COLORADO
Department of Public Health & Environment

Guidelines for Release of Disease Surveillance Data

Division of Disease Control and Public Health Response

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A. Background

Disease surveillance is an established component of public health disease control and prevention, and §25-1.5-102, §25-1-122 and §25-4-405, C.R.S. authorize the state Board of Health to promulgate rules concerning the required reporting of diseases and conditions of public health significance, without patient consent, by physicians, hospitals, and laboratories. Such diseases and conditions include epidemic and communicable diseases, environmental and chronic diseases, selected causes of morbidity and mortality, and cancer.

An important component of public health disease surveillance is the dissemination of data to appropriate local, state, and federal public health agencies, to providers and institutions that have reported cases, and to members of the public. All required disease reports made to state or local health agencies are strictly confidential. §25-1-122(4), C.R.S. governs the release of individual public health case reports. These statutes address the release of personal identifying information as well as surveillance data. For reportable conditions, §25-1-122(4)(a), C.R.S. allows for the release of medical and epidemiological information in a manner such that no individual person can be identified.

These guidelines are intended to address the release of disease surveillance data collected under Board of Health regulations. Other statutes, rules and policies may apply to other types of data (e.g., vital statistics, hospital discharge data) collected by the department and other Divisions may have alternative methods for protecting confidentiality. For example, when releasing birth and death data, any numerator less than three is suppressed. These guidelines are consistent with published privacy guidance.[1]

If data is received from an outside entity, the data use agreement with that entity must also be followed. These guidelines set standards for the release of data contained in disease surveillance reports and were developed primarily for promoting consistency in the release of data.

B. Definitions

- Disease surveillance data means data on reportable conditions other than name, date of birth, address and telephone number.
- Personal identifying information includes name, date of birth, address, and telephone number (which is different from protected health information, as defined by HIPAA).
- No restrictions means that all other data on the case(s) *besides* personal identifying information may be released without restrictions.

[1] Centers for Disease Control and Prevention. HIPAA Privacy Rule and Public Health. MMWR 2003;52:1-12 https://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm

- Population size could be the entire population of the state, a region of the state, a county, a 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 surveillance 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.

- Time period is the unit of time in which the cases occurred, such as the previous one month, one year, or the last 10 years.

- 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, gender) is at the discretion of the releasing public health official or program.

C. Release Of Personal Identifying Information For Disease Control Purposes

Current Board of Health regulations for communicable disease control and reporting of morbidity and mortality permit sharing of reported case data, including personal identifying information, between the state and the appropriate local health department. "Appropriate" in this context means the location of the public health problem or exposure or incident. For example, if a reported case of a communicable disease acquired the disease in one county but resides and could be contagious in another county, then it would be appropriate for the department to share case information with both local health agencies.

There are no set standards for the release of personal information for disease control purposes to physicians, hospitals, other state government agencies, etc. Managers should make a case-by-case judgment that release is necessary for the investigation and control of reportable conditions. If Department personnel need to release or are requested to release information on reportable conditions that contain personal identifiers, then one of two approaches could be used.

1. §25-1-122(4)(c), C.R.S states identifying data may be released if the department obtains written authorization from each subject to release his/her name to the requesting party. This approach may not always be practical or meet public health disease control needs.

2. §25-1-122(4)(b), C.R.S states that identifying data may be released "to the extent necessary for the treatment, control, investigation, and prevention of diseases and conditions dangerous to the public health; except that every effort shall be made to limit disclosure of personal identifying information to the minimal amount necessary to accomplish the public health purpose." Thus, **for disease control purposes**, the department is responsible for ensuring that the information requested meets the criteria of the law prior to release, i.e., that it is **necessary** for treatment, control, investigation, and prevention. To repeat the idea from the first paragraph of this section, based on Board of Health regulation, the criteria of "necessary" is met when the state health department provides case information to the local health agency where the reported case resides or where the public health problem exists.

D. Release Of Surveillance Data Such That No Person Can Be Identified

It is important to note that there are no national standards for data suppression. Below is one strategy for aggregation when denominators are small. Other strategies could be used after careful consideration but must follow statutory requirements (i.e. §25-1-122(4)(a), C.R.S.).

Data can be presented so that a person might be able to determine the identity of the case, even if the name is not released. For example, a report stating there was one case of gonorrhea in a 35-year-old black female in the month of May in Saguache County could enable one to determine the name of this woman. The criteria below are intended to address those statutes that state data may be released so long as no individual person can be identified. The policy prescribes the characteristics of disease surveillance data that may be released by:

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

Criteria For Release Of Surveillance Data:

I. *Release of disease surveillance data to public health agencies/officials*:

1. To the local public health agency(ies) where the case(s) reside(s) or that have responsibility for disease control activities: **no restrictions.**

2. To the Centers for Disease Control and Prevention (CDC) for reporting nationally notifiable conditions (contact State Epidemiologist or CDC/Epidemiology Program Office if you have a question): **release must only include the minimum data necessary to accomplish the public health purpose**.

3. To other divisions/personnel within the department: **no restrictions if there is legitimate programmatic interest and the recipient(s) acknowledge(s) that release of the data are subject to these guidelines**; otherwise, follow II (below).

4. To official departmental advisory board/committee members or the Board of Health: **no restrictions if there is legitimate programmatic interest and the recipient(s) acknowledge(s) that release of the data are subject to these guidelines**; otherwise, follow II (below).

II. *Release of disease surveillance data to the general public or other agencies of local, state, or federal government 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 (summarized in table below)*:

1. When the population size is ≥100,000[2]:
   a. Age can be released if <89 years. It should be released as a single category if age ≥90 years.
   b. Gender 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/geographic region is 15,000-99,999:

[2] U.S. Department of Health and Human Services. National Center for Health Statistics Staff Manual on Confidentiality. 2004. https://www.cdc.gov/nchs/data/misc/staffmanual2004.pdf

a. Age should be grouped at least by five-year intervals and grouped as a single category if age ≥90 years.
b. Gender 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 <15,000:
   a. Age or age groups may not be released.
   b. Gender 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. The number of cases should be for a time period:
      i. Greater than or equal to one year for any condition with a duration greater than eight weeks, such as chronic diseases, lead poisoning, tuberculosis, and AIDS. In other words, the number of cases in a six-month period cannot be released.
      ii. May be greater than one year for acute conditions, such as measles, plague, pertussis and hantavirus.

Table summarizing guidelines for release of surveillance data:

	Population ≥100,000	**Population ≥15,000**	**Population <15,000**
Age (years)	Ungrouped if <89 As a single category if ≥90	5-year interval As a single category if ≥90	Cannot release
Gender	No restrictions	No restrictions	No restrictions
Race/ethnicity	No restrictions	Cannot release	Cannot release
Time period	No restrictions	No restrictions	For chronic diseases, must be ≥1/year No restriction for acute diseases
Risk Factors	No restrictions	Cannot release	Cannot release
Whether cases are alive/dead	No restrictions	No restrictions	Cannot release

III. *Tables with small numerators*

Small numerators can also threaten confidentiality. For example, if a table is produced for the frequency of gonorrhea by race/ethnicity, and there are cells in which n=1, and there are tables of county frequencies produced for gonorrhea, then it would be easy to determine the county of the single case in the state race/ethnicity table. This is not a problem if the county has a population

≥100,000. However, in small populations it may be possible to identify a single individual in a specific age-race-sex group.

Therefore, prior to publishing reports in which there are tables of case characteristics from state data as well as frequencies by county, department personnel are expected to:

1. Determine the county for each disease in which the state total = 1;
2. Determine the size of the county and use the criteria above in sections D.II.(2) and D.II.(3) to determine what case characteristics may be released for that size county
3. Suppress the cells in state tables of those characteristics (i.e., Do not list the age, race/ethnicity, etc.) by using an asterisk (*) in state tables for instances in which the county population is too small to report the case characteristic. A footnote shall be added to those tables explaining the use and need for the asterisk.

IV. *Release of disease surveillance data to the general public at the individual case level (i.e., as a line list)*:

1. Time period should be at least one year.
2. Age may be released ungrouped if <89. It must be released as a single category if ≥90 years.
3. Gender may be included.
4. Race/ethnicity may be included.
5. The first 3 digits of a zip code containing ≥20,000 people may be released. Otherwise, county, zip code and census tract may not be included.
6. Location can also be grouped as metropolitan Denver (five- or seven-county)/rest of state.
7. Hospital, physician and laboratory may not be included.
8. Exact date of onset/diagnosis cannot be released. The month of onset/diagnosis may be released except for births and deaths for which month should not be included.
9. For birth and deaths only the year may be released.
10. Risk factor data may be included.

V. *Release of disease surveillance data to the general public at the facility level*:

As described in Section C of this policy, reportable disease information and investigations into such diseases and conditions are confidential pursuant to state statute. Release of public information pertaining to disease reporting and investigations is limited to release for the treatment, control, investigation and prevention of diseases and conditions dangerous to the public's health, in which case only the minimum amount necessary to accomplish the public health purpose may be released. Section 25-1-122(4), C.R.S. In a statewide declared public health emergency, release of disease surveillance information may be made at a level that includes facility-specific identifiers as well as aggregate numbers of cases and deaths. In no instance shall any protected health information, as described in the list of 18 HIPAA identifiers[3], be released with respect to any individual, with the

[3] List of 18 Identifiers

exception of the geographic subdivision identifier. Releasing information at the facility level should only occur in situations where the public has significant reason to be concerned about disease spread and could be more inclined to help mitigate such disease spread by complying with public health orders or other disease mitigation strategies.

E. Release Of More Detailed Surveillance Data To Researchers Such As Individual Case Level Data

If the person(s), researcher(s) or agencies requesting data want data in any form that contains excluded information, then it is concluded the data would provide sufficient detail such that a person could be identified. The purpose of the release is covered by §25-1-122(4)(b), C.R.S. if the research goal is understanding of disease epidemiology and improving prevention. §25-1-122(4)(b), C.R.S. states that identifying data may be released "to the extent necessary for the treatment, control, investigation and prevention of diseases and conditions dangerous to the public health; except that every effort shall be made to limit disclosure of personal identifying information to the minimal amount necessary to accomplish the public health purpose."

It is suggested that the department official who is contemplating release of surveillance data on reportable conditions under the provisions of §25-1- 122(4)(b), C.R.S.:

1. Obtain a copy of the protocol from the researcher.
2. Make a judgment as to whether the protocol provides sufficient rationale for release. Criteria include whether the release is necessary for treatment, control, investigation or prevention.
3. If yes, then write a short memo to the file documenting the decision and rationale.
4. Require the researcher to complete a data use agreement, per the Departmental policy on Data Privacy 15.27.

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1. Names;
2. All geographical subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code, if according to the current publicly available data from the Bureau of the Census: (1) The geographic unit formed by combining all zip codes with the same three initial digits contains more than 20,000 people; and (2) The initial three digits of a zip code for all such geographic units containing 20,000 or fewer people is changed to 000.
3. All elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death; and all ages over 89 and all elements of dates (including year) indicative of such age, except that such ages and elements may be aggregated into a single category of age 90 or older;
4. Phone numbers;
5. Fax numbers;
6. Electronic mail addresses;
7. Social Security numbers;
8. Medical record numbers;
9. Health plan beneficiary numbers;
10. Account numbers;
11. Certificate/license numbers;
12. Vehicle identifiers and serial numbers, including license plate numbers;
13. Device identifiers and serial numbers;
14. Web Universal Resource Locators (URLs);
15. Internet Protocol (IP) address numbers;
16. Biometric identifiers, including finger and voice prints;
17. Full face photographic images and any comparable images; and
18. Any other unique identifying number, characteristic, or code (note this does not mean the unique code assigned by the investigator to code the data).