



**USER'S GUIDE
FOR
ACCESS TO PROTECTED DATA
FOR
GOVERNMENT AGENCIES**

BUREAU OF HEALTH STATISTICS & REGISTRIES
PA DEPARTMENT OF HEALTH
555 WALNUT ST - 6TH FL
HARRISBURG, PA 17101-1914
(717) 783-2548

November 2017
(revised)

INTRODUCTION

The Bureau of Health Statistics & Registries oversees the release of protected data as established by two legislative mandates.

1. Release of individual vital statistics information is governed in Pennsylvania by the **Vital Statistics Act of 1953**. This Act does permit access to individual certificates for the purpose of medical research; however, the Act states that any release of information is permitted only under the approval and strict supervision of the Department of Health. Also, government agencies may be permitted access to identifiable data in pursuance of their official duties.
2. Release of individual case specific cancer data is governed in Pennsylvania by Act 67 which amended Act 224, the **Cancer Control, Prevention, and Research Act of 1980**. This Act permits the Department of Health to allow access to individual case data only for the purpose of specific research, and only under the approval and strict supervision of the Department of Health.

In order to assist in the processing of requests for protected data, the Department of Health makes use of an application form to be completed by requestors. This application form is designed to serve three purposes:

1. To provide the Department of Health with sufficient information to determine whether the proposed use of the information conforms to the Department's approval criteria.
2. To obtain assurances from the user that the confidentiality of the information obtained will be protected and that the data provided by the Department will be used only for the proposed study.
3. To provide the Department with an indication of whether the user will be able to submit data on persons in the proposed study in a manner which meets the Department's technical requirements for location of records.

Requests for Behavioral Risk Factor Surveillance System (BRFSS) data should be directed to Jeff Ernst at 717-547-3631, or ra-dhicontactus@pa.gov. All other requests should be directed to (717) 783-2548, or RA-DHPROTECTEDDATA@pa.gov so an application form can be obtained.

DEFINITIONS

BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM (BRFSS) refers to a telephone survey based on a probability sample of adult residents of Pennsylvania. The Department of Health prepares standard data products based on the survey, which are located on the Health Statistics web site (www.statistics.health.pa.gov). The Centers for Disease Control and Prevention (CDC) maintains a web site with extensive information about BRFSS and provides access to publicly releasable files of record-level state data, which exclude geographical identifiers (www.cdc.gov/brfss).

CANCER REGISTRY FILES refer to facsimiles containing reported conditions if the diagnosis includes the words cancer, carcinoma, leukemia, lymphoma, malignant, and sarcoma in addition to other malignant conditions on the Pennsylvania Cancer Registry list of reportable conditions. Reportable conditions correspond to the ICD-9-CM codes for malignant neoplasms. Basal and squamous cell carcinomas of the skin are not reportable unless they occur at a mucocpidermoid site. Benign conditions are not required to be reported. Carcinoma in situ of the cervix (CIS) is not reportable.

CERTIFICATIONS are when the requestor provides birth or death data to the Department to check against the official state record on file.

CONFIDENTIALITY is a status accorded to data indicating that it is sensitive and, therefore, needs to be protected and carefully controlled. Confidentiality is a short-hand term referring to how information once collected, will be treated. Confidential treatment means that no one outside the immediate data-collecting organization will have access to identifiable individual responses without thorough prior review and approval by the Pennsylvania Department of Health in accordance with existing legislation.

GOVERNMENT AGENCY includes federal, state, and municipal governments.

IDENTIFIABLE DATA refers to any information which could permit the identification of any individual. This is not only name and address, but also individual case record data where other demographic items such as age, sex, race, and place of residence could possibly be used to identify subjects.

INDIVIDUAL is a natural person, living or dead.

INDIVIDUAL CASE RECORD DATA are data about a single person as opposed to statistical aggregate data; for example, computer line listings are individual case record data. Individual case record data can be identifiable data.

PROTECTED DATA are data that are kept confidential because they are identifiable. The protected data maintained by the Bureau of Health Statistics & Registries includes certificates of births, deaths, and fetal deaths, and reports of cancer.

VERIFICATIONS are when the requestor provides a birth or death certificate to the Department to check against the official state record on file.

PROCESS FOR REQUESTING ACCESS TO PROTECTED DATA

Government agencies interested in obtaining identifiable or individual case record data from the Pennsylvania Department of Health's Bureau of Health Statistics & Registries files should submit a completed Application for Access to Protected Data to:

BUREAU OF HEALTH STATISTICS & REGISTRIES
PA DEPARTMENT OF HEALTH
555 WALNUT ST - 6TH FL
HARRISBURG, PA 17101-1914

PROCESS FOR OBTAINING PROTECTED DATA

After written approval is received from the Bureau of Health Statistics & Registries to access vital records data, requests for specific information should be submitted along with the approved application number to:

Division of Vital Records
Pennsylvania Department of Health
P.O. Box 1528
New Castle, PA 16103

After written approval is received from the Bureau of Health Statistics & Registries to access individual case specific cancer data, requests for specific information should be submitted along with the approved application number to:

Division of Statistical Registries
Bureau of Health Statistics & Registries
Pennsylvania Department of Health
555 Walnut St - 6th Floor
Harrisburg, PA 17101-1914

COMPLETION OF THE APPLICATION FORM

All answers to questions must be typed or printed. "NA" should be entered for those questions which are not applicable. Responses are to be as specific as possible. If additional space is required for some answers, a separate page(s) may be inserted, and each answer should be numbered.

If assistance is required in completing any part of the application form or if additional copies are needed, contact (717) 783-2548, or RA-DHPROTECTEDDATA@pa.gov.

DATA AVAILABILITY

1. Vital Records Documents

The Bureau of Health Statistics & Registries maintains vital records documents from 1906 to the present. Noncertified copies of death records and fetal death records are available for approved studies. Only abstracted information from birth records is available for approved studies.

2. Vital Statistics Computer Files

The Bureau of Health Statistics & Registries maintains vital statistics computer files from 1960 to the present.

3. Cancer Records/Facsimiles

1985 was the first full calendar year all hospitals in Pennsylvania reported cancer cases to the Department of Health.

CHARGES

1. Noncertified Copies (Death and Fetal Death Records), Verifications, Certifications

If actual dates of death are supplied by the requestor, the Division of Vital Records will search the year given as well as one year prior to and one year after the given year. If the date of the last contact or date last known alive is supplied by the requestor, the Division will search that year plus the next two succeeding years. For this reason, it is important that all dates be properly labeled when submitted. This three year search is done free of charge. Additional searching can be provided, upon request, at the current searching fee of \$10.00/hour. Study subjects must be grouped alphabetically within the year of death. Fee structured is outlined below.

	Noncertified copies	Verifications	Certifications
Death Files	\$3.00	No charge	\$9
Birth Files	Not Available	No charge	\$10

2. **Facsimiles of Cancer Records**

Facsimiles of cancer records are computer-generated. Therefore, the costs are the same as those for computer charges which are listed below.

3. **Computer Charges**

The standard charge for data is \$200 for the first year of data and \$100 for each additional year. These amounts will be charged for each separate data file for which data is produced. Exact charges will depend upon specific requirements of the study, and a cost estimate will be provided upon approval of the application.

Output is by encrypted CD, secure website, or computer listing as requested. Charges are the same regardless of the mode of output.

4. **Linking Charges**

Charges for linking to cancer or vital statistics data is \$200 for the first year matched and \$100 for each additional year of match requested. In addition, there is a charge of \$0.001 per record per year of match for vital statistics data and \$0.005 per record submitted for cancer data. All matching **must** be completed in the Bureau of Health Statistics and Registries.

Guidelines for Providing Files to be used for Linkages

Data items needed to produce accurate linkage results:

- Last name
- First name
- Date of birth (mm/dd/yyyy)
- Social Security Number (or at least the last 4 digits)
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Additional data items used when available to resolve questionable matches:

- Address – street
- Address – city
- Address – state
- Address – zip code
- Maiden Name

PAYMENT

For certifications and verifications, payment is required at the time of the request, made payable to Division of Vital Records.

For all other requests, do not send payment in advance. The Bureau of Health Statistics & Registries prefers to invoice upon completion of approved requests for data and text files or requests for noncertified copies for research studies. If it is necessary to make any advance payment, please contact (717) 783-2548 or RA-DHPROTECTEDDATA@pa.gov.

RE-RELEASE OF PENNSYLVANIA PROTECTED DATA

A “Supplemental Assurances Form” must be completed by each organization and/or individual who will obtain identifiable information or individual case record data from Pennsylvania files. This includes consultants, contractors, data processing vendors, subcontractors, and sponsoring or participating agencies or organizations. This form is found on pages 7-10 of the “Application for Access” to Protected Data, and additional copies may be made as required. Individually identifiable data may not be released without prior written approval of the Pennsylvania Department of Health, Bureau of Health Statistics and Registries.

PUBLICATION AND DISCLAIMER

If data extracted from Pennsylvania records are used in any publication, the following statement must be included in such publication or any other release of the data:

These data were supplied by the Bureau of Health Statistics & Registries,
Pennsylvania Department of Health, Harrisburg, Pennsylvania.
The Pennsylvania Department of Health specifically disclaims
responsibility for any analyses, interpretations or conclusions.

A copy of any published materials or study results should be made available to the Pennsylvania Department of Health upon request.