



## Bureau of Public Health Informatics Research Data Request Application Form

Call BPHI at (785) 296-8627 if you have questions on how to complete this form.



Kansas Department of Health and Environment  
Division of Health  
Bureau of Public Health Informatics  
Office of Health Assessment  
Kansas.Health.Statistics@kdheks.gov  
RD-1  
Rev 5-2009

Our Vision – Healthy Kansans Living in Safe and Sustainable Environments

As the state's environmental protection and public health agency, KDHE promotes responsible choices to protect the health and environment for all Kansans. Through education, direct services, and the assessment of data and trends, coupled with policy development and enforcement, KDHE will improve health and quality of life. We prevent illness, injuries and foster a safe and sustainable environment for the people of Kansas.

# Data Request Instructions

1. New applications – All new applications may be reviewed by a number of staff within BPHI and the Kansas Department of Health and Environment (KDHE). This review may include evaluation of the request by the KDHE Institutional Review Board. Please take into account evaluation time in planning your request.
2. Kansas Statutes Annotated 65-2422d(d) governs the use of vital statistics data for research purposes. The law states “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.” Identifying use is considered the ability to directly identify an individual based on the data or to indirectly identify an individual by linking data with some other data or information regardless of sources.
3. Kansas Administrative Regulation 28-17-21 states in pertinent part, “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.” Requests involving extraction and preparation of record level data or special analyses are subject to data access and analyst/programming fees. Please ask for an estimate of those costs.
4. This form must be used for all data requests involving record level data. The form is optional for requests for copies of standard, publicly-available reports and tables. If an aggregate level request requires a special analysis to prepare the results, completing this form helps the analyst to know how to prepare the data.
5. The Kansas Open Records Act addresses the release of printed reports and data tables. These materials will be provided as long as the release of the tabular data does not violate the KSA 65-2422d(d) prohibition against identifying use of the records. In such instances the counts or numbers may be suppressed in order to prevent identifying use of the records. The Kansas Open Records Act does not require a record to be created if none exists.
6. Use of BPHI datasets is restricted to statistical purposes for medical and public health research. BPHI data may not be used as a basis for legal, administrative, or other actions which may directly affect particular individuals or establishments as a result of their records being included in a given study or project.
7. A separate BPHI application form must be submitted for each study or project, even if you plan to use data you previously obtained from BPHI.
8. Please use this Word version of the form. Take as much space in the fields as needed. The application form will expand to fit the information. You may e-mail a copy for review but the final application will require a signature.
9. This application is not considered complete until it has the required signatures pertaining to data confidentiality and security.
10. Followback is considered the practice of using a vital event record exclusively to contact an individual. For purposes of vital records, individuals are considered any person or institution named in the record.
11. Data requests involving an organization with a list of individuals to be linked to vital records for evaluation of public health outcomes is not considered followback. Any linking of this external information to BPHI information must be performed by BPHI. Please contact BPHI for additional information.
12. A partial list of datasets available for analysis are: births, deaths, stillbirths, marriage, marriage dissolution, abortion, health professional FTEs, Medicaid, health insurance, hospital discharge. Requirements on each of these datasets vary thus limiting what BPHI can provide. If you need detailed information, please ask for a data dictionary. BPHI does not analyze other agency public health datasets but can direct you to the responsible KDHE program.
13. Depending on the nature of your request, you may also be required to agree to: a memorandum of understanding, or additional restrictions on data use. Your request may also result in the attachment of State of Kansas forms, including but not limited to DA-146a. If such documents are needed they will be supplied in advance of your request being approved.



Kansas Department of Health and Environment  
 Division of Health  
 Bureau of Public Health Informatics  
 Office of Health Assessment  
 Curtis State Office Building 1000 SW Jackson, Suite 130  
 Topeka, Kansas 66612-1354  
 Phone (785) 296-8627 — Fax (785) 368-7118

<b>BPHI RD-1          Data Request Form          Rev. 7/2009</b>
Number

1. Individual and Organization Requesting BPHI 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 BPHI ) 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.

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 BPHI 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 approval and provide the following:

Name of the IRB:

IRB's Multiple Project Assurance (MPA) or Federalwide Assurance (FWA) number:

Date of the IRB's approval:

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

9. 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

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

Describe Delivery Method

Describe Data Format

11. 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.

12. 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.

The undersigned hereby agrees to the following terms and conditions associated with this Bureau of Public Health Informatics application and to the use of the information obtained from the center. They prohibit the knowing disclosure of any information that could be used directly or indirectly to identify individuals.

- A. Except for persons or organizations specified in the approved BPHI application form, no data will be published or released in any form to any party if a particular individual or establishment is identifiable. The data will not be used in an identifying manner including but not limited to followback of individuals or providers, record matching or linking to other data, creation or distribution of mailing lists or offering for sale of any product or service to any individual or any address.
- B. The data will be used **ONLY** for statistical purposes in medical and health research. The information will not be used as a basis for legal, administrative, or other actions.
- C. The data will be used only for the study or project proposed and the purpose described in the approved BPHI application form. Use of the information for a research project other than the one described in the application form will not be undertaken until after a separate BPHI application form for that project has been submitted to, *and approved by*, the Bureau of Public Health Informatics.
- D. In accepting access to data, either as record-level or summary form, I agree to the following:
  - 1. I will not permit individuals not identified in this agreement to use the data. I will not release record-level data to other parties. I will refer requests from legal authorities to BPHI.
  - 2. I will acknowledge, in all reports based on these data the original source of the data was the "Bureau of Public Health Informatics, Kansas Department of Health and Environment."
  - 3. I will not imply or state, either in written or oral form, that interpretations based on the data are those of KDHE or BPHI, unless the data user and BPHI are formally collaborating on the proposed analyses.
  - 4. I will send notification of any reports, presentations, slides, interviews, and publications to BPHI.
  - 5. I will release only aggregate findings, review all printed or electronic output, and delete or blackout any direct or indirect identifiers and any small cell counts (<6).
  - 6. I will destroy any data once my access rights or project have terminated, pursuant to applicable state laws.
  - 7. If I download data from the secure portal, I will comply with the following mechanisms for preservation of confidentiality:
    - i. I will password protect the data file(s) I downloaded.
    - ii. I will not produce copies of record-level data, other than that necessary to accomplish the project.
    - iii. I will treat all data at my desk confidentially and not give unauthorized persons access to the data.
    - iv. I will keep all hard copies of data runs containing small cells locked in my desk when not in use, shredding them when they are no longer useful to my analysis.
  - 8. I will not attempt to learn the identity of any person included in the data and will not deliberately combine this data with other data for the purpose of matching records to identify individuals. If I should inadvertently discover the identity of any person, I will make no disclosure or other use of that information and will report the discovery to BPHI.
- E. I have reviewed this BPHI application. I understand the disclosure of individual identifying information may subject me to a \$100 fine and denial of all future data requests. I agree to accept any cell suppression and/or data coarsening necessary to reduce the risk of identifying individuals. I understand that receipt of these data is also subject to any attachments: forms, restrictions, or memorandum of understanding.
- F. All the statements made in this application and in any confidentiality assurances related to this application are true, complete, and correct to the best of my knowledge and belief.

**Signature** of the requester, principal investigator, project director, project officer, or other responsible official

*Signature* *Date*

Name (Please type or print)

Title

Organization

**Signature** of "official authorized to execute agreements"

*Signature* *Date*

Name (Please type or print)

Title

Organization

**BPHI Staff Use Only**

Number		Fee Amount	
Date Received			
By		Notes:	
Date Approved			
By			
Assigned to			
Date Due			
Date Finished			
By			
Date Logged			
Attachments Required:			