Getting Research Data Sets from the USRDS

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NIH, NIDDK, DKUHD

American Society of Nephrology
Renal Week
Philadelphia
November, 10, 2011
### Approved USRDS requests for standard analytic files and approved manuscripts: 2001 to 2011 (October)

<table>
<thead>
<tr>
<th>Year</th>
<th>Data Requests</th>
<th>Manuscripts</th>
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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


- 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)

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...

THE NIDDK CENTRAL REPOSITORY

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

What are the Benefits of the Repository?

- Many datasets and sample collections are available.
- Design your own study using the dataset and sample collection you select.
- Pay for only the samples you select to match your research criteria.
- The data is free and it is easy to apply for access.
- The samples are a worthwhile investment for your proposed research.
- Combine studies to increase the power of your results.
- Statistical consultation available (speak directly with Repository staff).

Take advantage of the Repository resources that are available to enhance your research!
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)

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<tr>
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Thank you