

**Data Sharing Agreement (DSA)
Policy #CO 01-16-001**

Purpose

The purpose of this policy is to outline the requirements for the review and approval of data sharing agreements for access to confidential or implied confidential Department data for use in public health practice or surveillance, or other statistical or verification purposes as allowed by statute or Administrative Code.

This policy does not apply to the review or approval of research applications in which research is the basis for the request. Research requests for confidential or implied confidential IDPH data must be processed according to the procedures outlined in **IDPH Policy # CO 07-12-004, Research Agreement and Research and Ethics Review Committee**. This policy also does not apply to the review or approval of Public Records requests for public data. Public records requests must be processed according to the procedures outlined in **IDPH Policy # IM 11-04-015, Public Records**.

Definitions

Confidential Public Health Information, Record, or Data: A record, certificate, report, data, dataset, or information which is confidential under federal or state law. As a general rule, public health records which contain personally identifiable information of a health-related nature are confidential under Iowa law. More information about confidential public health records can be found in **IDPH Policy #CO 01-16-002, Disclosure of Confidential Public Health Information, Records, or Data**.

Data Custodian: The IDPH employee who is in the position responsible for the safe custody, transport, and storage of the data. The data custodian is also responsible for the technical environment and database structure that hosts data. The custodian for IDPH data may be indicated by statute (e.g., State Registrar of Vital Records); however, the physical custodian for the majority of IDPH data is the Bureau of Information Management and Bureau of Health Statistics.

Data Owner: The IDPH employee who is in the position that is responsible for the dataset, as designated by the director or director's designee or as indicated by statute. The data owner may authorize or deny access to certain data within IDPH in accordance with procedures described below, and is responsible for accuracy and integrity of the data and timely response to data inquiries.

Data Requestor: The individual requesting and using confidential or implied confidential IDPH data. The requestor is the point of contact for all communication with IDPH related to the review of the application and is also responsible for non-IDPH individuals who are authorized to access data received through the DSA.

Data Sharing Agreement (DSA): A legal contract between IDPH and any external entity (including other departments within state government and Regent's institutions), or between two internal IDPH programs in which parties agree to the exchange of specified variables within an IDPH dataset, and use of the data does not meet the definition of research

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constituting a need for a Research Agreement.

Data Steward: The IDPH employee who is in the position responsible for data content, context, and associated rules for interpretation of each data source. The data steward(s) serves as an intermediary between the data owner and data custodian. Data stewards have the responsibility of ensuring that the appropriate steps are taken to protect the data and that respective policies and guidelines are being properly implemented. The data owner and steward might be the same person.

Implied Confidential Public Health Data: Data which could be used to indirectly establish the identity of a person named in a confidential public health record by the linking of the released information or data with known external information which allows for the identification of such person. This commonly includes de-identified, row level information about an individual, and can also include some small count sizes. More information about implied confidential public health data can be found in **IDPH Policy #CO 01-16-002, Disclosure of Confidential Public Health Information, Records, or Data.**

Personal Gain: Efforts by any employee that benefit an IDPH employee personally or professionally and where the “effort” is outside of the scope of normal job duties. Examples of efforts qualifying as “personal gain” include, but are not limited to using IDPH data for a dissertation or other graduate work, in consulting work, or in other supplemental employment.

Research¹: A systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge. Activities that meet this definition constitute research for the purposes of this policy, regardless of whether or not they are conducted or supported under a program that is considered research for other purposes. Examples of “research” are included in **Appendix A of IDPH Policy #CO 07-12- 004, Research Agreement and Research and Ethics Review Committee.**

Research Agreement: A legal contract between IDPH and any external entity (including other departments within state government and Regent’s institutions) in which IDPH agrees to release specific variables within a dataset for the purposes of bona-fide research. A research agreement is required when the receiving entity intends to use the requested dataset for the purpose of research and the user is bound by the confidentiality requirements in the research agreement. Research agreements must align with processes outlined in **IDPH Policy # CO 07-12-004, Research Agreement and Research and Ethics Review Committee.**

Research and Ethics Review Committee (RERC): The Research and Ethics Review Committee (RERC) is responsible for evaluating and approving or denying requests for IDPH- owned data for the purposes of research. More information about the RERC can be found in **IDPH Policy #CO 07-12-004, Research Agreement and Research and Ethics Review Committee.**

¹ For the purposes of defining research within this policy, the Department has used 45 CFR § 46.102(l), which describes research activities according to the Revised Common Rule. Accessed September 2019, from <https://www.ecfr.gov/>.

Policy

The following non-research data requests must be submitted to the IDPH Data Management and Health Equity Program and reviewed and approved by the Division Director (or the State Registrar or Deputy State Registrar for Vital Records data):

- All non-research requests for confidential data,
- Non-research request for implied confidential data released external to IDPH, and
- Non-research requests for implied confidential data for Vital Records, HIV, Substance Use, Traumatic Brain Injury, and Child Death Review released outside of the program for which the data was collected.

Additionally, non-research data requests shall be reviewed by the Assistant Attorney General assigned to IDPH when needed (as determined by the Data Management and Health Equity Program).

An agreement must be executed prior to the release of these data as described below. Data sharing agreements shall not be executed for more than a maximum of five years. Any data released to an internal or external entity regardless of whether or not it has been approved via this policy must follow **IDPH Policy # CO 01-16-002, Disclosure of Confidential Public Health Information, Records, or Data**.

Data Requestors:

Those requesting confidential or implied confidential IDPH data for non-research purposes who are external to the Iowa Department of Public Health (including other departments within state government and Regents' institutions) shall:

1. Submit an application and a list of variables for all requests for access to confidential or implied confidential data for non-research to the IDPH Data Management and Health Equity Program. A fee may be assessed for the requested data. Refer to the **Fee Schedule for Vital Records Data (Appendix A)** for more information about fees related to Vital Records.
2. Follow all terms and conditions of the data sharing agreement if data release is approved.
3. Resubmit an application to the Data Management and Health Equity Program for continuation of the data sharing agreement at least 60 days prior to the expiration date of the agreement if IDPH data are still required. If agreement is not renewed, follow all destruction terms within data sharing agreement.

IDPH Employees:

1. IDPH employees who receive data requests shall refer requests for confidential or implied confidential IDPH data from a person or entity **outside of their program** to the Data Management and Health Equity Program. This includes requests from other internal programs or external sources.
2. IDPH employees who would like to request access to confidential or implied confidential IDPH data for surveillance, public health practice, or verification purposes that are owned by another IDPH program shall contact the IDPH Data Management and Health Equity Program for assistance with executing a data sharing agreement.
 - a. IDPH employees may be required to submit an application to the Data

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Management and Health Equity Program.

- b. A fee may be assessed for the requested data. Refer to the **Fee Schedule for Vital Records Data (Appendix A)** for more information about fees related to Vital Records.
3. If data sharing will occur through a contract, IDPH employees shall include data sharing terms (found in the special conditions template) and data sharing appendices, including variables and ensure data sharing terms are reviewed by the Data Management and Health Equity Program.
4. If data sharing is for a federal grant requirement, IDPH employees shall consult with the Data Management and Health Equity Program to ensure the protection of data is outlined adequately in the grant agreement. The Data Management and Health Equity Program is available to IDPH employees for consultation on release concerns and guidance as to the need for a DSA.
5. IDPH employees shall follow all terms and conditions of the data sharing agreement if data release is approved.
6. IDPH employees shall resubmit an application to the Data Management and Health Equity Program for continuation of the data sharing agreement at least 60 days prior to the expiration date of the agreement if IDPH data are still required. If agreement is not renewed, follow all destruction terms within DSA.

IDPH Data Management and Health Equity Program:

The IDPH Data Management and Health Equity Program shall:

1. Receive and review all requests and applications for access to confidential and implied confidential IDPH data for public health practice or surveillance, or other statistical or verification purposes as allowed by statute or Administrative Code and determine the need for a data sharing agreement.
2. In consultation with the requestor and the data owner, determine if the purpose of the request is for research **OR** for public health practice, surveillance, other statistical, or verification purposes.
3. Coordinate the review and approval of data sharing agreements for the release of:
 - a. confidential data outside of the program for which the data were collected,
 - b. implied confidential data external to IDPH, and
 - c. implied confidential data for Vital Records, HIV, Substance Abuse, Traumatic Brain Injury, or Child Death Review outside of the program for which the data were collected.
4. Facilitate the review and approval of all data sharing agreements by the Data Owner, Director of the Division where the data are owned or when appropriate the State Registrar or Deputy State Registrar for Vital Records, and when needed, the Assistant Attorney General assigned to the Iowa Department of Public Health.
5. In collaboration with the Data Owner, evaluate and determine the need for a data sharing agreement for additional internal releases of implied confidential data. Data sharing agreements shall be executed for releases of confidential or implied confidential data that will be re-released to another entity or when the data is being used outside of the scope of normal job duties and/or for personal gain of any kind.

Data Owner and Bureau Chief

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The Data Owner and Bureau Chief shall:

1. Review data requests based on information provided by the Data Management and Health Equity Program and an evaluation of the requestor's need for confidential public health data and the benefit of the proposed data sharing. The Data Owner and Bureau Chief will make a recommendation to the Division Director to approve or deny the request. All Vital Records requests will be evaluated by the State Registrar or Deputy State Registrar.
2. Fulfill approved data requests or appoint a staff person to fulfil the data request. The Data Owner and Data Custodian will receive approval in the form of a copy of the DSA from the Data Management and Health Equity Program.

Division Director

The Division Director shall:

1. Approve or deny and sign data sharing agreements. The Division Director, or when applicable the State Registrar or Deputy State Registrar for Vital Records, are the only persons authorized to obligate IDPH data through approval and execution of a DSA.

Policy/Procedure Violations

For IDPH employees - violations of the policy are grounds for disciplinary action, up to and including discharge.

For all persons and entities participating in a DSA with IDPH – IDPH has the authority to employ penalties for misuse of data. Penalties for violations of the DSA may include, but are not limited to:

- Revocation of the DSA and notice to the immediate supervisor of the violating party.
- Notice of revocation of the DSA to the entity's director.
- Immediate destruction of data confirmed by independent third party, and may need to be verified by IDPH.
- Restitution of funds to the grantor agency as appropriate
- Removal of the violating party from the particular project, or special monitoring of future work
- Letter of reprimand, probation, suspension, or termination of employment for the violating party
- Withdrawal or correction of all pending or published documents emanating from the research where the misconduct was found
- Denial of future requests by the violating requestor and other implicated parties.
- Other sanctions as authorized by federal or state law.

The signatory is responsible for all violations of the DSA, including anyone under their authority with access to confidential or implied confidential data shared through the DSA.

Appendix A: Policy #CO 01-16-001

Fee Schedule for Processing Vital Records Data Requests

Setup and estimate fee- \$150 minimum (one-time)

A minimum of \$150 will be charged to cover the cost of creating an export and setting up a program to extract the data. The setup fee will only be charged once for any new and recurring request resulting from a data sharing or research agreement as long as the data request does not change in successive years.

In addition to the \$150 set up fee, additional fees may apply. These additional fees are outlined below.

Programming and analysis- \$85/hour

If a request for data requires development of a program to extract data from an IDPH system, the requestor will be charged an hourly fee based on the current salary estimate for a database analyst. Estimates are based on the number of hours taken to develop a program for extraction of data and to perform the service.

Data access fee - \$150 per month (\$1,800 annually)

For each data agreement that requires routine data exports of all birth, marriage, fetal death or death records, a fee of \$150 per month will be charged. For agreements that request historical data, a fee of \$150 per month will be calculated based on the number of months requested. The fee will be billed on an annual basis, for the length of the agreement, and invoiced prior to the data being delivered. The fee is based on administrative costs for the vital record system and may be revised as needed. The data access fee is charged as authorized by Iowa Code section 144.46; 641 IAC 95.6(6); 641 IAC 95.6(7).

or

Per record fee- \$1.00/record (\$50 minimum annual charge)

A fee per record will be charged based on ongoing maintenance and support required to sustain data systems when the minimum annual fee for the data export will not exceed the annual data access charge. The per record fee is charged as authorized by Iowa Code section 144.46; 641 IAC 95.6(6); 641 IAC 95.6(7).

or

Vital records certificate requests- \$20 per certificate

Each certificate requested from the Bureau of Health Statistics, Vital Records requires a fee of \$20 which is collected to cover the costs of conducting the search of our records and making a copy.

For questions about this fee schedule, contact:

Melissa Bird

Chief, Bureau of Health Statistics

Melissa.bird@idph.iowa.gov

515-281-6762

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Director's Signature

Date