

PROCEDURE FOR REQUESTING / USING NETWORK 6 DATA

SOURCE OF DATA/CITATION

Data for the Network 6 databases are provided by the dialysis and transplant facilities in North Carolina, South Carolina and Georgia. The Network has authority to collect these data under its contract with the Centers for Medicare & Medicaid Services, Contract 500-00-NW06. Certain transplant data are obtained from the UNOS Transplant database.

All users of Network data should acknowledge that use. Publications based upon data obtained from the Southeastern Kidney Council, ESRD Network 6, must include the following statement:

The analyses upon which this publication is based were performed under Contract Number 500-00-NW06 entitled End Stage Renal Disease Network Organization for the State of North Carolina, 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, 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.

DATA GOALS

In order to meet its commitment to collect and disseminate data, Network 6 has established these goals:

Maintain a current, accurate, patient-specific information system to support quality improvement/management activities and supply data for the CMS PMMIS, in support of the national ESRD registry.

Provide data feedback, educational materials, training and support to help patients and healthcare professionals improve ESRD care in the Network 6 area.

DATA REQUESTS

The Data Committee reviews all requests to the Southeastern Kidney Council 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 Network 6 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.

Family History file

The family history database contains those patients who have a first level family member with ESRD. The database includes patient's name, family member name and relationship, family member age at onset of ESRD and primary cause of ESRD, number of siblings and children of the patient and a family member contact name.

DATA RELEASE POLICY FOR INVESTIGATOR INITIATED RESEARCH/ PUBLICATION

To request research data from the Southeastern Kidney Council:

1. The investigator will provide the Southeastern Kidney Council with a detailed description of the proposed investigation. The project summary must include goals, background data, an in-depth 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. Patient specific information, such as name, HIC, SSN, or any other identifying information, will not be released by the Network.
3. The project will be reviewed by the Data Committee for technical merit and conformity with patient confidentiality. The Data Committee Chair will notify the investigator(s) of the approval or disapproval, discussing the reason for a disapproval.
4. 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 \$50 per hour.
5. Use of the data to identify and/or contact patients or their families, facilities, or providers is prohibited by the Southeastern Kidney Council.
6. At least 2 weeks are required for data profiling. If the time needed to fill the data request will be longer than 2 weeks, the Southeastern Kidney Council will notify the investigator of the expected completion date.
7. All publications using the released data must contain the standard disclaimer, *The analyses upon which this publication is based were performed under Contract Number 500-00-NW06, entitled End Stage Renal Disease Network Organization for the State of North Carolina, 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.*

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The investigator is requested to send copies of all final publications resulting from this research to the Southeastern Kidney Council.

Send requests to:

Southeastern Kidney Council, Inc.
1000 Saint Albans Dr., Suite 270
Raleigh, North Carolina 27609
or email to : info@nw6.esrd.net
(919) 855-0882; FAX: (919) 855-0753.

**PROCESS FOR REQUESTING NON RESEARCH RELATED DATA
FROM THE SOUTHEASTERN KIDNEY COUNCIL**

1. Requests must be in writing and must be specific as to which data will be needed. Patient specific information, such as name, HIC, SSN, or any other identifying information, will not be released by the Network. The request must state the proposed use of the data.
2. All data requests will be reviewed by the Network 6 Data Committee and notification of the review results will be given the investigator making the request. If the request is approved, the cost of fulfilling the request will be provided. The fee for data requests is \$50/hr.
3. At least 2 weeks are required for data profiling. If the time needed to fill the data request will be longer than 2 weeks, the Southeastern Kidney Council will notify the investigator of the expected completion date.
4. Data will be released when payment is received by the Southeastern Kidney Council. Submit payment to the address below.

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**SOUTHEASTERN KIDNEY COUNCIL
NETWORK 6
ESRD DATA AVAILABILITY**

Network data is made available by means of the following:

1. Geographic incident and prevalent data will be published in the Network 6 Annual Report and will be available on the Network 6 web site at <http://www.esrdnetwork6.org>.

2. More specific data will be released under the following specifications:

- Requests will be submitted to the Data Committee, via the Southeastern Kidney Council. The Data Committee will:
Review for availability of the data;
Establish cost for development and release, if necessary;
Monitor use of the data through the publishing cycle.
- Published articles using Network data must credit the Network for collection and providing the data.
- Requests requiring new data collection will be submitted to the Data Committee and Board of Directors for approval and, if necessary, for funding.

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