

 TEXAS Health and Human Services	Revision Date (most recent)	04/2021
	Approval Authority (title)	EAIDU Unit Director
	Signed by <i>John Lopez</i>	

**Emerging and Acute
Infectious Disease Unit
Data Release Policy**

Table of Contents

<u>Section</u>	<u>Page</u>
1.0 Purpose	2
2.0 Authority	2
3.0 Policy	2
4.0 Definitions	2
5.0 Persons Affected.....	3
6.0 Roles and Responsibilities	4
7.0 Special Data Requests	5
7.1 Incident Command Structure.....	5
7.2 Legal	5
7.3 Legislative.....	5
7.4 Media	5
7.5 Open Records	5
7.6 Research.....	5
8.0 Identifiable Data containing PHI	6
9.0 Routine Data Release Guidelines.....	6
9.1 Entity Access	6
9.1.1 Internal DSHS Partners.....	6
9.1.2 DSHS External Partners	7
9.1.2.2 Centers for Disease Control and Prevention (CDC) & Other Public Health- Related Entities	7
9.1.3 General Public	7
9.2 Aggregate Data	8
9.2.1 Certified data	8
9.2.2 Provisional data	8
10.0 Submitting Data Requests	9
Revision History	9

1.0 Purpose

This policy describes guidelines for the release of infectious disease surveillance and epidemiology data collected and managed by the Emerging and Acute Infectious Disease Unit (EAIDU) of the Texas Department of State Health Services (DSHS). The most current version of this policy is available online at [Infectious Disease Data Request](#).

2.0 Authority

All information obtained and compiled by DSHS related to a disease report is confidential and may be used or released only as permitted by the [Texas Health and Safety Code §81.046](#). Additionally, this policy is written in accordance with the [Texas Administrative Code Title 25 §97.10](#).

3.0 Policy

The policy of DSHS EAIDU is to ensure that infectious disease data are released and/or published in a manner that benefits public health while maintaining patient confidentiality. EAIDU will assess the potential impact of proposed data releases on patient confidentiality. EAIDU will take appropriate steps to prevent the identification of individuals. The policy is also to ensure that individual record-level data are only released in rare circumstances with proper legal authority.

4.0 Definitions

4.1 Aggregate data: data based on combining individual level information with no personally identifiable information.

Aggregate data has the potential to be identifiable depending on the population level for which it is released.

4.2 Certified data: data that has been certified as correct, final data approved by the DSHS State Epidemiologist. It is useful to note, that it may take months for a previous year's data set to be finalized and certified (e.g. 2016 data may not be certified until late 2017).

4.3 Confidential data: all public health infectious disease surveillance data unless it is sufficiently de-identified and/or aggregated to reasonably prevent identification of individuals.

4.4 De-identified data: individual record-level data that has been stripped of personal identifiers (e.g., name, address, social security number) but may contain potentially identifying information (e.g., age, sex, race/ethnicity, locality information).

4.5 Emerging and Acute Infectious Disease Unit

(EAIDU): the DSHS EAIDU program is responsible for collection, maintenance, oversight, and responsible release of notifiable infectious disease data.

4.6 DSHS Institutional Review Board (IRB): the [DSHS Institutional Review Board \(IRB\)](#) is an administrative body established to protect the rights and welfare of human subjects in research conducted under the auspices of DSHS and requests submitted to DSHS programs that involve the use of identifiable information or specimens. Any data deemed too specific for release under the provisions outlined below may be sent to the DSHS IRB to review, approve the initiation of, or conduct periodic review of research programs to assure the protection of the rights and welfare of human research subjects.

4.7 Identifiable information: any information that can be used to identify, distinguish, or trace an individual's identity (e.g., name, social security number, date of birth, medical record number).

4.8 Jurisdiction: refers to the data of a population(s) within a specified geographical area over which a public health entity has authority.

4.9 National Electronic Disease Surveillance System

(NEDSS): NEDSS is the electronic database used to report and capture infectious disease surveillance data for Texas.

4.10 Notifiable condition: refers to a disease or health condition that is subject to the requirement of being reported to the public health authority. A current list of Texas notifiable conditions can be found at <http://www.dshs.texas.gov/idcu/investigation/conditions/>.

4.11 Provisional data: case information that has not been certified by the DSHS State Epidemiologist as being correct and final data as submitted to the CDC. Provisional data is subject to change at any time, so it is important to note the as of date.

4.12 Protected health information (PHI): data 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 (e.g. name, address, date of birth, social security, or telephone number).

5.0 Persons Affected

Persons affected by this policy are internal DSHS employees and entities external to DSHS that are granted EAIDU surveillance and epidemiologic data.

6.0 Roles and Responsibilities

	Role	Responsibility
6.1	EAIDU Unit Director	• Implementing, overseeing, and enforcing data release guidelines to ensure proper release of information. • May appoint a designee within EAIDU to oversee the data release process. • Reserves the ultimate prerogative to either limit or enhance the release of EAIDU data as deemed necessary to benefit public health while maintaining patient confidentiality. • Will determine when a data request requires further analysis and consultation with DSHS legal counsel is warranted.
6.2	EAIDU Unit Director Designee	• Commissioned by the EAIDU Unit Director to act and serve as backup and fulfill all responsibilities listed in 6.1. • Will comply with this policy when providing oversight and approval on data requests.
6.3	EAIDU Team Manager, Leads, and Staff	• Will comply with this policy when fulfilling data request assignments. • Requests for data may come from a variety of stakeholders (e.g. public, media, etc.). EAIDU staff that handle data requests will extend the most professional, courteous, accurate, and rapid service available.

7.0 Special Data Requests

7.1 Incident Command Structure

In a public health emergency response effort where an incident command structure (ICS) is in place, provisional de-identified aggregate data shall be released to the incident commander (IC) and parties the IC deems appropriate after the EAIDU Unit Director or designee and the IC concur that data are needed for public health response.

7.2 Legal

Requests for individual EAIDU surveillance or epidemiologic records initiated via court orders, subpoenas, or legal counsel for a patient must be directed to the DSHS Office of General Counsel (OGC). Patients and/or their lawyers must sign a medical record release form before any data are released. The EAIDU Unit Director or designee must see the medical record release form and approve before the data is released to OGC.

7.3 Legislative

Legislative requests must be routed through DSHS Government Affairs group. Legislative requests must be submitted either by email to GovtAffairs@dshs.texas.gov, by phone at 512-776-7263, or fax at 512-776-7624. EAIDU staff will follow guidance as directed by the DSHS Government Affairs group.

7.4 Media

Direct media requests must be routed through the DSHS Press Office. Inquiries from the media can be made through email at PressOfficer@dshs.texas.gov or by phone at 512-776-7119. Additional information can be found at <https://www.dshs.texas.gov/news/>. EAIDU staff will follow protocol and complete requests from the DSHS Press Office in a timely manner.

7.5 Open Records

Open records requests or Public Information Act requests should be submitted to the Open Records Coordinator at openrecords@dshs.texas.gov. Additional guidance on open records can be found at <https://www.dshs.texas.gov/policy/openrecords.shtm>.

7.6 Research

Any data request going beyond the restrictions of the routine data release guidelines listed below may be submitted to the [DSHS Institutional Review Board \(IRB\)](#) for approval. Prior to submission, the request must initially be approved by the EAIDU Team Manager. Secondly, the EAIDU Unit Director or designee must also

approve and will refer the applicant to the DSHS IRB to begin approval process.

8.0 Identifiable Data containing PHI

The EAIDU strongly discourages the release of individual patient records that contain personal identifiers. In very rare circumstances, a patient's personal records may be released to providers, legal entities and/or directly to the patient. For requests through the EAIDU, providers, patients and/or their lawyers may request only data relating to the patient. EAIDU shall consult the Office of General Counsel whenever a request is made for identifiable patient records. If a written request for data cannot be released per this policy, the request will be forwarded to the EAIDU Unit Director who will then consult with the [DSHS Open Records Coordinator](#).

9.0 Routine Data Release Guidelines

9.1 Entity Access

EAIDU data (surveillance, epidemiologic and public health follow-up) as described below **may** be released to the entities identified below. The EAIDU Unit Director reserves the right to limit data access to any entities when it is determined to be necessary to protect patient confidentiality.

9.1.1 Internal DSHS Partners

9.1.1.1 DSHS Partner Programs

No data restrictions apply to DSHS internal EAIDU partners (e.g., DSHS infectious disease epidemiology and surveillance staff, DSHS laboratory staff, DSHS pharmacy staff). They may obtain identifiable data and provisional data. Internal partners are responsible for upholding strict confidentiality of EAIDU data.

9.1.1.1.1 No identifiable data may be released to the public or externally outside of DSHS without approval from EAIDU Unit Director.

9.1.1.2 DSHS Regional Health Departments

Regional health departments (RHDs) have access to all data within their region in the Texas National Electronic Disease Surveillance System (NEDSS). There are no data restrictions on RHD data within their own jurisdiction. Any request from an RHD requesting data from outside of their region

will be treated as a request from the general public unless the request is related to an ongoing disease investigation. RHDs are responsible for upholding strict confidentiality of data.

9.1.2 DSHS External Partners

9.1.2.1 Local Health Departments (LHDs)

Local health departments have access to all data within their jurisdiction in NEDSS. There are no data restrictions on LHD data within their own jurisdiction. Any request from an LHD requesting data from outside of their jurisdiction will be treated as a request from the general public unless the request is related to an ongoing disease investigation. LHDs are responsible for upholding strict confidentiality of data.

9.1.2.2 Centers for Disease Control and Prevention (CDC) & Other Public Health-Related Entities

9.1.2.2.1 On a routine basis, de-identified data and/or provisional data may be shared with the CDC in compliance with cooperative agreements or other collaborative activities. In some circumstances, identifiable data may also be shared with CDC.

9.1.2.2.2 Other public health entities such as Food and Drug Administration (FDA), United States Department of Agriculture (USDA), and law enforcement may receive identifiable, de-identifiable and/or provisional data in accordance with Texas statutes.

9.1.3 General Public

The restrictions below apply to data released to entities external to DSHS that will be accessed by the public (e.g. websites, press releases, personal use).

9.1.3.1 State-level and county level counts of cases of certified data and incidence rates computed from those case counts may be granted to any requestor.

9.1.3.2 See 9.2.2 for info on provisional data release to general public.

9.1.3.3 No identifiable data will be released.

9.2 Aggregate Data

9.2.1 Certified data

9.2.1.1 Certified data at the county level or larger geographic area for the following variables to most requestors:

- Exposure variables associated with the disease (e.g. seafood consumption, travel abroad),
- Age group by CDC groupings (<1, 0-4 years, 5 year age groups through age 84, age 85 and older) or broader age groupings,
- Month of event or broader date groupings,
- Gender, or
- Race/ethnicity to most requestors.

9.2.1.2 Age, event month, gender, race/ethnicity or exposure variables described above stratified by only one other of these variables at the state, RHD level, or established multi-county geographic area (e.g. Panhandle, Texas-Mexico border counties) to most requestors.

9.2.1.3 Without prior approval from EAIDU Unit Director, zip code level will not be released at any level of stratification.

9.2.1.4 In most cases it will be appropriate to release information from one of the variables in 9.2.1.1 stratified by a variable listed in 9.2.1.2. If patient confidentiality may be potentially breached, especially when small denominators and/or small numerators are involved, the EAIDU may recommend collapsing variables (e.g. expanding years or age group brackets).

9.2.2 Provisional data

Provisional data not associated with an ongoing outbreak or unusual event investigation may be released at the county level or larger geographic area for the above bulleted variables (9.2.1).

9.2.2.1 The EAIDU reserves the right to exclude release of provisional data deemed too sensitive for release and/or provisional data of rare conditions.

9.2.3 Outbreak or Unusual Events/Incidents data

During outbreaks or unusual events, provisional case counts data validated by the EAIDU Unit Director

or designee at the county level or higher may be released.

9.2.3.1 The EAIDU Team Manager or Team Lead Epidemiologist leading the outbreak investigation will consult with the EAIDU Unit Director to determine when in the course of the outbreak it is appropriate to release county-level provisional validated case counts.

9.2.3.2 The EAIDU Team Manager or Team Lead Epidemiologist leading the outbreak investigation will define “case” for the purposes of the outbreak and what constitutes validation of case status.

9.2.3.3 The case numbers will be released with the understanding that case counts are provisional and may change at any time during an outbreak, and case counts released by EAIDU may be different than those released by other entities.

9.2.3.4 No stratification below the county level will be provided.

10.0 Submitting Data Requests

10.0 All data requests for EAIDU information should be emailed to EAIDB.DataRequests@dshs.texas.gov. Requestor will receive an EAIDU data request form to complete and return as instructed.

10.1 EAIDU will respond to most requests within 10 business days. If a request will take longer the requestor will be notified accordingly.

10.2 Questions or concerns about infectious disease data requests should also be submitted to EAIDB.DataRequests@dshs.texas.gov.

Revision History

(Show list of changes to this document. Used for new documents and all subsequent changes. Action notations should include all document reviews, with or without changes. Section notations identify the location of any change e.g. 1.0, 2.3, etc.)

Date	Action	Section
04/2021	Significant changes throughout entire document. Copy of original language with edits available upon request.	All