

## Background

Data is essential to core public health functions and release outside of the Public Health and Safety Division within the Montana Department of Health and Human Services (PHSD) can be necessary to effectively achieve our mission to protect and improve the health of every Montanan through evidence-based action and community engagement. However, public health data often includes both personally identifiable information and protected health information which create a legal and moral obligation to protect the privacy of the individuals represented in the data. This policy seeks to maintain individual privacy while still achieving public health goals and to ensure that the release of public health data complies with applicable state and federal privacy laws.

## Scope

This policy governs data released by the PHSD during the course of normal operations and with the purpose of disease control and prevention. It also covers public data requests from the media or citizens. It does not cover the release of data for research.

## Definitions

- **Cell suppression:** A method of protecting confidentiality by omitting the calculated value of a particular cell of a data table due to statistically unstable estimates or risk of identification, which can be more common in presence of small numbers.
- **Complementary suppression:** A method of protecting confidentiality related to cell suppression, whereby the calculated values of any additional components of a table (e.g., row or column total, another cell in that row or column) that would allow a person to calculate the value of a suppressed cell are also suppressed/omitted.
- **Confidentiality:** The practice of keeping data or information private and prohibiting disclosure to unauthorized persons or processes.
- **De-identified public health data:** public health data that has all identifying or potentially identifying information removed per the “Safe Harbor” or “Expert Determination” methods specified in HIPAA.
- **Minimum necessary standard:** The concept of only releasing or disclosing the information necessary to satisfy a particular purpose or carry out a function and nothing more.
- **Personal identifying information:** Information which directly identifies a person including name, date of birth, address, and telephone number. This is different from Protected Health Information, as defined by [HIPAA](#).
- **Population size:** The total number of people included in the group from which the data is taken. The group can be defined by the geographic region, the total time period, and demographic sub-groups, including those at risk for a disease. For example, *County X* might have 10,000 people, but if the data is for childhood lead poisoning, the population would be smaller (*i.e.*, only children). Conversely, if the time period were 24 months, the population size would be 20,000.
- **Protected Health Information:** any health information that can identify an individual. This information can relate to a patient’s past, present, or future health, and can include demographic information.
- **Privacy:** The right to not have one’s personal identifying information or protected health information released or disclosed without specific consent or permissible uses of the data in order to perform essential public health functions in accordance with applicable state and federal privacy laws.
- **Probable Identification:** The ability to identify a specific patient or group by combining data from

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several publicly available data sources.

- Statistical instability: The property of statistical estimates being highly influenced by a small amount of data.

### Release of Personally Identifiable Information for Disease Control Purposes

Public Health data containing personally identifiable information may be released following the specific provisions in both the Government Health Care Information Act ([Mont. Code Ann. § 50-16-603](#) (3) (5) and (7)) and the Health Insurance Portability and Accountability Act.

In brief, the Government Health Care Information Act allows for public health data containing personally identifiable information may be released to:

- Local and tribal public health agency(ies) where the case(s) reside(s); OR
- Another state or local public health agency(ies), including those in other states, that have responsibility for disease prevention or control activities involving the case(s); OR
- Medical personnel directly involved in the medical care of the case(s).

The release of any case level data (identified or not) for research or other activities not directly related to disease control is governed by the Public Health and Safety Division Data Sharing Policy (not yet published).

### Release of Public Health Data with no Directly Identifying Information

State and federal statutes that govern the confidentiality and disclosure of public health data, including, but not limited to, the Health Insurance Portability and Accountability Act (HIPAA), the Government Health Care Information Act (Mont. Code Ann. § 50-16-603), and the Vital Statistics Act ([Mont. Code Ann. § 50-15-122](#)). Generally, these statutes allow the release of public health data for statistical purposes, if no identification of individuals can be made from the information released. However, each law has slightly different definitions and some data may be covered by multiple statutes. See Appendix A for which laws apply to each data system housed within PHSD.

Additionally, even when personally identifying information has been removed, data can be presented in ways that pose a risk of re-identifying the case. The criteria below generally [follow de-identification standards under HIPAA](#) as outlined in guidance from Office for Civil Rights and are intended to ensure the risk of patient confirmation and probable identification are minimized while also ensuring the utility of the release of data. Below is a discussion of the benefits and harms that should be considered and criteria for when public health data may be released by:

1. Type of recipient(s) for the information;
2. Population size or geographic region; and
3. Time period.

### Considerations for Data Release or Suppression

#### Individual Confidentiality

Presenting aggregate data for small geographical areas, granular time periods (e.g., single diagnosis year), or by other levels of stratification (e.g., race/ethnicity, sex, rare conditions) could lead to the presentation of small case counts, which in turn could allow identification of individual patients. In small

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communities, where instances of the disease/condition are relatively rare (by virtue of the population size), small numbers may allow for patient confirmation, whereby some characteristics of the patient are known by other members of the community and this knowledge allows for the identification of this patient in the data. Patient confirmation poses a threat to confidentiality as it may provide details about the patient's health status that were previously unknown. This may be particularly harmful when the nature of the data or diagnosis may be stigmatizing, such as sexually transmitted infections, or mental health conditions. Small numbers may also pose a risk of probable identification when the characteristics of the count are combined with other publicly available data, such as census data or social media accounts. Probable identification is also problematic even though it is not a definitive identification of a patient or group.

### Appropriate Interpretation of Statistics

Small case numbers and small populations may lead to statistically unstable estimates with wide confidence intervals. Statistically unstable estimates are likely to be misinterpreted by audiences with little or no understanding of statistics, and lead to inappropriate concern, interventions and/or allocation of resources. The focus on statistically unstable point estimates by policymakers and the media can have important consequences for communities – geographic or otherwise. Unstable estimates are likely to change dramatically depending on the sample, and relying on these estimates for developing policies or allocating resources could lead to inappropriately targeting one community over another for provision of services. Unstable estimates can also give the impression that health behaviors, conditions, or issues around health services are problematic when they are not and can lead to unwarranted concern. To avoid these problems unstable estimates should be suppressed unless they are able to be distributed with very clear explanation of the limitations of the data and proper interpretation.

### Equitable Access to Public Health Data

Despite these important concerns of maintaining confidentiality and limiting distribution of unstable statistics, there are harms associated with suppressing data. In some cases the small amount of data for a given population represents 100% or nearly 100% of that population. Thus, there is no way to augment the available sample and consistent suppression over time due to small numbers may mask real instances of health disparities. The injustices related to not monitoring trends in small populations may outweigh confidentiality concerns. It is critical that we find ways to study small populations who are experiencing health disparities in a way that accurately represents them and maintains their confidentiality. These populations have unique characteristics and needs that will be masked when their data are combined with the data of larger groups. Small communities need to have access to statistics that represent them as much as possible. The benefits and harms of very granular data need to be considered carefully.

Additionally, some public health events, for example, a case of measles, demand quick action and communication of small numbers for effective control measures to be put in place. In these situations, the risk of continued spread of disease may outweigh the risk of breaching confidentiality.

### Criteria for Reporting Public Health Data

The first consideration of whether and how to release public health data is based on who is receiving the information.

#### Release of de-identified public health data to public health agencies/officials

- a. To the local and tribal public health agency(ies) where the case(s) reside(s) or that have

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responsibility for disease control activities: **no restrictions**. Local and tribal public health agencies may receive case-level data or summary statistics pertaining to their community in order to effectively carry out their responsibilities for disease control and prevention as outlined in applicable state and federal statute (See Appendix A).

- b. To the Centers for Disease Control and Prevention (CDC) for reporting nationally notifiable conditions: **release must only include the minimum data necessary to accomplish the public health purpose**.
- c. To other divisions/personnel within the Department of Public Health and Human Services: **no restrictions if there is legitimate programmatic interest and the recipient(s) acknowledge(s) that release of the data are subject to these guidelines**.

Release<sup>1</sup> of de-identified public health data to the public or other non-public health agencies of local, state, or federal government.

The release of any case level data for research or other activities not directly related to disease control is governed by the Public Health and Safety Division Data Sharing Policy. The following guidelines apply to summary statistics only.

It is important to note that there are no national standards for data suppression. Below is one strategy for aggregation to ensure privacy is protected when counts or populations are small. Other strategies could be used after careful consideration but must follow statutory requirements of the data source from which the data is derived (See Appendix A).

Data released to the public or non-public health agencies must generally adhere to the following restrictions.

### *Limits to control for statistical stability*

PHSD staff should suppress rates based on less than 16 cases in most applications.<sup>2</sup> This approach is best for public facing dashboards or data query systems where users will be accessing rates with little or no discussion of limitations and little opportunity to provide guidance on interpretation of statistical significance. However, setting the strict limit of having at least 16 cases may prohibit any release of rates for small communities or for rare conditions even when using 5 or 10 years of data. To ensure equitable data access in these situations, programs can consider releasing rates with fewer than 16 cases as long as a measure of uncertainty is included with the rate and there is an opportunity to explain limitations of the data and provide clear guidance on how to interpret it. Explanations should consider the target audience and be written specifically for their needs and abilities.

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<sup>1</sup> through published reports, grant applications, grant progress reports, correspondence, newsletters, oral presentations, public meetings, telephone conversations, press releases or research projects in which the state health department is a participant.

<sup>2</sup> 16 cases is the limit used by CDC's National Programs for Cancer Registries and the National Cancer Institute. Many other national programs set the limit at 20 events (such as the CDC National Center for Health Statistics) but since national cancer data will be released at 16 events it was determined that the lower count was more appropriate.

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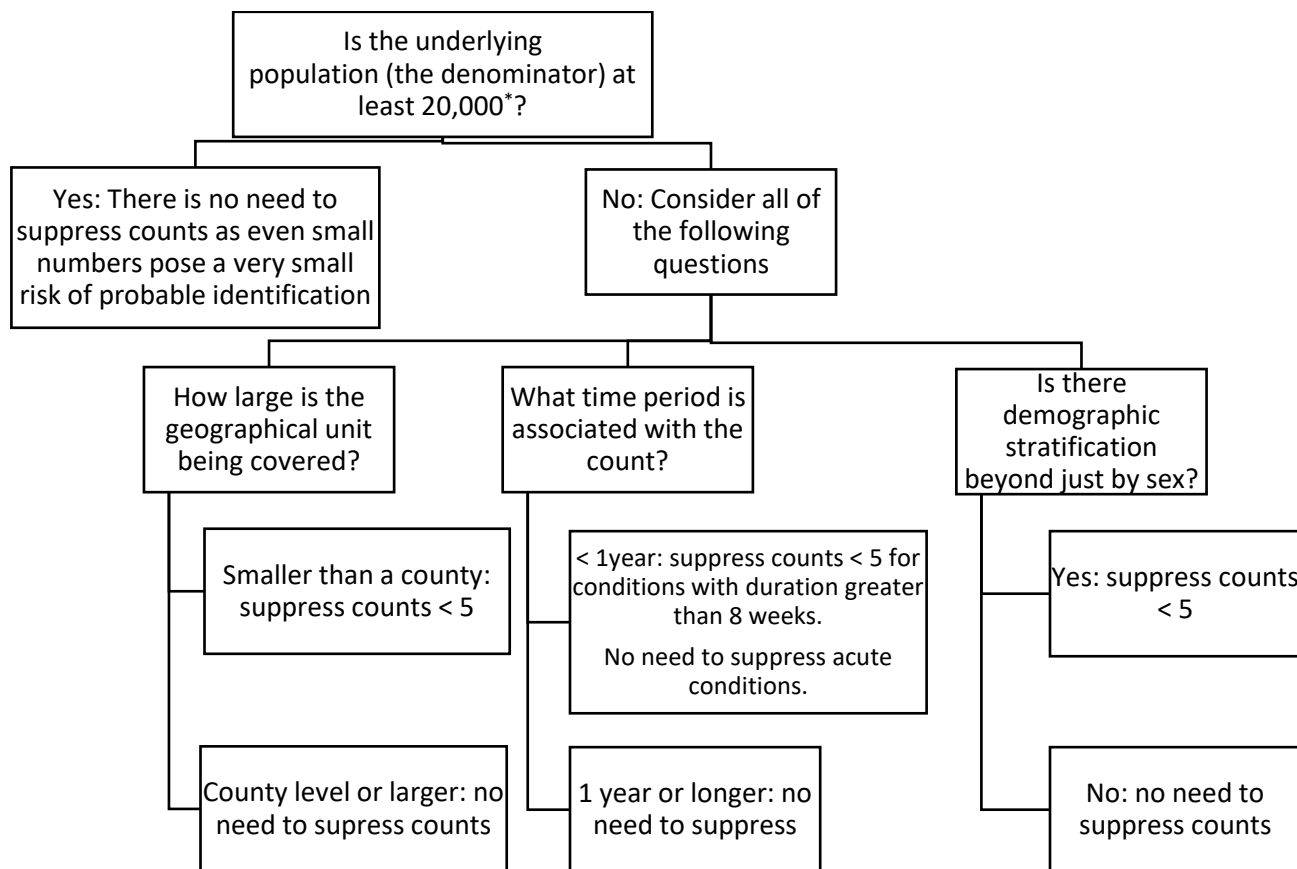
*Limits to protect confidentiality*

When releasing aggregate data, small counts (less than 5) could pose a threat to patient or group confidentiality. However, the level of risk is highly dependent on the overall size of the population the count is pertaining to and how specifically the count is described. A small count taken from a large population with no demographic description poses very low or no risk of probable identification. In contrast, a small count taken from a small population that is identified by a 5-year age group, sex, and race has a much higher risk of probable identification. Considering these dimensions when setting suppression criteria will allow for the maximum release of data without compromising confidentiality.

Additionally, it is highly recommended that release of small counts is coordinated with local and tribal health department officials to ensure state and local agencies are releasing comparable information.

The following decision tree can be used as a guide for determining when to suppress counts. When it is determined that a count should be suppressed, complementary suppression should also be employed to ensure the suppressed count cannot be determined using the other data in the report.

Figure. Decision tree for determining when to case suppress counts.



\*the minimum population size of 20,000 follows the HIPAA standard for determining whether a geographic area smaller than the state is considered identifying information.

The following criteria can be used to determine how much demographic information to release about a small number of cases (*i.e.*, when releasing case or death counts associated with an outbreak) (See

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Table).

1. When the population size is  $\geq 100,000$ :
  - a. Single year age can be released if  $< 89$  years. It should be released as a single category if age  $\geq 90$  years.
  - b. Sex may be released.
  - c. Race / ethnicity may be released.
  - d. Time period is not restricted.
  - e. Risk factors may be released.
  - f. Status of cases (dead or alive) may be released.
2. When the population size is 20,000 – 99,999:
  - a. Age should be grouped at least by five-year intervals and grouped as a single category if age  $\geq 90$  years.
  - b. Sex may be released.
  - c. Race / ethnicity may not be released.
  - d. Time period is not restricted.
  - e. Risk factors may not be released.
  - f. Status of cases (dead or alive) may be released.
3. When the population size is less than 20,000:
  - a. Age or age groups may not be released.
  - b. Sex may be released.
  - c. Race / ethnicity may not be released.
  - d. Risk factors may not be released.
  - e. Status of cases (dead or alive) may not be released.
  - f. If the number of cases should be for a time period:
    - i. Reporting period must be at least one year for any condition with a duration greater than eight weeks, such as chronic diseases, lead poisoning, tuberculosis, and AIDS.
    - ii. May be less than one year for acute conditions, such as measles, plague, pertussis, and hantavirus.

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Table. Summary of guidelines for release of public health data<sup>3</sup>

	<b>Population<sup>a</sup> ≥100,000 persons</b>	<b>Population<sup>a</sup> 99,999 to 20,000</b>	<b>Population<sup>a</sup> &lt;20,000</b>
<b>Age (years)</b>	Can release specific age if < 89  As a single category if ≥90	5-year age groups if <89  As a single category if ≥90	Cannot release
<b>Sex</b>	May be released <sup>b</sup>	May be released <sup>b</sup>	May be released <sup>b</sup>
<b>Race / ethnicity</b>	May be released <sup>b</sup>	Cannot release	Cannot release
<b>Time period<sup>c</sup></b>	May be released <sup>b</sup>	May be released <sup>b</sup>	For conditions with a duration greater than 8 weeks, must be ≥ 1 year (e.g., chronic disease, HIV/AIDS, tuberculosis)  No restriction for acute diseases
<b>Risk factors</b>	May be released <sup>b</sup>	Cannot release	Cannot release
<b>Cases status (alive / dead)</b>	May be released <sup>b</sup>	May be released <sup>b</sup>	Cannot release

<sup>a</sup> Population size could be the entire population of the state, region of the state, county, zip code, or census tract. Thus, defining the geographic region is the first step in defining the population size. The population size may be restricted to those at risk for a disease in a geographic region. For example, *County X* might have 10,000 people, but if the data is for childhood lead poisoning, the population would be smaller (*i.e.*, only children). Conversely, if the time period were 24 months, the population size would be 20,000.

<sup>b</sup> May be released is permissive and should not be interpreted to mean “is required to be released.” The release of the particular characteristic (*e.g.*, age, sex) is at the discretion of the releasing public health official or program.

<sup>c</sup> Time period is the unit of time in which the cases occurred, such as the previous one week, one month, one year, or the last 10 years.

When these criteria are met, programs can release data following standard review procedures and have no need for additional consultation. If these criteria are **not** met but the program staff believes the public health need or the benefit to the community is great enough to outweigh the risk to individual

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<sup>3</sup> These guidelines were taken from the Colorado Department of Public Health and Environment and edited for the needs of Montana.

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confidentiality, they should consult the State Epidemiologist, PHSD Public Health Physician, and PHSD Administrator to determine whether releasing the data is necessary and permissible under applicable state and federal privacy laws.



**Appendix A**

<b>Covered by HIPAA</b>	<b>Data System</b>	<b>Montana Code Annotated statute governing release</b>
<b>No</b>	Death Records	<p>Mont. Code Ann. § 50-15-121(4)            A certified copy or other copy of a death certificate must be issued upon request of any person.</p> <p>Mont. Code Ann. § 50-15-122(2)            The execution of a research agreement that protects the confidentiality of the information provided to a researcher in response to a written request is required for disclosure of information that may identify a person or institution named in a vital record or report. This agreement must be made in compliance with this chapter or rules adopted to implement this chapter. Each agreement must prohibit the release by the researcher of any information that might identify a person or institution, other than releases that may be provided for in the agreement.</p>
	Birth Certificates	<p>Mont. Code Ann. § 50-15-121(6)            This section may not be construed to permit disclosure of confidential information contained in a birth certificate for medical or health use or of information for statistical purposes only contained in a certificate of marriage or report of dissolution of marriage unless disclosure is specifically authorized by law for statistical or research purposes or unless ordered by a court.</p> <p>Mont. Code Ann. § 50-15-122(5)            Immediately upon the filing of a record with the department, the fact that a birth or death has occurred may be released to the public without restriction. Notwithstanding the restrictions provided in <b>50-15-121</b>, complete birth records may be released to the public 30 years after the date of birth. The department shall adopt rules that provide for the continued safekeeping of the records.</p> <p>Mont. Code Ann. § 50-15-122(2)            The execution of a research agreement that protects the confidentiality of the information provided to a researcher in response to a written request is required for disclosure of information that may identify a person or institution named in a vital record or report. This agreement must be made in compliance with this chapter or rules adopted to implement this chapter. Each agreement must prohibit the release by the researcher of any information that might identify a person or institution, other than releases that may be provided for in the agreement.</p>
	Marriage/Divorce	<p>Mont. Code Ann. § 50-20-122            (5)</p>

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		<p>(b) Upon the filing of a record of marriage with the clerk of the district court, information that may be released to the public without restriction is specifically limited to:</p> <p>(i) the names of the parties, the age of the parties, and their place of birth;</p> <p>(ii) the date and place of the marriage;</p> <p>(iii) the names and addresses of the parents of the parties;</p> <p>(iv) the name of the officiant; and</p> <p>(v) the type of ceremony.</p> <p>(c) Any other information contained in a marriage license application that is not authorized to be disclosed under subsection (5)(b) is considered confidential and is subject to the disclosure limitations and penalties provided in <b>50-15-114</b>.</p> <p>(d) Notwithstanding the restrictions provided in <b>50-15-121</b> and this section, the information contained in a marriage license and marriage certificate may be released to the public 30 years after the date of the marriage.</p> <p>(e) Upon the filing of a record of a dissolution of marriage with the clerk of the district court, that record may be released to the public without restriction unless designated confidential by the court. A record of dissolution of marriage designated confidential by the court may be provided to a federal, state, or local government agency upon request when the record is used solely in the conduct of the agency's official duties.</p>
	Tumor Registry	<p>Mont. Code Ann. § 50-15-704</p> <p><b>Confidentiality.</b> Information received by the department pursuant to this part may not be released unless:</p> <p>(1) it is in statistical, nonidentifiable form;</p> <p>(2) the provisions of Title 50, chapter 16, part 6, are satisfied;</p> <p>(3) the release or transfer is to a person or organization that is qualified to perform data processing or data analysis and that has safeguards against unauthorized disclosure of that information;</p> <p>(4) the release or transfer is to a central tumor registry of another state and is of information concerning a person who is residing in that state; or</p> <p>(5) the release is to a health care practitioner or health care facility that is providing or has provided medical services to a person who has or has had a reportable tumor.</p>
Yes	MIDIS	Government Healthcare Information Act (Mont. Code Ann. § 50-16-603 and 604)
	ImMTrax	Mont. Code Ann. § 50-16-603 and 604
	Emergency Medical Services (EMS) data	Mont. Code Ann. § 50-16-603 and 604

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	Syndromic Surveillance	Mont. Code Ann. § 50-16-603 and 604
	State Trauma Registry	<p>Mont. Code Ann. § 50-16-603 and 604          Mont. Code Ann. § 50-6-415</p> <p>(1) Data in a health care facility's hospital trauma register and reports developed from that data pertaining to quality of trauma care may be given by the facility only to:</p> <ul style="list-style-type: none"> <li>(a) the facility's peer review committee;</li> <li>(b) the regional trauma care advisory committee of the region in which the facility is located;</li> <li>(c) the trauma care committee; or</li> <li>(d) the department.</li> </ul> <p>(2) Data in the state trauma register and hospital trauma registers is not subject to discovery in a civil action and may not be introduced into evidence in a judicial or administrative proceeding.</p> <p>(3) Data and reports concerning peer review, quality improvement, or the quality of the trauma care provided by a health care facility or a health care provider that are produced by a regional trauma care advisory committee or the trauma care committee or provided by a health care facility to a regional trauma care advisory committee or the trauma care committee, as well as the proceedings of those committees concerning peer review and quality improvement, are not subject to discovery in a civil action and may not be introduced into evidence in a judicial or administrative proceeding.</p> <p>(4) A statistical report on trauma and trauma care developed by the department that does not identify specific health care facilities, health care providers, or patients is not confidential and is considered public information.</p> <p>(5) A statistical report developed by a health care facility from information in its hospital trauma register that does not pertain to peer review or quality improvement is not confidential and is considered public information.</p> <p>(6) Information in a department record or report that is used to evaluate and improve the quality of emergency medical service and trauma care by a health care facility or emergency medical service is not subject to discovery and may not be introduced in evidence in a judicial or administrative proceeding.</p> <p>(7) Information in a department record or report that is used to determine whether a health care facility will be designated or lose its designation as a trauma care facility is not confidential</p>

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		and is considered public information.
	Abortion	<p>Mont. Code Ann. § 50-20-110 (5)</p> <p>All reports and documents required by this chapter shall be treated with the confidentiality afforded to medical records, subject to such disclosure as is permitted by law. Statistical data not identifying any individual involved in an abortion shall be made public by the department annually, and the report required by subsection (4) of this section to be filed with the department shall be available for public inspection except insofar as it identifies any individual involved in an abortion. Names and identities of persons submitting to abortion shall remain confidential among medical and medical support personnel directly involved in the abortion and among persons working in the facility where the abortion was performed whose duties include billing the patient or submitting claims to an insurance company, keeping facility records, or processing abortion data required by state law.</p> <p>Mont. Code Ann. § 50-16-603 and 604</p>
	BRFSS, PNA	Mont. Code Ann. § 50-16-603 could apply if we have readily identifiable information on respondents.
	YRBS	YRBS data are available to PHSD staff through agreement with the Office of Public Instruction. This agreement governs all use and disclosure of YRBS data.
	MHDDS	MHDDS data are available to PHSD staff through agreement with the Montana Hospital Association. This agreement governs all use and disclosure of MHDDS data.

## Appendix B Crude Rate and Age-Adjusted Rate Calculation

Crude Rate=(Number of events/Total at risk population)\*constant

The constant is most commonly 100,000 but it may be any multiple of 10 that will produce a rate that is a whole number and makes sense for your population and event type.

Age-Adjusted Rate=Sum (age-group specific rate\*age-group weight from standard population)

In PHSD we routinely use the 2000 U.S. Standard population as the standard population in age-adjustment. See [CDC statistical notes for age adjustment](#) for the appropriate weights for different age-group structures.

### Using the Poisson Exact Method to Compute the 95% Confidence Interval for 16 to 99 Events

The Poisson Exact Method should be used to calculate 95% confidence intervals when the event count is less than 100.

Refer to Table 1 on the next page to look up the critical values corresponding to the number of events and use the upper and lower critical values to calculate the upper and lower bounds of the confidence interval.

*Example:*

If there were 52 events in a population of 129,936, the crude rate is  $(52/129,936) * 100,000 = 40.0 / 100,000$

*From the table below, the critical values for 52 events are:*

Lower critical value: 38.8

Upper critical value:68.2

Lower bound =  $(38.8/129,936) * 100,000 = 29.9$  Upper bound =  $(68.2/129,936) * 100,000 = 52.5$

**Table 1. Critical Values for Computing 95% Confidence Intervals for Small Numbers of Events by the Poisson Exact Method.**

Number of Events	95% CI: Lower Critical Value	95% CI: Upper Critical Value	Number of Events	95% CI: Lower Critical Value	95% CI: Upper Critical Value
16	9.1	26.0	58	44.0	75.0
17	10.0	27.2	59	44.9	76.1
18	10.7	28.4	60	45.8	77.2
19	11.4	29.7	61	46.7	78.4
20	12.2	30.9	62	47.5	79.5
21	13.0	32.1	63	48.4	80.6
22	13.8	33.3	64	49.3	81.7
23	14.6	34.5	65	50.2	82.8
24	15.4	35.7	66	51.0	84.0
25	16.2	36.9	67	51.9	85.1
26	17.0	38.1	68	52.8	86.2
27	17.8	39.3	69	53.7	87.3
28	18.6	40.5	70	54.6	88.4
29	19.4	41.6	71	55.5	89.6
30	20.2	42.8	72	56.3	90.7
31	21.1	44.0	73	57.2	91.8
32	21.9	45.2	74	58.1	92.9
33	22.7	46.3	75	59.0	94.0
34	23.5	47.5	76	59.9	95.1
35	24.4	48.7	77	60.8	96.2

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36	25.2	49.8	78	61.7	97.3
37	26.1	51.0	79	62.5	98.5
38	26.9	52.2	80	63.4	99.6
39	27.7	53.3	81	64.3	100.7
40	28.6	54.5	82	65.2	101.8
41	29.4	55.6	83	66.1	102.9
42	30.3	56.8	84	67.0	104.0
43	31.1	57.9	85	67.9	105.1
44	32.0	59.1	86	68.8	106.2
45	32.8	60.2	87	69.7	107.3
46	33.7	61.4	88	70.6	108.4
47	34.5	62.5	89	71.5	109.5
48	35.4	63.6	90	72.4	110.6
49	36.3	64.8	91	73.3	111.7
50	37.1	65.9	92	74.2	112.8
51	38.0	67.1	93	75.1	113.9
52	38.8	68.2	94	76.0	115.0
53	39.7	69.3	95	76.9	116.1
54	40.6	70.5	96	77.8	117.2
55	41.4	71.6	97	78.7	118.3
56	42.3	72.7	98	79.6	119.4
57	43.2	73.9	99	80.5	120.5
			100	81.4	121.6