Data Release Guidelines for the
Nationally Notifiable Disease Surveillance System
Division of STD Prevention, CDC
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I Introduction

This document updates the Data Release Guidelines of the Council of State and Territorial Epidemiologists for the National Public Health Surveillance System (June 1996) for the Division of STD Prevention in accordance with the CDC/ATSDR Policy on Releasing and Sharing Data and the CSTE Position Statement (11-SI-01): CSTE Endorsement of the CDC-ATSDR Data Release Guidelines and Procedures for Re-release of State-Provided Data. These documents acknowledge that public health and scientific advancement are well served when data are available to other public health agencies, academic researchers and the general public in an open, timely and appropriate way. However, they also recognize that CDC programs have a responsibility in collaboration with the states and territories to ensure that CDC program re-release procedures meet the needs of those responsible for protecting data confidentiality.

NNDSS (Nationally Notifiable Disease Surveillance System) data are collected and reported voluntarily to CDC by U.S. states and territories. The Council of State and Territorial Epidemiologists (CSTE) represents the collective voice of the U.S. states and territories with regard to the development of surveillance systems for conditions/diseases that have public health importance, the development of surveillance data confidentiality protections, and other important issues. A fundamental premise in effective public health practice is that surveillance data should be useful for the control and prevention of disease and disability while at the same time protecting confidentiality.

The CDC collects NNDSS data from all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. These areas

submit data for the following sexually transmitted diseases: syphilis, congenital syphilis, chlamydia, gonorrhea and chancroid. Case report records are submitted at the individual-level (i.e., "line listed") and include date of report and specimen collection, state and county of residence, core demographics, and information source. The submission of detailed testing results, treatment, and risk data are required for syphilis and optional for chlamydia, gonorrhea and chancroid reports.

The Surveillance and Data Management Branch (SDMB), Division of STD Prevention (DSTDP), National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) administers and maintains the NNDSS for STDs at CDC. NNDSS data are maintained as provisional and final data. Provisional NNDSS data are reported to DSTDP each week throughout the year and are subject to continual updating as new information becomes available to surveillance staff. Each year, once data are finalized by the states and territories and are approved by the State Epidemiologist and STD Data Management Team, DSTDP creates a permanent (final) annual analysis data set from the NNDSS data.

II Release of NNDSS data

As stewards of the NNDSS surveillance data, DSTDP is responsible for protecting the security of the data and the confidentiality of the individuals represented in the data, while sharing the data for legitimate purposes.

Publically released NNDSS STD data will conform to the following rules:

With regard to the following variables: disease/condition, year, event month, age grouped as <1, 1-4 years and by 5 year intervals thereafter; sex, race, ethnicity, state, county, only aggregated data will be released. DSTDP will suppress small cells before releasing data. Data suppression involves removing cell values that correspond to groups small enough to be potentially identifiable. To prevent back-calculation of suppressed cells, primary suppression should be augmented with

complementary (or secondary) suppression in which additional cells will also be removed from the data. The data will be suppressed using two techniques at once: a denominator-rule of 100 and a numerator-to-denominator proportion-rule of 20%. Any denominator with cells of less than 100 and cells for which the proportion of the numerator-to-denominator is 0.20 or greater will be suppressed. Suppression will focus on all potentially identifying variables, including age, race, ethnicity, sex, and geographic variables, including state, county, and zip code. If suppression is required at or below the state level of geography, complementary suppression will be employed.

With regard to release of other variables submitted to CDC, requests for aggregate data will be considered on an ad hoc basis and prioritized by the SDMB branch chief. These data will be released only for geographic units where

- At least 70% of the cases reported are informative values (not missing, refused, or unknown);
- Denominator rule of 100 and proportion rule of 20% as described above are met;
- A signed document is obtained stating that the requesting agency or program will not disclose or re-release the data in any format that might inadvertently disclose the identity of any individual.
- There is a written agreement that CDC clearance (which may or may not include CDC co-authorship) of any publication or presentation resulting from the released data will be obtained.

These guidelines only apply to re-release of data by CDC. States are encouraged to establish their own local guidelines. States also have the ability to opt-out of these guidelines at which time the 1996 guidelines will remain in effect for CDC's re-release of data from those states that opt-out. States that opt-out will be given an opportunity to opt-in on an annual basis.

DSTDP will not release individual-level data for any purpose.*

Requests for individual level data should be made directly to the state and local health departments which report to CDC.

III. Use of NNDSS data by DSTDP

Original case reports included detailed line-listed NNDSS data may be shared within DSTDP. Internal DSTDP policy and procedures should be established and enforced to ensure that data are not subsequently released to users outside CDC in a format inconsistent with this policy. The data must not be presented or published showing frequencies or cross-tabulations with more detailed information than could be obtained from release of aggregate data as described above in section II.

IV. Data requests from agencies, institutions, or persons outside CDC, including other federal agencies:

There will be no release of data in formats other than those described here unless the format is more restrictive. Anyone seeking from CDC more detailed data than available under these guidelines will be directed by CDC to each state.

V. Release of NNDSS data to the Epidemiology Branch of the Indian Health Service

Case reports, including line listed NNDSS data and extended case records, may be released to the Epidemiology Branch of the Indian Health Service. Internal policies and procedures should be established and enforced to ensure that the Epidemiology Branch of the Indian Health Service does not subsequently release the case reports and extended records or the detailed, line listed NNDSS data to users outside the Program, including Tribal Nations in a format inconsistent with this policy. The data must not be published or presented in a form showing frequencies and cross-tabulations with more detailed information than is permissible under the guidelines described above (section II).

*An exception may be with regard to Indian Health Service; see section V.