

PROCEDURE FOR REQUESTING / USING HEARTLAND KIDNEY NETWORK DATA

SOURCE OF DATA

Data for the Heartland Kidney Network (formerly known as Network 12) databases are provided by the dialysis and transplant facilities in Missouri, Kansas, Iowa and Nebraska. The Network has authority to collect these data under its contract with the Centers for Medicare & Medicaid Services, Contract 500-2006-NW012C. Certain transplant data are obtained from the UNOS Transplant database.

FREE DATA ON THE WEB

The following data for Heartland Kidney Network is freely available and periodically updated at www.heartlandkidney.org/info_management.html :

- Geographic incident and prevalent data is published in the Heartland Kidney Network Annual Report. Each year's Annual Report is posted in the August/September timeframe.
- Prevalence reports are created and posted to the web site twice a year in March for data as of the end of the previous year, and in September for data as of the end of June. The data details the counts by modality, and is sorted by State, County and Zip code. For privacy requirements, zip codes or counties with less than 6 patients will be marked as such, and not give the actual count.
- Facility Directories listing the name, address, phone and fax number of the dialysis unit, and the number of treatment stations and services rendered is available. This report is sorted State, and alphabetically by City, and is updated several times per year.

DATA REQUESTS

The Data Committee reviews all requests to Heartland Kidney Network for release of data to ensure that Network data are made available to investigators in the pursuit of legitimate biomedical research.

Use of the Network's data requires that the research investigator's proposal be approved and that the researcher sign the Network's ***Agreement for Release of Data***, agreeing to observe the prescribed restrictions.

CONTENT OF HEARTLAND KIDNEY NETWORK DATA FILES

All files in the Network database have a unique patient identifier to allow linking of elements from various files.

Master file

The master file has one record per patient in the Network and contains basic demographic and ESRD related data about the patient.

Event file

The status file contains a history of non-clinical events occurring to each patient, such as transfers into and out of dialysis facilities, recovery of function, deaths, and modality changes.

Agreement for the Release of Data for Investigator Initiated Research and/or Publication

To request research data from Heartland Kidney Network:

1. The investigator will provide Heartland Kidney Network with a detailed description of the proposed investigation. The project summary must include goals, background data, an indepth description of the study design and analytic methodology and resources available for completing the project.
2. The request must be specific as to which data will be needed. Due to Privacy Act and HIPAA regulations, the Network will not release patient specific information, such as name, HIC, SSN, or any other identifying information.
3. The Data Committee will review the project for technical merit and conformity with patient confidentiality. In the event that further medical review is required, the request will be forwarded to the Data Committee Chair who sits on the Network's Medical Review Board. The Data Committee will notify the investigator(s) of the approval or disapproval, discussing the reason for disapproval.
4. At least 2 weeks are required for data profiling. If the time needed to fill the data request will be longer than 2 weeks, Heartland Kidney Network will notify the investigator of the expected completion date.
5. The charge for the data will be determined and the investigator will be notified of the charge. Payment must be received before the data are released. The fee for data requests is \$100 per hour.
6. Data will be released when Heartland Kidney Network receives payment. Submit payment to the address below.

***Heartland Kidney Network
7505 NW Tiffany Springs Pky Suite 230
Kansas City, MO 64153***

7. Heartland Kidney Network prohibits use of the data to identify and/or contact patients or their families, facilities, or providers.
8. At least 2 weeks are required for data profiling. If the time needed to fill the data request will be longer than 2 weeks, Heartland Kidney Network will notify the investigator of the expected completion date.
9. All publications, either print or electronic, using the released data must cite the Network by using the following standard disclaimer:

The underlying data supporting the analyses upon which this publication is based were collected in performance of Contract Number 500-2006-NW012C, entitled End Stage Renal Disease (ESRD) #12 Network Coordinating Council, Inc (dba Heartland Kidney Network),

sponsored by the Centers for Medicare and Medicaid, Department of Health and Human Services. The content of this publication does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

The author assumes full responsibility for the accuracy and completeness of the ideas presented. This article is a direct result of the Health Care Quality Improvement Program initiated by the Centers for Medicare and Medicaid, which has encouraged identification of quality improvement projects derived from analysis of patterns of care, and therefore required no special funding on the part of this contractor. Ideas and contributions to the author concerning experience in engaging with issues presented are welcomed.

The investigator is requested to send copies of all final publications resulting from this research to Heartland Kidney Network Data Committee.

I, the undersigned, am the principal researcher, and agree to adhere to all the requirements listed above.

Print _____ Date _____

Signature _____

Email _____ Phone _____

Address _____

Please attach a **detailed** request answering the following questions:

- The specific data needed, including sort orders, and format such as Excel, Access or Word documents.
- The purpose and proposed use of the data.
- If publishing, where you plan to publish the data, and in what format.

Please mail this agreement and your detailed request to:

Heartland Kidney Network
Attn: Data Committee
7505 NW Tiffany Springs Pky #230
Kansas City, MO 64153

Our office hours are from 8 AM to 5PM CST, and we can be reached at 816-880-9990.