

**Disclosure of Confidential Public Health Information,
Records, or Data Policy #CO 01-16-002**

Purpose

This policy provides guidance to Iowa Department of Public Health (IDPH) employees regarding appropriate disclosures of IDPH data, including confidential public health records, and use of aggregate counts and statistics in public health reports and publications. This policy also provides guidance to local boards of health and health departments (including county, city, and district boards and departments) regarding the release of data and reportable disease information, and to persons external to IDPH who have access to confidential or implied confidential public health data through a contract, data sharing agreement or research agreement with IDPH.

The Iowa Department of Public Health is governed by Iowa's Public Records law and generally provides public access to records it collects under IDPH legal authority (Iowa Code Chapter 22, **IDPH Policy # IM 11-04-015, Public Records**). In addition, IDPH is committed to providing information, data, and records to the public and the media to protect and improve the health of the population. However, Iowa law also provides that certain information, data, and records collected under IDPH legal authority are confidential and may not be disclosed to the public. Examples of some, but not necessarily all, records and data IDPH is required by law to maintain as confidential can be found in **Appendix A**.

The guidelines below are generally applicable to all public health information, records, or data collected under the legal authority of IDPH that are confidential or that could lead to the identification of an individual named in a confidential public health record when combined with other known sources of information. However, certain confidential public health records are governed by additional regulations as well as specific exemptions. Please see **Appendix B** for a list of some of the limited exceptions which authorize release of confidential or personally identifiable information without a data sharing agreement, research agreement, or contract.

Definitions

Business: Business means and includes every trade, occupation, or profession. This includes organizations or entities with identifiable proper names. Examples include, but are not necessarily limited to, schools, non-profit organizations, restaurants, companies, hospitals, or health care clinics.

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. Examples of some, but not necessarily all, records IDPH is required by law to maintain as confidential can be found in **Appendix A**.

Data Sharing Agreement: 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 constituting a need for a research agreement. Data

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sharing agreements must align with processes outlined in **IDPH Policy # CO 01-16-001, Data Sharing Agreement (DSA)**.

Data User: Any person with access to confidential or implied confidential IDPH data, including small count sizes. This includes, but is not limited to, IDPH employees, interns, temporary workers, contractors, and individuals external to IDPH with access to IDPH data through an agreement.

Denominator: The number below the line in a common fraction; a divisor. For example, 3 in 2/3. For the purposes of this policy, the denominator typically represents the total population or the total number of persons or events from which the numerator is a subset.

Implied Confidential 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.

Numerator: The number above the line in a common fraction showing how many of the parts indicated by the denominator are taken, for example, 2 in 2/3. For the purposes of this policy, the numerator is the number of cases or the number of individuals with a health condition or that perform a health-related behavior within a proportion.

Personally Identifiable Information (PII): Information that can be used to distinguish or trace an individual's identity, either alone or when combined with other personal or identifying information that is linked or linkable to a specific individual.

For the purposes of this policy, the following variables are considered PII¹:

- Name, including alias
- Geographic identifiers smaller than state (e.g., complete or partial street address, zip code, census tract, county) when directly related to an individual
- Dates (other than year alone) directly related to an individual. For example:
 - Date of Birth
 - Date of Death
 - Date of Service
 - Date of Admission
 - Date of Discharge
- All ages over 89 years and all elements of dates (including year) indicative of such age
- Phone Number
- Fax Number
- Email Address
- Social Security Number (full or partial)
- Medical Record Number
- Certificate Number
- Device Identifiers and Serial Numbers
- Account Number

¹ For the purposes of determining PII for this policy IDPH has used 45 CFR § 164.514(b)(2), which describes the "Safe Harbor" method for deidentification within the Health Insurance Portability and Accountability Act (HIPAA). Accessed June 2019 from <https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/>.

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- Health Insurance beneficiary numbers (including Medicaid ID number)
- Internet Protocol (IP) Address Numbers
- Web Universal Resource Locators (URLs)
- Biometric identifiers, including finger, retinal and voice print and DNA
- Full face photographic images
- Any other unique identifying number, characteristic, or code

Note that additional variables may become PII when combined with other pieces of information.

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 an IDPH 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**.

Policy

Data Users:

1. Confidential IDPH data shall not be released outside of the IDPH program for which the data was collected unless there is an approved data sharing agreement, research agreement, or data sharing terms within a contract OR the release is authorized according to one of the limited exceptions outlined in state or federal law. Some of the most common exceptions are outlined in **Appendix B**. See **IDPH Policy # CO 0-01-16-001, Data Sharing Agreements** and **IDPH Policy # CO 07-12-004, Research Agreement and Research and Ethics Review Committee**.
2. Implied confidential IDPH data shall not be released outside of IDPH unless there is an approved data sharing agreement, research agreement, or data sharing terms within a contract OR the release is authorized according to one of the limited exceptions outlined in state or federal law. Some of the most common exceptions are outlined in **Appendix B**.

Additionally, implied confidential data from a few select datasets shall not be released outside of the program for which the data was collected without an approved data sharing agreement, research agreement, or data sharing terms within a contract OR the release is authorized according to one of the limited exceptions outlined in state or federal law. These datasets are Vital Records, HIV, Substance Use, Traumatic Brain Injury, and Child Death Review. Data sharing agreements or research agreements may be required in additional situations for internal transfers of implied confidential data at the discretion of the Data Owner and IDPH Data Management and Health Equity Program. See **IDPH Policy # CO 0-01-16-001, Data Sharing Agreements** and **IDPH Policy # CO 07-12-004, Research Agreement and Research and Ethics Review Committee**.

3. Any IDPH data received through a data sharing agreement, research agreement, or data sharing terms within a contract may not be re-released unless authorized in writing within the agreement or an amendment to the agreement.

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4. IDPH employees or those with access to IDPH data shall not respond to inquiries about confidential data in a manner which confirms or denies the inquiry unless the release is authorized according to one of the limited exceptions outlined in state or federal law (see **Appendix B** for some exceptions).
5. In some situations, IDPH data may not be released, even in aggregate format, if it identifies a business or presents proprietary concerns. This includes the release of the name of a business in a reportable disease investigation. Contact the IDPH Data Management and Health Equity Program or State Medical Director/State Epidemiologist with questions.
6. Statistical or aggregate data (for example: counts or rates based on counts) may be released publicly if:
 - a. The count (numerator) is 6 or greater² AND the total population (denominator) is 100 or greater AND a count of less than 6 cannot be derived through simple math when data is presented in a table; OR
 - b. The value is considered appropriate to release according to the Data Release Analysis Protocol³ (as determined by the Data Management and Health Equity Program) (see **Appendix C**); OR
 - c. Approval for an exception to the Data Release Analysis Protocol is received in writing from the IDPH State Medical Director/State Epidemiologist as outlined in **Appendix D**; OR
 - d. Data is appropriately suppressed.

IDPH Data Management and Health Equity Program

The IDPH Data Management and Health Equity Program shall:

1. Provide training and technical assistance to Data Users on data suppression, the Data Release Analysis Protocol (see 6b above and **Appendix C**), and determining the need for a data sharing agreement, research agreement, or data sharing terms within a contract.
2. Work with the IDPH State Medical Director/State Epidemiologist as requested to make decisions regarding requested exceptions to the Data Release Analysis Protocol for the release of small count sizes.
3. Receive and process all applications for Data Sharing Agreements and Research Agreements.
4. Maintain documentation for approved agreements and requests for exceptions to the Data Release Analysis Protocol for release of small count sizes.

² A count of zero may be released when it is not a threat to the confidentiality of individuals. If using zero in the negative to indicate that an entire population has a disease, condition, event or behavior, zero should not be released. For example, stating that zero children in a school suffered from influenza is acceptable. Stating that zero children in a school did *not* suffer from influenza identifies that all children within that school had influenza and therefore violates those children's confidentiality (and should not be released).

³ The Iowa Department of Public Health's Data Release Analysis Protocol has been adapted from the following sources: Alaska Section of Epidemiology Confidentiality Policies and Procedures and Data Release Protocols, November 2018 (available here: http://dhss.alaska.gov/dph/Epi/Documents/confidentiality/SOE_ConfidentialityPPData.pdf), California Department of Health Care Services Data De-identification Guidelines Version 2.0, November 2016 (available here: <https://www.dhcs.ca.gov/dataandstats/Documents/DHCS-DDG-V2.0-120116.pdf>), and State of New Hampshire, Division of Public Health Services, Health Statistics and Data Management Section Guidelines for the Public Release of Public Health Data, April 2016 (available here: <https://www.dhhs.nh.gov/dphs/hsdm/documents/publichealthdata.pdf>).

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IDPH Medical Director/State Epidemiologist

The IDPH State Medical Director/State Epidemiologist shall:

1. Review and approve or deny requests for exceptions to the Data Release Analysis Protocol as described in **Appendix C**.
2. Contact and consult with legal counsel and/or the Department Director (or designee) when necessary to make decisions about exceptions to the Data Release Analysis Protocol.
3. Provide documentation to the IDPH Data Management and Health Equity Program of all Data Release Analysis Protocol exception requests and the decision for record-keeping.

Supervisor

It is management's responsibility to have sufficient knowledge of this policy to direct employees to the correct contacts and resources for making decisions about releases of data.

Policy/Procedure Violations

Violations of this policy are grounds for disciplinary action, up to and including discharge.

Additionally, a person who knowingly violates confidentiality statutes and administrative rules regarding IDPH data may be subject to criminal prosecution for a simple misdemeanor and may be subject to disciplinary action under IDPH or the relevant entity's personnel policies, up to and including discharge from employment. A person who releases HIV/AIDS information is subject to criminal prosecution for an aggravated misdemeanor and is subject to civil action and civil penalties, and may be subject to disciplinary action under IDPH or the relevant entity's personnel policies, up to and including discharge from employment (Iowa Code §§ 139A.25,141A.11).

In addition, while IDPH is not a covered entity under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), local boards of health and health departments generally are covered entities, and may therefore be subject to an enforcement action under HIPAA if the local board of health or health department releases protected health information in violation of that regulation. Local boards of health and health departments should seek advice from their legal counsel to ensure their compliance with the federal law.

**Disclosure of Confidential Public Health Information,
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Examples of Records IDPH is Required by Law to Maintain as Confidential

The following is a list of many, but not necessarily all, IDPH data and records that Iowa law requires be kept as confidential:

1. Hospital records, medical records, and professional counselor records of the condition, diagnosis, care, or treatment of a patient. Iowa Code § 22.7(2).
2. Personal information in confidential personnel records. Iowa Code § 22.7(11).
3. Records pertaining to participants in the gambling treatment program. Iowa Code § 22.7(35).
4. Medical examiner records and reports, including preliminary reports, investigative reports, and autopsy reports. Iowa Code § 22.7(41).
5. Personally identifiable medical information provided for the purpose of studies to reduce morbidity or mortality. Iowa Code §§ 135.40, 135.41.
6. Social security numbers. 42 USC 405(c)(2)(C)(viii)
7. Personally identifiable information and business identity related to a reportable disease or condition. Iowa Code § 139A.3; Iowa Code §§ 139A.30 - 32.
8. Personally identifiable information related to HIV/AIDS. These reports are maintained as “strictly confidential medical information” and specific provisions prevent disclosure of this information except under very limited circumstances. Iowa Code §§ 141A.6, 141A.9.
9. Personally identifiable information contained in IDPH registries, including the Statewide Trauma Registry, Iowa EMS Patient Registry, Immunization Registry, Central Registry for Brain or Spinal Cord Injuries, and Congenital and Inherited Disorder Registry. Iowa Code §§ 147A.25, 147A.26; 641 IAC 132(8)(7)(c); 641 IAC 136.2(5); Iowa Code section 22.7(2); 641 IAC 7.12; Iowa Code § 135.22; Iowa Code § 136A.7.
10. Professional licensing board information, including EMS. All complaint files, investigative files, investigative reports, and all other investigative information of a licensing board or its employees or agents which relates to licensee discipline are confidential. Iowa Code § 272C.6(4). However, the statement of charges, notice of hearing, and the final decision of a board, whether after hearing or through a settlement agreement, are public.
11. Vital statistics records. Iowa Code § 144.43.
12. Substance abuse program patient information and some licensing information. Iowa Code § 125.37; Iowa Code sections 22.7(2), 22.7(18), or 125.37; 641 IAC 155.16(5).
13. Iowa Domestic Abuse Death Review Team and Iowa Child Death Review Team records pertaining to a specific death. Iowa Code § 135.111; Iowa Code § 135.43(3).
14. Records which contain identifiable information related to a child’s newborn hearing screening, rescreening, and diagnostic audiologic assessment. 641 IAC 3.10.
15. Perinatal program surveys and reports. Iowa Code § 135.11(28).
16. All medical, health and nutrition information collected regarding WIC program participants. 7 CFR 246, Iowa Code section 22.7(2), 641 IAC 73.7(7).
17. Names of patients and primary caregivers issued a medical cannabidiol registration card. Iowa Code § 124E.11.
18. Radon testing information. Iowa Code § 136B.2.

**Disclosure of Confidential Public Health Information,
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Examples of limited exceptions which authorize release of confidential or personally identifiable information.

Exceptions to this policy are provided by Iowa Code and Iowa Administrative Code. Other exceptions beyond those listed here may exist. Please contact the IDPH Data Management and Health Equity Program or legal counsel for assistance with exceptions.

1. Public health records may be released to the subject of the record upon receipt of a written authorization for release from the subject or the subject's legal representative (641 Iowa Administrative Code 175.12, Iowa Code § 141A.9(2)"a"). IDPH should exercise caution to ensure that other confidential information (for example reference to other ill individuals) contained in the report is redacted prior to release to the subject.
2. Public health records may be released in response to a court order or subpoena (641 IAC 175.9(2)"g", Iowa Code § 141A.9(2)"g"). Review shall be performed by the IDPH's legal counsel or local board of health and health department's legal counsel prior to release.
3. IDPH may share personally identifiable information regarding diseases, health conditions, unusual clusters, or suspicious events that may be the cause of a public health disaster with the department of public safety, the homeland security and emergency management division of the department of public defense, and other appropriate federal, state, and local agencies and officials (Iowa Code § 135.145(2)). The sharing of such information must be restricted to only that information necessary to prevent, control, and investigate the public health disaster (Iowa Code § 135.145(3)).
4. Iowa Immunization Registry Information System (IRIS) records may be released to enrolled users of the registry who have completed an enrollment form that specifies the conditions under which the registry can be accessed and who have been issued an organization code and user name by the department (641 Iowa Administrative Code 7.11(4)(a)(2)) and to the person or the parent or legal guardian of the person immunized or screened (641 Iowa Administrative Code 7.11(4)(a)(1)).
5. Information concerning the identity of a business involved in a disease investigation may be released to the public when the State Epidemiologist or the Director of IDPH determines such a release of information necessary for the protection of the public (Iowa Code § 139A.3(2)"c"). In these limited circumstances, efforts should be made to actively involve the business in the release of the information to mitigate damages to the reputation of the business to the extent feasible.

Prior to releasing the name of a business, local boards of health and health departments must obtain a determination from the State Epidemiologist or the Director of IDPH that such a release is necessary to protect the public. Local boards of health and health departments and officials

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are not authorized under law to make such a determination independently. IDPH will typically consult with legal counsel prior to reaching this determination to ensure that the release of information is appropriate from a legal and a public health perspective.

If a federal regulatory agency announces a recall of or issues a statement publicly identifying a particular product, the State Epidemiologist automatically deems the release of the name of any business identified in the recall or statement as necessary for the protection of the public. Hence IDPH and local boards of health and health departments may refer to the proper name of the business identified in a federal recall announcement or statement in any public release of information about the investigation. However, information which identified any person involved in such recall or investigation remains confidential.

6. Iowa law also allows IDPH to disclose reportable disease information under the following circumstances:
- Reportable disease records and information may be shared by and between IDPH and local public health employees and health care providers, hospitals, and laboratories, as necessary to effectively conduct an investigation and to provide appropriate medical care (Iowa Code § 139A.3, 641 IAC 1.4, 641 IAC 1.17(3)“c”)
 - Reportable disease information may be included in a quarantine or isolation order or site placard as necessary to prevent the spread of a quarantinable disease (Iowa Code § 139A.4, 139A.5, 641 IAC 1.9, 641 IAC 1.17(3)“e”). Public health officials should exercise caution prior to posting such placards, and consult with IDPH’s legal counsel or the local board of health and health department’s legal counsel prior to taking action.
 - Personally identifiable information regarding AIDS/HIV may be released only in the limited circumstances authorized by Iowa Code Section 141A.9.

**Disclosure of Confidential Public Health Information,
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Data Release Analysis Protocol⁴

Introduction

The Iowa Department of Public Health recognizes that the determination of whether or not a piece of information could result in the identification of an individual is not always straightforward. Therefore, the decision to release small count sizes based on confidential public health information, records, and data is complex and involves the consideration of many factors. The Data Release Analysis Protocol allows for the completion of a calculation to approximate the risk of an individual being identified if a small count size is released. The specific factors considered in this calculation are as follows:

- Statewide incidence or prevalence of the condition or behavior (how common)
- Geographic size
- Time interval for data presented
- Age range of individuals represented within data
- Sex distribution of individuals represented within data
- Race distribution of individuals represented within data

The procedure below provides step by step instructions on how to implement and evaluate the results of the Data Release Analysis Protocol. As a general principle, the Data Release Analysis Protocol demonstrates how common demographic variables interact with each other to make the unintentional identification of an individual more or less likely. The equation can be manipulated to allow the release of desired information by broadening categories of least importance to your message. For example, this protocol may allow for the release of detailed race and ethnicity information by broadening the described geographic area or increasing the number of years of data. Additional examples can be found on pages 20 through 24 of this policy. Please note that all examples used in this document are fictional.

This protocol considers the most commonly used demographic variables. Other descriptors (for example: language spoken, sexual orientation, detailed income breakdowns, occupation, education level, insurance status, immigration status, country of origin, military service, and others) may be just as or more identifying than those described in these pages. It may be appropriate to multiply the final answer of the protocol by 1/2 for each additional identifier that is provided. Because it is not possible to outline every possible additional identifier, Data Users and the Data Management and Health Equity Program should do this at their discretion. A list of additional considerations for the release of small

⁴ The Iowa Department of Public Health's Data Release Analysis Procedure has been adapted from the following sources: Alaska Section of Epidemiology Confidentiality Policies and Procedures and Data Release Protocols, November 2018 (available here: http://dhss.alaska.gov/dph/Epi/Documents/confidentiality/SOE_ConfidentialityPPData.pdf), California Department of Health Care Services Data De-identification Guidelines Version 2.0, November 2016 (available here: <https://www.dhcs.ca.gov/dataandstats/Documents/DHCS-DDG-V2.0-120116.pdf>), and State of New Hampshire, Division of Public Health Services, Health Statistics and Data Management Section Guidelines for the Public Release of Public Health Data, April 2016 (available here: <https://www.dhhs.nh.gov/dphs/hsdm/documents/publichealthdata.pdf>).

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count sizes can be found in **Appendix D**. All requests for the release of small count sizes ($n \leq 5$) through the use of the Data Release Analysis Protocol should be emailed to the IDPH Data Sharing Coordinator, the Director of Data Management and Health Equity, or to RERC@idph.iowa.gov.

Protocol

1. For statistical or aggregate data, if the count (numerator) is 6 or greater AND the total population (denominator) is 100 or greater AND a count of less than 6 cannot be derived through simple math when data is presented in a table, the value can be released publicly. Do not continue with this procedure.

2. If any of the following situations apply, please consider their impact on data release before proceeding:
 - a. Iowa Youth Survey data cannot be released when counts sizes are $n \leq 10$ due to informed consent documents provided to parents, students, and schools.
 - b. Behavioral Risk Factor Surveillance System (BRFSS) data cannot be released for a geographic region of county or smaller without approval from the BRFSS Program due to limitations in sampling methodology for small geographic areas.
 - c. Pregnancy Risk Assessment Monitoring System (PRAMS) data cannot be released for a geographic region of county or smaller without approval from the PRAMS Program due to limitations in sampling methodology for small geographic areas.
 - d. Any releases of data received through a data sharing agreement, research agreement, or contract must first comply with all terms set forth in the agreement. The procedure below would apply after all conditions within the agreement are satisfied.

3. Begin the Data Release Analysis Protocol by completing the Data Release Analysis Table (see Table 1 below) for your intended data release. Do this by replacing a-f in the Data Release Analysis Table with the appropriate numerical values as provided within Tables 3-1 through 3-6. See Table 2 for an example of a completed Data Release Analysis Table.

Table 1			
Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence		Scoring criteria within Table 3-1	a
Population Size		Scoring criteria within Table 3-2	b
Time Interval		Scoring criteria within Table 3-3	c
Age Range Distribution		Scoring criteria within Table 3-4	d
Sex/Gender Distribution		Scoring criteria within Table 3-5	e
Race/Ethnicity Distribution		Scoring criteria within Table 3-6	f
Total Score		(a)(b)(c)(d)(e)(f)=	X
Release (Y/N)?	If $X \geq 1$, release data, If $X < 1$, do not release data		

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Table 2: Example			
Example: Two Iowa children aged 1-14 years had a hospital visit for asthma in 2018.			
Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	Asthma Hospitalizations - Incidence rate of 301 per 100,000	Common	1
Population Size	Iowa	Statewide	5
Time Interval	2018	1 yr	1
Age Range Distribution	1 - 14	5 to 19 year range	1/2
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	All Races	All	1
Total Score	$(1*5*1*1/2*1*1)=$		2.5
Release (Y/N)?			Yes

3-1. Using the scoring criteria in Table 3-1, assign a score for the commonality of the situation represented within the intended data release. This can be done through incidence, prevalence, or statewide count of events. Notice that deaths from any cause are treated differently from other data sources. This is due to the large amount of publicly available information within obituaries.

Table 3-1: Incidence or Prevalence of Condition/Behavior		
Numerator Condition	Description	Assigned Score
Death (This score should be used anytime releasing data about death, regardless of the cause).	Death	1/2
Rare Condition, Behavior, or Event (This score should generally be used when a condition or behavior has a statewide incidence or prevalence rate of less than 6 per 100,000 population in the year of data release. This score should also be used in situations when 190 or fewer events occurred statewide within the year for the data release).	Rare	1/2
Common Condition, Behavior, Event (This score should generally be used when a condition or behavior has a statewide incidence or prevalence rate of 6 or greater per 100,000 population in the year of data release. This score should also be used for events when more than 190 events occurred statewide within the year for the data release).	Common	1

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3-2. Using the scoring criteria in Table 3-2, assign a score for the population size of the geographic area for which the data will be released. This should include individuals of all ages, sexes, races, and ethnicities, even if data release is only for a specific subset of the geographic region’s population. These variables are accounted for elsewhere within the protocol. Population estimates can be located on the Iowa State Data Center website (<https://www.iowadatacenter.org/>). Data for geographic regions of less than 300 should not typically be released. Please skip directly to **Appendix D** if wanting to release data for smaller geographic regions.

Table 3-2: Population Size for Geographic Region		
Population Size	Description	Assigned Score
301 to 1,000	301 to 1,000	1/4
1,001 to 3,000	1,001 to 3,000	1/2
3,001 to 20,000	3,001 to 20,000	1
20,001 to 50,000	20,001 to 50,000	2
50,001 to 100,000	50,001 to 100,000	3
100,001 and up to statewide population	100,001 to state	4
Statewide (3.156 million)	Statewide	5

3-3. Using the scoring criteria in Table 3-3, assign a score for the time interval or reporting period for which the data will be released. Data for time intervals of less than one month should not typically be released. Please skip directly to **Appendix D** if wanting to release data for smaller time intervals.

Table 3-3: Time/Reporting Period		
Time/Reporting Period	Description	Assigned Score
1 month (Example: June of 2019)	1 mo	1/12
3 months (Example: First quarter of 2019)	3 mo	3/12
1 Year (Example: 2019)	1 yr	1
2 Years (Example: 2018-2019)	2 yr	2
3 Years (Example: 2017-2019)	3 yr	3
4 Years (Example: 2016-2019)	4 yr	4
5 or More Years (Example: 2015-2019)	5+ yr	5

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3-4. Using the scoring criteria in Table 3-4, assign a score for the age range of individuals included in your intended data release. This scoring criteria is based on the number of years spanning the age range of individuals represented within the data. In the event that a table, chart, graph, or spreadsheet includes multiple age ranges, use the scoring for the smallest/narrowest age range (lowest score). Note: Consider an upper age limit of 100 years when presenting data at the top end of the age scale. For example, 65+ would be an age grouping of 35 years and 85+ would be an age grouping of 15 years.

Table 3-4: Age Range		
Age Range	Description	Assigned Score
Single Age or Single Grade in School (For example: infant, 1 year old, 14 year old, 30 year old, second graders, etc.)	Single Age	1/8
Two, Three, or Four Year Age Range (For example: 1-3 year olds, 3-5 year olds, 12-15 year olds, 18-21 year olds)	2,3, or 4 year range	1/4
Five Years to 19 Years Age Range (For example: All children, 0-4 year olds, 1-14 year olds, 15-24 year olds, 85+ years)	5 to 19 year range	1/2
20 or More Years Age Range (For example: Adults, 25-44 year olds, 45-64 year olds, 65+ years)	20+ year range	1

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3-5. Using the scoring criteria in Table 3-5, assign a score for the sex or gender distribution of individuals included in your intended data release.

Table 3-5: Sex or Gender Distribution		
Sex or Gender	Description	Assigned Score
<p>Male/Female/Any Additional Category(ies) (if describing sex) or Man/Woman/Any Additional Category(ies) (if describing gender)</p> <p>(This score should be used when tables/graphs/figures break data down into sex or gender categories that are further disaggregated than male/female. Examples are male/female/not determined and man/woman/transgender/genderqueer/another gender identity. This score should also be used when the intended data release describes transgender men, transgender women, genderqueer, gender neutral, non-binary, or another gender identity not described as man or woman.)</p>	3+ Categories	1/4
<p>Male/Female (if describing sex) or Man/Woman (if describing gender)</p> <p>(This score should be used when tables/graphs/figures break data down into male and female categories OR when the intended data release includes only males or only females).</p>	2 Categories	1/2
<p>All sexes or all genders</p> <p>(This score should be used when explicitly stating that all sexes or genders are included or when no information about sex or gender is provided and it can be assumed that all sexes or genders are included.)</p>	All	1

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3-6. Using the scoring criteria in Table 3-6, assign a score for the race and/or ethnicity distribution for your data release scenario. The scoring below is based on 2018 US Census population estimates for Iowa and may change in the future as the demographic profile of Iowa changes.

Table 3-6: Race/Ethnicity Distribution		
Race or Ethnicity	Description	Assigned Score
<p>Race/ethnicity disaggregation within a table/graph/figure or single race that include any of the following (regardless of other categories included):</p> <ul style="list-style-type: none"> • American Indian and Alaska Native, • Native Hawaiian and Other Pacific Islander, • Hispanic Black or African American, • Hispanic American Indian/Alaska Native, • Hispanic Asian, • Hispanic Native Hawaiian/Other Pacific Islander, • Hispanic 2 or More Races, • Non-Hispanic American Indian or Alaska Native, • Non-Hispanic Native Hawaiian or Other Pacific Islander 	Detailed	1/4
<p>Race/ethnicity disaggregation within a table/graph/figure or single race that include any or all of the following with <i>no</i> additional categories:</p> <ul style="list-style-type: none"> • White, • Black or African American, • Asian, • 2 or More Races, • Other • All Hispanic or Latino, • All Non-Hispanic • Non-Hispanic White, • Non-Hispanic Black or African American, • Non-Hispanic Asian, • Non-Hispanic Mixed or Multiple Races (2 or more races), 	General	1/2
<p>All races, all ethnicities</p> <p>(This score should be used when no disaggregation by race or ethnicity is completed and when no race/ethnicity information is given.)</p>	All	1

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4. After assigning scores for each of the six characteristics, **multiply** (do not add) the six assigned values within the score column. Place the answer in the total score box of the Data Release Analysis Table. See example below.

Example: Two Iowa children aged 1-14 years had a hospital visit for asthma in 2018.			
Table 4: Example			
Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	Asthma Hospitalizations - Incidence rate of 301 per 100,000	Common	1
Population Size	Iowa	Statewide	5
Time Interval	2018	1 yr	1
Age Range Distribution	1 - 14	5 to 19 year range	1/2
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	All Races	All	1
Total Score	$(1*5*1*1/2*1*1) =$		2.5
Release (Y/N)?			

5. Based on the total score, determine whether or not the data within your current scenario can be released.
- a. A score of 1 or greater indicates that the data can be released without suppression or a data sharing agreement, research agreement, or data sharing terms within a contract. Data Users should still confirm appropriateness of release with their supervisors, as appropriate.
 - b. A score of less than one indicates that the data cannot be released unless proper suppression is applied, a data sharing agreement, research agreement, or data sharing terms within a contract are executed, or a formal exception from the IDPH State Medical Director/State Epidemiologist according to the process outlined within **Appendix D**.

Example: Two Iowa children aged 1-14 years had a hospital visit for asthma in 2018.			
Table 5: Example			
Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	Asthma Hospitalizations - Incidence rate of 301 per 100,000	Common	1
Population Size	Iowa	Statewide	5
Time Interval	2018	1 yr	1
Age Range Distribution	1 - 14	5 to 19 year range	1/2
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	All Races	All	1
Total Score	$(1*5*1*1/2*1*1) =$		2.5
Release (Y/N)?	Yes		

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6. If Data Users disagree with the results of the Data Release Analysis Protocol and would like the scenario reviewed by the IDPH State Medical Director/State Epidemiologist, please refer to **Appendix D** below.

**Disclosure of Confidential Public Health Information,
Records, or Data Policy – Appendix D**

**Procedure for Requesting an Exemption from State Medical
Director/Epidemiologist**

1. To request an exception to the Data Release Analysis Protocol from the IDPH State Medical Director/State Epidemiologist, the following procedures shall be followed:
 - a. Send an email to the IDPH State Medical Director/State Epidemiologist and copy the following individuals: Deputy State Epidemiologist, Director of Data Management and Health Equity, and Data Sharing Coordinator. This email shall have the subject line: Approval Requested for Exemption to Data Release Policies
 - b. In the body of the email, include the following information:
 - i. Description of data to be released
 - ii. Description of how and where the data will be released (for example: within report, on webpage, to media, etc.)
 - iii. Explanation for why the release is necessary to improve and protect the health of Iowans. This explanation should clearly outline why providing a suppressed value is not sufficient.
 - iv. Explanation for how this release will not violate the confidentiality of individuals
 - v. Results of the Data Release Analysis Protocol (See **Appendix C**)
 - vi. Any additional information requested by the State Medical Director/State Epidemiologist

Contacts for Assistance		
Position	Name	Email
State Medical Director/State Epidemiologist	Caitlin Pedati, MD, MPH, FAAP	caitlin.pedati@idph.iowa.gov
Deputy State Epidemiologist	Ann Garvy, DVM, MPH, MA	ann.garvey@idph.iowa.gov
Director of Data Management and Health Equity	Betsy Richey, PhD, MPH	betsy.richey@idph.iowa.gov
Data Sharing Coordinator	Kelsey Feller, MPH	kelsey.feller@idph.iowa.gov

Last edited date: 10/1/19

**Disclosure of Confidential Public Health Information,
Records, or Data Policy – Appendix E**

**Additional considerations for determining the potential for indirectly identifying
an individual based on the release of small count sizes:**

The following are not required to be considered within the Data Release Analysis Protocol. However, Data Users and the Data Management and Health Equity Program should be aware of the following concepts, and may make the decision to suppress or withhold small count sizes for these reasons.

1. The Data Release Analysis Protocol considers the most commonly used demographic variables. Other descriptors (for example: language spoken, sexual orientation, detailed income breakdowns, occupation, education level, insurance status, immigration status, country of origin, current or former military service, and others) may be just as or more identifying than those described in these pages. It may be appropriate to multiply your final answer from the Data Release Analysis Protocol by 1/2 for each additional identifier that is provided. Because it is not possible to identify every possible additional identifier, Data Users and the Data Management and Health Equity Program should do this at their discretion.
2. For the purpose of the Data Release Analysis Protocol, no distinction is made between the geographic region of incidence versus the geographic region of residence. However, Data Users should be aware that providing data for geographic region of residence is generally a larger concern for confidentiality because of the high number of publicly available records that identify an individual's home address. Exceptions to this may occur when a highly publicized or high profile incident or accident occurs, in which case the geographic region of incidence may be more identifying.
3. There may be situations when despite the fact that a data release includes all ages, all sexes, or all races/ethnicities, there are reasons to believe that the majority of individuals included within the small number are of a specific sex, race, or ethnicity category. For example sickle cell disease is most common in Black or African American individuals, cystic fibrosis is most common in white individuals, breast cancer is most common in females, and heart attacks are most likely to occur in adults and not children. While it is not possible to be aware of all of these situations, Data Users should consider them when they are aware of these circumstances.
4. There are some circumstances when releasing a large number is equally concerning for indirect identification than a small number. For example, if 27 students within a class report that they have not used alcohol in the last 30 days and we know that the class size is 30, we unintentionally released that 3 students within the class have used alcohol in the last 30 days. Likewise, if we state that 100 people that attended a wedding suffered from a food-borne illness and there were only 110 people total at the wedding, the confidentiality of those 100 wedding guests could be compromised. Use caution anytime reporting in situations when a number released represents a large proportion of the total population.
5. Some health conditions, events, and behaviors are apparently visible. Some are almost impossible to identify unless an individual chooses to disclose the information. For example,

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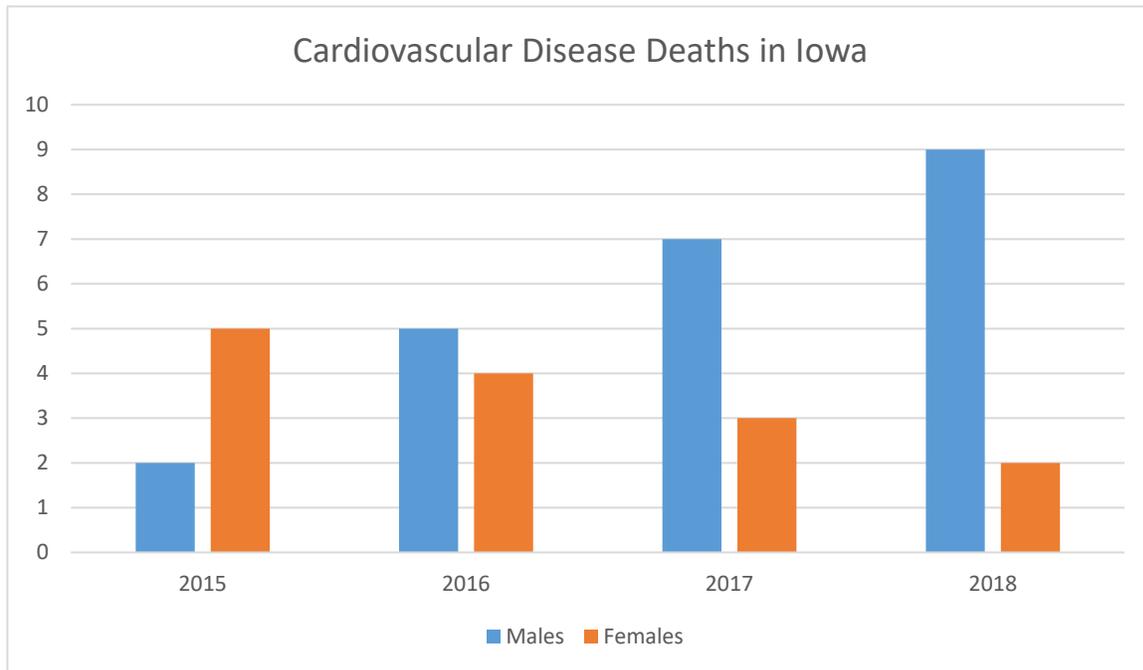
obesity, varicella (chicken pox), having an ambulance arrive at your residence (EMS runs), pregnancy, or smoking are examples of visible behaviors, events, or conditions that may increase the likelihood of unintentional identification. Other examples such as whether or not an individual has received a vaccination or conditions such as diabetes or heart disease are less visible. Data Users may wish to consider using additional precautions for visible conditions or traits.

6. At times, Data Users may wish to release multiple tables from the same dataset. Data Users should be aware that this can increase the likelihood of unintentional identification of an individual. Because of this, Data Users should consider the full body of information they have released on a topic and known sources from other agencies when making data release decisions.
7. This document speaks to protecting the confidentiality of Iowans through appropriate data use. There are times when data should not be released due to concerns with reliability, validity, or specific sampling methodologies. Those situations are beyond the scope of this policy, but are still of extreme importance. Data Users should consult epidemiologists and data owners when questions about this arise.

**Disclosure of Confidential Public Health Information,
Records, or Data Policy – Appendix F**

Additional Examples⁵: Data Release Analysis Protocol

Example 1:



Example: Cardiovascular disease deaths in Iowa, 2015-2018			
Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	Death	Death	1/2
Population Size	Iowa	Statewide	5
Time Interval	2015, 2016, 2017, 2018	1 yr	1
Age Range Distribution	All Ages	All	1
Sex/Gender Distribution	Male/Female	2 Categories	1/2
Race/Ethnicity Distribution	All Races	All	1
Total Score	$(1/2 * 5 * 1 * 1 * 1/2 * 1) =$		1.25
Release (Y/N)?			Yes

Notes: Even though four years of data are presented, the time interval unit for each small count is a single year.

⁵ Note that all examples used within this policy are fictional.

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Example 2:

E. Coli Cases in Iowa, 2018				
	Floyd County	Polk County	Bremer County	Warren County
Non-Hispanic, White	2	3	2	3
Non-Hispanic, Black	5	2	3	2
Hispanic	2	1	4	2
Other	6	4	2	3

Example: E. Coli Cases in Floyd County, 2018			
Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	E. Coli (9.85/100,000)	Common	1
Population Size	Floyd County – 15,761	3001 to 20,000	1
Time Interval	2018	1 yr	1
Age Range Distribution	All Ages	All	1
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	Black, White, Hispanic, Other	General	1/2
Total Score	(1*1*1*1*1*1/2)=		
Release (Y/N)?			No

Example: E. Coli Cases in Polk County, 2018			
Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	E. Coli (9.85/100,000)	Common	1
Population Size	Polk County – 487,204	100,000 to state	4
Time Interval	2018	1 yr	1
Age Range Distribution	All Ages	All	1
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	Black, White, Hispanic, Other	General	1/2
Total Score	(1*1*1*1*1*1/2)=		2
Release (Y/N)?			Yes

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Example: E. Coli Cases in Bremer County, 2018			
Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	E. Coli (9.85/100,000)	Common	1
Population Size	Bremer County – 24,947	20,001 to 50,000	2
Time Interval	2018	1 yr	1
Age Range Distribution	All Ages	All	1
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	Black, White, Hispanic, Other	General	1/2
Total Score	(1*1*1*1*1*1/2)=		1
Release (Y/N)?			Yes

Example: E. Coli Cases in Warren County, 2018			
Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	E. Coli (9.85/100,000)	Common	1
Population Size	Warren County – 51,056	50,001 to 100,000	3
Time Interval	2018	1 yr	1
Age Range Distribution	All Ages	All	1
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	Black, White, Hispanic, Other	General	1/2
Total Score	(1*1*1*1*1*1/2)=		1.5
Release (Y/N)?			Yes

Notes: In this example, the size of the county of residence impacts the release decision. The small counts can be released for all counties except Floyd. This is demonstrated below, with the small counts for Floyd County suppressed in the final table.

E. Coli Cases in Iowa, 2018				
	Floyd County	Polk County	Bremer County	Warren County
Non-Hispanic, White	*	3	2	3
Non-Hispanic, Black	*	2	3	2
Hispanic	*	1	4	2
Other	6	4	2	3

Example 3:

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Example: 2 Iowans had a Hepatitis C Virus (HCV) diagnosis in 2017.

Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	HCV (45.3 per 100,000)	Common	1
Population Size	Iowa	Statewide	5
Time Interval	2017	1 yr	1
Age Range Distribution	All Ages	All	1
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	All races/ethnicities	All	1
Total Score	(1*5*1*1*1*1)=		5
Release (Y/N)?			Yes

Example 4:

Example: 2 Iowans who identify as American Indian/Alaska Native had a HCV diagnosis in 2017.

Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	HCV (45.3 per 100,000)	Common	1
Population Size	Iowa	Statewide	5
Time Interval	2017	1 yr	1
Age Range Distribution	All Ages	All	1
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	American Indian/Alaskan Native	Detailed	1/4
Total Score	(1*5*1*1*1*1/4)=		1.25
Release (Y/N)?			Yes

Example 5:

Example: 2 Iowans in Keokuk County who identify as American Indian/Alaska Native had a HCV diagnosis in 2017.

Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	HCV (45.3 per 100,000)	Common	1
Population Size	Keokuk County – 10,149	3001 to 20,000	1
Time Interval	2017	1 yr	1
Age Range Distribution	All Ages	All	1
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	American Indian/Alaskan Native	Detailed	1/4
Total Score	(1*1*1*1*1*1/4)=		0.25
Release (Y/N)?			No

Example 6:

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Example: 2 Iowans in Polk County who identify as American Indian/Alaska Native had a HCV diagnosis in 2017.

Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	HCV (45.3 per 100,000)	Common	1
Population Size	Polk County – 481,086	100,000 to state	4
Time Interval	2017	1 yr	1
Age Range Distribution	All Ages	All	1
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	American Indian/Alaskan Native	Detailed	1/4
Total Score	(1*4*1*1*1*1*1/4)=		1.00
Release (Y/N)?			Yes

Example 7:

Data Release Analysis Table			
Characteristic	Current Scenario	Description	Score
Incidence/Prevalence	Death	Death	1/2
Population Size	Iowa	Statewide	5
Time Interval	2017	1 yr	1
Age Range Distribution	Children	5 to 19 Year Range	1/2
Sex/Gender Distribution	All sexes	All	1
Race/Ethnicity Distribution	Black or African American	General	1/2
Total Score	(1/2*5*1*1/2*1*1/2)=		0.625
Release (Y/N)?			No

Director's Signature

Date