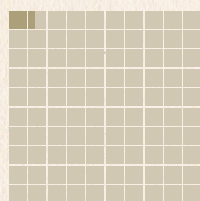
**Dialysis unit ownership**



**6 in 10** dialysis patients are treated in units owned by **FRESENIUS** or **DAVITA**

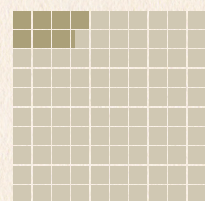
**Costs of caring for patients with ESRD, 2011**

**1.4%** of Medicare patients have ESRD



ESRD: 429,000 patients

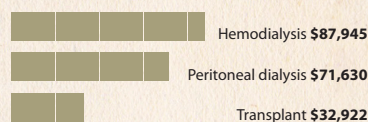
They account for **7.2%** of Medicare spending



\$25.6 billion 1%

TOTAL MEDICARE SPENDING  
**\$355 BILLION**

Medicare spending per patient year, by type of renal replacement therapy



**\$49.3 BILLION**  
total costs per year for ESRD patient care

Diabetes & hypertension; race: Table p.a  
Vascular access: Figures 2.12 & 1.22  
Transplant wait list: Figures 7.1 & 7.6

Mortality: Figure 5.1  
Unit ownership: Figure 10.1  
Costs: Figure p.1; Figure 11.7; Table p.a

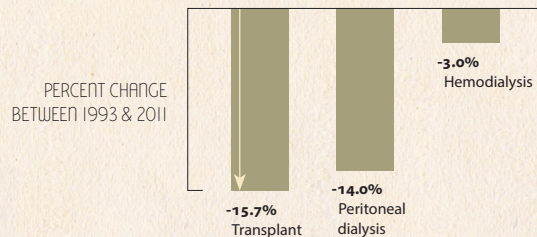
# hospitalization & part d

## IN THE ESRD POPULATION

**Hospital days per year** Patients with ESRD are now spending fewer days each year in the hospital.

1993		2011
8.7	Transplant	<b>5.7 days per year</b>
18.3	Peritoneal dialysis	<b>11.7</b>
15.0	Hemodialysis	<b>11.7</b>

**Hospitalization Rates** And all-cause hospitalization rates have fallen since 1993.



But **INFECTION** remains a major cause of **HOSPITALIZATION** among patients with ESRD

And data on rates of admission **WITH** infection (primary or secondary code) compared to rates **FOR** infection (primary only) show that infections associated with hospitalization have been under-reported.

Admissions for infection, per 1,000 patient years

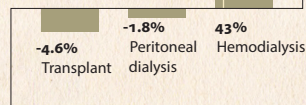
**233**  
transplant

**551**  
peritoneal dialysis

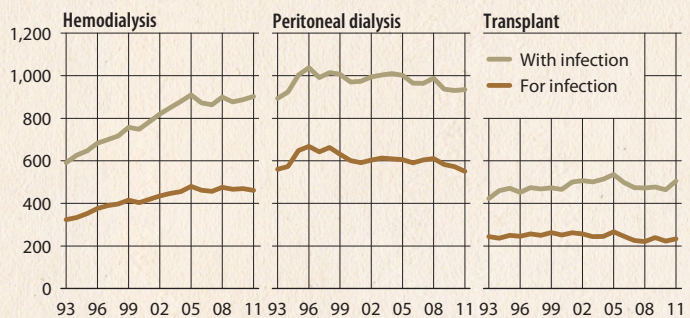
**462**  
hemodialysis

**Change in rates of hospitalization due to infection**

PERCENT CHANGE BETWEEN 1993 & 2011



Admissions per 1,000 patient years

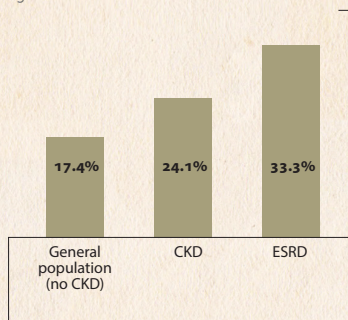


ESRD patients also face a high risk of **REHOSPITALIZATION** after discharge from the hospital

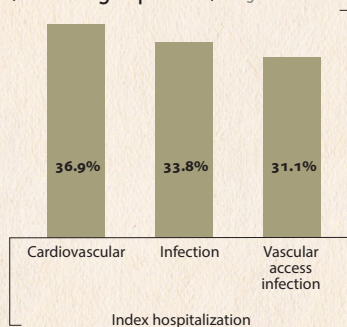
Patients rehospitalized within 30 days of a live hospital discharge

**All-cause rehospitalization**

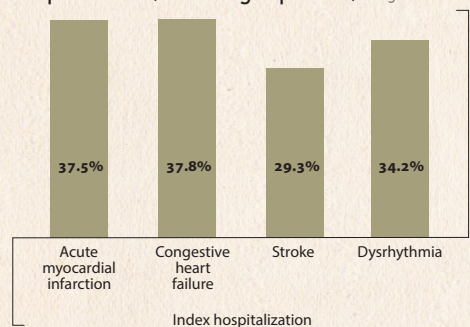
age 66 & older



**All-cause rehospitalization (hemodialysis patients)** all ages



**Rehospitalization after a cardiovascular index hospitalization (hemodialysis patients)** all ages



**JANUARY 1, 2006: MEDICARE PART D GOES INTO EFFECT**

to help subsidize the costs of prescription drugs in Medicare beneficiaries

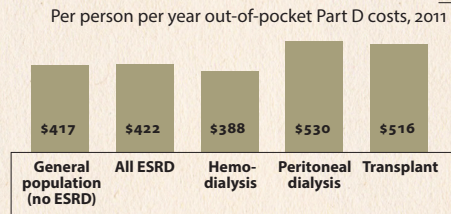
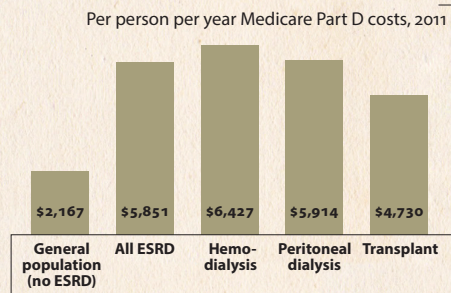
NET PART D COSTS FOR  
MEDICARE **DIALYSIS**  
PATIENTS IN 2011

**\$1.69  
BILLION**

**COSTS** top three drug classes used  
by Part D enrollees on **dialysis**

**\$517 million** 33.1%  
phosphate binder agents  
**\$295 million** 18.9%  
calcimimetic agents  
**\$80 million** 5.1%  
insulin

**57.1%**  
of total Medicare  
Part D drug costs  
in 2011



NET PART D COSTS FOR  
MEDICARE **TRANSPLANT**  
PATIENTS IN 2011

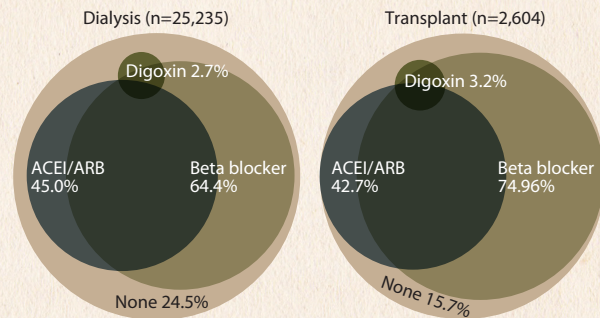
**\$315  
MILLION**

**COSTS** top three medications used  
by Part D enrollees on **transplant**

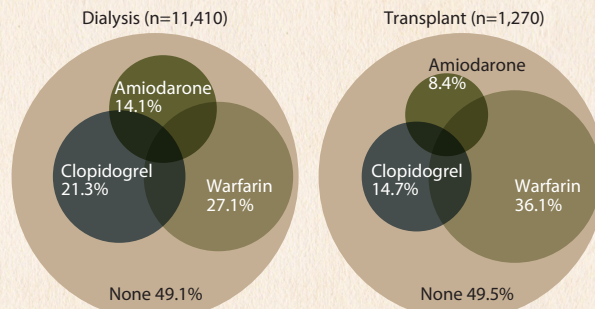
**year one**  
**\$20.6 million**  
valganciclovir  
**\$5.7 million**  
cinacalcet  
**\$5.1 million**  
sevalamer

**year two**  
**\$10 million**  
valganciclovir  
**\$3.2 million**  
insulin  
**\$2.6 million**  
cinacalcet

**Medication use in patients treated  
for congestive heart failure**



**Medication use in patients  
treated for atrial fibrillation**



Total Part D costs: Figure 6.9  
Dialysis Part D medication costs: Figures 6.18  
Transplant Part D medication costs: Table 7.b  
PPPY & OOP costs: Figure 6.10  
Cardiovascular medication use: Figures 4.14-15

This is the twenty-fifth *USRDS* Annual Data Report, marking a quarter century of continued comprehensive reporting on the end-stage renal disease (*ESRD*) population in the United States, and marking as well 40 years since the inception of the U.S. *ESRD* program in July, 1973.

As noted in the introduction to Volume One, this year's *ADR* uses the evolving understanding of the earth's geography throughout history as a metaphor for increased knowledge of the terrain of kidney disease. Past inaccuracies in cartography led many sailors and ships to adverse consequences, a parallel to the potential outcomes of inadequate knowledge of kidney disease and its collateral impact across many organ systems. As tools for navigation and cartography improved, human travel across the planet became less uncertain. The advancement of the maritime chronometer by John Harrison forever changed exploration, as relative east/west longitude and north/south latitude could now mark a position on the globe. Today, the use of global positioning systems has markedly enhanced navigation not just at sea but on land as well.

In the same way, knowledge of the landscape of kidney disease has progressed substantially over the past 50 years, particularly in the last decade, as our evolving understanding of its effects across the body has led us to alter routes of diagnosis and treatment in our efforts to reduce complications and improve outcomes.

Volume Two continues to focus on *ESRD*, and on the historical surveillance data that were the basis of the first *USRDS* reports. We summarize the *ESRD* program in the United States and, in the context of specific goals for improving care, examine public health issues such as changing trends in disease rates, treatment modalities, and morbidity and mortality in the first year of therapy — an area in which there have been recent changes. This year we also report on mortality from the first *ESRD* service date as well as from day 90, to highlight the early risk to incident dialysis patients. And we show data from the first full year under the new “bundled” Prospective Payment System, looking at dialysis modality selection, hospitalization, survival, and injectable medications.

In this year's program highlights, infographics, and *Précis* we again provide an overview of *ESRD* patient care and expenditures. We examine pre-*ESRD* care, reported on the Medical Evidence (*ME*) form (2728) used to register all *ESRD* patients. We also look at dialysis 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. Mortality rates in both the incident and prevalent populations have been falling for a number of years; mortality in the first year of dialysis, declining since 2004, has reached rates which are the lowest in 30 years and down nearly 18 percent from just a decade ago.

At the end of 2011, 615,899 dialysis and transplant patients were receiving treatment for ESRD — a 3.2 percent increase from 2010 (Table p.a). There were 115,643 new cases of ESRD reported; this was a 1.5 percent decrease from 2010, and the first decline in actual counts of new ESRD patients over the last 30 years. While changes in the incident population should be viewed with caution, as it may take several years to determine whether they are sustained, this milestone is truly a new finding.

Introductory figures on ESRD expenditures show per person and total costs in the program. Total Medicare expenditures for separately billed intravenous medications have been stable since 2004, reflecting changes in payment policies implemented by CMS. Data from the transition to the new payment system are highlighted in Chapter Ten of this year's ADR as well.

Next we provide a full layout of Healthy People 2020 goals related to kidney disease. As the targets for HP2020 were more modest than those for HP2010, some have already been met; new targets will be developed in the mid-course assessment of progress in 2013 and 2014.

In Chapter One we present information on incidence, prevalence, patient characteristics, treatment modalities, and insurance coverage. We examine trends in the incidence of ESRD due to diabetes and hypertension for younger and older age groups, showing that, in those older than 50, rates of ESRD due to diabetes have been falling for some time, and that the gap between blacks/African Americans and whites has narrowed substantially, a finding not evident in younger populations. We look at nephrology referral prior to ESRD — a challenging issue for analysis, as self-reporting may not be as accurate as data obtained from claims — and at

levels of estimated kidney function at initiation, using the CKD-EPI formula to calculate the estimated glomerular filtration rate (eGFR). Questions have been raised about the eGFR determined from creatinine data on the ME form, in that frailty and loss of muscle mass in patients with advancing kidney disease may lead to overestimates of true GFR; caution is needed, then, in fully interpreting these data as indicating early initiation of dialysis.

We next report on the use of hemodialysis, peritoneal dialysis, and home hemodialysis to show how use of these modalities may change under the new dialysis Prospective Payment System. And we present data on the degree of anemia at initiation, on pre-ESRD treatment with erythropoiesis stimulating agents (ESAs), and on laboratory values at initiation.

Chapter Two, on clinical indicators of care, assesses dialysis adequacy, vascular access, anemia treatment and correction in the first months of ESRD, IV iron therapy, and preventive care in the diabetic and general ESRD populations, and illustrates the marked differences in vascular access complication rates associated with the use of fistulas, catheters, and grafts.

Data on hospitalization are presented in Chapter Three. In the prevalent hemodialysis population, the continued high rate of hospitalization due to infection needs to be addressed by providers. In 2011 this rate was 43 percent greater than in 1993, and the difference has remained above 40 percent since 2004.

This year we present rates of hospitalizations from two perspectives, a traditional one using the principal diagnosis code from the hospital claims, and a second incorporating both principal and secondary codes. We adopted this second approach because hospitals have begun to use different DRGs to enhance payments, making the principal diagnosis code field vulnerable to changes over time, and thus complicating trend analyses. The use of secondary codes to complete a case definition may, however, be vulnerable to use of codes for complicating conditions, which also alter DRG payments. These two

approaches will be investigated in the future to determine their strengths and weakness, and to enhance a complete assessment of morbidity while reducing reporting biases.

We next examine rehospitalization after a prior discharge. Thirty-six percent of hemodialysis patients are rehospitalized within 30 days of discharge — a number substantially higher than the rates of 17.4 and 24.1 percent noted for the general Medicare and CKD populations. We also look at data by organ systems as they relate to the index event, comparing causes of the index and repeat hospitalizations, and at outcomes 30 days after discharge.

In Chapter Four, on cardiovascular disease in the ESRD population, we look at event rates, causes of death, and sudden cardiac death. We present data on the use of cardiovascular drugs, examine the relationship of body mass index and cardiovascular event rates with outcomes after bariatric surgery, and present detailed assessments of patient characteristics and survival by heart failure type in the hemodialysis and peritoneal dialysis populations.

We begin Chapter Five, on mortality, by highlighting trends in the first and subsequent years on ESRD therapy, presenting new data on death rates from day one of ESRD versus the traditionally used day 90. Data now show similar reductions in mortality rates among patients of all vintages, and there is continued progress in the first year of hemodialysis therapy. Mortality rates for dialysis patients, however, remain eight times greater than those in the general Medicare population.

Figures on mortality during the first year of hemodialysis illustrate a sharp increase in all-cause rates in month two of treatment, following by a steady decline during the rest of the year. These rates are defined from the first ESRD service date, with no 90-day waiting period. Survival in the first six months of treatment has improved for the peritoneal dialysis and transplant populations; for hemodialysis patients, in contrast, rates since 1997 show little change.

This issue of early survival clearly merits increased attention, and the role of infectious complications — particularly those related to dialysis catheters — needs to be

addressed. Perhaps the changing incentives in the new bundled payment system, directed at lowering costs and complications, will translate to reductions in the use of dialysis catheters and to a focus on preventive care.

Chapter Six looks at Part D prescription drug coverage in the ESRD population, presenting data on coverage sources, use of the low income subsidy (LIS), patient payments, and overall costs, and looking at the use of antibiotics and of bone and mineral medications.

As we illustrate in Chapter Seven, the number of transplants from deceased donors, which had declined in the past few years, has now returned to levels similar to those seen in 2006, reaching 11,835 in 2011. The number of transplants from living donors has been variable, reaching 5,772 in 2011 — just below the 6,389 reported for 2009. Waiting times, however, continue to grow, due to the continued shortage of donated kidneys. The rate of influenza vaccinations among transplant patients is still far lower than that in the dialysis population, with only a small increase since 2001. And data on the use of prescription drugs illustrate the shifting patterns of use in the first three years post-transplant.

Chapter Eight, on the pediatric ESRD population, begins by showing rates of incidence and prevalence by age, gender, and race. We follow this with detailed data on incident patients by disease category, showing rates of first-year transplant and mortality. Vaccination data show that rates of influenza vaccinations among pediatric patients, as reported in claims data, continue to be low, despite high rates of pneumonia and other respiratory infections. We also look at one-year adjusted hospitalization and mortality rates, at five-year survival rates, and at anemia treatment and medication use.

In Chapter Nine, the Rehabilitation/Quality of Life and Nutrition Special Studies Centers present data from the ACTIVE/ADIPOSE study, focusing on frailty and its association with patient falls, with the need for assistance with activities of daily living, and with inflammation, nutritional status, and comorbidity.



The landscape of dialysis providers continued to evolve in 2011, with growth in some of the smaller dialysis organizations (SDOs) as well as the large dialysis organizations (LDOs). The LDOs now treat 66 percent of dialysis patients in the United States; SDOs account for 12 percent, hospital-based units 8.7 percent, and independently owned units 13.6 percent.

This year we continue our evaluation of the major changes that have occurred after the start of the bundled Prospective Payment System in January, 2011. Using claims data from July of 2010, 2011, and 2012, we look at changes in the use of EPO, IV iron, and IV vitamin D, at average hemoglobin levels, and at trends in the percentage of patients with a transfusion event. The chapter concludes with comparisons of standardized hospitalization and mortality ratios across provider groups.

Chapter Eleven, on expenditures related to ESRD, begins with data on dialysis expenditures by payer. Medicare paid claims accounted for 66 percent of total ESRD spending in 2011, up from 62.7 percent in the previous year. The chapter then presents updated data on the overall costs of ESRD and on costs for Part D prescription medications.

In Chapter Twelve we summarize data from the international community, and present a map of ESRD incidence worldwide. We are, as always, grateful to the registries providing this information, allowing us to see the U.S. ESRD community through a wider lens.

Most of this ADR contains data through December 31, 2011; data on patient characteristics, obtained from the ME form, are complete through June, 2012, and data on changes under the new bundled payment system are shown through July, 2012. Current estimated incident and prevalent counts can be found on the USRDS website.

### *query system & 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 (CC) annually updates 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 United States, 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*

Project Officers (POs) Lawrence Agodoa, MD, and Paul Eggers, PhD, provide direct oversight of the CC and Special Studies Centers (SSCs), 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 POs, and includes representatives from CMS, the National Institutes of Health, the CC, and 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 ADR production.

The USRDS External Expert Committee plays a major role in advising POs on special studies, data studies, and analyses. It is also responsible for reviewing manuscripts and ADRs.

The Special Studies Review and Implementation Committee, 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 reviews data requests requiring more than two hours of staff time to fulfill, and makes recommendations to the POS based on the datasets requested and the ways in which the CC can improve data availability.

### *reading the maps*

Many maps in the ADR are 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 here present data divided into quintiles, with each range in a legend containing approximately one-fifth of the data points. In the sample map, for example, one-fifth of all data points 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 with 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 listed colors or ranges.

Numbers in the first and last boxes 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. Mean numbers within the quintiles can be calculated as a simple half-way point.

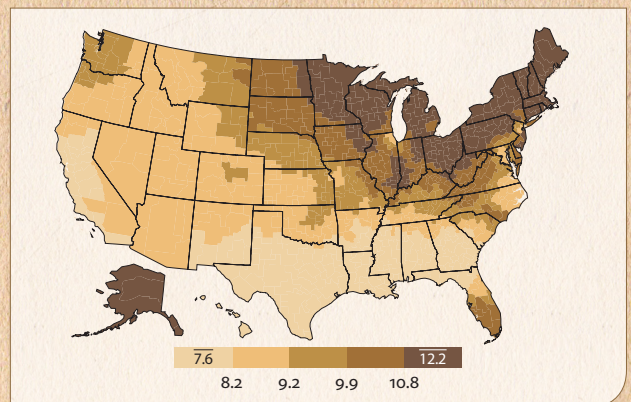
On the Excel page for each map (found on the website and CD-ROM) we include several numbers to help you interpret the maps and their relation to other data in the ADR. The map-specific mean is calculated using only

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.

### *acknowledgements*

The ADR 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 the providers themselves are crucial in the collection of data used by the USRDS, and their dedication to this task is greatly appreciated.

We welcome feedback on all elements of USRDS work. All comments are reviewed by the Director, Deputy Director, and staff of the USRDS in order to improve future materials and to ensure a strong working relationship between the USRDS and the clinicians, researchers, patients, and others involved in the care of ESRD patients across the U.S. and throughout the world.



*Throughout the ADR, with the exception of NHANES data, CKD cohorts exclude ESRD patients.*