

Getting Research Data Sets from the USRDS

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Approved USRDS requests for standard analytic files and approved manuscripts: 2001 to 2011(October)

Year	Data Requests	Manuscripts
2011 (Oct)	35	37
2010	54	30
2009	35	21
2008	31	24
2007	27	24
2006	38	29
2005	45	23
2004	38	24
2003	35	25
2002	38	30
2001	33	7

Outline for research proposals using USRDS data

- I Research topic and submission date
- II Background information
- III Study design
 - Objectives
 - Hypothesis(es)
 - Analytical methods
- IV Data being requested
 - a. List of Standard Analytical Files needed
 - b. Description of data security: responsible party, computer access, etc
 - c. Timeframe for the project
 - d. Statement that data will be returned to the USRDS or destroyed at the end of the project.**
- V Outline of estimated costs of requested data: source of funding
- VI **IRB clearance (or waiver)**
- VII Signed agreement for release of data (DUA)
- VIII Investigator information for principal investigator and co-authors, supply:
 - Name
 - Affiliation
 - Business address
 - Business phone number
 - Business fax number
 - Email address

Outline for research proposals using USRDS data linkages with other data sets

- I Research topic and submission date
- II Background information
- III Study design
 - Objectives
 - Hypothesis(es)
 - Description of data linkage – variables to be used in linkage**
 - Analytical methods
- IV Privacy Issues
 - a. **Statement describing that patient consent allows such a merge or a statement why patient consent could not be obtained.**
 - b. IRB clearance (REQUIRED)
- V Data being requested
 - a. List of Standard Analytical Files needed
 - b. Description of data security: responsible party, computer access, etc
 - c. Timeframe for the project
 - d. Statement that data will be returned to the USRDS or destroyed at the end of the project.
- VI Outline of estimated costs of requested data: source of funding
- VII Signed agreement for release of data (DUA)
- VIII Investigator information for principal investigator and co-authors

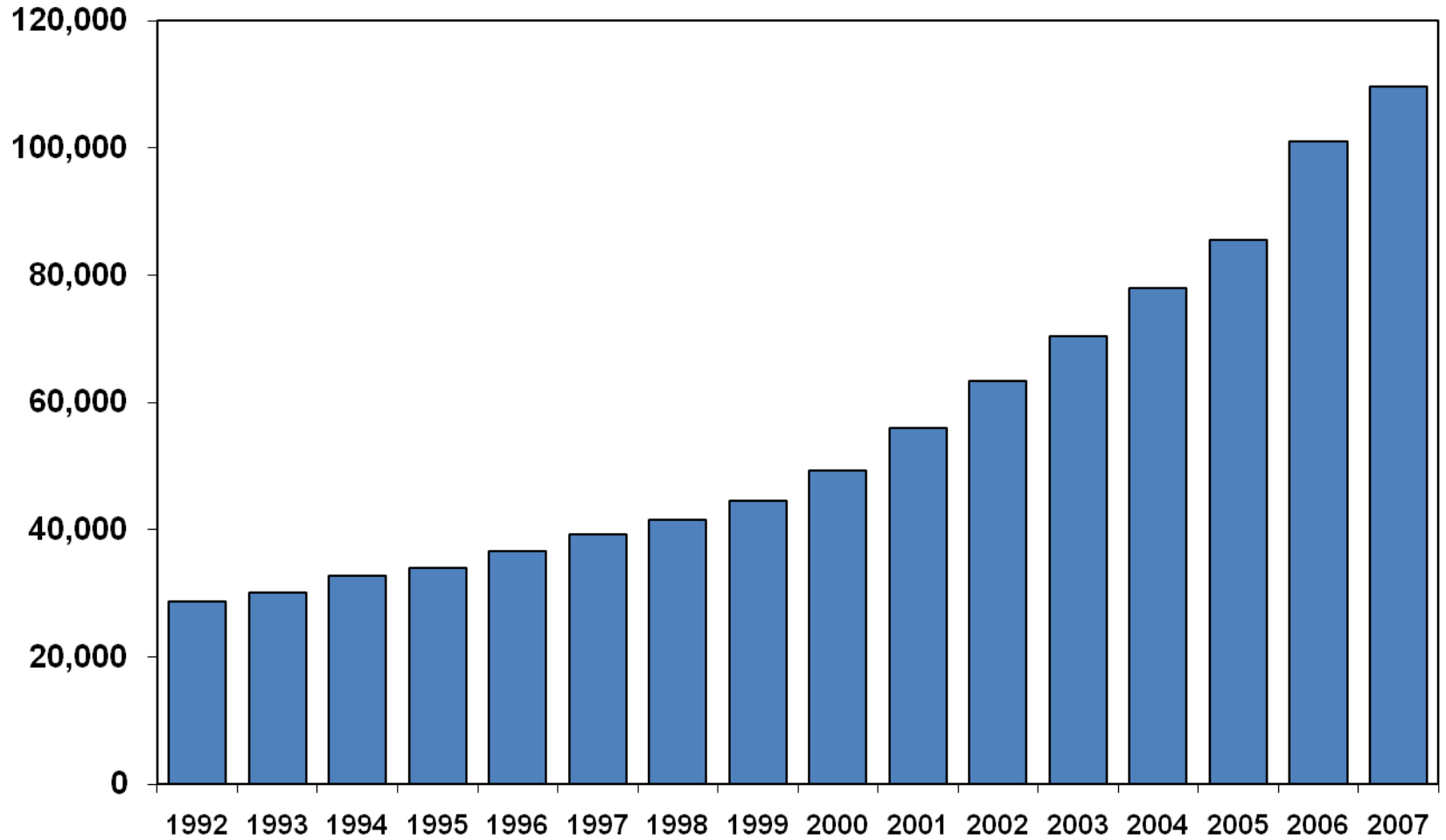
USRDS Available Data Sets

- Standard Analysis Files (SAF)
 - Core CD – Patient, treatment history, payer sequence, transplant, wait list, DMMS, medical evidence, facility
 - Transplant CD – follow-up data, immunosuppressives
 - Hospital CD – dates, diagnoses and procedures
 - Claims CDs – institutional and physician/supplier
 - “Backcasted” data (ages 67 +)
- Clinical Performance Measures (CPM) merged data
- Case Mix Adequacy (1986-87), DMMS (1993, 1996)
- Comprehensive Dialysis Study (2005-08)
- Veterans Administration (VA) linked data? **NO!**

5 % Medicare sample

- 1992 through 2009 defined cohorts
- Follow-up data including
 - Hospitalization
 - Mortality
 - ESRD
 - Medicare expenditures
 - All billing data

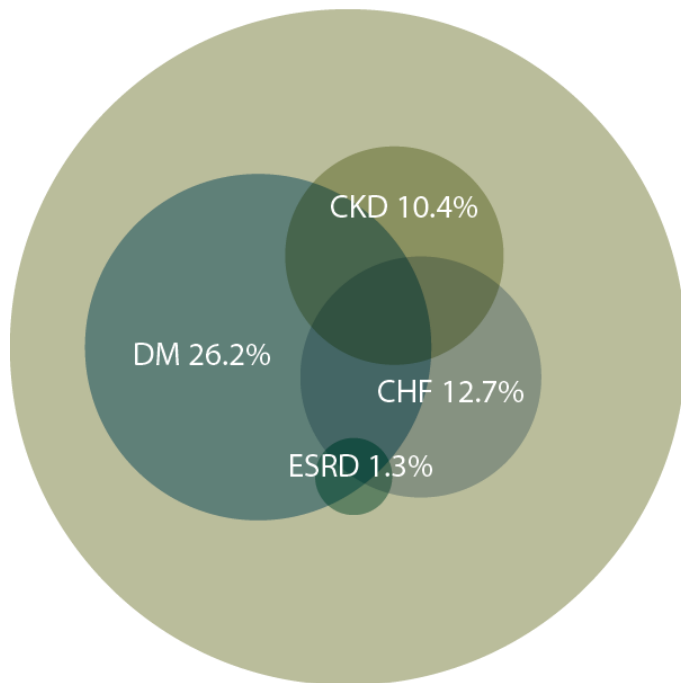
Size of 5% Medicare sample for CKD patients



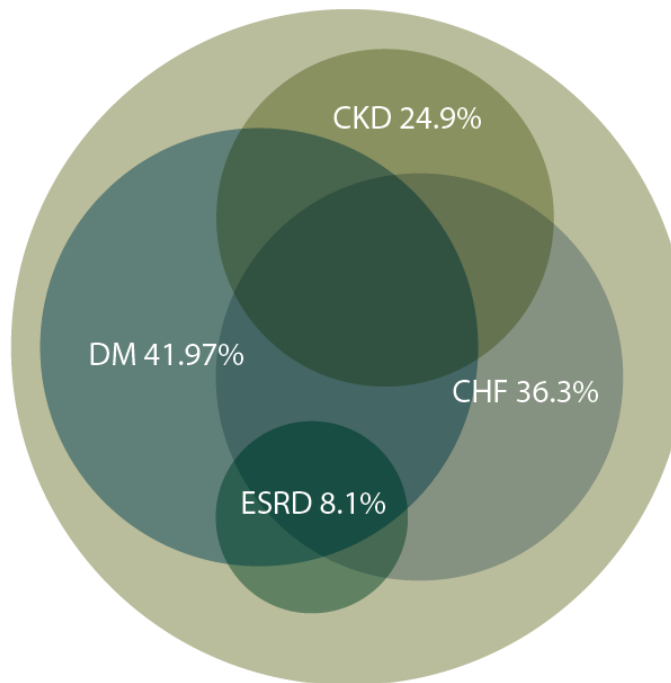
Distribution of general (fee-for-service) Medicare patients & costs for CKD, CHF, diabetes, & ESRD, 2009

Figure p.1 (continued; Volume 2)

General Medicare: population, 2009
(n = 31,156,428; mean age 69.2)



General Medicare: costs, 2009
(\$289 billion)



Period prevalent general (fee-for-service) Medicare patients. Diabetes, CKD, & CHF determined from claims, 2008–2009; costs are for calendar year 2009.

USRDS Available Data Sets – **NEW**

Part D – pharmaceutical data

1. Years 2006 through 2008
2. Enrollment data
 - part D, credible coverage, unknown
 - LIS
 - Gap coverage type
 - Monthly premium
3. Drug data
 - Service date
 - Quantity, days supply, dosage
 - Brand name, generic name, product service ID (NDC)
 - Benefit phase (gap, catastrophic, etc)
 - Total cost, beneficiary co-pay

NIDDK central repository components

- Biosample repository (Fisher):
 - archival storage of biological specimens
- Database repository (RTI):
 - maintain archival datasets,
 - respond to queries about data and stored samples
- Genetics repository (Rutgers Univ.):
 - create immortalized cell lines, DNA extraction
 - <https://www.niddkrepository.org/niddk/home.do>

Read the article authored by the Central Repository team and published in the journal [Database](#):

["The NIDDK Central Repository at 8 years--Ambition, Revision, Use and Impact."](#)

WE HAVE DATA AND SAMPLES AVAILABLE FOR YOU! JUST ASK...

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We offer phenotypic data and biological samples to approved researchers to answer important scientific questions.

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- The samples are a worthwhile investment for your proposed research.
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CRIC Data

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DAC - Fistula Data

DAC - Fistula study data is available on the website [Additional information...](#)

Studies search tool

A new search tool is available on the web site. This tool displays the contents of available repository products. [Additional information...](#)

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FAQ

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[NIDDK Repositories FAQ](#)

[Common Repository Definitions \(PDF\)](#)

Current kidney repository holdings

AASK (The African American Study of Kidney Disease and Hypertension Study)

ATN (Acute Renal Failure Trial Network)

CDS (Comprehensive Dialysis Study)

CRIC (The Chronic Renal Insufficiency Cohort Study)

CRISP (The Consortium for Radiological Imaging Studies of Polycystic Kidney Disease)

DAC - Fistula (The Clopidogrel Prevention of Early AV Fistula Thrombosis Study)

DAC - Graft (The Aggrenox Prevention of Access Stenosis Study)

FIND (Family Investigation of Nephropathy and Diabetes)

GoKinD (The Genetics of Kidneys in Diabetes)

HEMO (The Hemodialysis Study)

MDRD (The Modification of Diet in Renal Disease)

NANS (National Analgesic Nephropathy Study)

Approved data requests for research files from NIDDK Repository (to date)

Total Data Requests	128
<u>AASK</u>	8
<u>ATN</u>	4
<u>BACH</u>	1
<u>CKD BioCon</u>	1
<u>CRISP</u>	6
<u>GoKind</u>	9
<u>HEMO</u>	8
<u>MDRD</u>	13

Thank you