Data and Statistical Requests
Vital and Health Statistics Data Analysis

Guidance Document

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Division of Public Health
Bureau of Epidemiology and Public Health Informatics
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Introduction

The Vital and Health Statistics Data Analysis Section (VSDA) of the Bureau of Epidemiology and Public Health Informatics (Bureau) supports the use of datasets it maintains for research and public health surveillance/practice in order to improve the population health of Kansas. VSDA also has a duty to protect the confidentiality of the individuals named in the data or who might be identified based on record level information. Laws and regulations prohibit the use of data in an identifying manner.

VSDA produces hundreds of data tables, statistical analyses, and publications using vital records data to support population health surveillance. This approach includes support of two online tools to obtain public health statistics, Kansas Information for Communities and Kansas Health Matters. These sites are public and updated annually. VSDA encourages prospective data users or requesters to search these resources before making a data request.

Purpose

This guidance document, prepared in accordance with K.S.A 77-438, applies to data and statistics requests received by the Vital and Health Statistics Data Analysis Section of the Kansas Department of Health and Environment Bureau of Epidemiology and Public Health Informatics involving only datasets maintained by the section. It is intended to enhance access to public health statistics and facilitate lawful use bureau datasets for public health surveillance/practice and research.

Data requests fall into one of three categories, confidential-level data, restricted-level data, and public-level statistics. These terms enable VSDA to structure its response to data requests.

Data requests are handled in accordance with laws and regulations in Attachment 5. VSDA staff process most routine data requests.

This document addresses research and public health surveillance involving record level or tabular information for:

- Vital Statistics,
- Hospital Discharge,
- Syndromic Surveillance, and
- PRAMS information.

The guidance also covers specially prepared research datasets involving:

- Linked birth/infant death,
- Expanded PRAMS datasets, and
- Birth records linked with Medicaid, WIC, or Hospital Discharge data.

Elevated blood lead testing and infectious disease data collected by the Bureau are addressed under separate directives, laws, and regulations.
VSDA does not handle requests for record-level Medicaid, Kansas Health Insurance Information System, Hospital Discharge, and health professions or workforce data from local health departments or other external researchers. These requests should be made to the KDHE Division of Health Care Finance (DHCF). Requests for Hospital Discharge data should be made to the Kansas Hospital Association.

This document is designed to be practicable, so procedures can be used consistently. The guidance represents the minimum standards and recommended practices, but does not preclude more stringent requirements.

These policies are intended to:
1) Prevent a breach of confidentiality,
2) Maintain public trust,
3) Provide a framework for lawful use of confidential- or restricted-level data or information by KDHE programs and approved researchers,
4) Define individual responsibility for use and protection of Bureau datasets,
5) Clarify how information or tabular data may be published,
6) Comply with requirements of laws, policies, and agreements addressing use of Medicaid, WIC, or Hospital Discharge data, and
7) Facilitate access to pre-existing statistical reports and tables.

This document does not address requests for individual vital event certificates. Those requests should be directed to the Office of Vital Statistics (OVS) at Vital.Records@kdheks.gov or (785) 296-1400.

Authority

KDHE is empowered to adopt rules, policies, and procedures to enable it to carry out its statutory obligations. This guidance document was developed in accordance with applicable laws and regulations. VSDA and Bureau actions are subject to a final decision by the agency Secretary as defined by law. Applicable statutes and regulations are:

- KSA 65-2401 through KSA 65-2438, as amended comprise the Uniform Vital Statistics Act,
- KAR 28-17-1 through KAR 28-17-21 comprise regulations authorized under the Uniform Vital Statistics Act,
- KSA 65-445 and KSA 65-6701 through KSA 65-6721 address confidentiality of abortion reports,
- KSA 45-215 through KSA 45-223 comprise the Kansas Open Records Act (KORA),
- KSA-65-6801 through KSA 65-6809 comprise statutes governing the use of the health care database of KDHE,
- KAR-28-67-1 through 28-67-12 comprise regulations authorized under the health care database law, and
- KSA 65-177, as amended, addresses use of data for maternal and child health surveillance and monitoring.
Other statutes may be a factor when requests involve Medicaid, WIC, or Hospital Discharge data. The most pertinent legal requirements are contained in Attachment 5.

**Policy Changes**

The Bureau reserves the right to reassess these policies and procedures, making changes that include but are not limited to, declaring data fields and records confidential in accordance with applicable state law and regulations. Updated guidance can always be found at: [http://www.kdheks.gov/phi/data_requests.htm](http://www.kdheks.gov/phi/data_requests.htm).
Definitions and Requirements

This section addresses definitions and requirements involving VSDA-supplied record-level data and statistics derived from these data.

Attribution or acknowledgement

Reports, journal articles, publications, or other public use of statistics generated from record-level restricted or confidential data or information provided by VSDA requires source citation. Source citation should read: KDHE Bureau of Epidemiology and Public Health Informatics. When PRAMS data are used, published materials shall include the keyword “PRAMS”. When Syndromic Surveillance data are used, published materials shall include the keyword “Biosense” or “NSSP”.

Audit provisions

KDHE or other agencies of Kansas State government may opt to audit records associated with an approved data request. The data user shall provide research-related project files upon request.

Breach of Confidentiality

A breach of confidentiality is the disclosure of confidential- or restricted-level data or information to: 1) any unauthorized person outside KDHE or any KDHE employee who lacks legal right of access, or 2) individuals who do not require access to the data/information for completion of assigned duties or research.

Bureau of Epidemiology and Public Health Informatics

The staff, programs, resources, and data maintained by any of the Bureau’s organizational units on PCs or mini-computers. The bureau is part of the KDHE Division of Public Health.

Cell suppression

Cell suppression is the process of blanking the contents of either single cells or all cells except for row and column totals to protect the confidentiality of individuals.

Confidentiality

BEPHI reserves the right to limit the release of statistics where the level of demographic or geographic detail or community sensitivity could result in the unauthorized identification of individuals. The data user shall abide by these limitations or may be subject to prosecution or termination of data access privileges.

Confidential-level data/information

Any record-level data or information regarding an individual, whether in the form of computer file, computer diskette, paper, or oral information that:
1. Contains any information of a medical or personal nature or which by KSA 65-445, KSA 65-6701 to KSA 65-6721, KSA 65-2422d, KSA-65-6801 to KSA 65-6809, or other statute that is prohibited from release,
2. Contains information which might reasonably be considered personal (e.g., performance evaluations),
3. Identifies the person by name (directly or by linkage to a unique key), social security number, phone number, or address, or

This does not apply to information in a legally declared public record.

Based on statutes the Bureau considers the following data elements confidential information. This list includes but is not limited to:

- Individual’s first name,
- Maiden name,
- Generation name,
- Last name,
- Middle name or initial,
- Residence street address,
- Mailing street address,
- Any social security numbers,
- Attendant’s name, and street address,
- Names and addresses of physician, embalmer, or funeral home, and
- Names and addresses of hospitals and hospital officials.

Consultation
The data user shall consult with VSDA as needed regarding use of data and information. VSDA staff will contact the data user every six months to monitor progress.

Contact with individuals (follow-back)
The practice of contacting family members, parents, hospital officials, physicians and health care providers based solely on information in the vital event record is considered follow-back. This practice is permitted under law [see KSA 65-177 and KSA 65-2422d(d)] in limited instances and only with the approval of the KDHE Institutional Review Board. All approved data requests involving follow-back must have a signed data use agreement.

If a data user proposes contact (follow-back) with individuals named in birth, death, and stillbirth records, such requests should be presented to the KDHE Institutional Review Board (IRB) for prior approval. Once the IRB has approved the research involving followback, a data request may be submitted to VSDA for review. VSDA will not coordinate the IRB process.
If approved, contact shall involve the use of the KDHE IRB approved interview consent form. No interviews shall occur in the absence of a signed consent form. Consent forms shall be maintained by the data user.

Data

Data, as used in these policies, is any information maintained electronically or on paper, in a record-by-record state (record-level) with information organized into separate and unique fields to describe a particular aspect of an area of interest or facilitate analysis.

Data access to authorized persons

The data user of record-level data shall:

1. Limit access to the data only to collaborators or persons analyzing the data who were named in the data use agreement,
2. Explain the provisions of the data use agreement to all collaborators or persons analyzing the data, and
3. Ensure compliance with requirements of the DUA and KDHE IRB approvals.

Data coarsening

Data coarsening is the process of presenting small cell values by aggregating multiple years of data; categorizing variables like age and county; recoding techniques such as broader category for mortality codes, top coding, bottom coding, and truncation; and the use of rates in lieu of frequency counts. This process may be used to prepare data prior to release or use by an approved data user. It may also be employed when tabular statistics may result in unambiguous identification of individuals.

Data confidentiality form

This is a form individuals who acquire, manage, store, analyze or otherwise come into contact with confidential record-level data must sign. The form is required as part of the data use agreement.

Data destruction/disposal

The data user shall destroy or return all record level data provided by VSDA at the end of a research project. VSDA shall be notified of this process by the data user. Destruction can be accomplished by the following methods:

1. Return of any physical records and/or copies to VSDA,
2. Shredding of any physical records or copies,
3. Erasure of all electronic files from any storage media, or
4. Physical destruction of any optical storage CDs.

The data user shall notify VSDA in writing or email of the destruction. Include in the notification the date of destruction and the method of destruction. Physical notification of destruction should be signed by the data user. Data user may use email notification.
Data ownership

All record level data provided by VSDA pursuant to data requests remains the property of the State of Kansas and the Kansas Department of Health and Environment. The Data Use Agreement is a limited data use license provide a privilege to use these data for approved public health practice or public health research. Once the research or practice is complete, the data user shall destroy or return the data. Statistics and indicators created by the data user or provided by VSDA are not record level data and are not covered by this provision.

Data repurposing

This is the re-use of or re-release of record level data provided by VSDA for another project not addressed in a data use agreement. Repurposing data supplied by VSDA without advance approval is prohibited.

Data use agreement

This is an agency level agreement that defines the conditions for the use of vital records data. A data use agreement (DUA) is in essence a limited license to use data maintained by VSDA. DUAs stipulate conditions and limitations regarding the use, security, review requirements, and retention of record level data. Requirements and restrictions vary with the nature of the request. The agreement, must be signed by the principal investigator, all collaborators and analysts, and a representative of the organization requesting the data/statistics. The terms of use will be stipulated in the DUA. By virtue of signing a data use agreement (DUA) and accepting record level data or statistics from VSDA, data users (individually and the organization) agree to adhere to Kansas laws, regulations, the DUA requirements, and provisions of this guidance document. Prohibitions on the use or misuse of statistics and indicators or record-level data do not expire at the conclusion of a DUA.

Data user

This is an organization, any individual, researcher, collaborator, data analyst or contractor – individually and collectively – that is submitting a data request or – upon approval – analyzes data for public health practice or public health research involving data provided by VSDA.

Disclosure liability

The data user shall be solely liable for any and all losses, claims damages, liabilities, costs and expenses (including without limitation, reasonable attorney's fees and costs) arising from any claim from any third party, concerning use by the data user of the data from the records provided by VSDA or from the unauthorized use or disclosure by employees, contractors or other agents of the data user of data obtained from records supplied by VSDA. KDHE, the Bureau, or VSDA will not be held liable for the results or consequences of data user’s use of Bureau-supplied data.
**Event reporting period**
This is a period starting on January 1 of a calendar year and concluding on June 30 of the following calendar year. This 18-month period allows for inclusion of all late reported vital events that occurred in Kansas and births, deaths, stillbirths, and abortions that occurred to Kansas residents out of state.

**Event year**
This is a 12-month period coinciding with a calendar year and is the standard timeframe for reporting statistics or providing record level data.

**Fees**
Data requests prepared by VSDA may be subject to access and analytical fees. These fees reimburse the State of Kansas for the effort to prepare the information requested. VSDA will prepare an estimate of fees to process a data request. Confidential data, provided at the request of an approved researcher, may result in a fee being assessed to an individual to cover staff time, database use, and copying. Upon acceptance of a Bureau estimate of costs, the data user shall pay fees to reimburse the state. VSDA does not charge for copies of pre-existing statistics and indicators that can be sent by PDF.

VSDA will submit an invoice to the data user along with the data/information requested. Fees are due within two weeks of invoice receipt. VSDA may require prepayment of data fees. In those instances, work will begin when payment is received. A copy of the invoice, marked paid, will be provided on request.

Unpaid data request fees are subject to collection. A list of overdue fees will be sent to KDHE internal management or KDHE legal counsel for collection. VSDA will not provide data to any data user that owes a balance for prior data requests.

**Fee waivers**
VSDA recognizes that certain prospective data users may not have the resources to reimburse it for data and programming services. Bureau use Fee Waiver Criteria is optional. Final authority for fee waiver approval rests with the Bureau Director and Bureau Deputy Director.

**Final data**
Final data are record-level data collected during an event reporting period that have been edit-checked and validated, and deemed by the Bureau as suitable for use in ad hoc and standard analyses performed by VSDA. Statistics based on final data are no longer considered research data in the process of analysis and may be released publicly. In the case of PRAMS data, final data are data that have been weighted by the Centers for Disease Control and Prevention.

**Followback**
See Contact with individuals (followback).
Geocoding
This is the process of using Geographic Information System (GIS) software to assign longitude and latitude to address information in a record to facilitate analysis or to plot address information on a map. Plotting addresses is an identifying use of the data and is prohibited by data users. VSDA, upon request and at its discretion, may use geocoded information on records to assign records to specific geopolitical boundaries.

Identifying use
Identifying use of data is the a) inadvertent discovery of an individual’s identity for whatever purpose b) unauthorized use of vital records data to contact an individual or b) any release of the identity of an individual directly or indirectly based on restricted level or confidential level data, or statistics and indicators tabular information.

Individual
An individual is any person, entity, association, partnership, or corporation about which data/information is collected as part of the Bureau’s statute-defined responsibilities. In vital records, individuals include but are not limited to: the individual named on the record, a spouse, parents, physicians, or other health care providers attesting to the details of the event, funeral director submitting the event, judge or minister performing the event, and hospital and its officials where an event occurred.

Individual disclosure risk
Individual disclosure risk is an assessment of the potential that statistics and indicators would result in the unambiguous identification of an individual. High individual disclosure risk exists when the level or dimension of detail in a statistical table provides a sufficient number of characteristics about an individual. Individual disclosure risk may also exist when tabular or record-level data are used in conjunction with other information sources. Risk levels are low, moderate, and high. Individual disclosure risks identified by VSDA as moderate or high may result in modification of a request for tabular statistics so that unambiguous identification of individuals is prevented. By definition all record-level data are considered to be high risk for individual disclosure.

Institutional review board role
The KDHE Institutional Review Board (IRB) is required by state law to approve requests for vital records data when contact or follow-back with individuals named in the vital record is proposed for maternal and child health surveillance. The IRB evaluates human subjects issues involved. In such instances, IRB approval must be obtained prior to submission of a data request to VSDA. Provisions of the KDHE IRB approvals are incorporated by reference in the data use agreement prepared by VSDA. Approvals by other IRBs do not obviate the requirement for KDHE IRB approval. Failure to comply with IRB requirements invalidates the data use agreement.

Kansas Open Records Act (KORA)
KSA 45-215 through KSA 45-223 encompass the Kansas Open Records Act (KORA). The Vital Statistics Act exempts vital event records from KORA. Release of identifiable
information from Syndromic Surveillance Data is prohibited under KAR 28-67-4. KSA 65-177 and KSA 65-2422d(d) are laws that prevent the release of identifiable PRAMS data/information.

Pre-existing public documents comprised of statistical tables prepared from data maintained by VSDA are available under KORA. Work product of attorneys and preliminary drafts and research data in the process of analysis are also exempt from release under KORA. However, KORA does not require VSDA to create a public document where none exists.

The laws and regulations addressing release of record-level data also affect persons who are analyzing record-level data from VSDA. If a data user, analyzing line-level data from VSDA subject to re-release/repurposing provisions, receives a KORA or FOI request for record-level, the data user shall refer that person to VSDA to address the request.

**Misrepresentation**

The data user is prohibited from implying or stating KDHE or the Bureau agrees with the findings, approves the methodology, or endorses the data user’s research. The data user shall exclude such claims from reports, publications, and presentations.

**Non-discrimination**

The data user shall not discriminate against any person on the basis of race, ancestry, national origin, color, sex, disability, age, or religion, and the Parties shall conform to the applicable provisions of the federal and state anti-discrimination acts. Data users shall also comply with the applicable provisions of Title VI of the Civil Rights Act of 1964, the Age Discrimination in Employment Act, the Americans with Disabilities Act, the Rehabilitation Act of 1973, the Kansas Acts Against Discrimination, and the Kansas Discrimination in Employment Act.

**Notification and review**

All oral and written presentation of the results of the analyses of VSDA maintained datasets will be submitted to VSDA at least three weeks prior to presentation or submission to a journal. VSDA will have two weeks to submit comments on the presentation/manuscript to the author. VSDA will be notified upon final publication of an article and provided with citation information and a printed copy.

**Preliminary data**

Preliminary data are those data for which collection is at least 99% complete and the event reporting period has ended, but finalization of the dataset has not yet occurred. Quality assessment and tabulation remains to be completed. Limited uses such as public health surveillance, provisional reporting for grants, data quality evaluation and statutorily-required preliminary reports [Preliminary Report of Abortions in Kansas] are permitted. Otherwise, statistics from preliminary data constitute “Research Data in the Process of Analysis,” and are exempt from disclosure under the Kansas Open Records Act.
**PRAMS data**

PRAMS data are information collected in the course of Pregnancy Risk Assessment Monitoring System project. A PRAMS data contains weighted information from a randomly selected sample of Kansas birth records and responses to a survey of the birth mothers conducted 3-6 months after a baby’s birth. An expanded PRAMS dataset may contain additional approved variables from the birth record in accordance with PRAMS protocol.

**Provisional data**

Provisional data are those data for which collection is considered to be less than complete and the event reporting period is still underway. Provisional that may be used for public health surveillance, provisional reporting for grants and data quality evaluation. These limited uses may include weekly or monthly provisional statistical reports and release of indicators about imminent public health risks. Otherwise, statistics based on provisional data constitute “Research Data in the Process of Analysis” and are exempt from disclosure under KORA.

**Public-use data or information**

Public-Use Data or information are [statistics and indicators](#) - whether in the form of computer file, table, paper, or verbal communication among a group of individuals and presented in a fashion that does not result in the identifying use or is declared by law to be public record, i.e., credentialing data.

**Published materials**

Published materials are reports and documents prepared by VSDA and approved by the State Registrar or State Epidemiologist that meet the following definition:

"published" is defined as follows: "to make public; to circulate; to make known to people in general; to issue; to put it into circulation".  

Published materials are public documents subject to release under [KORA](#).

**RD-1 data request form**

The RD-1 form is the VSDA-provided application form to be used when requesting data and statistics. RD-1 use is mandatory for any requests involving restricted- or confidential-level data. Use of the form is optional for requests involving pre-existing public documents involving tables of [statistics and indicators](#). Once the application has been approved, the data user will be asked to sign a data use agreement.

**Record linking**

Record linking is the process of matching one record to another based on a process of comparing identifying or other fields that two datasets have in common. Linking of data is prohibited unless approved in advance by VSDA.
**Reporting confidentiality breaches**
The data user shall notify VSDA of breaches in confidentiality or data security within one business day of discovery. Reporting may be by phone contact to VSDA at 785-296-8627 or by email to KDHE.HealthStatistics@ks.gov. Notification should include a description of the breach and the type and amount of records disclosed.

**Re-release or re-use of data**
The data user shall not re-release or re-purpose data. The data user is prohibited from re-releasing any Bureau-supplied individual record-level data, regardless of whether it identifies individuals.

The data user shall not re-use data without prior approval. Data users are prohibited from re-using Bureau-supplied data for other research projects without prior approval from VSDA. Data users shall submit a new Data Request Form (RD-1) for every new project using previously provided supplied record level data or information.

Violators of re-release and re-use restrictions are subject to termination of data access and any applicable legal action. Data users may release aggregated summary statistics derived from Bureau-supplied data.

**Research data in the process of analysis**
As permitted in KSA 45-221(a)(20), notes, interim analytical computer files, tables, statistical programming, rates, frequency counts, and other work, including draft findings, created in the process of preparing reports, documents, publications, and responses to public and private inquiries that are exempt from disclosure.

**Research-related project files**
These files are adjunct documents and records pertaining to the data request. They include but are not limited to: contracts with vendors associated with the project, work agreements, financial records, job descriptions, records of communications involving persons authorized to use the data.

**Restricted-level data/information**
Restricted-level data/information is any record-level information from which any identifying data have been removed, yet sufficient demographic details remain that might permit an individual to be unambiguously identified. Public health practice or research involving restricted-level data/information requires a data use agreement. This does not apply to information legally declared public record.

**Retention of record-level information**
See Data Destruction/Disposal.

**Retention of statistical tables**
The data user may maintain Statistics and Indicators until no longer useful or in accordance with general record retention policies of the Kansas State Historical Society.
Security
The data user shall maintain the supplied records, data, and/or analyses in a secure fashion. Data shall be maintained physically and electronically in a secure manner. A physical secure area is considered office space that is not accessible to the public due to: 1) locked doors, or 2) presence of other staff capable of intercepting and excluding unauthorized individuals. Secure data storage may include printed materials that would be maintained in a “secure area.” Secure electronic storage on a personal computer/workstation or network server involves password access, password protected e-mail, and password-protected screen savers. See Attachment 1 for more information.

Signatures
Data use agreements should be signed the researcher/principal investigator, all others that collaborate on the research, individuals that are involved in the analysis and a representative of the organization responsible signing binding agreements. DUAs with incomplete signatures will be returned to the data user.

Small numbers issues
Data users of record level data shall take appropriate actions to maintain the confidentiality of individuals. Statistical tables shall suppress counts of less than six in tabular information. Complementary suppression of other counts in tabular information should be used to prevent individuals from deducing the value of suppressed counts. Rates shall be flagged as unreliable when based on less than 20 events.

Statistics and indicators
Several related terms are used to describe concepts in the field of health statistics and information. In common professional usage, the terms statistics and measures are often used interchangeably to refer to an aggregate data point (or set of data points) about a phenomenon, such as disease specific mortality in a particular age group over a given period. Statistic is also used in the field to indicate a type of measure, such as a mean, a median, a proportion or an age-adjusted rate.

A specific statistic or measure is commonly called an indicator when it is widely acknowledged to be useful for monitoring something of concern to policy-makers, researchers, or to the public. Examples include the monthly unemployment rate and the annual poverty rate as indicators of the health of the national economy1.

Statistics may be presented in rows and columns in summary or aggregate analytical reports. Cross tabulations may also include nested levels or dimensions within the rows and columns. The term tabular statistics is synonymous with the terms “statistical tables”, “summary data”, “aggregate data,” and “analytical tables.”

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1 For the public’s health: the role of measurement in action and accountability / Committee on Public Health Strategies to Improve Health, Board on Population Health and Public Health Practice, Institute of Medicine.
**Subpoenas**

Data users shall refer all subpoenas for any datasets covered by this guidance to the Kansas Department of Health and Environment legal office. The KDHE Legal office will respond in accordance with state law. Do not provide the data to anyone in response to a subpoena without the approval of the KDHE Legal Office.

**Syndromic surveillance data**

Syndromic Surveillance data is information from Kansas hospital emergency departments collected through the Biosense Portal of the Centers for Disease Control and Prevention’s National Syndromic Surveillance Program and accessed through the ESSENCE (Electronic Surveillance System for the Early Notification of Community-based Epidemics) system. These data are submitted in a de-identified, record-level manner. Since data is collected in a near real time, public health surveillance is possible. This data collection and provision of record-level data is subject to the provisions of KSA 65-6801 to KSA 65-6809, and KAR 28-67-4.

**Termination of data use**

Violation of any the requirements in this guidance document, the RD-1 data request form, or the data use agreement will result in termination of any data sharing. The data user shall be required to return/dispose of the data and notify VSDA of the disposition. Failure to maintain the confidentiality of the information shall result in permanent termination of data request privileges.

**Vital statistics and abortion data**

Records of live births, still births, deaths, marriages, and marriage dissolutions are collected by the Bureau’s Office of Vital Statistics pursuant to the Uniform Vital Statistics Act (KSA 65-2401 to KSA 65-2438 and KAR 28-17-1 to KAR 28-17-21) and reports of induced terminations of pregnancy (ITOP) are collected pursuant to abortion statutes, KSA 65-445 and KSA 65-6701 to KSA 65-6724.
Instructions - Requesting Data from VSDA
Updated 2/28/2018

No two data requests are alike. This outline is the generic series of steps for prospective data users and actions by VSDA in response to requests.

1. Research the information or statistics you would like to obtain.
2. Search existing reports and query tools for available reports, tables or information. See Attachment 4 for a list of statistical resources at VSDA. Review information at http://kic.kdhe.state.ks.us/kic/OHA/requests.html.
   a. If what you are seeking is part of a previously prepared public document, email KDHE.HealthStatistics@ks.gov.
   b. You do not need to file a KORA request
   c. You do not need to file a data request (RD-1) application
3. If the statistics or information can’t be found, download the full Data Request Guidance document at URL.
4. Review the requirements and definitions and what VSDA can provide contained in the Data Request Guidance Document.
5. If there are additional questions, contact VSDA at KDHE.HealthStatistics@ks.gov or call 785-296-8627.
6. If you desire to reuse data provided by VSDA from a prior request, a new data request will be required.
7. If you decide to file a data request take the following steps
   a. Use the Microsoft Word version of the RD-1 as it expands to give you all the space you need for answers.
      i. The RD-1 application may be used to request data or statistics involving:
         1. final Pregnancy Risk Assessment Management System data,
         2. final Syndromic Surveillance data,
         3. final annual data for births,
         4. deaths, and stillbirths,
         5. statistical analysis only of abortion data,
         6. final blood lead program data/statistics,
         7. if record linking is involved or for data areas outside this list, contact VSDA.
      ii. The RD-1 application must be used if record-level data of any type is requested.
   b. Evaluate what it is you need.
      i. If you are uncertain of the data/statistics needed email KDHE.HealthStatistics@ks.gov to obtain a copy of a data dictionary.
         1. Data dictionaries are available for birth, death and stillbirth. Dictionaries for birth and death are included in this guidance document as attachments to the PDF file.
         2. Data collection forms are available for birth, death, stillbirth and abortion.
c. Complete the RD-1 application.
d. Be sure to provide detailed information regarding:
   i. Description of the proposed study/research or statistics needed
   ii. Purpose of the study
   iii. Description of the proposed use and release of findings.
   iv. Any proposed data linkages
   v. Any proposed follow-back or contact with named individuals
   vi. Variables to be included in a dataset
   vii. Description of data security procedures
   viii. Person(s) responsible for leading the research
   ix. Person(s) responsible for data security
   x. Names of persons who will be involved in analyzing or will have
      access to the data provided
   xi. Institutional Review Board review/approval for the study. IRB re-
      view of the research/study within your organization is required for
      requests involving record-level data.
   xii. Format for the data to be provided. VSDA can provide data in .csv,
        Excel, SAS, Stata, and SPSS formats.
e. Responses may be provided as attachments to the RD-1.
f. If your request involves analyses for public health practice, contact
   VSDA.

8. Submit your completed application via email KDHE.HealthStatistics@ks.gov, fax
to 785-559-4213, or send by U.S. Mail to:
   VSDA Data Requests
   Bureau of Epidemiology and Public Health Informatics
   Kansas Department of Health and Environment
   1000 SW Jackson Street, STE 130
   Topeka, KS 66612

9. Once received your RD-1 will be:
   a. Logged in to the project tracking system
   b. Reviewed for completeness. VSDA may request additional information.
   c. Reviewed to determine whether publicly available statistics or information
      will satisfy the request.
   d. Reviewed to determine if the information can be provided under state
      law/regulation.
   e. Assessed whether a data use agreement will be required for the request.
   f. Evaluated to determine if the prospective data user owes any outstanding
      data fees.
   g. Evaluated to determine if the current request requires programming/data
      access fees.
   h. Evaluated to determine whether follow-back or contact with named indi-
      viduals for maternal child health surveillance will occur.

10. Review of the RD-1 application may take 4-6 weeks depending on the backlog of
     other projects and the amount of reviews required.
11. If the data request involves statistics or data on blood lead screening, VSDA will
    forward the request to Environmental Health Epidemiology for processing.
12. Incomplete RD-1 applications will be returned to the prospective data user.
13. If the request involves follow-back or contact for maternal child health surveillance, the prospective data user will be advised:
   a. KDHE IRB review of a research/study involving maternal child health surveillance is required by state law.
   b. Organizational IRB review is not a substitute for KDHE IRB Review.
   c. The request is on hold until the KDHE IRB approves the research/study.
   d. The individuals to contact on the KDHE IRB to begin the human subjects research review process.
   e. KDHE IRB review may take at least four months.
   f. The IRB meets only quarterly.
   g. VSDA is not able to facilitate that process.
14. If programming/data access fees are required, VSDA will;
   a. Prepare an estimate,
   b. Provide if to the prospective data user, and
   c. Explain the fee structure.
15. If the prospective data user accepts the estimate, notify VSDA.
16. If the request is approved, the following steps may occur:
   a. If the request involves preparation of statistics and any applicable cost estimate has been accepted by the prospective data user, VSDA staff will initiate work to prepare the analyses.
   b. If the request involves record-level data or preparation of sensitive statistics a data use agreement will be prepared. The data use agreement will incorporate requirements of any applicable KDHE IRB approval.
   c. VSDA will prepare the data use agreement using the information supplied by the prospective data user. The data use agreement will have an expiration date at which point VSDA will re-evaluate the need for the data.
   d. VSDA will discuss the data file delivery process. VSDA can supply a CD, DVD or transfer via a secure FTP transfer process. Files will be encrypted and password protected. Passwords will be provided separately from data files.
17. Once the proposed data use agreement has obtained the requisite approvals, it will be submitted to the prospective data user.
18. The prospective data user should sign and obtain signatures of others involved in the study/research including the signature of the organizational representative responsible for signing binding legal agreements. Everyone who signs the agreement is attesting they:
   a. Have read the agreement.
   b. Will comply with requirements and limitations on the use of statistics/data provided.
19. The signed agreement may be returned by email of scanned copy to KDHE.HealthStatistics@ks.gov, fax to 785-559-4213, or by US Mail at the address noted above.
20. No work on the on the request will occur until the signed data use agreement has been returned.
21. Incomplete data use agreements will be returned to the prospective data user.
22. Preparation of statistics or research/study datasets may take up to 6 weeks depending on whether VSDA is preparing annual published reports, complexity of the analyses to be performed, or the backlog of pending requests.

23. If new individuals become involved in the research/study, the approved data user shall:
   a. Explain to these individuals the requirements of any applicable KDHE IRB approval and any applicable data use agreement.
   b. Obtain signatures of these individuals on the supplemental data request signature form.
   c. Submit the supplemental data request signature form to VSDA.

24. If individuals involved in the research/study discontinue employment to are no longer involved in the project the following steps should occur:
   a. Discontinue access to record-level data.
   b. If the staff person is/was associated with a local health department, notify the appropriate individuals within KDHE to terminate online access under the provisions of the KDHE Aid-to-Local agreement.
   c. Notify the individuals they no longer have permission to use the data.
   d. Notify VSDA of the changes.

25. If the research/study ends:
   a. Notify VSDA.
   b. Advised on how any record-level will be disposed of.
   c. Dispose of the record-level data.
   d. Notify VSDA of the disposition.

26. If the approved data user receives a Kansas Open Records Act or a court subpoena request for record level data, refer such requests to VSDA for action by the KDHE Legal Office.
Attachment 1 - Security Practices

This section identifies recommended minimum practices for security of information or data. In some instances, higher levels of protection may be required. If organization requirements are more stringent, follow that guidance.

Responsibility

Every individual who works with or receives Bureau-supplied data, is responsible for maintaining the security and confidentiality of the information. By signing the data use agreement, data user(s) accept the obligation to protect record-level data or information, and acknowledge that careless or willful breach of confidentiality may result in disciplinary action or criminal prosecution. Every individual is responsible for notifying KDHE and their organization of a data breach and to take steps to mitigate the breach.

Data users should
- Provide for data management to assure data security,
- Establish and maintain appropriate administrative, technical, and physical safeguards to ensure data confidentiality and prevent unauthorized access to the data.

General Security

General security restrictions on vital records data prohibits:
1. Verbally communicating confidential or restricted data or information when within the hearing range of unauthorized individuals, including co-workers,
2. Sharing of confidential or restricted data or information with anybody else, including a family member, outside of the completion of one's duties, and
3. Accessing confidential or restricted data or information about oneself, family member, or friends for personal reasons without using the agency procedures in effect for the agency employees or for the public. For example, an employee with access to vital records is not allowed to review the vital record of a friend or relative thereby circumventing the regular process individuals use to request such records.

Physical security

Confidential- or restricted-level information should be in a locked file cabinet when not in use. Such information may be left unattended on a desk briefly if the desk is in a secure area. The data user is responsible for ensuring that the area is secure before leaving any confidential or restricted data or information in an unlocked area.

Examples of physical security best practices include:
1. Employees who need to store confidential or restricted information in their office should have a file cabinet that locks in their office or nearby. Hard copies and any electronic media containing supplied data shall be maintained in locked storage.
2. Confidential or restricted information routinely used by several persons should be locked in a central accessible area and each person should have a key or an electronic lock accessed with a key card or personal identification number (PIN).
3. No storage of confidential or restricted data/information with non-confidential materials (e.g., supplies or desk) as access to non-confidential materials poses a security risk.

4. Confidential or restricted papers must be shredded prior to disposal. Persons using such data should have easy access to a shredder or a locked bin that provided by a commercial disposal firm that shreds records.

5. Individuals working with vital records data separating from employment should surrender keys to file cabinets holding confidential data and to offices prior to separation and provide a list of all confidential or restricted files and needed passwords to a supervisor prior on separation.

6. Storage areas or file cabinets in private offices that contain confidential or restricted information shall be kept locked during weekend and evening hours.

7. Private areas should have locks.

8. Keys to all offices in a given area may use the same key, or alternatively, copies of keys to private offices should be available through the employee’s supervisor to permit legitimate access to the private office during working hours in the absence of that employee.

9. Access to an office suite shall be secured during evening and weekend hours.

10. If an office suite connects to other suites, lockable barriers should be installed to control access to areas containing confidential or restricted data or information.

**Computer security**

Every individual using vital records data shall have appropriate computer security in place. Examples of computer security best practices include:

1. Electronic storage of data shall be on a password-protected secure server.

2. Personal computers should be password protected including a password protected screen saver. Use of laptops and tablets for analysis and storage is discouraged. If used, laptops and tablets should also have encrypted file storage in addition to password requirements.

3. Passwords are not written down.

4. Password protected screen savers are used.

5. Passwords must be changed every 90 days and adhere to the minimum standards of the organization for whom the data user works. Passwords should be at least eight characters and include a number, uppercase letter, and a symbol.


7. Group level permissions should be used to limit access to network-stored data to authorized users.

8. Data stored on a personal computer or tablet should be stored in an encrypted fashion using state of the art AES 256 bit or better encryption.

9. Record level data is not stored on portable media, flash drives, diskettes, CDs, DVDs, or smartphones.

10. Emails containing vital records data are sent using encryption email software.

11. Data user has a protocol for reporting suspected security breaches, concerns, problems, or missing file.
The undersigned, as a data user, gives the following assurances:

1. I understand that in order to use/analyze the data provided by the Bureau of Epidemiology Vital and Health Statistics Data Analysis (VSDA) everyone involved needs to sign the data use agreement (DUA).
2. I understand and agree to comply with all conditions in the RD-1 data request application, the VSDA Data Request Guidance Document, the DUA, and any applicable KDHE Institutional Review Board (IRB) approval.
3. I will never release nor allow any person to release information from this data request, either in part or in their entirety, to anyone who is not associated with the project or who was not specifically approved by KDHE.
4. I will never use this information for any project or purpose that was not specifically approved by VSDA.
5. I will never nor will I permit any person to copy, sell, loan, or otherwise gain access to the data nor any portion of the data covered by this form.
6. I will never release any information that identifies persons, directly or indirectly.
7. I will never attempt to link nor permit others to attempt to link the records of persons in the certificates with personally identifiable records from any other source, other than those used in this Project.
8. I will never make a statement nor will I permit others to make statements indicating or suggesting that interpretations drawn are those of data sources or KDHE unless KDHE representatives are co-authors.
9. I will acknowledge in all reports based on this research the data source as required in the DUA or VSDA Data Request Guidance Document.
10. I understand that I may be audited by KDHE to ensure that I am using this data as authorized by law and approved for this project pursuant to this Agreement.

I have read the above information and agree to its content. I understand that KDHE will not be held liable for the results or consequences regarding misuse of data provided.

Research/Practice Research Title __________________________________________

My signature indicates my agreement to comply with all requirements listed above.

Signature: ___________________________ Date: ________________

Note: Any person newly associated with the research data request shall sign this form and be bound by the data use agreement, RD-1 request, and Data Request Guidance Document.
1. Individual and Organization Requesting Data or Analysis

Principal Investigator
Or Project Director:
Title:

Organization:
Complete mailing address
(include street address,
room number, city, state,
and ZIP Code)

2. Project or Study Title:

Phone no.: Fax no.: E-mail:

Who should be contacted if more information is needed?
Phone no.: Fax no.: E-mail:

3. What type of data would you like to obtain? (See instructions for the dataset(s) available through BEPHI) Enter those types
you want to access or have summarized.

3a. Describe the manner in which you wish to receive the data: Summary (aggregated) Restricted record Level

4. What data elements are needed? Describe the level of data detail requested, listing the specific fields requested.

Attach separate list if desired

5. Purpose of project, study, or analysis - Describe the public health issues addressed by your research. Include some
background information to support why the study or project is being done. What are the primary objectives? If appropriate,
include a description of the hypotheses to be tested.

6. Study protocol or project activities – Summarize the study protocol or project activities. Conclude your summary by
describing how data obtained from BEPHI will be used.

7. Institutional Review Board (IRB) for Protection of Human Subjects – Evidence of a current IRB approval is encouraged for
record-level data requests and some tabular data requests.
7a. Has this study or project been reviewed and approved by an IRB?  
Yes □  No □

7b. If Yes, attach a copy of the IRB action and provide the following:

Name of the IRB:

IRB’s Multiple Project Assurance (MPA) or Federal-wide Assurance (FWA) number:

Date of the IRB’s action:

8. Potential date by which analysis will be completed:

9. How are the results of this research to be released?

10. What are some ways that your organization might put the results into action? (i.e., awareness campaigns, informing existing programs, educating specific agencies/groups, etc.)

11. Data Confidentiality and Security – Evidence of procedures and protocols to maintain data security and prevent a breach of confidentiality is required for record-level data requests. Describe the data security/confidentiality procedures you or your organization will follow.

Name of person responsible for data security

Name(s) of other persons accessing the data

12. Data or Results Delivery Format – BEPHI can provide the results in a variety of formats via a number of delivery methods.

Describe Delivery Method

Describe Data Format

13. Followback is the process contacting individuals, hospitals, or physicians identified on a vital record. Describe the kind of followback you propose to do in your project or study.

14. Record linking is the where you match or link data or summary results to other information about individuals or entities. Describe any linking you plan to do in your project or study.
Each year Vital and Health Statistics Data Analysis Section in the Bureau’s Public Health Informatics Group prepares a series of reports and printouts of data involving vital events reported. These documents summarize the births, fetal deaths, deaths, marriages, marriage dissolutions, and abortions for a given year. The number of reports has grown over the years, as well as the tables and charts created. Some tables and figures may not be available in earlier years. Some reports and tables may involve a copying fee. Most reports are available at http://www.kdheks.gov/phi/index.htm. Although some preliminary reports are issued earlier, vital event final reports are released starting in September. This is due to fact that reports of births and deaths to Kansas residents in other state take time to arrive. The analytical files are created July 1 of the year following the event year.

The reports created are:

- Adolescent and Teenage Pregnancy Summary http://www.kdheks.gov/hci/teenpreg.html
- Preliminary Analysis of Abortion Data: http://www.kdheks.gov/hci/absumm.html
- Perinatal Casualty Study Reports (on request)
- Special research & ad hoc summaries: http://www.kdheks.gov/phi/khsr.html
- Adequacy of Prenatal Care Utilization Index: http://www.kdheks.gov/hci/kacui.html

**Kansas Information for Communities**

The Kansas Information for Communities interactive query web page, http://kic.kdheks.gov/ enables users to create queries for many types of public health data. Questions about health data maintained by the Bureau can be sent to Kansas.Health.Statistics@kdheks.gov

The system went online in 2000 providing birth and death statistics in a query environment. As other programs contributed data, the number of query modules expanded. Pregnancy outcomes, population, cancer, and hospital discharge data were added. Infectious disease information was included for a time. Initially conceived as a data query tool, KIC is now branded as a one stop point of contact for all sorts of health statistic information.

What distinguishes KIC from the static paper based reports generated by the department is the ability to craft tabular reports to a variety of population segments. KIC queries can report results by county, zip code, sex, race, Hispanic origin, and age-group. For deaths, tabulations can be stratified by selected causes of death. In the event of hospitalizations, stratification by procedure or diagnosis category is possible along with total and mean length of stay calculations.

KIC’s target audience is local public health agencies and public health managers. The public, ranging from social service agencies, hospitals, universities, to businesses, also use KIC to dig deeper into the measures and indicators of Kansas health outcomes.

Supported with technical notes and documentation, KIC queries can be performed around the clock. Users can take advantage of multiple queries to compare outcomes of different cohorts. KIC is designed to return query results in less than 15 seconds – even when using slower Internet dialup connections. Results can be downloaded or printed and include the date the query was made.

Confidentiality of the individuals events are based on is fully protected. The KIC system uses a special dataset that removes identifying information. In order to prevent someone from deducing enough information to identify a person by the selected characteristics, KIC employs up to three suppression methods to block users from seeing the confidential information.

KIC offers more than mere counts of the number of persons who died or number of babies with low birthweight. Birth KIC will compute percentage rates. Death and several other KIC modules will calculate population-based rates. These
rates, and the ability in some modules to create confidence intervals, enable the users to not only reliably compare results among years, counties or other groupings, but to assure themselves the results are statistically meaningful. The KIC system became more than a query tool when demand grew for information on social determinants of health and quick access to simple birth and death data. Users expressed the desire for a one-button approach to obtaining all the statistics for their county. The response was KIC’s FastStats module.

**Kansas Health Matters**

The Kansas Health Matters website brings community health-related statistical data, local resources, and a wealth of information to one accessible, user-friendly location. The intent is to give our communities the tools they need to read and understand the public health indicators that affect the quality of our residents’ lives. The tools help the community set goals and evaluate progress.

Kansas Health Matters is intended to help hospitals, health departments, community members and policy makers learn about the health of the community and ways to help improve it. Community groups, schools, health associations, chambers of commerce, tourism, and many other organizations can use this information to show the great benefits of living in Kansas as alongside potential opportunities for improvement, with specific information. Master planners and government representatives can use this data to establish community goals on a variety of platforms. The evolving nature of this website allows all users of Kansas Health Matters to contribute information and ideas.

Kansas Health Matters was created by the Kansas Partnership for Improving Community Health http://www.kansashealthmatters.org/. Use the links at the top of the page to learn more about the history behind Kansas Health Matters and site features.

**History**

The Kansas Partnership for Improving Community Health began in March 2011 as a public-private partnership. Eight cross-sectoral agencies came together to create and provide the vision and leadership for Kansas’ most comprehensive online source of state-specific data and relevant health improvement resources (www.kansashealthmatters.org). At its inception, the partnership’s mission was to empower communities and health care providers to improve health by providing data, supporting community health assessment, and identifying best practices through partnerships and collaboration.

The partners created an initial Memorandum of Agreement in July 2011. This memorandum set several goals, including: making public data accessible in a meaningful context; supporting local organizations with tools to address complex health issues; and establishing a collaborative partnership to guide and sustain efforts. Additionally, the memorandum described the partnership responsibilities. Since 2011, the partnership continued to evolve and strengthen its operations. As the result, in 2013 members developed a strategic plan, which outlined new goals and objectives in the areas of governance, maintenance, sustainability, and marketing/communication. The partnership also changed its name to Kansas Health Matters: A Partnership to Improve Community Health in order to be consistent with the site brand.

Current members of the Kansas Health Matters Partnership are:

- Kansas Association for the Medically Underserved
- Kansas Association of Local Health Departments
- Kansas Department of Health and Environment
- Kansas Health Foundation
- Kansas Health Institute
- Kansas Hospital Association
- United Way of the Plains
DATA USE AGREEMENT

Click here to enter text.

Provided to

Click here to enter text. (Data User)

1. Data and Records provided under this Agreement contain confidential and personal information. The information shall be maintained as confidential with access to identifiable information to those that need to know.

2. The Data User shall notify the KDHE Bureau of Epidemiology and Public Health Informatics (BEPHI) as soon as possible after receiving a request for information which the Data User believes require Data User to disclose the information, to allow the KDHE to intervene. Birth/death/stillbirth certificates serve as legal records of vital events and identity and are for public health analyses only. To prevent the added risk of identity theft, the US Intelligence Reform Act §7211 has placed further restrictions on access to US birth certificates and/or disclosure of confidential birth certificate data.

3. The Data User shall provide written notice to KDHE-BEPHI within three (3) days of discovery by Data User of any breach of security, of any data, encrypted or otherwise, in use by the Data User where such breach of security arises out of the acts or omissions of the Data User or its employees. Upon the discovery of such security breach, the Data User shall take reasonable steps to remediate the cause or causes of such breach and shall provide notice to the KDHE-BEPHI of such steps. In the event of such breach of security, without limiting any other right of the KDHE, the KDHE shall have the right to take actions mandated by any Law, or administrative or judicial order, to address the breach, and including any fines or disallowances imposed by the State or federal government as a result of the disclosure.

4. The Data User shall restrict access to data/information to individuals who have a legitimate work-related purpose to access such information. Data User agrees to instruct its officers, employees, and agents to maintain the confidentiality of any and all information required to be kept confidential by this Agreement. Data disclosure to personnel for uses not described in this agreement and the RD-1 Data Request Form (incorporated by reference) is strictly prohibited.

5. At KDHE-BEPHI request, Data User shall return to KDHE-BEPHI any and all confidential information in Data User’s possession. If Data User is legally required to retain confidential information, Data User shall notify KDHE in writing and set forth the confidential information that it intends to retain and the reasons why it is legally required to retain such information. The Data User shall destroy the data/information when it is no longer needed, or this Agreement expires or is not renewed. A breach of this Section shall constitute a material breach of this Agreement for which the KDHE BEPHI shall terminate this Agreement. KDHE-BEPI reserves any and all other rights and remedies in the event of unauthorized disclosure.

6. The Data User shall maintain data securely in accordance with the Data User’s organizational requirements or KDHE data request guidance Attachment 1. Data User will be responsible for violations of HIPAA or other applicable federal, state, or local law or regulation governing the data use while it is in the Data User’s possession and control.

7. The Data User and its officers, employees, and agents shall notify KDHE-BEPHI electronically, at any time either during or after completion or termination of this Agreement, of any intended statement issuance of any material for publication in any media of communication (print, news, television, radio, Internet, etc.) regarding the services provided or the data collected pursuant to this Agreement at least twenty-four (24) hours prior to any public release or at least five (5) business Days prior to the submission of the material for publication, or such shorter periods as are reasonable under the circumstances. The Data User shall not issue any statement or submit any material for publication that includes confidential information.

8. The Data User shall not attempt to link the data set with individually identifiable records from any other data sets without written permission of the KDHE-BEPI.

9. The Data User shall acknowledge the data source as the “Kansas Department of Health and Environment - Bureau of Epidemiology and Public Health Informatics” in any publication or report using the data and provide a copy of any non-proprietary report or publication based on the data supplied to the KDHE-BEPI. Data use shall also include acknowledgements for use of PRAMS or Syndromic Surveillance data.

10. Data are provided under one of the following authorities:

- Vital statistics data under K.S.A. 65-2422d(d)
- Syndromic Surveillance data under K.S.A. 65-6801(c) and K.A.R. 28-67-4.
- Pregnancy Risk Assessment Monitoring System (PRAMS) under K.S.A. 65-2422d(d) and K.S.A. 65-177.
11. Data user shall include signatures from all staff and analysts, and the person authorized to sign binding agreements for your organization. If needed, make additional copies of the signature pages. Once done, scan and email this signed form to KDHE.healthstatistics@ks.gov or fax to 785-559-4213. New staff shall sign the signature page and submit to KDHE. Data User shall notify KDHE of staff departures.

12. Data Provided Under this Agreement:

<table>
<thead>
<tr>
<th>Data type</th>
<th>Indicate data type</th>
<th>Data years requested and any additional description</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Aggregate Data (requiring DUA; please provide data shell)</td>
<td>☐ Birth</td>
<td>Click here to enter text.</td>
</tr>
<tr>
<td>☐ Standardized Limited Use Dataset</td>
<td>☐ Death</td>
<td></td>
</tr>
<tr>
<td>☐ Standardized Limited Use plus limited additional variables*</td>
<td>☐ Linked Birth-Infant Death</td>
<td></td>
</tr>
<tr>
<td>☑ Customized dataset*</td>
<td>☐ Syndromic Data</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Stillbirth</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ PRAMS Data</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Other</td>
<td></td>
</tr>
</tbody>
</table>

List of direct identifiers data elements and reason for use below:

<table>
<thead>
<tr>
<th>Data type</th>
<th>Indicate data type</th>
<th>Data Years Requested and Data Elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Personally identifiable items (e.g. name, address, SSN, birthdate)</td>
<td>☐ Birth</td>
<td>Click here to enter text.</td>
</tr>
<tr>
<td>☐ Literals</td>
<td>☐ Death</td>
<td></td>
</tr>
<tr>
<td>☐ Other Exact Dates</td>
<td>☐ Linked Birth-Infant Death</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Syndromic Data</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Stillbirth</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ PRAMS Data</td>
<td></td>
</tr>
<tr>
<td></td>
<td>☐ Other</td>
<td></td>
</tr>
</tbody>
</table>

Otherwise, all direct identifiers (names, social security numbers) have been omitted from the data set. Nevertheless, it may be possible in rare instances, through complex analysis and/or with outside information, to ascertain from the data sets the identity of particular persons. Considerable harm could ensue if this were done. Any effort to use the information for any purpose other than the activity indicated above violates confidentiality restrictions and the conditions of this agreement. Data shall not be re-disclosed (unless specifically documented below).

Uses Permitted and Limitations Under this Agreement:

<table>
<thead>
<tr>
<th>Type of Use</th>
<th>Description:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Administrative* (cite legal code and text supporting administrative use)</td>
<td></td>
</tr>
<tr>
<td>☐ Public Health Practice (e.g. Surveillance/Assessment/Program Evaluation)</td>
<td></td>
</tr>
<tr>
<td>☐ Research (involving no living human subjects)</td>
<td></td>
</tr>
<tr>
<td>☐ Research (involving living human subjects)</td>
<td></td>
</tr>
</tbody>
</table>
Data User shall pay KDHE Click here to enter text. annually for providing information and technical assistance under this Agreement.

This Agreement expires on Click here to enter text. Either party may terminate this Agreement with 30 days’ notice. This Agreement must be signed by an organizational authority accountable for maintaining the provisions of this Agreement and the person requesting the data. These may be the same person.

My signature indicates my agreement, and that of the data user, to comply with 1) applicable laws and regulations, 2) requirements contained in this Agreement, 3) terms of the RD-1 data request submitted, 4) requirements of any KDHE Institutional Review board, and 5) requirements in the Vital and Health Statistics Data Analysis (VSDA) Data and Statistics Guidance Document (available at http://www.kdheks.gov/phi/data_requests.htm). The RD-1 form, IRB approval, and Data and Statistics Guidance Document are incorporated herein and hereby made a part of this Agreement.
DISCLOSURE OF RECORDS

K.S.A. 65-2422d. DISCLOSURE OF RECORDS; DISCLOSURE OF CHILD BIRTH INFORMATION; MONTHLY REPORTS OF DECEASED RESIDENTS TO COUNTY ELECTION OFFICERS; SECTION NOT APPLICABLE TO CERTAIN RECORDS CREATED PRIOR TO JULY 1, 1911; SOCIAL SECURITY NUMBER, AVAILABILITY; FACT OF DEATH INFORMATION; USE OF INFORMATION FOR MATERNAL AND CHILD HEALTH SURVEILLANCE AND MONITORING. (a) The records and files of the division of public health pertaining to vital statistics shall be open to inspection, subject to the provisions of the uniform vital statistics act and rules and regulations of the secretary. It shall be unlawful for any officer or employee of the state to disclose data contained in vital statistical records, except as authorized by the uniform vital statistics act and the secretary, and it shall be unlawful for anyone who possesses, stores or in any way handles vital statistics records under contract with the state to disclose any data contained in the records, except as authorized by law.

(b) No information concerning the birth of a child shall be disclosed in a manner that enables determination that the child was born out of wedlock, except upon order of a court in a case where the information is necessary for the determination of personal or property rights and then only for that purpose, or except that employees of the office of child support enforcement of the federal department of health and human services shall be provided information when the
information is necessary to ensure compliance with federal reporting and audit requirements pursuant to title IV-D of the federal social security act or except that the secretary for children and families or the secretary's designee performing child support enforcement functions pursuant to title IV-D of the federal social security act shall be provided information and copies of birth certificates when the information is necessary to establish parentage in legal actions or to ensure compliance with federal reporting and audit requirements pursuant to title IV-D of the federal social security act. Nothing in this subsection shall be construed as exempting such employees of the federal department of health and human services or the secretary for children and families or the secretary's designee from the fees prescribed by K.S.A. 65-2418, and amendments thereto.

(c) Except as provided in subsection (b), and amendments thereto, the state registrar shall not permit inspection of the records or issue a certified copy or abstract of a certificate or part thereof unless the state registrar is satisfied the applicant therefor has a direct interest in the matter recorded and the information contained in the record is necessary for the determination of personal or property rights. The state registrar's decision shall be subject, however, to review by the secretary or by a court in accordance with the Kansas judicial review act, subject to the limitations of this section.

(d) The secretary shall permit the use of data contained in vital statistical records for research purposes only, but no identifying use of them shall be made. The secretary shall permit the use of birth, death and still birth certificates as identifiable data for purposes of maternal and child health surveillance and monitoring. The secretary or the secretary's designee may interview individuals for purposes of maternal and child health surveillance and monitoring only with an approval of the health and environmental institutional review board as provided in title 45, part 46 of the code of federal regulations. The secretary shall inform such individuals that the participation in such surveillance and monitoring is voluntary and may only be conducted with the written consent of the person who is the subject of the information or with the informed consent of a parent or legal guardian if the person is under 18 years of age. Informed consent is not required if the person who is the subject of the information is deceased.

(e) Subject to the provisions of this section the secretary may direct the state registrar to release birth, death and stillbirth certificate data to federal, state or municipal agencies.

(f) On or before the 20th day of each month, the state registrar shall furnish to the county election officer of each county and the clerk of the district court in each county, without charge, a list of deceased residents of the county who were at least 18 years of age and for whom death certificates have been filed in the office of the state registrar during the preceding calendar month. The list shall include the name, age or date of birth, address and date of death of each of the deceased persons and shall be used solely by the election officer for the purpose of correcting records of their offices and by the clerk of the district court in each county for the purpose of correcting juror information for such county. Information provided under this subsection to the clerk of the district court shall be considered confidential and shall not be disclosed to the public. The provisions of subsection (b) of K.S.A. 45-229, and amendments thereto, shall not apply to the provisions of this subsection.

(g) No person shall prepare or issue any certificate which purports to be an original, certified copy or abstract or copy of a certificate of birth, death or fetal death, except as authorized in this act or rules and regulations adopted under this act.
(h) Records of births, deaths or marriages which are not in the custody of the secretary of health and environment and which were created before July 1, 1911, pursuant to chapter 129 of the 1885 Session Laws of Kansas, and any copies of such records, shall be open to inspection by any person and the provisions of this section shall not apply to such records.

(i) Social security numbers furnished pursuant to K.S.A. 65-2409a, and amendments thereto, shall only be used as permitted by title IV-D of the federal social security act, and amendments thereto, or as permitted by section 7(a) of the federal privacy act of 1974, and amendments thereto. The secretary shall make social security numbers furnished pursuant to K.S.A. 65-2409a, and amendments thereto, available to the Kansas department for children and families for purposes permitted under title IV-D of the federal social security act.

(j) Fact of death information may be disseminated to state and federal agencies administering benefit programs. Such information shall be used for file clearance purposes only.


K.A.R. 28-17-21. DISSEMINATION OF CERTAIN INFORMATION TO STATE AND FEDERAL AGENCIES. Certain information extracted from death records may be released to state and federal agencies in the form of a computer data tape to include name of deceased, date of death, date of birth, county of residence, and social security number. This information shall be released on an annual basis upon written request. The written request shall include: a statement as to how the information shall be used; a statement of confidentiality assuring the information shall be used for the agreed upon purpose only; and assurance that no contact shall be made based upon information obtained. The information shall be disseminated to the requestor in a standard format to be determined by the department. The state registrar shall determine the fee to be charged for the data tape based on costs for providing those services and shall prescribe the manner in which those costs are to be paid. (Authorized by K.S.A. 65-2402; implementing K.S.A. 65-2422, as amended by L.1987, Ch. 241, Sec. 1; effective May 1, 1988.)
65-177. Study of diseases and deaths from maternal, perinatal and anesthetic causes; "data" defined; confidentiality, use; admissibility as evidence; reports, contents. (a) The term "data" as used in K.S.A. 65-177 through 65-179, and amendments thereto, shall be construed to include all facts, information, records of interviews, written reports, statements, notes, or memoranda secured in connection with an authorized medical research study.

(b) The secretary of health and environment shall receive data secured in connection with medical research studies conducted for the purpose of reducing morbidity or mortality from maternal, perinatal and anesthetic causes. Such studies may be conducted by the secretary of health and environment and staff or with other qualified persons, agencies or organizations. If such studies are conducted with any funding not provided by the state of Kansas, then the source of such funding shall be clearly identified in such study. Where authorization to conduct such a study is granted by the secretary of health and environment, all data voluntarily made available to the secretary of health and environment in connection with such study shall be treated as confidential and shall be used solely for purposes of medical research. Research files and opinions expressed upon the evidence found in such research shall not be admissible as evidence in any action in any court or before any other tribunal, except that statistics or tables resulting from such data shall be admissible and may be received as evidence. This section shall not affect the right of any patient or such patient's guardians, representatives or heirs to require hospitals, physicians, sanatoriums, rest homes, nursing homes or other persons or agencies to furnish such patient's hospital record to such patient's representatives upon written authorization, or the admissibility in evidence thereof.

(c) No employee of the secretary of health and environment shall interview any patient named in any such report, nor any relative of any such patient, unless otherwise provided in K.S.A. 65-2422d, and amendments thereto. Nothing in this section shall prohibit the publication by the secretary of health and environment or a duly authorized cooperating person, agency or organization, of final reports or statistical compilations derived from morbidity or mortality studies, which reports or compilations do not identify individuals, associations, corporations or institutions which were the subjects of such studies, or reveal sources of information.

History: L. 1961, ch. 289, § 1; L. 1974, ch. 352, § 46; L. 2010, ch. 143, § 1; May 27.
65-6801. Health care database; legislative intent; use of information. (a) The legislature recognizes the urgent need to provide health care consumers, third-party payors, providers and health care planners with information regarding the trends in use and cost of health care services in this state for improved decision-making. This is to be accomplished by compiling a uniform set of data and establishing mechanisms through which the data will be disseminated.

(b) It is the intent of the legislature to require that the information necessary for a review and comparison of utilization patterns, cost, quality and quantity of health care services be supplied to the health care database by all providers of health care services and third-party payors to the extent required by this section and K.S.A. 65-6805, and amendments thereto. The department of health and environment shall specify by rule and regulation the types of information which shall be submitted and the method of submission.

(c) The information is to be compiled and made available in a form prescribed by the department of health and environment to improve the decision-making processes regarding access, identified needs, patterns of medical care, price and use of health care services.


65-6802. Same; request for and use of data by department of health services administration of university of Kansas. (a) The department of health services administration of the university of Kansas and any institute or center established in association with the department is hereby authorized to request data for the purposes of conducting research, policy analysis and preparation of reports describing the performance of the health care delivery system from public, private and quasi-public entities.

(b) The department of health services administration of the university of Kansas may request data for purposes of conducting research, policy analysis and preparation of reports describing the performance of the health care delivery system from any quasi-public or private entity which has such data as deemed necessary by the department.


65-6803. Same; appointment of task forces; health care data policies and procedures. (a) The secretary of health and environment may appoint a task force or task forces of interested citizens and providers of health care for the purpose of studying technical issues relating to the collection of health care data. The secretary of health and environment or the secretary's designee shall be a member of any task force appointed under this subsection.

(b) The department of health and environment shall develop policy regarding the collection of health care data and procedures for ensuring the confidentiality and security of these data.

65-6804. Health care database; duties of the secretary of health and environment; health data collection contracts; acceptance of data; system of fees; rules and regulations; data confidential; penalties for violations. (a) The secretary of health and environment shall administer the health care database. In administering the health care database, the secretary shall receive health care data from those entities identified in K.S.A. 65-6805, and amendments thereto, and provide for the dissemination of such data.

(b) The secretary of health and environment may contract with an organization experienced in health care data collection to collect the data from the health care facilities as described in subsection (h) of K.S.A. 65-425, and amendments thereto, build and maintain the database. The secretary of health and environment may accept data submitted by associations or related organizations on behalf of health care providers by entering into binding agreements negotiated with such associations or related organizations to obtain data required pursuant to this section.

(c) The secretary of health and environment shall adopt rules and regulations governing the acquisition, compilation and dissemination of all data collected pursuant to this act. The rules and regulations shall provide at a minimum that:

(1) Measures have been taken to provide system security for all data and information acquired under this act;

(2) data will be collected in the most efficient and cost-effective manner for both the department and providers of data;

(3) procedures will be developed to assure the confidentiality of patient records;

(4) users may be charged for data preparation or information that is beyond the routine data disseminated and that the secretary of health and environment shall establish by the adoption of such rules and regulations a system of fees for such data preparation or dissemination; and

(5) the secretary of health and environment will ensure that the health care database will be kept current, accurate and accessible as prescribed by rules and regulations.

(d) Data and other information collected pursuant to this act shall not be disclosed by the department of health and environment or made public in any manner which would identify individuals. A violation of this subsection (d) is a class C misdemeanor.

(e) In addition to such criminal penalty under subsection (d), any individual whose identity is revealed in violation of subsection (d) may bring a civil action against the responsible person or persons for any damages to such individual caused by such violation.

65-6805. Same; medical, health care and other entities to file health care data; exception. Each medical care facility as defined by subsection (h) of K.S.A. 65-425, and amendments thereto; health care provider as defined in K.S.A. 40-3401, and amendments thereto; providers of health care as defined in subsection (f) of K.S.A. 65-5001, and amendments thereto; health care personnel as defined in subsection (e) of K.S.A. 65-5001, and amendments thereto; home health agency as defined by subsection (b) of K.S.A. 65-5101, and amendments thereto; psychiatric hospitals licensed under K.S.A. 75-3307b, and amendments thereto; state institutions for people with intellectual disability; community facilities for people with intellectual disability as defined under K.S.A. 65-4412, and amendments thereto; community mental health center as defined under K.S.A. 65-4432, and amendments thereto; adult care homes as defined by K.S.A. 39-923, and amendments thereto; laboratories described in K.S.A. 65-1,107, and amendments thereto; pharmacies; board of nursing; Kansas dental board; board of examiners in optometry; state board of pharmacy; state board of healing arts and third-party payors, including, but not limited to, licensed insurers, medical and hospital service corporations, health maintenance organizations, fiscal intermediaries for government-funded programs and self-funded employee health plans, shall file health care data with the department of health and environment as prescribed by the secretary of health and environment. The provisions of this section shall not apply to any individual, facility or other entity under this section which uses spiritual means through prayer alone in accordance with the tenets and practices of a recognized church or religious denomination for the treatment or cure of disease.


Revisor's Note:

Section was also amended by L. 2012, ch. 102, § 28, but that version was repealed by L. 2012, ch. 166, § 24.

65-6806. Same; availability of data. The department of health and environment shall make the data available to interested parties on the basis prescribed by the department and as directed by rules and regulations.


65-6807. Same; annual report to governor and legislature. The department of health and environment shall on or before February 1 each year make a report to the governor and the legislature as to health care data activity, including examples of policy analyses conducted and purposes for which the data was disseminated and utilized, and as to the progress made in compiling and making available the information specified under K.S.A. 65-6801, and amendments thereto.


65-6809. Health care database fee fund; fees credited; authorized uses; interest earnings credited; administration. (a) There is hereby established in the state treasury the health care database fee fund.
The secretary of health and environment shall remit to the state treasurer, in accordance with the provisions of K.S.A. 75-4215, and amendments thereto, all moneys collected or received by the secretary from the following sources:

1. Fees collected under K.S.A. 65-6804, and amendments thereto;
2. Moneys received by the secretary in the form of gifts, donations or grants;
3. Interest attributable to investment of moneys in the fund; and
4. Any other moneys provided by law.

Upon receipt of each such remittance, the state treasurer shall deposit the entire amount in the state treasury to the credit of the health care database fee fund.

(b) Moneys deposited in the health care database fee fund shall be expended to supplement maintenance costs of the database, provide technical assistance and training in the proper use of health care data and provide funding for dissemination of information from the database to the public.

(c) On or before the 10th of each month, the director of accounts and reports shall transfer from the state general fund to the health care database fee fund interest earnings based on:

1. The average daily balance of moneys in the health care database fee fund for the preceding month; and
2. The net earnings rate of the pooled money investment portfolio for the preceding month.

(d) All expenditures from the health care database fee fund shall be made in accordance with appropriation acts upon warrants of the director of accounts and reports issued pursuant to vouchers approved by the secretary of health and environment or the secretary's designee for the purposes set forth in this section.


65-6821. Kansas health information technology act. K.S.A. 2013 Supp. 65-6821 through 65-6834 and 65-6835, and amendments thereto, shall be known and may be cited as the Kansas health information technology act.


65-6822. Same; definitions. As used in the Kansas health information technology act:

(a) "Act" means the Kansas health information technology act.

(b) "Approved health information organization" means a health information organization operating in the state under a valid certificate of authority issued by the department.
(c) "Authorization" means a document that permits a covered entity to use or disclose protected health information for purposes other than to carry out treatment, payment or health care operations, and that complies with the requirements of 45 C.F.R. § 164.508.

(d) "Covered entity" means a covered entity as the term is defined in 45 C.F.R. § 160.103.

(e) "Department" means the Kansas department of health and environment.

(f) "Disclosure" means disclosure as that term is defined by the HIPAA privacy rule.

(g) "Health care" means health care as that term is defined by the HIPAA privacy rule.

(h) "Health care provider" means a health care provider, as that term is defined by the HIPAA privacy rule.

(i) "Health information" means health information as that term is defined by the HIPAA privacy rule.

(j) "Health information organization" means any entity operating in the state which:

1) Maintains technical infrastructure for the electronic movement of health information among covered entities; and

2) promulgates and enforces policies governing participation in such sharing of health information.

(k) "Health information technology" means an information processing application using computer hardware and software for the storage, retrieval, use and disclosure of health information for communication, decision-making, quality, safety and efficiency of health care. "Health information technology" includes, but is not limited to: (1) An electronic health record; (2) a personal health record; (3) the sharing of health information electronically; (4) electronic order entry; and (5) electronic decision support.

(l) "HIPAA privacy rule" means the privacy rule of the administrative simplification subtitle of the health insurance portability and accountability act of 1996 (Pub. L. No. 104-191) contained in 45 C.F.R. part 160 and 45 C.F.R. part 164, subparts A and E.

(m) "Individual" means individual as that term is defined by the HIPAA privacy rule.

(n) "Individually identifiable health information" means individually identifiable health information as that term is defined by the HIPAA privacy rule.

(o) "Participation agreement" means a written agreement between a covered entity and an approved health information organization concerning the covered entity’s participation in the approved health information organization on terms consistent with K.S.A. 2013 Supp. 65-6832, and amendments thereto.

(p) "Personal representative" means the person who has the legal authority to act on behalf of an individual.
(q) "Protected health information" means protected health information as that term is defined by the HIPAA privacy rule.

(r) "Secretary" means the secretary of health and environment.

(s) "State" means the state of Kansas.

(t) "Use" means, with respect to individually identifiable health information, use as the term is defined by the HIPAA privacy rule.


65-6823. Same; purpose. It is the purpose of this act to harmonize state law with the HIPAA privacy rule with respect to individual access to protected health information, proper safeguarding of protected health information, and the use and disclosure of protected health information for purposes of facilitating the development and use of health information technology and the sharing of health information electronically.


65-6824. Same; duties of covered entity. (a) A covered entity shall provide an individual or such individual's personal representative with access to the individual's protected health information maintained, collected, used or disseminated by or for the covered entity in compliance with 45 C.F.R. § 164.524.

(b) A covered entity shall implement and maintain appropriate administrative, technical and physical safeguards to protect the privacy of protected health information in a manner consistent with 45 C.F.R. § 164.530(c).


65-6825. Same; use and disclosure of protected health information. (a) No covered entity shall use or disclose protected health information except as follows:

(1) In a manner consistent with an authorization that satisfies the requirements of 45 C.F.R. § 164.508;

(2) in a manner as permitted under 45 C.F.R. §§ 164.502, 164.506, 164.508, 164.510 and 164.512; or

(3) in a manner as required under 45 C.F.R. § 164.502.

(b) A covered entity may disclose an individual's protected health information to a health information organization without an authorization if such covered entity:

(1) Is a party to a current participation agreement with an approved health information organization at the time the disclosure is made;
discloses the individual's protected health information to that approved health information organization in a manner consistent with the established procedures of the approved health information organization; and

(3) furnishes to the individual, or such individual's personal representative, whose information is to be disclosed to the approved health information organization, the notice required under K.S.A. 2013 Supp. 65-6832, and amendments thereto.

(c) A covered entity that uses or discloses protected health information in compliance with this section shall be immune from any civil or criminal liability or any adverse administrative action arising out of or relating to such use or disclosure.


65-6828. Same; controlling law on confidentiality of protected health information. To the extent any provision of state law regarding the confidentiality, privacy, security or privileged status of any protected health information conflicts with, is contrary to, or more stringent than the provisions of this act, the provisions of this act shall control, except that: (a) Nothing in this act shall limit or restrict the effect and application of the peer review statute, K.S.A. 65-4915, and amendments thereto; the risk management statute, K.S.A. 65-4921 through 65-4930, and amendments thereto; or any statutory health care provider-patient evidentiary privilege applicable to a judicial or administrative proceeding; and

(b) nothing in this act shall limit or restrict the ability of any state agency to require the disclosure of protected health information by any person or entity pursuant to law.


65-6829. Same; disclosure of protected health information, when required or permitted. A covered entity may disclose protected health information without authorization to any state agency for any public health purpose that is required by law. Nothing in this act shall be construed to limit the use, transfer or disclosure of protected health information as required or permitted by any other provision of law for public health purposes.


65-6830. Same; health information organizations; standards for approval and operation. (a) The department shall establish and revise, as appropriate, standards for the approval and operation of statewide and regional health information organizations operating in the state as approved health information organizations including, but not limited to, the following:

(1) Adherence to nationally recognized standards for interoperability, that is, the capacity of two or more information systems to share information or data in an accurate, effective, secure and consistent manner;
(2) adoption and adherence to rules promulgated by the department regarding access to and use and disclosure of protected health information maintained by or on an approved health information organization;

(3) demonstration of adequate financial resources to sustain continued operations in compliance with the standards;

(4) participation in outreach activities for individuals and covered entities;

(5) conduct of operations in a transparent manner to promote consumer confidence;

(6) implementation of security breach notification procedures; and

(7) development of procedures for entering into and enforcing the terms of participation agreements with covered entities which satisfy the requirements established by the department pursuant to K.S.A. 2013 Supp. 65-6832, and amendments thereto.

(b) The department shall ensure that approved health information organizations operate within the state in a manner consistent with the protection of the security and privacy of health information of the citizens of Kansas.

(c) No expenditure shall be made from the state general fund for the purposes of administration, operation or oversight of the health information organizations defined in K.S.A. 2013 Supp. 65-6821, and amendments thereto, except that the secretary of health and environment may make operational expenditures for the purpose of adopting and administering the rules and regulations necessary to implement the Kansas health information technology act.


65-6831. Same; process established for approval and investigation of HIOs. The department shall establish and implement:

(a) A process by which a health information organization may apply for and receive a certificate of authority issued by the department by demonstrating compliance with the standards promulgated by the department pursuant to K.S.A. 2013 Supp. 65-6830, and amendments thereto;

(b) a process by which an approved health information organization shall be re-approved on appropriate intervals by demonstrating continued compliance with the standards promulgated by the department pursuant to K.S.A. 2013 Supp. 65-6830, and amendments thereto; and

(c) a process for the investigation of reported concerns and complaints regarding an approved health information organization and imposition of appropriate remedial and proactive measures to address any identified deficiencies.

65-6832. Same; participation agreements; specification of procedures and requirements. The department shall establish requirements to be used by approved health information organizations in participation agreements with covered entities and shall include the following:

(a) Specification of procedures by which an individual's protected health information will be disclosed by covered entities, will be collected by approved health information organizations and will be shared with other participating covered entities and with the department as required by law for public health purposes;

(b) specification of procedures by which an individual may elect that protected health information be restricted from disclosure by approved health information organizations to covered entities;

(c) specifications of purposes for, and procedures by which a covered entity can access an individual's protected health information from the approved health information organization, including access to restricted information by a covered entity in an emergency situation when necessary to properly treat the individual;

(d) specification of the written notice to be provided by the covered entity to any individual, or such individual's personal representative that explains how and what protected health information will be shared with the approved health information organization. Such written notice, which may be incorporated into the covered entity's notice of privacy practices required under the HIPAA privacy rule, shall include the following that:

(1) The individual's protected health information will be disclosed to the approved health information organization to facilitate the provision of health care to the individual;

(2) the approved health information organization maintains appropriate safeguards to protect the privacy and security of protected health information;

(3) only authorized individuals may access protected health information from the approved health information organization;

(4) the individual, or such individual's personal representative, has the right to request in writing that the individual's protected health information not be disclosed by the health information organization;

(5) the health information organization is required to honor a written request not to disclose an individual's protected health information, except that disclosure is permitted (A) in an emergency situation when necessary to properly treat the individual, or (B) when necessary to satisfy a covered entity's legal obligation to report certain information to a government official; and

(6) the inability to access restricted information by a covered entity may result in a health care provider not having access to information necessary to provide appropriate care for the individual;

(e) specification of documentation requirements to demonstrate delivery of such notice to an individual, or such individual's personal representative, by or on behalf of the covered entity.
65-6833. Same; health information organizations; eligibility for financial support from the state. Any health information organization which is not an approved health information organization shall not be eligible for any financial support from the state, or assistance or support from the state in securing any other source of funding.


65-6834. Same; use and disclosure of protected health information; immunity from liability. (a) No use or disclosure of protected health information maintained by or on an approved health information organization shall be made except pursuant to rules and regulations adopted by the department consistent with this act. An approved health information organization that uses or discloses protected health information in compliance with such rules shall be immune from any civil or criminal liability or any adverse administrative action arising out of or relating to such use or disclosure.

(b) Protected health information in the possession of an approved health information organization shall not be subject to discovery, subpoena or other means of legal compulsion for the release of such protected health information to any person or entity. An approved health information organization shall not be compelled by a request for production, subpoena, court order or otherwise, to disclose protected health information relating to an individual.


65-6835. Same; advisory council on health information technology established; membership; compensation. (a) There is hereby established an advisory council on health information technology. The advisory council on health information technology shall be advisory to the secretary of health and environment and shall be within the division of health of the department of health and environment.

(b) The advisory council on health information technology shall be composed of 23 voting members, as follows:

(1) The secretary of the Kansas department of health and environment, or such secretary's designee;

(2) the governor of the state of Kansas, or such governor's designee;

(3) four legislators selected as follows: The chairperson and ranking minority member or their designees of the committee on health and human services of the house of representatives, and the chairperson and ranking minority member or their designees from the committee on public health and welfare of the senate;

(4) two members appointed by the secretary who represent consumers;

(5) one member appointed by the secretary who represents employers;

(6) one member appointed by the secretary who represents payers;
(7) one member appointed by the secretary who represents local health departments from a list of three names submitted by the Kansas association of local health departments;

(8) three members appointed by the secretary who represent hospitals, from a list of three names for each position submitted by the Kansas hospital association. One of the hospital representatives appointed herein shall be involved in the administration of a critical access hospital;

(9) three members appointed by the secretary from a list of three names for each position by the Kansas medical society. At least two of the members appointed herein shall be practicing physicians, and one of the physicians shall be a physician in a primary care specialty;

(10) two members appointed by the secretary who represent pharmacists, from a list of three names submitted by the Kansas pharmacists association. At least one of the members appointed herein shall be a practicing pharmacist;

(11) one member appointed by the secretary who represents the university of Kansas center for health information from a list of three names submitted by the university of Kansas center for health information;

(12) one member appointed by the secretary who represents the Kansas foundation for medical care from a list of three names submitted by the Kansas foundation for medical care;

(13) one member appointed by the secretary who represents the Kansas optometric association from a list of three names submitted by the Kansas optometric association; and

(14) one member appointed by the secretary who represents the association of community mental health centers of Kansas from a list of three names submitted by the association of community mental health centers of Kansas.

(c) At the first meeting of the council, following the effective date of this act, terms of its members, except the secretary and governor or their designees, shall be determined by lot with five members serving for one year, five members serving for two years, five members serving for three years, and six members serving for four years. Following their initial term, members of the council shall be eligible for re-appointment and, if re-appointed, shall serve for terms of four years. Members shall only be eligible to serve two consecutive four-year terms. Whenever a vacancy occurs regarding a member of the council due to the resignation, death, removal or expiration of a term, a new member shall be appointed prior to the next meeting, according to the process and to the specific position on the council as provided in subsection (b). In the event of a vacancy during an unexpired term due to resignation, death or removal of a council member, the appointment shall be for the remainder of the unexpired portion of the term. Each member of the council shall hold office for the term of appointment and until a successor has been appointed. Any member of the council may be removed by the secretary for malfeasance or misfeasance in office, regularly failing to attend meetings, or for any cause which renders the member incapable of the discharge of the duties of a member.
(d) The council shall meet at least four times per year and at such times as the council deems appropriate or as called by the secretary.

(e) Members of the council are entitled to compensation and expenses as provided in K.S.A. 75-3223, and amendments thereto. Members of the council attending council meetings or subcommittee meetings authorized by the council shall be paid mileage and all other applicable expenses, provided such expenses are consistent with policies established from time-to-time by the council.

History: L. 2013, ch. 112, § 20; July 1.
Article 67.—HEALTH CARE DATABASE

28-67-1. Definitions. For purposes of the regulations in this article, the following words, terms and phrases are hereby defined as follows:

(a) "Aggregate data" means data which is obtained by combining like data in a manner which precludes specific identification of an individual.
(b) "Board" means the health care data governing board.
(c) "CHES" means the center for health and environmental statistics.
(d) "Compilation" means the arrangement of data collected by and furnished to the secretary acting under agreement with the secretary for release and dissemination to the public.
(e) "Fee fund" means the health care database fee fund created by K.S.A. 65-6804 and amendments thereto.
(f) "Health care data" means any data relating to health care, health status, including environmental factors, the health care system, costs and outcomes.
(g) "Health care information" means any health data that has been transformed from its raw form into a more general, less-technical form.
(h) "Health care provider" means any person, organization or entity that renders health care services as described in K.S.A. 65-6805 and amendments thereto.
(i) "Individual" means a single human being.
(j) "Patient or client" means an individual who receives any health care service.
(k) "Person" means any individual, association, partnership, corporation or other entity.
(l) "Primary data collection" means data that were previously unavailable for distribution to the public and are initially collected pursuant to this act.
(m) "Public domain data" means data that were previously collected and available to the public by another source.
(n) "Public health data" means data including epidemiological, health status and community health assessment data.
(o) "Public use data" means data that are available to the general public. This includes data available in electronic or any other form.
(p) "Record identifier" means a unique code generated and assigned to an individual record and used to identify that individual record among databases.

(q) "Secretary" means the secretary of the Kansas department of health and environment.

(r) "State agency" means any regents institution or department under the direction of a cabinet secretary, an elected official or regulatory board.

(s) "Third party payer" means any public or private payer of health care services and includes accident and sickness insurers, health maintenance organizations, health plans and alliances, nonprofit medical and hospital service organizations, and fiscal intermediaries for government-funded programs. (Authorized by and implementing K.S.A. 65-6804, as amended by L. 1994, Ch. 90, sec. 3; effective Dec. 19, 1994.)

**28-67-2. Health care database; information collected.** Information regarding various health factors shall be obtained. The health factors shall include, but not be limited to:

(a) mortality and natality, including accidental causes of death;

(b) morbidity;

(c) health behavior;

(d) disability;

(e) health care costs and financing;

(f) health care human resources;

(g) health service utilization and availability;

(h) environmental contaminants;

(i) demographics;

(j) familial, social, and economic conditions affecting health status; and

(k) population-based health care outcomes. (Authorized by and implementing K.S.A. 65-6801, as amended by L. 1994, Ch. 90, sec. 2; effective Dec. 19, 1994.)

**28-67-3. Health care data collection and submission.** (a) Data shall be:

(1) collected and submitted under uniform parameters established by the secretary and approved by the board;

(2) obtained from existing data sources in the public and private sector, where available to minimize the imposition and cost of new reporting requirements;

(3) submitted by licensing boards and agencies, credentialing and registering agencies and health care providers on a schedule defined by the secretary and approved by the board;

(4) submitted by third party payers, on a calendar year basis, annually by July 1 of the following calendar year and shall:

(A) be derived from standard billing or data collection documents or their replacements; and

(B) include only information for services rendered in the calendar year; and adjustments made for 180 days after the close of the calendar year; and

(5) submitted in a manner that does not identify individuals except through the use of a record identifier established by the secretary and approved by the board; except for public domain data, where data may be submitted that includes identification of individuals.

(b) Special data collections.

(1) Special primary data collection and extrapolations may be used as an alternative to or to supplement collection of existing health data from health care providers. The use of primary data collection shall be approved by the board to the extent it can be shown that the information being requested is consistent with the act and will meet validity and quality standards established by the secretary and approved by the board.

(2) Data may also be collected by the secretary from third party payers and health care providers for the purposes of population-based health outcomes comparisons.

(c) The secretary may be delegated by the board the authority to carry out any of the responsibilities granted to the board under these regulations. (Authorized by and implementing K.S.A. 65-6805, as amended by L. 1994, Ch. 90, sec. 4; effective Dec. 19, 1994.)

**28-67-4. Health care data release and re-release.** (a) Data and information received by the secretary and maintained in the health care database shall be used for:

(1) health policy decisions;

(2) health research;

(3) consumer information; and

(4) epidemiological and other public health functions necessary to protect and promote the health of the state.

(b) Public use data.

(1) Public use data shall be developed and compilation of data shall be made available for general distribution which shall not include:

(A) record identifiers;

(B) social security numbers;
(C) patient or client health insurance identification numbers; or

(D) health care provider identifiers.

(2) The board shall review and approve the content and format of these public use data and compilation formats.

(3) The data and compilation shall be made public information and may be released on magnetic media or any other form.

(c) Special studies and analyses.

(1) Special studies and analyses may also be conducted by the secretary to:

(A) assist in health policy decision-making;

(B) fulfill statutory mandates for health policy or public health purposes; or

(C) minimize the duplicate collection of similar data elements.

(2) Prior to the release of any special studies or analyses conducted by the secretary, the board shall review all products generated and approve those not mandated by statute.

(d) Persons or state agencies making requests for data or information from the database other than those from standard reports shall be required to respond to a set of questions developed by the secretary and approved by the board that defines the information needed, description of the project and the intentions for rererelease of the information. Any request which includes record identifiers, social security numbers, patient or client health insurance identification numbers or health care provider identifiers shall be specifically approved by the board. If the request indicates an appropriate use of the data according to the specifications in K.A.R. 28-67-4(a), the data shall be provided to the person making the request. The request shall be denied by the secretary if the request is not consistent with those specifications in K.A.R. 28-67-4(a). A written explanation for the denial shall be filed with the person making the request.

(e) Subject to K.S.A. 65-6804(d), when compilation and special studies are generated by the secretary which identify health care providers, the health care providers shall be provided a copy of the data referencing them and given the opportunity to submit written comments to the secretary. When comments are received by the secretary within 30 days of the postmark on the notification from the secretary, such comments received shall be released with the data.

(f) Data other than those provided in compilation, public domain and public use data, that includes record or health care provider identifiers may be released to persons or state agencies for research purposes. Any request for these data shall comply with K.A.R. 28-67-4(d) and be approved by the board. These data with record or health care provider identifiers shall not be rereleased by the person or state agency in any form with these identifiers that does not comply with K.A.R. 28-67-6 and approval of the board.

(g) Any person or state agency may apply to the secretary for data to be used in a research study. A research protocol shall be submitted which shall include, but not be limited to:

(1) a description of the proposed study;

(2) the purpose of the study;

(3) a description of the data elements needed for the study;

(4) a description of the information medium or format requested;

(5) where applicable, a statement indicating whether the study protocol has been reviewed and approved by a human subjects review board;

(6) a description of data security procedures, including who shall have access to the data; and

(7) a description of the proposed use and release of the data.


(i) Prior to the release of a subset of data or compilation, a statement instructing the user or reader about the meaning and significance of the data and the restrictions about redisclosure of the information shall be included.

(j) A data provider may obtain data it has submitted to the database as well as aggregate data. A data provider shall not obtain data submitted by another data provider without approval from that provider. Agreement to grant access to data submitted by another provider shall be filed in writing with the secretary.

(k) Unauthorized use of health care data obtained or collected under K.S.A. 65-6805 and amendments thereto by any person or state agency shall result in termination of system access and no further provision of data.

(l) The board may delegate the secretary the authority to carry out any of the responsibilities granted to the board under these regulations. (Authorized by and implementing K.S.A. 65-6804, as amended by L. 1994, Ch. 90, sec. 3; effective Dec. 19, 1994.)
28-67-5. Electronic access to public use data. (a) Persons or state agencies may be granted electronic access to public use data. Definitions of allowable access for data submitted to the database shall be established by the secretary and approved by the board.

(b) All persons or state agencies requesting electronic access to public use data shall complete an application established by the secretary and approved by the board that describes the security procedures to be used to safeguard the data provided according to K.A.R. 28-67-6 and K.A.R. 28-67-8. (Authorized by and implementing K.S.A. 65-6504, as amended by L. 1994, Ch. 90, sec. 3; effective Dec. 19, 1994.)

28-67-6. Confidentiality of the health care database. (a) Data or information that in any manner identifies an individual shall not be released. Researchers demonstrating the need for data containing record identifiers or names of health care providers shall be subject to the release, confidentiality and security requirements pursuant to K.A.R. 28-67-4, K.A.R. 28-67-6, and K.A.R. 28-67-8 and approval of the board.

(b) Any information generated from manipulations of data provided by the database shall be subject to release, confidentiality and security requirements pursuant to K.A.R. 28-67-4, K.A.R. 28-67-6 and K.A.R. 28-67-8.

(c) The individual forms, computer tapes or other forms of data collected by and furnished to the database shall not be available to the public. Special reports prepared for any data requester shall not be made public if the report identifies an individual.

(d) Public domain data obtained for the health care database may be made public through compilation and as public use data in a manner that identifies health care providers.

(e) Primary data collected which identify individuals shall be kept confidential and shall not be made public. Individual data associated with patient numbers, social security numbers and patient or client health care coverage identification numbers, or any other data that can identify individuals shall be kept confidential and shall not be made public. Any release of primary data shall be subject to K.A.R. 28-67-4.

(f) Primary data collected that identifies health care providers shall be kept confidential and shall not be made public except that public health data which identifies health care providers may be released. Release of these data shall be subject to K.A.R. 28-67-4.

(g) In this subsection, “small number” means any number that is not large enough to ensure that the identity of individuals and health care providers is protected. Any data element category which contains small numbers shall be aggregated using procedures established by the secretary. The procedures shall follow commonly accepted statistical methodology. (Authorized by and implementing K.S.A. 65-6504, as amended by L. 1994, Ch. 90, sec. 3; effective Dec. 19, 1994.)

28-67-7. Fees established. (a) Routine compilations produced by the secretary shall be made available to state agencies, health care providers, purchasers, employers, consumers and other interested parties. A fee sufficient to recover the costs of production or duplication may be charged.

(b) Requests for non-routine compilation requiring special analyses shall be billed under contract between the requester and the secretary to include the hourly rate of the analyst or analysts plus all computer, printing and other costs. State agencies asking for data solely for the purposes of analysis may be exempt.

(c) Compilation or data made available on computer tape or other electronic media shall include the cost of the magnetic tape, diskette, or other electronic media.

(d) Providers of data, board members and interested parties shall receive one free copy of the secretary’s routine annual and quarterly compilation.

(e) Persons and state agencies requesting electronic access to public use data may be charged a monthly fee for that access.

(f) Providers contributing data to the system may be charged reduced rates for special reports not to exceed seventy-five percent of the fees charged to the public.

(g) The secretary, on behalf of the health care database and as chairperson of the board, shall reserve the right to request a portion of revenues generated from use of data provided to any person that is above the cost of production of products.

(h) All fees collected pursuant to K.A.R. 28-67-7 shall be deposited in the health care database fee fund. (Authorized by and implementing K.S.A. 65-6504, as amended by L. 1994, Ch. 90, sec. 3; effective Dec. 19, 1994.)

28-67-8. Record security. (a) All staff en-
engaged in the collection, handling, and dissemination of health care data shall be informed of the responsibility to protect the data and the consequences of failure to do so. When employees are hired, each employee shall be instructed on the current procedures used to assure the security and confidentiality of the data. A copy of the confidentiality policy shall be provided to all personnel and a statement of responsibility for data confidentiality shall be explained as a condition of employment.

(b) Employees shall be held accountable for the appropriate use of individual data and for safeguarding the information in their possession. Confidential data may be used only for purposes reviewed and approved by the secretary. Any unauthorized use of health care data from the database shall be strictly prohibited and may subject an employee to termination.

(c) Access to the database shall be restricted to those who specifically require access in order to perform their assigned duties. Access policies and staff members needing to access the database shall be established by the secretary.

(d) Supervisors shall be responsible for maintaining the security for data in the area of their responsibility. Persons or state agencies engaged in the collection, handling, and dissemination of health care data shall develop procedures to govern the release of information. (Authorized by and implementing K.S.A. 65-6804, as amended by L. 1994, Ch. 90, sec. 3; effective Dec. 19, 1994.)

28-67-9. System security. (a) All health care data shall be maintained on computer systems administered by CHES. A password system shall be used to limit access to computer files. Passwords shall be changed on a schedule determined by CHES staff, and an individual account shall be deleted whenever a staff member terminates employment or is no longer authorized access to the system.

(b) Only CHES staff shall be authorized to load data tapes and install software and file servers. All software shall be checked for computer viruses before being installed.

(c) General access to the central computer area shall be limited to normal work hours only. Access shall be restricted to CHES staff at all other times unless an individual obtains authorization to access the computer area.

(d) Network tape backups shall be stored on-site in a secure fire-retardant location. Additional copies of software, documentation, and backups shall be stored at a secure, off-site location.

(e) Non-Kansas department of health and environment staff shall set up a CHES user account in order to access the health care information system. Passwords shall only be issued to non-Kansas department of health and environment users if they are under contract to Kansas department of health and environment or under the terms of a data sharing agreement. Unauthorized use of health care data by any other person or governmental subdivision granted access to the database shall result in termination of system access and no further provision of data.

(f) Network backups shall be done weekly and at the end of each month. Two copies of the monthly backup tape shall be produced. All network files shall be checked for computer viruses before backup. (Authorized by and implementing K.S.A. 65-6804, as amended by L. 1994, Ch. 90, sec. 3; effective Dec. 19, 1994.)

28-67-10. Eligible contractors. (a) A contractor may be designated to provide data processing services for the collection of health care information. The contractor may be a public or private organization. Eligible contractors shall provide to the secretary assurances that there are no conflicts of interest.

(b) Persons who shall not be contractors include, but shall not be limited to:

(1) a major purchaser, payer or provider of health care services in Kansas;

(2) a subcontractor of an organization in K.A.R. 28-67-10 (b)(1), except those commissioned to perform only data processing functions;

(3) a subsidiary or affiliate of an organization in K.A.R. 28-67-10 (b)(1) in which a controlling interest is held and may be exercised by that organization either independently or in concert with any other organization in K.A.R. 28-67-10 (b)(1), or

(4) an association of major purchasers, payers or providers of health care services.

(c) State agencies are exempt from the requirement under subsection (b) of this regulation regarding eligibility to contract and may offer a bid if the secretary decides to bid the contract for services.

(d) The contractor may be granted the authority to examine confidential materials and perform other functions authorized by the secretary and approved by the board. The contractor shall com-
ploy with all confidentiality and record security requirements pursuant to K.A.R. 28-67-6 and K.A.R. 28-67-8. The release of confidential information by the contractor shall constitute grounds for the secretary to terminate any agreement between the contractor and the secretary. (Authorized by and implementing K.S.A. 65-6804, as amended by L. 1994, Ch. 90, sec. 3; effective Dec. 19, 1994.)

28-6-7-11. Cooperative agreements. (a) Where the need for cooperative agreements and memoranda of understanding facilitate the cost-effectiveness of health care data collection, cooperative agreements and memoranda of understanding may be established by the secretary with organizations described in K.A.R. 28-67-10 (b).

(b) Organizations entering cooperative agreements and establishing memoranda of understanding shall provide the secretary assurances that the data will be collected and utilized for their intended purpose only.

(c) Organizations entering cooperative agreements and establishing memoranda of understanding shall be subject to the confidentiality and record security requirements in K.A.R. 28-67-6 and K.A.R. 28-67-8. (Authorized by and implementing K.S.A. 65-6804, as amended by L. 1994, Ch. 90, sec. 3; effective Dec. 19, 1994.)

28-6-7-12. Data validation. (a) All data submitted to the health care database shall be evaluated for accuracy and standardization.

(b) Any inconsistencies and non-standard reporting of data submitted to the database shall be documented and reported to the providers of the data. Data providers shall be given 30 days to reconcile the inaccuracies or inconsistencies identified by the secretary.

(c) Comments provided to the secretary pursuant to K.A.R. 28-67-4 (e) may be used to reconcile any inaccuracies or inconsistencies identified by the data provider. (Authorized by and implementing K.S.A. 65-6804, as amended by L. 1994, Ch. 90, sec. 3; effective Dec. 19, 1994.)