CDC COVID-19 Case Surveillance Restricted Access Detailed Data Registration Information and Data Use Restrictions Agreement (RIDURA)

Introduction

To protect Americans from serious infectious diseases and other health threats, public health authorities conduct national case surveillance to monitor more than 120 diseases and conditions. For these conditions, public health collects information on individuals with the infection in a population, which is known as case surveillance. The goal of case surveillance is to provide information necessary to control outbreaks and inform public health action. Case surveillance is especially important for new diseases, such as COVID-19, in order to understand the similarities and differences between cases, including:

- demographic, clinical, and epidemiologic characteristics,
- · exposure and contact history, and
- course of clinical illness and care received.

Legislation, regulation, or other rules in jurisdictions require health-care providers, hospitals, laboratories, and others to provide information on reportable conditions to public health authorities or their agents, with reporting either at the local level (shared up to the state) or directly to the state health department. COVID-19 is a mandatory reportable condition in all U.S. state health departments, several territorial health departments, and two local health departments (New York City and District of Columbia). These state, territorial and local health departments determine what information laboratories and health-care providers in their area are asked to collect. The state, territorial and local health departments confirm cases of COVID-19 based on national standardized criteria and may gather additional information on the cases reported. Requested data elements are provided in CDC's Human Infection with 2019 Novel Coronavirus Case Report Form (CRF). (https://www.cdc.gov/coronavirus/2019-ncov/downloads/pui-form.pdf). These jurisdictions then voluntarily notify CDC of COVID-19 cases using the National Notifiable Diseases Surveillance System (NNDSS).

Sharing timely and accurate COVID-19 data with the public is a key activity of CDC's COVID-19 Emergency Response. CDC offers several tools and datasets for public use and an updated list of datasets available for public use can be accessed at https://data.cdc.gov/browse?tags=covid-19. To share COVID-19 case surveillance data with the public, CDC currently publishes microdata in two formats: a public use file and a restricted access file. More information on the public use file is available at https://data.cdc.gov/Case-Surveillance/COVID-19-Case-Surveillance-Public-Use-Data/vbim-akqf.

Information about the restricted access file, including description of the dataset and data dictionary can be found at https://data.cdc.gov/Case-Surveillance/COVID-19-Case-Surveillance-Restricted-Access-Detai/mbd7-r32t/. Please review this information prior to submitting a request for access to the restricted access dataset to ensure the data available are appropriate for your use, including for your research/analysis questions. The restricted access data files includes 31 fields and is available through a private GitHub website after completing a registration process, completing the information below and approval from CDC.

How do I request data?

• Review the requirements below

- Request access using the web form with information on you and your project
- If approved, you will receive an email with an invitation to join the private GitHub project web site containing the data

Registration Information

Access to COVID-19 restricted access case surveillance detailed data is maintained by the Surveillance Review and Response Group (SRRG) in CDC's COVID-19 Emergency Response. Access is provided to the primary requester and all corequesters based on submission of registration information and agreements to the data use restrictions. Access is intended for those who have reviewed the dataset description, the data dictionary and the data release guidelines, and who have provided the information requested below.

Data Use Restrictions Agreement

Upon submission of this request for access and granting of that access to the data, I attest and agree to comply with the following terms:

Security

- 1. I understand and agree to the following security practices:
 - a. All listed requesters must use appropriate safeguards to protect the data from misuse or inappropriate disclosure and prevent any use or disclosure of the data other than as provided in this RIDURA or as otherwise required by law.
 - b. I will password protect the restricted access data provided herein.
 - c. I will treat the restricted access data provided herein confidentially and will not give other persons access, other than approved co-requesters, unless otherwise required by law.
 - d. Any hard copies of data will be kept in a locked office cabinet, with access limited only to the primary requester and any co-requesters.
 - e. The primary requester must report any loss or misuse of data to the CDC (eocevent394@cdc.gov) within three (3) business days after the loss or misuse is discovered.
 - f. Data will not be transmitted between computer systems, or via email or email attachment, unless the transmission uses Secure Socket Layer (SSL) RC4 128 bit algorithms, SSL Server-Gated Cryptography (SGC) 128 bit algorithms, TLS 1.11 128 bit algorithms, or other algorithms accepted and certified by the National Institute of Standards and Technology.
 - g. The Requester agrees to maintain, store, protect, archive and/or dispose of data in accordance with applicable law.

Access and Use

2. I am responsible for obtaining Institutional Review Board review of projects when appropriate.

- 3. Access and use of the data and/or information does not grant me permission to use any trade names, trademarks, services marks, product names, or logos of CDC or the Department of Health and Human Services, except as may be required for reasonable and customary use in describing the CDC or the data and/or information. I will obtain express written approval from CDC prior to any use of the aforementioned. Though I agree to identify CDC as the source of the data provided, I further agree to not imply or state in any written form, that use of or any interpretation based on the data are those of the original data sources or of CDC.
- 4. I understand that use of these data does not imply endorsement by CDC. I will not attribute any analysis conducted using these data to CDC.
- 5. I agree that while matching cases for public health purposes is acceptable, I will not deliberately participate in or support the combination of case surveillance data sets with other data sets for the specific purpose of matching records to identify individuals.
- 6. I understand that CDC has taken all reasonable steps for privacy protections to ensure the identity of data subjects cannot be disclosed. No direct identifiers or characteristics that might lead to identification have been included in the data provided. As such, I will not use the data to re-identify or attempt to re-identify any individual included in the data and will not use, publish or release the data in any personally identifiable form. Should I inadvertently re-identify an individual, I will notify CDC of such re-identification within three (3) days of any such discovery.

Presentations, Publications and Dissemination

- 7. CDC requests a copy of any presentations, publications, or other material shared with the public, sent no later than 4 weeks post-publication/event to **eoceyent394@cdc.gov**.
- 8. CDC does not warrant that the data and/or information will meet my requirements and disclaims all other warranties and conditions either expressed or implied, including the warranty of merchantability and fitness for a particular purpose.
- 9. All publications and/or presentations using the restricted access data must include the following disclaimer: "The CDC does not take responsibility for the scientific validity or accuracy of methodology, results, statistical analyses, or conclusions presented."
- 10. For oral or written presentations or publications, the source of the data must be attributed to the CDC: "Centers for Disease Control and Prevention, COVID-19 Response. COVID-19 Case Surveillance Data Access, Summary, and Limitations (*version date*)" (Please check the GitHub project to include the version date of the dataset that you used for the publication.)

This Agreement is governed by applicable federal law.

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Submit the following information using the web form, https://forms.gle/pCvbosyaoqRvQmeb7, to start your access request for the COVID-19 Case Surveillance Restricted Access Detailed Dataset.

Information Required:

Primary Requester

Email address

Name

Title

Affiliation

Affiliation Mailing Address

Telephone

What GitHub Account ID would you like to use?

Your GitHub ID will be granted access to a private repository containing data that we use to make it easier to share data with you. If you do not have an ID, you can create one for free at GitHub.com. After approval, you will receive an email invitation from a CDC staff member. Please email eocevent394@cdc.gov if you have any questions.

Proposed use of the data

Title of Analysis

Brief description of proposed analysis

Purpose of analysis / Public health significance

Describe the intended products from this analysis

Note: If other individuals are working on any analyses with the primary requester, please provide their information as co-requesters. If the primary requester is a trainee, student, intern, fellow or requesting the data for use in any type of training program, please provide the primary requester's supervisor as a co-requester.

Co-Requesters

Email address

Name

Title

Affiliation

Affiliation Mailing Address