USRDS Products and Services

Products and services provided by the USRDS to support the work of the renal community are detailed in Table A. The entire Annual Data Report (ADR) is available at www.USRDS.org, with PowerPoint slides of all figures and Excel files of the data behind the graphs, as well as PDF files of the Researcher's Guide. The site's RenDER system allows users to create customized data tables and regional maps.

Table a. USRDS Products and Services

Annual Data Report DVD
Annual Data Report DVD contains the text and graphics of the ADR, data tables, and PowerPoint slides, and is available from the USRDS Coordinating Center.
Researcher's Guide to the USRDS database
Provides a detailed description of the USRDS database and of the USRDS Standard Analysis Files; the basic reference for researchers who use USRDS data files.
www.usrds.org
Contains PDF files of the chapters, reference tables, and the Researcher's Guide; PowerPoint slides of ADR figures and USRDS conference presentations; Excel files of table and figure data; notices regarding current news and analyses; links to related Internet sites; and email addresses for contacting the USRDS.
RenDER
The USRDS Renal Data Extraction and Referencing (RenDER) System is a querying application that allows users to create data tables and interactive maps. It can be accessed at http://www.usrds.org/render/xrender_home.asp following a short registration; a tutorial is also available on this site to help new users.
Requests for data
Data requests: Two-hour Questions and data requests that are not answered directly by the ADR can be addressed to the Coordinating Center; those that require less than two hours of staff time to fulfill will be processed without charge.
Data requests: More than two hours Questions and data requests that require over two hours of staff time must be submitted in writing and approved by the USRDS Project Officer. Fulfillment of these requests is subject to staff availability, and costs are assessed on a case-by-case basis.
Standard Analysis Files: SAFs provide patient-specific data from the USRDS to support ESRD research. Users must sign a Data Release Agreement with the NIDDK.
Merged data files: Merged files can be created by the Coordinating Center for a limited number of approved research projects. Users must sign a data release agreement with the NIDDK. Contact the USRDS Coordinating Center for more information.
Publications and presentations
Most USRDS research studies result in published papers or presentations at national meetings. Figures from abstracts and presentations can be found on the website, while published abstracts and papers can be found in relevant journals.
Contact information
USRDS Coordinating Center 1415 Washington Hts Ste 3645 SPH I Ann Arbor, MI 48109 734.763.7793 or 1.888.99 USRDS fax 734.763.4004 usrds@usrds.org

Data Requests

Making information on end-stage renal disease (ESRD) available to the renal community is a primary objective of the USRDS, and we are committed to the timely fulfillment of data requests. In many cases, requests can be answered through data published in the ADR or elsewhere. Requests for data not available in material published by the USRDS, and that require two hours or less of staff time, are fulfilled by the Coordinating Center without charge, usually within one week. However, more complex requests — requiring more than two hours of staff time — as well as requests for Standard Analysis Files (SAFs) and custom files, must be accompanied by a written proposal (see details below), and will be completed only upon written approval by the USRDS Project Officer.

Research Files

The Coordinating Center maintains a set of SAFs to meet diverse research needs and provide easy access to data used in the ADR. The SAFs were introduced in 1994, as the NIDDK began awarding new grants focusing on research using the USRDS data. The result has been an annual increase in the number of files provided by the USRDS.

Prior to 1994, all researcher files were created for specific projects. Since the introduction of the SAFs, however, custom files are generally limited to cases in which a researcher provides a patient finder file to be matched with the USRDS database. For more information on merged data requests, please contact the Coordinating Center at USRDS@USRDS.org.

The Core SAF set contains basic patient data, and is required to use all of the other SAFs. Included are each patient's demographic information, payer and treatment history, limited transplant data, provider data, and data from many of the USRDS Special Studies. Approximately half of the researchers using the USRDS SAFs need only this dataset. The Transplant dataset contains detailed transplant and transplant follow-up data collected by the Centers for Medicare & Medicaid Services (CMS) and the United Network for Organ Sharing (UNOS). Data on hospital inpatient stays are found on the Hospital dataset. All Medicare billing data are available by individual year (see Table B).

Table b. USRDS Standard Analysis Files

Standard Analysis Files	
Core dataset	Needed in order to use all other files.
Transplant dataset	Detailed transplant data from CMS and UNOS.
Hospital dataset	Derived from the institutional claims; contains diagnosis and surgical procedure codes for each stay, but does not include the cost data from the institutional claims records.
CDS survey dataset	Survey information and laboratory values from the Comprehensive Dialysis Survey.
DMMS claims	Contains all of the Institutional and Physician/Supplier claims data for the patients in the USRDS Dialysis Morbidity and Mortality (DMMS) Special Study. Survey data are included in the Core dataset.
Case Mix Adequacy claims	Contains all institutional and physician/supplier claims data for patients in the USRDS Case Mix Adequacy Special Study. Survey data are included in the Core dataset.
ESRD Medicare payment data	
Institutional claims	pre-1989 through 2012*
Physician/supplier claims	1991–2012
Part D Prescription Drug	2006–2012
CKD 5 Percent Medicare Sample Standard Analysis Files	
Patient cohort finder	
Hospital file	
Institutional claims	1992–2012
Physician/supplier claims	1992–2012
Part D	2006–2012
ESRD CPM Survey data	Includes 1994–2008 hemodialysis survey years and 1995–2008 peritoneal dialysis survey years
ESRD CPM/SAF linked files	Core, Hospital, Transplant
ESRD CPM Medicare participant institutional and physician/supplier claims	pre-1989 through 2011

Standard Analysis Files

SAF use is governed by the USRDS policy on data release for investigator-initiated research. Research proposals must be approved by a USRDS Project Officer, and institutions and researchers must sign the USRDS "Agreement for Release of Data," found later in these appendices.

Most SAFs provide patient-specific data and are considered limited datasets. All patient identifiers are removed or encrypted, but data confidentiality remains a serious concern. The USRDS Agreement for Release of Data describes restrictions on SAF use and disposition. The agreement must be signed by the appropriate institutional authority responsible for IT and privacy security, then co-signed by the investigators/analysts as well to acknowledge their responsibility for protecting the privacy of this kind of individual patient data. SAFs include an encrypted ID number to allow patient data from multiple SAFs to be merged.

Core Dataset

The Core Standard Analysis Files contain the most frequently used data and are required for use of the Transplant, Hospital, or ESRD Medicare claims. Included files are as follows (also listed in Table C).

Patient

Contains one record per patient in the USRDS database, and gives basic demographic and ESRD-related data.

Residence

A longitudinal record of residence by ZIP code.

Payer History

Contains a new record for each patient at each change in insurance payer.

Treatment History/Modality Sequence

Contains a new record for each patient at each change in modality or dialysis provider.

Medical Evidence

Contains full data from the 1995 and 2005 versions of the CMS Medical Evidence form. In April 1995 a new version of the form went into use, with data on comorbidity, employment status, lab values at initiation, and Hispanic ethnicity; an expanded form was later implemented in 2005.

Transplant

Contains basic data for all transplants reported by CMS and UNOS, including the date of graft failure (detailed transplant data are contained in a separate transplant dataset).

Transplant Waiting List

Beginning with 2001 data (used in the 2002 ADR), this file has been updated to include basic patient demographic data and, from UNOS, all unique waiting-list periods for each dialysis patient.

Facility

Conducted annually, the CMS End-Stage Renal Disease Facility Survey is the source of data for the Facility SAF. Geographic variables that could identify facilities are deleted. The survey period is January 1 through December 31.

Facility Cost Reports

CMS hospital and independent facility cost reports for 1989–1995 and 1989–1993, respectively, are available as SAFs. All geographic variables are deleted to ensure confidentiality. The files may be linked to the Facility SAF using the USRDS provider ID, though analyses at less than a regional or network level are not possible. Because these files are rarely used, additional data will be added only if there is sufficient demand.

Dialyzers

The Case Mix Severity, Case Mix Adequacy, and DMMS Special Studies collected information on patient dialyzers in the late 1980s to mid-1990s. SAFs for these studies describe the dialyzer through a code, which must be matched to information in the Dialyzer file to find the manufacturer and model, along with characteristics such as membrane type and clearance. We believe that these data, available from published sources at the time of the study, accurately represent the dialyzer characteristics, but they should be used with caution.

Data From Special Studies

Topics for USRDS Special Studies are approved by the NIDDK, with recommendations from CMS, the Scientific Advisory Committee, the ESRD networks, and the Renal Community Council. Design and sampling plans are developed, samples are selected, and data collection forms and instructions are drafted, tested, and finalized. The main studies to date are summarized below, and are detailed in the Researcher's Guide.

Dialysis Morbidity and Mortality Study (DMMS)

The DMMS was a USRDS Special Study in which data on demographics, comorbidity, laboratory values, treatment, socioeconomic factors, and insurance were collected, using dialysis records for a random sample of U.S. patients. Waves 1, 3, and 4 are historical prospective studies on a total of 16,812 participants in which data were collected for patients on in-center hemodialysis on December 31, 1993. Data were abstracted from medical records, and patients were followed to the earliest of data abstraction, death, transplant, change in modality, or transfer to another facility. Wave 2 is a prospective study of incident hemodialysis and peritoneal dialysis patients for 1996 and early 1997 and includes 4,024 participants.

Case Mix Adequacy Study of Dialysis

The objectives of this USRDS Special Study were to establish the relationship between the dose of delivered dialysis therapy and mortality, determine the strength of this relationship when data are adjusted for comorbidity, assess how this relationship changes with dialysis dose, assess how this relationship is affected by dialyzer reuse, and examine the impact of different dialysis membranes on patient morbidity and mortality.

The study consisted of two groups: an incident sample of ESRD patients who began hemodialysis in 1990, and a prevalent sample of hemodialysis patients whose ESRD began prior to 1990. A total of 7,096 patients from 523 dialysis units were included, with approximately 3,300 patients having both the pre- and post-BUN values needed to calculate delivered dialysis dose. Ninety-four percent of these cases were matched to the USRDS database. The ESRD networks collected these data in conjunction with their Medical Case Review data abstraction.

Case Mix Severity Study

For this USRDS Special Study, data were collected on 5,255 patient incidents in 1986–1987 at 328 dialysis units nationwide. Objectives were to estimate the correlation of comorbidity and other factors existing at the onset of ESRD to mortality and hospitalization rates, while adjusting for age, sex, race, and primary diagnosis; evaluate possible associations of these factors with reported causes of death; assess the distribution of comorbidity and other factors among patients on different modalities; and compare relative mortality rates by treatment modality, adjusting for comorbid conditions and other factors.

Pediatric Growth and Development

The objectives of the USRDS Pediatric Growth and Development Study were to establish a baseline for assessing the relationship of patient growth and sexual maturation to modality, and establish a prototype for the ongoing collection of pediatric data. All patients prevalent in 1990 and born after December 31, 1970, were included in the study, a total of 3,067 patients at 548 units.

Continuous Ambulatory Peritoneal Dialysis (CAPD) and Peritonitis Study

The USRDS CAPD and Peritonitis Study examined the relation of peritonitis episodes in CAPD patients to connection device technology and other factors. The study population included all patients newly starting CAPD in the first six months of 1989, a maximum of 14 patients per dialysis unit. All units providing CAPD training participated in the study. The sample contains data on 3,385 patients from 706 units.

Transplant Dataset

- Due to changes in data collection sources over the years, data related to transplants are now presented in eight separate files. The first two are included on the Core SAF, and the remaining six are included in the Transplant SAF set.
- TX includes minimum details on all transplants from all sources
- TXWAIT contains one record for each patient in the USRDS database per waiting-list event
- TXHCFA includes transplant information collected by CMS's Program Management and Medical Information System (PMMIS) system prior to 1994
- TXUNOS includes transplant information collected since 1987 by UNOS, currently the main source of transplant data for the USRDS
- TXIRUNOS includes information on immunosuppressive drugs collected by UNOS at the time of transplantation events
- TXFUHCFA includes transplant follow-up reports collected by CMS prior to 1994; reports are completed at discharge, six months, each year post-transplant, and at graft failure
- TXFUUNOS includes transplant follow-up reports collected by UNOS since 1988

- TXIFUNOS includes information on immunosuppressive drugs, collected by UNOS at follow-up visits

Tables in Reference Sections E and F are produced primarily from the CMS and UNOS transplant files.

In July of 1994, CMS and the Health Resources Services Administration (HRSA) consolidated transplant data into a single collection by UNOS under its HRSA contract. Expanded transplant data are shared among HRSA, CMS, and the NIH, and are thus available to the USRDS. This has resulted in the addition of data on a substantial number of non-Medicare transplant patients, including children.

CMS and UNOS transplant files overlap for 1988–1993, and some Medical Evidence forms and institutional claims records indicate transplants not included in either file. To resolve conflicts among all sources and create the transplant SAF, all UNOS transplants are first accepted into the file, with all pre-1988 CMS transplants accepted next. CMS transplants from 1988–1993 are then accepted if there is no transplant in the file for that patient within 30 days of the CMS transplant (it is common for dates between sources to differ by one day). Finally, transplants indicated on the Medical Evidence form are accepted if no transplant is listed for the patient within 30 days of the Medical Evidence transplant date.

Hospital Dataset

Hospitalization inpatient data are a subset of the data in the Institutional Claims file. No payment or cost variables are included on this dataset, which is for researchers who need data on hospital inpatient stays and on diagnoses and procedures for those stays, but who do not need payment data.

Comprehensive Dialysis Study

This dataset contains information from the Comprehensive Dialysis Study (CDS), a USRDS special data collection study to assess rehabilitation/quality of life and nutrition issues in incident dialysis patients. The study was conducted between 2005 and 2008. All 1,677 participants answered questions on physical activity level, health-related quality of life, and work/disability status during the first six months of after the initiation of ESRD

therapy. In a subset of 400 participants, dietary intake and nutritional status were also assessed.

Dialysis Morbidity and Mortality Claims

This dataset contains Medicare claims for participants in the Dialysis Morbidity and Mortality Studies. Data are followed to the currently reported claims year.

Case Mix Adequacy Claims

This dataset contains Medicare claims for participants in the Case Mix Adequacy Special Study. Medicare payment data for these patients are followed to the currently reported claims year.

Medicare Payment Data

Medicare payment data are available as institutional and physician/supplier claim datasets for the ESRD population. Available years can be found in Table B.

Institutional claims consist of all inpatient/outpatient claims (inpatient, outpatient, skilled nursing facility, home health agency, and hospice), including outpatient dialysis claims. Physician/supplier claims account for 80 percent of claims but only 20 percent of dollars. The structure and content of the two types of claims differ, as do the files derived from them. Institutional claims are provided in two types of files: the Institutional Claims file, indicating claim type, dollar amounts, DRG code, type of dialysis involved (if any), and dates of service; and the Institutional Claims Detail file, containing details such as diagnosis and procedure codes. Many analyses require only the Institutional Claims files. Physician/supplier claims are contained in one type of file with one record for each claim line-item. The file includes dollar amounts, dates of service, diagnosis and procedure codes, and type and place of service.

Clinical Performance Measures Data Collection

The Clinical Performance Measures (CPM) data is a CMS project developed to collect information on the quality of care provided to the dialysis population. The data originates from yearly surveys of approximately 10,000 dialysis patients completed by the primary care facilities, and was formerly known as the ESRD Core Indicators Project. This project results in a rich source of detailed information, useful in analyses of health care delivery in a sample of the dialysis population.

To further expand the value and use of the CPM data, we have linked patient data from the USRDS SAFs, enabling complete claims extraction from the SAFs for all identified patients. The resulting claims history has been combined with the CPM data to form a complete mini-set of the USRDS data products with supporting files. This enables researchers to add patient-level laboratory and dialysis prescription detail to a broad range of health care service event data over many years.

The USRDS Coordinating Center has made the CPM data available as SAFs. The dataset contains CPM data collected in surveys from 1994–2008. A listing of available files can be found in Table B, or you may contact the USRDS Coordinating Center for further information.

CKD 5 Percent General Medicare Payment Data

The CKD cohort datasets are built from the 5 percent general Medicare Claims SAFs, and contain a patient master file, a payer sequence file, and a set of comorbidity files. We no longer produce datasets for diabetes and congestive heart failure based on the 5 percent Medicare claims.

Separately, a 5 percent general Medicare Hospital SAF (inpatient, outpatient, skilled nursing facility, home health, hospice, Part B, and durable medical equipment) for the CKD cohort is also available. Data are derived from the IP claims SAF files. No payment or cost variables are included, so these data are for researchers who need data on hospital inpatient stays and on diagnoses and procedures for those stays, but do not need payment data.

Pre-ESRD Medicare Claims

The pre-ESRD claims (also known as the back-casted claims) are a collection of Medicare institutional and physician/supplier billing records incurred prior to the onset of ESRD. Included in these claims are any and all claims available from Medicare for incident patients during their incident year and the two prior calendar years.

The USRDS has made the pre-ESRD data available as SAFs. The structure of the claims file is identical to the ESRD claims files and organized by calendar year. In addition, a pre-ESRD payer sequence is provided so researchers can determine Medicare enrollment for the periods prior to first ESRD service date. A listing of available files can be found in Table B.

Part D Data

Section 101 of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 amended Title XVIII of the Social Security Act by establishing the Voluntary Prescription Drug Benefit Program (Part D). Effective January 1, 2006, Part D is an optional prescription drug benefit for individuals who are entitled to Medicare benefits under Part A or enrolled in Medicare benefits under Part B. The data from the first few months of 2006, when the benefit was very new, may be incomplete, and should be interpreted with caution.

The Part D data is obtained from CMS annually, with finder files provided by the USRDS. The Part D data are divided into two separate files: an annual enrollment file containing monthly indicators of enrollment in Part D, and a prescription drug event file (PDE) containing details of prescriptions filled by Part D beneficiaries.

Since the Part D benefit is voluntary, not all Medicare beneficiaries are enrolled. The annual enrollment file contains 12 monthly indicators that detail whether the beneficiary is enrolled in Part D, and if so, the type of plan. There are also monthly indicators for dual eligibility (Medicare and Medicaid), the retiree drug Subsidy, and the low income subsidy (LIS).

Table c. Contents of the USRDS Core Standard Analysis CD-ROM

File name Unit of observation and uses. This two-CD set is required in order to use any of the other Standard Analysis Files.
Patient One record for each ESRD patient. Incidence, prevalence, patient survival. Most other files will need to be linked to this file using the encrypted patient ID.
Residence For each patient, one record for each period in a different residence. Regional analyses.
Treatment History One record for each period a patient is on one modality. Modality distribution and treatment patterns.
Payer History One record for each period a patient is covered by one payer; each patient can have many records. The impact of insurance payers on clinical outcomes.
Medical Evidence One record for each 2728 form filed (1995 version). ESRD first service date, initial treatment modality, comorbid conditions, patient status at start of ESRD.
Transplant One record for each transplant event; patients can have multiple events. Transplant and transplant outcome analyses.
Transplant Waiting List One or more records for each patient ever on list. Comparison of transplanted patients to dialysis patients who are transplant candidates. Patient selection to waiting list.
Dialysis Morbidity and Mortality (DMMS; Special Study) Wave 1: 5,670 patients; Wave 2: 4,024 patients; Wave 3–4: 11,142 patients. Comorbid conditions, adequacy of dialysis, dialysis prescription and other treatment parameters, laboratory test values, nutrition, vascular access.
Case Mix Adequacy (Special Study) 7,096 patients. Comorbid conditions, adequacy of dialysis, dialysis prescription and other treatment parameters, laboratory values.
Case Mix Severity (Special Study) 5,255 patients. Comorbid conditions, adequacy of dialysis, dialysis prescription and other treatment parameters, laboratory values.
Pediatric Growth and Development (Special Study) 3,067 patients. Growth, development, and other issues relating to pediatric ESRD patients.
CAPD Peritonitis (Special Study) 3,385 patients. CAPD and peritonitis.
Facility One record for each year facility has operated. Merge with the treatment history, transplant, or annual summary SAFs for analyses involving provider characteristics by encrypted ID.
Facility Cost Reports One record per facility per year (1989–1995). Costs and staffing of dialysis facilities.
Dialyzers Information on dialyzer characteristics; to be matched to patient dialyzer information in other files on CD. Relation of dialyzer characteristics to patient outcomes.
CLMCODES One record for each diagnosis, procedure, or HCPCS code appearing in claims files. Frequency of occurrence of each code. A starting point for analyses that will use diagnosis and procedure codes.
Formats.SC2 All USRDS-defined SAS formats used by SAFs. Format library used to format values of categorical variables.

Linkages To The USRDS Database

The USRDS does provide the service of linking population cohorts to the USRDS dataset to determine ESRD status and outcomes for epidemiological research. Please contact the USRDS Coordinating Center for more information on the application process.

File Media and Formats

SAFs are provided on DVDs as SAS files. The SAS format is widely used, easily transported, and largely self-documenting. SAS is a commercially available data management and statistical analysis software system that runs on most computers, and is almost universally available on university computer systems. The SAFs take full advantage of the program's ability to incorporate detailed documentation into the file. Researchers needing another format or medium must arrange for the conversion.

Documentation

The Researcher's Guide to the USRDS database provides most of the SAF documentation. It includes a codebook of variables, copies of data collection forms used by CMS, UNOS, and the USRDS Special Studies, and a chapter on using the SAFs in SAS. The guide may be downloaded from the USRDS website, and is included with the Core SAF DVD.

Data Use Acknowledgement

Publications using USRDS data should include an acknowledgment and this 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.

Data Release Policy

Since the SAFs and custom data files contain confidential, patient-specific data, their release requires the approval process described here. Investigators may contact the USRDS Project Officer at the NIDDK to discuss requests before preparing a proposal. To request and use USRDS data files, investigators must provide the Project Officer with a detailed description of the proposed investigation (see Table D). The summary must include goals, background data, an in-depth description of study design and methodology, and resources available for completing the project, and may be the description from a grant proposal or other application. The project must comply with the Privacy Act of 1974, and the summary

should provide enough information to enable assessment of compliance. Guidelines for Privacy Act adherence are found in the "Agreement for Release of Data," later in the appendices. With your completed research proposal, please include a signed agreement for release of information.

Investigators must also indicate needed USRDS SAFs by name. If these files cannot meet requirements of the proposed research, investigators must specify precisely which data elements are needed.

The investigator and the Coordinating Center will resolve any technical questions. The NIH will review the project for technical merit and for conformity with the Privacy Act. The Project Officer will notify the investigator(s) in writing of the outcome, and if the project is not approved, will discuss reasons for the decision. The Project Officer will send a copy of the approval letters to the Coordinating Center. The Coordinating Center will then prepare the files and documentation and send them to the investigator.

Any reports or articles resulting from use of USRDS data must be submitted to the Project Officer prior to submission for publication to assure adherence to the Privacy Act. The Project Officer must respond within 30 days. If a report or article is determined not to adhere to the Privacy Act, it shall not be published until compliance is achieved. Assessment of compliance will not depend on the opinions and conclusions expressed by the investigators, nor will the Project Officer's approval indicate government endorsement of the investigator's opinions and conclusions.

All publications using released data must contain the standard acknowledgement and disclaimer presented above. Investigators are requested to send copies of all final publications resulting from this research to both the Project Officer and the Coordinating Center.

Table d. Outline for Research Proposals Using USRDS Data

A data request applies only to the project stated in the proposal; a new proposal must be submitted for each additional use of the data files.

I. Research topic title and submission date.
II. Background information.
III. Study design
    a. Objectives
    b. Hypothesis(es)
    c. Analytical methods.
IV. Data being requested:
    a. List of Standard Analytical Files needed (please specify years required); include brief justification for each dataset
    b. Description of data security: responsible party, computer access, etc.
    c. Time frame for the project
    d. Statement that data will be returned to the USRDS or destroyed at the end of the project.
V. To address patient privacy issues, to be consistent with HIPAA policies, and to insure that researchers are adhering to local privacy standards as well as to USRDS and CMS privacy policies, the USRDS now requires IRB approval or waiver for all research proposals. IRB approval is not required from those requesting aggregate data.
VI. Agreement for Release of Data, signed by all researchers.
VII. Investigator information for principal investigator and coauthors, supply:
    a. Name
    b. Affiliation
    c. Business address
    d. Business phone number
    e. Business fax number
    f. Email address

Submit to

Kevin C. Abbott, MD, MPH
Director, Kidney and Urology Epidemiology
NIDDK
Room 621
6707 Democracy Blvd
Bethesda, Maryland 20892
301 594-7714
kevin.abbott@nih.gov

Caveats

This policy establishes conditions and procedures for the release of data from the USRDS, and is intended to ensure that data are made available to investigators in the pursuit of legitimate biomedical, cost-effectiveness, or other economic research.

The USRDS will not release data that identify individual patients. Since it might be possible, however, to infer identity from SAF data, these data are considered confidential. The USRDS "Agreement for Release of Data" contains a number of general and specific restrictions on the use of USRDS data, and investigators are expected to abide by these

restrictions. If individually identifiable data are needed, the request should be submitted directly to CMS. Use of these data to identify and/or contact patients, facilities, or providers is prohibited by USRDS policy and by the Privacy Act of 1974.

The USRDS Coordinating Center will provide data on DVD. Analytical services other than review of the proposal and preparation of the data file will not be provided under the USRDS contract, though Coordinating Center personnel may participate in analyses funded by other sources.