



**GEORGIA DEPARTMENT OF PUBLIC HEALTH
POLICY # CO-12007
DATA REQUEST POLICY**

Approval:		11/5/13
	James Howgate, Chief of Staff	Date

1.0 PURPOSE

This policy contains guidelines for the disclosure and protection of data maintained by the Georgia Department of Public Health to researchers undertaking research for legitimate scientific public health purposes.

This policy shall not apply to data requests from a news organization or other member of the media. All such requests shall be promptly referred to the Director of Communications.

This policy shall not apply to data requests from a governmental entity. All such requests shall be promptly referred to the Privacy Officer in the Office of the General Counsel.

1.1 AUTHORITY – The Georgia Department of Public Health Data Request Policy is published under the authority of DPH and in compliance with the following:

- 1.1.1 Health Insurance Portability and Accountability Act of 1996.
- 1.1.2 45 CFR Subparts 160, 162, and 164
- 1.1.3 O.C.G.A. §§ 31-22-9.1, 21-12-24

2.0 SCOPE

This policy applies to every person employed by DPH.

3.0 DEFINITION OF TERMS AND ACRONYMS

3.1 AIDS Information – Information which discloses that a person has been diagnosed as having AIDS, has been or is being treated for AIDS, has been determined to be infected with HIV, has submitted to an HIV test, has had a positive or negative result from an HIV test, has sought and received counseling regarding AIDS, or has been determined to be a person at risk of being infected with HIV or AIDS, and which permits the identification of that person.

3.2 DPH – Georgia Department of Public Health

3.3 IRB – Institutional Review Board

3.4 PHI - Protected Health Information

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PHI means any information, whether oral, written, electronic, visual, pictorial, physical, or any other form, that relates to an individual's past, present, or future physical or mental health status, condition, treatment, service, products purchased, or provision of care, and which (a) reveals the identity of the individual whose health care is the subject of the information, or (b) where there is a reasonable basis to believe such information could be utilized (either alone or with other information that is, or should reasonably be known to be, available to predictable recipients of such information) to reveal the identity of that individual. For example, if a health record contains sufficient information to identify an individual to whom it relates because it provides information which specifically narrows the class of individuals in an aggregate setting, such record may be considered identifiable in its existing form, and thus PHI.

- 3.5 **Data request** means an inquiry from any person or entity for data or information collected by or housed within the Department that requires compilation or aggregation by DPH staff.
- 3.6 **Disclosure** means the release, transfer, provision of, access to, or divulging in any other manner of information outside DPH.
- 3.7 **Legitimate scientific purpose** means a population-based activity or individual effort conducted pursuant to guidelines accepted by the research community.
- 3.8 **Public Health** means the physical, mental and social well-being of the community.
- 3.9 **Public Health Authority** means an agency or authority of the United States, a state, territory, a political subdivision of a state or territory or an Indian tribe or a person or entity acting under a grant of authority from or contract with such public agency that is responsible for public health matters as part of its official mandate.

4.0 PERMITTED DISCLOSURES AND RESTRICTIONS ON DISCLOSURES

- 4.1 **Permitted Disclosures:** DPH may disclose data for legitimate scientific research purposes relating to public health. DPH shall have the sole discretion to determine what constitutes a legitimate scientific purpose relating to public health.
- 4.2 **Restrictions on Disclosures:** Data maintained by DPH shall not be disclosed for commercial purposes.
- 4.3 **AIDS Information:** AIDS Information shall not be disclosed except in de-identified form, according to the protocol set forth in Paragraph 8.2.2.

5.0 RESPONSIBILITIES

- 5.1 DPH Governance Council is responsible for issuing and updating procedures to implement this policy.

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5.2 Each Division and Office is responsible for ensuring that all data requests are processed in compliance with this policy.

6.0 PROCEDURES

6.1 Submission of Data Requests. All data requests shall be submitted through the Georgia Public Health Information Portal (PHIP).

6.2 Functions of the Data Coordinator. The Data Coordinator is responsible for overseeing the process from receipt of the data request to release of the data to the requestor. Specific responsibilities include:

6.2.1 Reviewing each data request and identifying the information being requested;

6.2.2 Promptly referring all media requests to the Director of Communications;

6.2.3 Coordinating with the Privacy and Open Records Officer to determine whether the request is valid and the information can be released under applicable law;

6.2.4 Coordinating with the DPH IRB to determine if the data request will be used for research that requires IRB review and approval;

6.2.5 Routing request to appropriate program contact person or Data Analyst for completion, and following-up as necessary to ensure accurate and timely completion of the request;

6.2.6 Communicating with the requestor as necessary; and

6.2.7 Maintaining accurate records of the requests in the PHIP database.

6.3 Functions of the Data Analyst. The Data Analyst is responsible for compiling the data requested. Specific responsibilities of the Data Analyst include:

6.3.1 Timely completion of the data request;

6.3.2 Performing quality checks to ensure accuracy of the compiled data set.

6.4 IRB Review. When necessary, research for which data is requested shall be reviewed by the researcher's Institution's IRB and DPH IRB for compliance with all applicable laws and regulations.

6.5 Data Use Agreement. Prior to receiving any data, the requestor must sign a Data Sharing Agreement which is attached to this policy, along with the Terms and Conditions of the Data Sharing Agreement.

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7.0 USE OF DATA PROVIDED BY DPH IN PUBLICATIONS AND PRESENTATION

7.1 Credit and Authorship. DPH shall be referenced as the source of the data in all publications or presentations for which the requested data will be used, or, if appropriate, DPH and the researcher will agree upon the terms of authorship. DPH may request to review any draft publication or presentation and reject any such draft if the findings are inconsistent with the original purpose of the request, or with DPH's mission.

8.0 DATA REQUESTS INVOLVING PHI

8.1 Disclosure of PHI. If the data to be provided constitutes or includes individually identifiable PHI, then only the minimum amount of PHI necessary to accomplish the purposes of the research may be used or disclosed. The DPH Privacy Officer should be notified of any Data Use Agreement that calls for individually identifiable personal health information to be disclosed, along with the names of the individuals whose PHI will be disclosed, and the disclosure must be noted in the individual's designated record set.

8.2 The requirements of one of the following four paragraphs must be satisfied in connection with every Data Use Agreement that calls for the disclosure of PHI:

8.2.1. Institutional Review Board Approval. The Recipient provides documentation that an Institutional Review Board meeting the standards cited in 45 CFR 164.512(i)(1)(i)(A) has approved the waiver of the individuals' authorization for the release of their PHI, or has approved an alternation to such an authorization. This documentation must include the signature of the IRB chair; the name and contact information for the IRB and the date on which the alteration or waiver was approved; a description of the specific PHI needed for the research project; an affirmative statement that the IRB has reviewed and approved the request for waiver or alternation in accordance with the normal or expedited review procedures and other requirements of the Common Rule; and an affirmative statement that the IRB has determined that the waiver or alteration of the individuals' authorization satisfies the following criteria:

8.2.1.1. The use of the PHI involves no more than a minimal risk to the privacy of the individuals, based on an adequate plan to protect against the improper use and disclosure of identifiers, an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research (unless there is a health, legal, or research justification for retaining the identifiers), and adequate written assurances that the PHI will not be reused or disclosed except for lawful purposes;

8.2.1.2. The research could not practicably be conducted without the waiver or alteration; and

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8.2.1.3. The research could not practicably be conducted without the access to and use of the PHI.

8.2.2. **De-Identification of Data.** The Data is de-identified before disclosure to the Recipient using one of the following two methods:

8.2.2.1. A DPH employee with appropriate knowledge of and experience with generally accepted statistical and scientific principles and methods for de-identifying data applies such principles and methods to the Data, and documents that such application results in a very small risk that the de-identified data could be used, alone or in combination with other reasonably available information, to identify an individual whose de-identified PHI will be disclosed to the Recipient; or

8.2.2.2. The Data is scrubbed of the following identifiers of the individual or the individual's relatives, household members, and employers: name, addresses (except for the State and the first three digits of the zip code, if the current total population of all zip codes with those three digits is more than 20,000), month and day of all dates directly related to an individual, all ages over 89 and all elements of dates indicative of such ages, telephone and facsimile numbers, email addresses, biometric identifiers (including finger and voice prints), unique identifying numbers or codes, full face photographic images, and numbers relating to Social Security, medical records, health plans, accounts, certificates, licenses, motor vehicles and license plates, drivers licenses, device and serial numbers, Internet Protocol (IP), and Universal Resource Locators (URLs); and there is no actual knowledge that the information can be used alone or in combination with other information to identify the individual.

8.2.3. **Limited Data Sets.** The Data is provided to the Recipient in the form of a limited data set, from which the following identifiers of the individual or individual's relatives, household members, employers have been scrubbed: name, postal address information (other than town or city, State, and zip code), telephone and facsimile numbers, email addresses, biometric identifiers (including finger and voice prints), unique identifying numbers or codes, full face photographic images, and numbers relating to Social Security, medical records, health plans, accounts, certificates, licenses, motor vehicles and license plates, drivers licenses, device and serial numbers, Internet Protocol (IP), and Universal Resource Locators (URLs).

8.2.4. **Research on Deceased Individuals.** The Data pertains only to deceased individuals, and the Recipient affirms in writing that access to the Data is sought solely for the purpose of conducting research on the PHI of

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deceased individuals and that the PHI is necessary for its research purposes. If DPH does not already have information positively identifying the PHI as belonging to deceased individuals, then the Recipient must provide documentation of the death of the individuals whose PHI is sought.

9.0 PROCESSING FEES:

9.1 All data requests are subject to a processing fee, representing a reasonable estimate of the Department's cost to prepare and transmit the Data. The fee is non-refundable regardless of the outcome of the search and must be paid before the request is filled. The fee schedule is as follows:

9.1.1 Individual data requests: \$200 base fee + \$25 per variable used, per data year

9.1.2 Ongoing data requests / Subscriptions: \$200 base fee + \$25 per variable used for the initial request and \$200 for each renewal of the same data request

9.2 Exemptions from processing fees may be granted for the following:

9.2.1 Requests from academic faculty, unless the data will be used for a project funded from sources external to DPH

9.2.2 Requests from undergraduate or graduate students, unless the data will be used for a project funded from sources external to DPH

9.2.3 Requests from DPH employees, unless the data will be used for a project funded from sources external to DPH

9.2.4 Internal data exchanges between DPH programs/divisions

10.0 REVISION HISTORY

REVISION #	REVISION DATE	REVISION COMMENTS
0		Initial Issue
1		

11.0 RELATED FORMS

CO-12007A - Terms and Conditions for Data Sharing Agreements

CO-12007B - Data Sharing Agreement