

# APHL Data Sharing Policy

August 2022



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This Policy is effective as of August 2022 and replaces the previous Policy, which went into effect May 2013.

## OVERVIEW

For well over 25 years, the Association of Public Health Laboratories (APHL) has collected a variety of data on the public health laboratory system in the United States as part of its mission to promote the contributions of its members to the public's health. This Data Sharing Policy (the "Policy") establishes and codifies the association's policy for (1) sharing the data APHL has acquired or generated and (2) providing access to the data. This Policy also sets out APHL's responsibilities as the custodian of the data and the responsibilities of the users of the data.

## SCOPE OF POLICY

This Policy serves as APHL's default data sharing policy and, except as noted below, applies to all of the association's current and future data repositories.

This Policy **does not apply** to the following data repositories controlled by or maintained on behalf of APHL and its subsidiary organizations:

- The APHL Informatics Messaging Services (AIMS) Platform;
- The Newborn Screening Technical assistance and Evaluation Program (NewSTEPS) Data Repository;
- Repositories of data collected from APHL staff regarding the association's workspace; and
- Any other data repository maintained by or on behalf of APHL that has one or more unique, but equivalent or enhanced, data sharing or data access policies.

## BACKGROUND

APHL collects data to describe the features and characteristics of its member institutions and to evaluate the programs, practices and services provided by APHL, its member institutions and its partners. APHL's members provide their data voluntarily and may choose not to respond, in whole or in part, to surveys or other data collection instruments. The data and its analysis is intended to provide members, APHL, funders and interested third parties the status and functionality of the public health laboratory system in our country and to inform and influence public health policy.

APHL collects data and information that could potentially identify individuals and organizations (such as name, title, organization, business address and website address, as well as business phone, fax numbers or email address) to maintain a record of the program and study participants. While much of the data collected by APHL is in the public domain, there may be some data deemed more sensitive to individual study participants, public health laboratories or the public health system when considering the sharing of that data. In addition, if APHL were to allow unfettered access to data containing individually identifiable information (**Identifiable Information**) in its possession, APHL may be unwittingly bypassing freedom of information act safeguards that APHL's member laboratories or the state, territorial or local public health authorities might otherwise impose. Accordingly, except as noted in this Policy below, APHL will use aggregate or summary statistics derived from data collected to assess the current status of public health laboratories, laboratory staff or the public health community at large, both nationally and internationally.

As the data custodian, APHL will be responsible for the following:

- Acquiring raw data sets and identifying the source of the data;
- Identifying secondary data sets, where applicable;
- Establishing the means whereby APHL members can access the data;
- Establishing the policies for access rights for third parties to the data;
- Implementing processes which to maintain the integrity, accuracy, precision, timeliness, consistency, standardization and value of all data;
- Ensuring privacy of the data owners by maintaining security measures to prevent unauthorized access, modification and disclosure of identifiable data; and
- Ensuring archiving and regular backup of the data repository.

# PERMITTED ACCESS TO DATA

## Summary or Aggregate Data

Except as noted in this Policy below, APHL will only release summary or aggregate data collected from various data survey instruments. The data released will not contain any Identifiable Information that would allow a recipient to identify or easily re-identify one or more study participants. Even if Identifiable Information is publicly available from other sources, APHL will not release Identifiable Information in its possession to third parties unless authorized under this Policy.

In the event that a third party desires access to Identifiable Information, that party will need to complete and submit a Data Access Request Form (**DARF**), a copy of which is attached to this Policy as [Exhibit A](#). APHL will consider each individual completed DARF using the process described in the [Data Sharing Requests](#) section of this Policy.

## Data Containing Identifiable Information

APHL will not permit access to data that contains or may contain any Identifiable Information except as provided in this Policy. There are several categorical exceptions to this general prohibition, each as summarized below.

### APHL Staff

In order to evaluate survey data and to compile the aggregate or summary data for release, staff in APHL's Quality Systems and Analytics (**QSA**) program will have access to the raw data collected from various data survey instruments. In addition, there may be times when staff from other APHL departments or programs may need access to certain underlying raw data sets that may contain Identifiable Information. This means that these US-based staff members may have full access to any Identifiable Information in APHL's possession.

Any APHL staff accessing Identifiable Information must adhere the non-disclosure and confidentiality requirements set out in the Conduct of Business and Ethical Considerations policies of APHL's Employee Handbook (the "**Employee Handbook**") for US-based employees. APHL staff who fail to adhere to these requirements may be subject to the full range of disciplinary procedures, including termination of employment with APHL, outlined in the Employee Handbook.

### APHL Members

The Member-representative (i.e., the voting member) from each APHL member laboratory will have full access to their laboratory's Identifiable Information. The Member-representative may grant access to their laboratory's Identifiable Information to one or more other members of their laboratory staff. In order to grant such access, the Member-representative must email the Director, QSA the name, title and email address of each member of staff they wish to access that laboratory's Identifiable Information.

In addition, Member-representatives will have access to Identifiable Information from all other APHL member laboratories. APHL will have the right, in its sole and absolute discretion, to restrict access to data that its Board of Directors (**BOD**) deems sensitive in nature. Member-representatives with access to APHL survey data housed in repositories such as the Survey Resource Center (**SRC**) may freely use that data for internal purposes (including things such as benchmarking testing menus against other laboratories, evaluating potential equipment purchases, or justifying fee-for-service testing to their health official).

### Other Third Parties

If an APHL survey instrument indicates that APHL will release certain Identifiable Information to a specific third party (such as the Trust for America's Health or the US Centers for Disease Control and Prevention), that third party will have full access to the specified Identifiable Information. Prior to releasing the survey instrument for data collection, APHL will work with the specific third party to ensure that they have obtained all necessary internal approvals to receive the requested Identifiable Information and will work to ensure that the third party only uses the released Identifiable Information for a specific purpose.

## As Required by Law or Regulation

APHL may also release Identifiable Information as required by applicable law or regulation. To the extent possible, APHL will notify Member-representatives of the need to release their laboratory's Identifiable Information (and the specific Identifiable Information to be released) prior to releasing the information required by such law or regulation.

## DATA SHARING REQUESTS

Other than as noted in this Policy above, third parties must complete a DARF (found in [Exhibit A](#)) to request access any of APHL's data.

## Aggregate, Summary or Non-identifiable Data Requests

The Director, QSA must approve any third-party request to obtain aggregate, summary or non-identifiable data. The Director, QSA or a designee in the QSA department may work with the requestor to modify or limit the scope of requested data. If APHL approves of the request (whether as originally submitted or as modified by QSA), APHL may require the requestor to sign a Non-Disclosure Agreement or supplemental data use agreement or data sharing agreement, each in a form acceptable to APHL.

## Identifiable Information Requests

The Director, QSA, in consultation with the General Counsel, must approve of any third-party request for Identifiable Information (which approval APHL may grant in its sole and absolute discretion). The Director, QSA and the General Counsel may elevate any data access request involving Identifiable Information to APHL's Knowledge Management Committee (the **KMC**) for their review, input and advice. The KMC, in turn, may further elevate any data access request involving Identifiable Information to the BOD for additional review, input and advice.

As with requests for non-identifiable data, APHL may work with the requestor to limit or modify the scope of the data access request involving Identifiable Information. In the event that APHL determines to move forward with a request to access Identifiable Information, QSA will notify each data owner and ask for that owner's permission to release its respective Identifiable Information. In the event that a data owner does not grant permission to release its Identifiable Information, APHL will not grant the third party's request to access that data. APHL will only approve of a third-party request to access Identifiable Information if a respective data owner grants permission to release its Identifiable Information.

Once APHL obtains the relevant data owner permissions, APHL will work with the requestor to ensure that they have obtained all necessary internal approvals to receive the requested Identifiable Information and will work to ensure that the third party only uses the released Identifiable Information for a specific purpose. In addition, APHL may require the requestor to sign a Non-Disclosure Agreement or supplemental data use agreement or data sharing agreement, each in a form acceptable to APHL.

## Raw Survey Data or Unpublished Aggregate Results

APHL will not release any raw survey data and unpublished aggregate results collected as part of APHL's research efforts to member laboratory or third party not part of the research project until the earlier of (1) 180 days after collection of the survey data or (2) until an analysis of the survey data has been accepted for publication.

## **SURVEY INSTRUMENTS**

APHL will release survey instruments to its member laboratories and any federal agency that holds a cooperative agreement with the association upon written request to the Director, QSA or a designee within QSA. Other third parties will need to obtain written approval from APHL before accessing APHL- developed survey instruments. APHL may charge, in its sole discretion, a third party a fee before releasing any survey instrument.

Any survey instrument created by or on behalf of APHL is APHL's intellectual property and, as a result, use of these instruments (or any derivative product, instrument or material) will require the user to acknowledge APHL as the source. Survey instrument requests from third parties may be subject to an access fee as determined by APHL.

## **PUBLICATIONS**

Any publication, paper or journal article, press release, article, report, or other material that includes data (whether aggregate/summary or Identifiable Information) extracted from APHL surveys or the SRC must be approved, in writing, by APHL prior to its publication or release.

In the event APHL, its member laboratories or third parties wish to publish Identifiable Information, APHL will contact the impacted data owners for their approval (or disapproval) of the publication of their Identifiable Information. Only Identifiable Information that a data owner has authorized for publication or release may be included in the final publication or release.

Approval (or disapproval) by APHL will be provided in writing within 15 business days after APHL's receipt of the request or within five business days after APHL's receipt of all data owners approval. APHL may not unreasonably withhold or delay its approval.

The requester will forward one copy of the proposed publication to the Director, QSA no less than 45 days prior to submission for publication. APHL's must approve of the publication prior to distribution or submission for publication. If approved, the requester will later forward two copies of the published materials to the Director, QSA, who may deliver one copy to any federal agency who provided funding to collect the underlying survey data. The requestor must deliver these published materials to APHL within 30 days after publication or release.

In the event the underlying survey data was collected using federal or other grant funding, APHL will notify the requestor of any disclaimer and funding acknowledgment language that must be included in the final publication or release.

## EXHIBIT A: DATA ACCESS REQUEST FORM

You must complete this Data Access Request Form (DARF) to request access to data collected and managed by or on behalf of the Association of Public Health Laboratories (APHL) Quality Systems & Analytics program. In order for your request to be considered, you must fully complete, sign and date this DARF and, once complete, email the form to [lorelei.kurimski@aphl.org](mailto:lorelei.kurimski@aphl.org). If needed, [download a stand-alone DARF](#).

### Project Background

Name of project:

Expected start date:

Expected completion date:

One-paragraph summary of project that must provide the following information:

- Research objective/question
- Proposed methods/analysis
- Implications of project to public health laboratory/public health practice

Type(s) of publication:

Primary method(s) of distribution:

Language of publication:

### Lead Researcher Information

First or given name(s):

Last or family name(s):

Email address:

Phone number:

Job title/designation:

Employer or organization affiliation:

Employer or organization address:

APHL affiliation (if applicable):

## Co-author or Other Primary Researcher Information

### First Co-author or Other Primary Researcher

First or given name(s):

Last or family name(s):

Email address:

Phone number:

Job title/designation:

Employer or organization affiliation:

Employer or organization address:

APHL affiliation (if applicable):

### Second Co-author or Other Primary Researcher

First or given name(s):

Last or family name(s):

Email address:

Phone number:

Job title/designation:

Employer or organization affiliation:

Employer or organization address:

APHL affiliation (if applicable):

## Type of Data Requested

Are you requesting identifiable data?    No    Yes, please explain:

Specific data variables requested:

Data range requested:

Statement of storage method by which access to data will be limited to research team members only:

# Terms and Conditions for Use of APHL Data

By signing below, you agree to the following terms and conditions with regard to access and use of APHL data:

## General Terms

1. APHL is not required to grant you access to any of its data and will consider your DARF in accordance with its data sharing policies and procedures in effect at the time.
2. If requested by APHL, you will be required to sign Non-Disclosure Agreement (NDA) in the form provided by APHL; APHL will determine whether a separate NDA will be required upon its receipt and review of your completed DARF.
3. Regardless of whether APHL issues a NDA to you, any and all data provided by or on behalf of APHL remains the property of APHL and you may only use the data for the purposes for which data access was granted as outlined in this DARF.
4. APHL may request a processing fee, which will be explained to you after APHL reviews your DARF.
5. If you are conducting research at or on behalf of an institution of higher education or a governmental agency, you will meet the requirements of that institution's or agency's human subjects or corresponding committee.
6. You must ensure that APHL's data is stored in a secure location with access limited to research team members only.
7. You will ensure that APHL's data is used only for the purposes described in this DARF.
8. Your research must be for academic or practitioner educational purposes only.
9. Your research will not be used to denigrate or disparage APHL, one or more of its directors, officers, staff or contractors, one or more of the association's members, one or more public health agencies or in legal proceedings.
10. APHL's cooperation will be acknowledged in all research produced as a result of such cooperation and you will include any funding disclaimer or acknowledgement furnished by APHL.
11. For public or non-confidential reports written in English, you will email a copy of the report to [legal@aphl.org](mailto:legal@aphl.org) within one month of publication.
12. If the report is published in a language other than English or is released in a confidential manner, you will provide a one- to three-paragraph summary in English within one month of publication or release.

## Copyright Guidelines

1. Findings and materials based on APHL data must include the following copyright information: [Insert description of the data] was obtained from the Association of Public Health Laboratories, Inc. and is used with permission. APHL reserves and retains all rights with respect to this data.
2. APHL expects you to provide the association with an online link to finished reports so the reports can be made available to its members and/or posted as an online resource.
3. While APHL data should not be used to generate profits, you do have the option to obtain sponsors for reports as a way to raise funds to cover the cost of report development. Please contact [legal@aphl.org](mailto:legal@aphl.org) for more information about report sponsorship.

## Ethical Guidelines

1. You may not use APHL data for commercial purposes or marketing.
2. Any report containing APHL data must include a disclaimer stating that the views in the report reflect the researchers' opinions and are not intended to represent the position or policies of APHL.

## Academic Use Guidelines

1. Professors may request data to use in teaching undergraduate and graduate classes.
2. Doctoral students can request data for developing their dissertations.
3. Academic researchers are encouraged to produce peer-reviewed articles as a way to increase the body of knowledge about public health laboratories within the academic community.

By my signature below, I \_\_\_\_\_, the lead researcher on the project identified in this DARF do certify the truth and accuracy of the information I've provided in this request and I acknowledge and agree to the DARF's terms and conditions set forth above.

Signature

Date