## Registration Information and Data Use Restrictions Agreement (RIDURA)

Between a Non-CDC Organization/Agency/Institution/Person and CDC's Surveillance Review and Response Group (SRRG) for Access to COVID-19 Case Surveillance Data

## Introduction

COVID-19 case surveillance data are collected by U.S. jurisdictions (i.e., states, large cities) and territories. Case notifications with those data are provided voluntarily to the Centers for Disease Control and Prevention. 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.

## **Registration Information**

Access to COVID-19 case surveillance data maintained by CDC's Case Surveillance Task Force and the Surveillance Review and Response Group (SRRG) is limited to each "requestor" who has reviewed the data release guidelines, provided the required information as included below, and has received approval from both SRRG and appropriate representatives of their own organization. All individuals within the non-CDC organization who need data access must complete these requirements.

The **REQUESTOR** should complete the following information and submit this first page to the ASK SRRG email box at <u>eocevent394@cdc.gov</u>.

Signature:		
Date:		
Printed name:		
Affiliation:		
Office mailing address:		
Telephone number:		
Email address:		
Position within		
organization:		
Brief purpose for data		
access:		
COVID-19 Case dataset red	quested (choose ONE)	
☐ Limited Dataset (includes state of residence) ☐ Detailed Dataset (no residence info.)		
The <b>REQUESTOR'S SUPERVISOR</b> should complete the following information:		
Signature:		
Date:		
Printed name:		
Affiliation:		
Office mailing address:		



Telephone number:	
Email address:	
Position within	
organization:	
Notes:	

## **Data Use Restrictions Agreement**

I have read and agree to follow the guidelines listed below and in the "COVID-19 Case Surveillance Data Summary and Limitations" document from the Case Surveillance Task Force and SRRG in CDC's COVID-19 Response (<u>Attachment 1</u>). This document has been developed to describe how the data will be used, released, shared, and protected. While these guidelines do not prohibit linking or matching case surveillance data with other data, the guidelines do prohibit processes which would allow the identification of specific individuals. The guidelines represent a balance between the potential for inadvertent disclosure and the need for CDC to be responsive to information requests having legitimate public health application.

In accepting access to the case surveillance data made available to and maintained by CDC's COVID-19 response, I agree to the following:

- 1. I am permitted to release final and provisional national and regional tabulations, with appropriate references/citations, from the case surveillance database in either narrative or tabular format.
- 2. I am permitted to include in presentations, slides, interviews, and publications final case surveillance data in tabular or narrative format that reports information on the following variables: disease/condition; year; event month; age grouped as <1 year, 1-4 years, and by 5-year intervals thereafter; sex; race; ethnicity; and state. If the total number of cases in a jurisdiction for a given year and disease/condition is small (e.g., fewer than 3), then race and ethnicity at a minimum will be considered for suppression for all cases in that jurisdiction for that year.
- 3. I will not disclose or otherwise make public county-level data or data on any geographic unit smaller than state (or jurisdiction for NYC and DC) from case-specific data files made available to and maintained by CDC's COVID-19.
- 4. I understand that release of case surveillance data maintained by CDC's COVID-19 not specifically permitted by this agreement is prohibited unless an exemption in writing is first obtained.
- 5. I agree that access to case surveillance data is limited to the "Requestor" named within this Registration Information and Data Use Restriction Agreement form.
- 6. I agree to use the data in the case surveillance datasets for surveillance, statistical reporting, and analysis only.
- 7. I agree to make no disclosure or use of the identity of a person discovered inadvertently and will advise SRRG of any such discovery.
- 8. 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.



- 9. I am responsible for obtaining Institutional Review Board review of projects when appropriate.
- 10. I understand and agree to the following security practices:
  - a. The security of private information during electronic transmission to CDC is maintained by technologies (computers and servers) that use national public health standards for messaging systems. These systems provide security mechanisms for jurisdictions to use when submitting data. Most case records are encrypted and submitted from already existing databases through a secure network via automated electronic transfers. Electronic data are transmitted to and processed within the electronic information system platforms. The electronic data are treated in a secure manner consistent with the technical, administrative, and operational controls required by the Federal Information Security Management Act of 2002 (FISMA). These systems are also in compliance with more recent standards to protect information: the National Institute of Standards and Technology Recommended Security Controls for Federal Information Systems and Organizations, Special Publication 800-53, Revised January22, 2015.
  - b. I will password protect any case surveillance data, including any temporary or permanent analysis files, such as those produced by SAS or other statistical packages.
  - c. I will treat all data at my desk site confidentially and will not give other persons access.
  - d. I will keep all hard copies of analyses containing small cells (e.g., fewer than 3 cases) locked in my desk when not in use, shredding them when they are no longer necessary to my analysis. In addition, I will review all printed or electronic output and delete or blackout any direct or indirect identifiers, including any small cell counts (e.g., fewer than 3 cases) that involve race or ethnicity.
- 11. I have attached an addendum to this agreement, including the following:
  - a. Title and purpose of the data access and investigation;
  - b. Outline of the proposed analysis;
  - c. Names of variables to be used;
  - d. List of diseases/conditions and time period for which data are requested; and
  - e. Specification of systems in place to assure security and confidentiality of case surveillance data.
- 12. I understand that all analyses and reports will be reviewed by CDC staff and must be cleared by CDC prior to submission for publication.

Attachment: "COVID-19 Case Surveillance Data Access, Summary, and Limitations" [Link]

