

**ARKANSAS HIV/AIDS
DATA RELEASE POLICY**

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PURPOSE

This policy describes guidelines for the release or publication of data associated with HIV/AIDS surveillance. As appropriate, this policy aligns with standards and requirements set forth by the Centers for Disease Control and Prevention's (CDC) Technical Guidance for HIV/AIDS Surveillance Sections (Atlanta, GA; 2006).

AUTHORITY

All information obtained and compiled by the Arkansas Department of Health (ADH) related to a disease report is confidential and may be used or released only as permitted by the rules for the reporting of notifiable conditions. Additionally, ADH is legally bound by federal assurances of confidentiality which prohibit disclosure of any information that could be used to directly or indirectly identify patients.

POLICY

The policy of ADH is to ensure that HIV/AIDS data are released and/or published while maintaining confidentiality. The policy is also to ensure that individual record-level data containing personal identifiers are only released with proper legal authority. Staff in the ADH HIV/AIDS Registry Section (Section) must assess the potential impact of proposed data releases on confidentiality as well as take steps to prevent the identification of individuals.

RESPONSIBILITIES

The Overall Responsible Party (ORP) is responsible for implementing and enforcing this data release policy. The Section Chief is responsible for ensuring the proper release of data by Section staff. In responding to data requests, Section staff must adhere to the *Arkansas HIV/AIDS Security and Confidentiality Policy* for protecting individual privacy.

DATA RELEASE GUIDELINES

Aggregate Data

Aggregated HIV/AIDS surveillance data may be released if the underlying population (denominator, or the set of which the numerator is an immediate subset) consists of twenty or more individuals. Case data (numerator) will be released depending upon the levels of stratification being requested. Generally, if there are two or fewer data categories, case data will be released. If more than two levels of stratification are requested (i.e., county and sex and age), case data will be released only if there are at least four cases; cells will otherwise be suppressed. Cells that equal zero may be stated as such. Additional cells for totals, rates, and/or percentages may need to be suppressed to prevent the derivation of suppressed data.

Alternatively, data can be released at detailed levels if pooled to span a longer time period (i.e., three or five year periods).

All requests for data that does not meet these requirements must be reviewed and approved for release by the Section Chief. When data for the underlying population are not available, the Section Chief should be consulted.

De-identified Individual Record-Level Data

The Section rarely releases de-identified individual record-level data. These data are only released for research or public health purposes, and will only be released with a data sharing agreement in place and upon approval from the Section Chief and ORP.

In addition to approval by the Section Chief and ORP, data requests for research purposes are also subject to review and approval by an ADH Institutional Review Board (IRB). The University of Arkansas for Medical Science IRB currently serve as and IRB entity for ADH. Prior to release of datasets, all personal identifiers must be removed. Datasets that contain potentially identifying information must be maintained by the client in a manner consistent with the Section's confidentiality and security guidelines for physical and electronic security.

Confidential HIV/AIDS surveillance data are also routinely matched with data in other disease registries (i.e., tuberculosis) or data systems to improve data quality as a part of routine disease surveillance. All matching activities should be accomplished by Section staff.

Personally Identified Individual Record-Level Data

The Section strongly discourages the release of individual-level record data that contain personal identifiers. In very limited circumstances, such records may be released to providers, legal entities, and/or directly to the individual.

The Section may release individual-level records for public health purposes. This includes the use of HIV/AIDS surveillance data to link individuals, upon their consent, to partner services. These activities are described further in the *Partner Counseling and Referral Services Procedures*.

DATA RELEASE PROCEDURES

Responding to Aggregate Data Requests

Data clients usually initiate data requests by telephone or email. Section staff will work with the client to clearly define the specifics of the data request. For requests of data the Section does not have, Section staff should refer the client to other sources when possible.

Section staff will gather the client's contact information and document the request. Section staff should make every attempt to meet the client's deadline for receiving the data. If the deadline is unusually short, cannot be met, and/or another deadline cannot be negotiated, the Section Chief should be consulted.

In completing data requests, Section staff should save computer programming/syntax and output files for future reference. Data are most often saved in an electronic format (e.g., Word, Excel) and emailed to the client. All files should be clearly annotated, including titles and notes to thoroughly describe what the data represent. Additional notes should be included to describe any special circumstances or limitations of the data, including cell suppression.

If the data results are complete and follow the guidelines described in this policy, they may be sent directly to the client. If the data results require further approval, such as that needed for small underlying populations, the Section Chief should be consulted.

Responding to De-identified Individual Record-Level Data Requests

De-identified individual record-level data requests must be made in writing and are only released upon approval by the Section Chief and ORP. Approval or disapproval of any request will be based upon whether any pre-existing public data or standard reports will adequately meet the client's needs, whether the request is consistent with the policies and mission of the Section, and the general scientific soundness and feasibility of the project. If the request is denied completely, an explanation of this decision will be provided to the client. If the request is approved with some restrictions, these will be described. In some situations, the Section may determine that data will only be shared or released if Section staff are an integral part of the research project.

If the data request has been granted, an *Application for HIV/AIDS Surveillance Data* and *HIV/AIDS Data Confidentiality Statement* must be on record for the client prior to receipt of data. The *Application for HIV/AIDS Surveillance Data* is to be completed by the client and must specify 1) the individuals that will have access to the data, 2) the scope of the project for which the data is being requested, and 3) the security measures that will be taken to protect the data. The *HIV/AIDS Data Confidentiality Statement* is to be signed by the client and certifies that the client will adhere to Section policies on the permitted uses, disclosures, and final disposition of the data.

The dataset will be prepared by Section staff and provided to the client by a secured means upon approval. The Section Chief will maintain all original hard copies related to the data request, including the *Application for HIV/AIDS Surveillance Data* and *HIV/AIDS Data Confidentiality Statement* for each request.

Follow up with clients will be made by the Section to ensure that the data files have been destroyed by the date stated on the *Application for HIV/AIDS Surveillance Data* and *HIV/AIDS Data Confidentiality Statement*. Clients must provide official written confirmation that all data files have been destroyed. No data will be kept by clients after analyses are completed. If additional time is needed to complete approved projects, a written agreement must be completed with a new date for completion of work and destruction of all data.

Upon request, the client must allow the Section an opportunity to review and approve all data analyses and results prior to their presentation in any public forum. Presentation of the data should acknowledge the Section appropriately.

Responding to Identified Individual Record-Level Data Requests

Requests for identified individual record-level data must be directed to the ADH Office of General Counsel. The Section Chief and ORP will work with the ADH Office of General Counsel to fulfill requests.

The release of individual-level records for public health purposes does not require a data request as described above. Activities related to partner services are conducted by ADH staff.

Responding to Special Requests

Section staff who are contacted by the media should notify the Section Chief. In responding to the media, Section staff should follow *ADH* rules.

Section staff who are contacted by the legislature should notify the Section Chief who will coordinate the response with other relevant ADH Sections and personnel.