

Appendix 1. Data Sharing Agreement
CDC Firearm Surveillance Through Emergency Rooms
(CDC-RFA-CE20-2005)

1.0 Background

This appendix describes key ED data sharing and dissemination requirements for health departments that receive a *FASTER* award from CDC.¹ All recipients agree that by accepting a *FASTER* award they will provide CDC access to the following data:

- Visit-level ED data to facilitate collaborative development and improvement of syndrome definitions and near real-time monitoring of trends in firearm injuries.
- Aggregate ED data on the number of ED visits suspected to involve the following firearm injury indicators: overall firearm injuries, intentional firearm injuries, unintentional firearm injuries, and assault-related firearm injuries, as well as the total number of ED visits. Recipients will identify ED visits that involve each firearm injury indicator using standard definitions provided to recipients by CDC at the beginning of the funding period.
- Contextual information about their ED data including the percent of total ED visits with chief complaint text data and International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) codes.

CDC is required to disseminate data it has collected from funded entities, subject to limits imposed by law, resources, confidentiality, technology, and data quality in accordance with the following: “Open Data Policy—Managing Information as an Asset” (OMB M-13-13)²; Executive Order 13642 titled “Making Open and Machine Readable the New Default for Government Information”³; and the Office of Science and Technology Policy (OSTP) memorandum titled “Increasing Access to the Results of Federally Funded Scientific Research” (OSTP Memo)⁴. Public dissemination of ED data submitted by recipients to CDC is governed by general requirements that apply to all *FASTER* recipients (See Section 2.0, below).

Recipients must enter into a collaborative data sharing project with CDC using CDC’s BioSense platform maintained by CDC’s [National Syndromic Surveillance Program](#) (NSSP), described in Section 3.0, below. To the extent the NSSP BioSense data use agreement or above-referenced CDC templates conflict with any provision of relevant grant regulations and policies, the notice of award or this appendix, the grant regulations and policies, notice of award, and this appendix shall govern.

¹ While recipients retain ownership of ED data shared under the *FASTER* award, this appendix does not in any way limit or restrict CDC’s data or other rights described in 45 CFR Part 75 or relevant grants policies. Under 45 CFR § 75.322(d), CDC has the right to (1) obtain, reproduce, publish, or otherwise use the data produced under a Federal award; and (2) authorize others to receive, reproduce, publish, or otherwise use such data for Federal purposes.

² <https://project-open-data.cio.gov/policy-memo/>

³ <https://obamawhitehouse.archives.gov/the-press-office/2013/05/09/executive-order-making-open-and-machine-readable-new-default-government->

⁴ https://obamawhitehouse.archives.gov/sites/default/files/microsites/ostp/ostp_public_access_memo_2013.pdf

2.0 General ED dissemination and data sharing requirements for all *FASTER* recipients

CDC will use aggregate ED data received by recipients to assess data quality, inform firearm injury syndrome definitions, and disseminate data and results to a broad audience. CDC scientists will work closely with recipients to ensure high quality, complete, and timely data. As part of that process, CDC will collaborate with recipients to validate and confirm data submitted to CDC. Specifically, CDC will conduct quality control checks and solicit feedback from recipients on data quality issues prior to analyzing the data. After awards are made, CDC will provide additional guidance on the data validation process, including proposed timelines for review. Once CDC validates the ED results, CDC intends to widely and publicly disseminate results, including in the following ways:

- Print, including publications in peer-reviewed literature, published reports, data briefs, periodicals, brochures, books, and correspondence,
- Electronic, such as the CDC website, listserv, and e-mail,
- Audiovisual, broadcast scripts, audio or videotapes, and video casting,
- Oral, formal speeches, oral presentations, and interviews, or commentaries for publication or broadcast,
- Data briefs or tables shared with CDC, HHS, and other governmental leaders in response to internal requests,
- Web-based query system that would distribute aggregate state-level and could be accessed publicly similar to the CDC WISQARS system (<https://wisqars.cdc.gov:8443/nvdrs/nvdrsDisplay.jsp>).

CDC recognizes the critical importance of maintaining standards of data quality, upholding individual and institutional privacy and confidentiality, and ensuring impartiality in the sharing of public health data. Consequently, for any means of dissemination of *FASTER* data, CDC will apply the following data reporting rules:

- In order to prevent possible identification of an individual, CDC will suppress data when case counts range from 1 to 9 cases.
- CDC will not analyze rates (e.g., ED visits suspected to involve firearm injuries divided by total number of ED visits in a state) with fewer than 20 cases in the numerator (e.g., number of ED visits suspected to involve firearm injuries) because of possible statistical instability of rate estimates. For instance, CDC will not report the percent change in suspected firearm injury rates from January to February 2021 if only 19 ED visits were suspected to involve a firearm injury in January 2021.
- ED syndromic systems are designed to collect rapid preliminary data on changes in illness and injuries such as firearm injuries. These systems, however, often do not provide an accurate estimate of the full burden of illnesses and injuries because they are based on preliminary and limited data often collected from a subset of hospitals. In order to account for the limitations in many ED syndromic systems, CDC will not report *counts* of suspected firearm injuries (including overall firearm injuries, intentional firearm injuries, unintentional firearm injuries, and assault-related firearm injuries) without the consent of the submitting health department when the health department elects to share ED syndromic system data with CDC. Instead, CDC will publicly report monthly, quarterly,

and yearly changes in the rates of ED visits suspected to involve all firearm injury indicators as well as rates of suspected firearm injuries. For example, CDC would report that the rate of suspected unintentional firearm injuries increased by 25 percent from January to February 2021.

- Additional data quality and suppression rules may be established during the funding period as necessary and with feedback from recipients.

CDC intends to notify recipients before CDC disseminates to the public a product (e.g., peer-reviewed publications, MMWRs, or website updates showing data) that includes data from the recipient's jurisdiction. Recipients must embargo advance findings and publication dates unless provided a written waiver from their CDC project officer. Health departments may only use advance information on CDC data products to prepare their own press release or data products for simultaneous release post-release of the CDC data product.

Finally, CDC dissemination products will always acknowledge state and local participation in collecting the data. In some instances, CDC may ask representatives from the state or local health departments to serve as co-authors on any eventual publication because of their expertise in their data or if the report focuses solely on their jurisdiction. State and local representatives are encouraged to perform their own specific analyses. Depending on CDC resources, CDC staff may be available to help in these efforts.

3.0 Data sharing agreement for recipients sharing ED data with CDC through CDC NSSP BioSense platform

Recipients must agree to enter into a “collaborative data sharing project” with CDC using CDC’s BioSense platform maintained by the [National Syndromic Surveillance Program](#) (NSSP) to assist in the monitoring and reporting of data on firearm injury outcomes (including overall firearm injuries, intentional firearm injuries, unintentional firearm injuries, and assault-related firearm injuries) treated in ED to CDC.

The key requirements and benefits of the NSSP BioSense collaborative data sharing project are listed in CDC’s *FASTER* Notice of Funding Opportunity (NOFO) in the Strategies and Activities Section (pp.7). The NSSP BioSense Platform enables participating state health departments to provide CDC users electronic access to case-level ED visit information such as month of visit, chief complaint text, and ICD-10-CM codes through the ESSENCE program on NSSP BioSense. CDC intends to use case-level data for specific collaborative data sharing projects. By participating in this *FASTER* collaborative data sharing project, recipients agree to provide the *FASTER* User Group in ESSENCE, which includes a minimum of six CDC staff members, continuous access to real-time, case-level ED data in ESSENCE. CDC will use its case-level access for the following four purposes.

1. CDC staff will use data to validate the recipients’ required *FASTER* aggregate ED data and data quality reports as well as provide the health departments the reports to review and verify data quality (Note: aggregate reports include demographic information on suspected firearm injuries, including overall firearm injuries, intentional firearm injuries,

- unintentional firearm injuries, and assault-related firearm injuries at the jurisdiction level, such as by sex, age group, or county). CDC will review reports at least quarterly.
2. CDC staff will review recipients' case-level ED data to validate and improve firearm injury syndrome definitions (including overall firearm injuries, intentional firearm injuries, unintentional firearm injuries, and assault-related firearm injuries).
 3. CDC staff will track and share with recipients key indicators on ED data quality such as percent of ED visits missing chief complaint text data or ICD-10-CM codes and how data quality impacts firearm injury trends in their jurisdiction (including trends for overall firearm injuries, intentional firearm injuries, unintentional firearm injuries, and assault-related firearm injuries).
 4. CDC staff will analyze and disseminate required aggregate ED reports on suspected firearm injuries (including overall firearm injuries, intentional firearm injuries, unintentional firearm injuries, and assault-related firearm injuries) as well as aggregate data quality reports produced as part of the *FASTER* collaborative data sharing project in a manner consistent with Section 2.0 of this appendix. In addition, CDC staff may run other types of analysis with case-level data (e.g., multivariate analyses to predict firearm injury rates by sex, age group, etc.).
 5. CDC may share aggregate data with its contractors and partners who are engaged in surveillance, research, and evaluation activities where these data might be informative to their work.

CDC access to case-level ED data is intended to enhance CDC and recipients' ability to monitor data quality and to facilitate validation of *FASTER* quarterly reports by CDC. CDC will not use the data for any other purpose without first consulting with the providing jurisdiction. CDC intends to give notice two weeks prior to any other use.