

National Violent Death Reporting System Data Sharing Agreement for RAD Re-release

I. General Issues

1. Purpose

The NVDRS Data Sharing Agreement was created to govern the protection and use of sensitive or potentially identifiable NVDRS data, as required by the NVDRS Data Re-release Plan. Prior to release of NVDRS restricted access microdata (RAD) by the Centers for Disease Control and Prevention (CDC), a data sharing agreement must be established for any users who are not currently employed by the Division of Violence Prevention or the Office of Statistics and Programming, National Center for Injury Prevention and Control (NCIPC).

2. Background

The National Violent Death Reporting System (NVDRS) is a population-based, active surveillance system designed to obtain a complete census of all resident and occurrent violent deaths. Each participating state collects information on its own deaths from death certificates, medical examiner/coroner files, law enforcement records, and crime labs. Related fatal injuries involving multiple victims that occur within 24 hours of each other are linked in one incident. Over 270 unique data elements can be collected on each incident. The 17 state health departments of Alaska, California, Colorado, Georgia, Kentucky, Maryland, Massachusetts, New Mexico, New Jersey, North Carolina, Oklahoma, Oregon, Rhode Island, South Carolina, Virginia, Utah and Wisconsin are participating as of January, 2007. Cases consist of violent deaths from suicide, homicide, undetermined intent, legal intervention, and unintentional firearm injury. Information is collected on living suspects as well as victims.

The CDC receives information about violent deaths from the health departments of participating states pursuant to Cooperative Agreements for Development of the NVDRS. These data do not contain personal identifiers such as a name and street address, but they do include information that could potentially be identifying, such as city of residence, county of injury, and narrative of the incident. Some of the data will pertain to open investigations and will include sensitive information such as substance abuse and mental illness history.

To minimize the chances that individuals can be identified, requestors of RAD must submit a proposal describing the intended use of these data as well as measures to be taken to safeguard the data from inappropriate use (see below). All proposals will be reviewed by a scientific panel at the CDC. Prior to the release of any data, approved requestors of RAD and their collaborators (including any individuals who will have access to the requested data) must agree to comply with the NVDRS Data Sharing Agreement (DSA). The data must not be used for any other purpose beyond that specified in the approved request.

To further minimize the chances that individuals can be identified, the following procedures will apply to the release of all NVDRS restricted access datasets:

- Selected variables with one or more response options that will likely apply to only a

small fraction of all victims will be routinely omitted from all such datasets. These variables will include:

- i. Day of death and injury
 - ii. Month of death and injury
 - iii. Occupation and industry text and codes
 - iv. Make and model of firearm
 - v. Poison name and poison code
 - vi. Victim in custody when injured
 - vii. Hate crime
 - viii. CME and police narratives and child fatality review team “additional information”
- Ages of suspects will be recoded to <15, 60+, and five-year age groups in between. Age categories of victim/suspects will be recoded to <25, 25-54 and 55+.
 - The data requestor will have to provide special justification for obtaining any of the omitted variables or age by single year. Only those omitted variables essential for the intended use may be approved following review by the NCIPC Work Group. The Work Group may not approve releasing the omitted variables requested by the user if it believes the resulting risk of identifying individuals is significant.

The NVDRS Program will monitor compliance with the terms of the DSA. The Program will create a schedule of dates when data are to be returned or destroyed. It will contact the users on those dates for confirmation of destruction of the data if they have not been returned. The Program will also search the published literature quarterly for mention of the NVDRS to ensure that DSAs had authorized the use of NVDRS microdata for those publications. The Program will also maintain a bibliography of all publications that make use of NVDRS data, whether from public-use data or RAD.

II. Guidelines for Submitting an NVDRS RAD Request

1. Eligibility

To qualify as eligible for receipt of NVDRS RAD, investigators (i.e., persons to be primarily responsible for the care of the released data) must meet all of the following criteria:

- The principal investigator must have a Ph.D. or other terminal degree.
- The principal investigator must hold a research position or faculty appointment at his/her institution.
- The home institution of the principal investigator must be a research organization, government agency, institution of higher education or professional organization that has as their mission improving public health or promoting, implementing or evaluation of intentional injury prevention.
- The home institution of the principal investigator must have a history of using sensitive data according to commonly-accepted standards of research ethics and practice.

The state CDC Cooperative Agreement Principal Investigators for the NVDRS system may also request RAD data with data release subject to the same terms and conditions outlined below for all other qualified investigators.

2. Description of the Proposed (Research) Project

To request NVDRS restricted access case-level microdata (RAD), requestors must submit a proposal to the NVDRS Science Officer describing the purpose of the data request, limitations on usage of the data, and other important information. In particular, the research proposal must contain the following:

- i. Cover letter. All written requests for RAD must be on letterhead stationary.
- ii. Project Title.
- iii. Abstract: approximately 100-300 words summarizing the project.
- iv. Full personal identification, institutional affiliation, mailing addresses (including overnight express mail address), phone, and e-mail address of the person to be primarily responsible for care of the released data and for compliance with the terms of the data sharing agreement.
- v. The names of all other persons who will have access to the data.
- vii. Source of funding for the proposed project (if applicable).
- viii. Background of study:
 - a. Key study questions or hypotheses.
 - b. Public health benefits. Requestors must provide evidence that there is a legitimate public health purpose that justifies the use of the data.
- ix. A summary of the data requirements for the proposed research along with an explanation of why the data are needed:
 - a. Identification of variables to be included in the analytic file, including a data dictionary (a complete listing of the specific data requested--files, years, cases, variables, matching or linking variables, etc.). The complete NVDRS codebook, containing a description of data and variables in the NVDRS, may be downloaded at the following website:
<http://www.cdc.gov/ncipc/profiles/nvdrs/publications.htm>.
For an overview of the NVDRS, please visit:
<http://www.cdc.gov/ncipc/profiles/nvdrs/facts.htm>
 - b. A description of any data to be supplied by the researcher and merged with NVDRS data.
 - c. A description of why publicly available data (including NVDRS public-use data) are inadequate for the proposed project.
- x. Methods for the study:
 - a. A description of the analytic strategy and statistical methods to be used.
 - b. For tables in which raw or unweighted frequencies will appear, provide mock tables showing variable names and the layout of rows, columns, and cells.
- xi. A description of the anticipated products, reports, and publications to be derived from the data analyses.
- xii. A description of mechanisms that will be in place to secure the data, preserve confidentiality, and prevent unauthorized access (e.g., data storage plan, limitations on access to the data, technical security practices such as password protection, use of stand-alone computers, encryption, procedures covering networked computers and servers). At a minimum, the requestor must demonstrate that:
 - a. The data (whether in print or electronic form, whether stored on a mainframe computer, personal computer, or other device) will be maintained in a space that can only be accessed by authorized personnel.

- b. The use of computers storing or maintaining the data will be controlled by password protection.
- c. All printouts, tabulations, or reports associated with use of the data will be stored in a secure location when not in use (e.g., housed in a secure area, in locked cabinets or file drawers).
- xiii. If the requestor plans to use the data for research, notice of approval from an officially sanctioned Institutional Review Board (IRB) must be included with the project proposal.
- xiv. A completed and signed copy of the NVDRS Data Sharing Agreement should accompany the proposal (see below).

III. Terms and Conditions of the NVDRS Data Sharing Agreement

1. Terms Governing Use, Protection, and Reporting of Data

Prior to the release of any data, requestors, their collaborators, and an authorized institutional business official must agree to comply with all of the terms and conditions described below.

a. Use Limited to Research Project

The recipient agrees that the data will not be used in any research that is not disclosed and approved as part of the project. Furthermore, the recipient agrees to refrain from any attempt to link NVDRS RAD to any other dataset without prior permission from the CDC (any intention to link NVDRS RAD with other data should be specified in the initial request for RAD and approved by the CDC).

b. Non-transferability of Agreement

Substantive changes made to the project (including, but not limited to, the appointment of a new principal investigator to complete the project, the inclusion of additional collaborators who will have access to the data, or a change in the principal investigator's institutional affiliation) require the execution of a new data sharing agreement, or an amendment to the existing data sharing agreement. It is the sole responsibility of the recipient to alert the CDC of such changes without delay. If the recipient of NVDRS RAD changes positions or leaves an agency or institution, the recipient will be required to return or destroy the data as directed by the CDC.

c. No Distribution of Data

The recipient agrees to retain control over the data, and further agrees not to transfer the data, with or without charge, to any other entity or any individual without prior approval from the CDC.

In the event that the recipient receives a request for release of NVDRS data from legal authorities (such as under conditions of a declared public health emergency, a subpoena, or request filed under the Freedom of Information Act), the recipient must (1) immediately notify NCIPC by phone call and fax of their receipt of a compulsory legal process; (2) refuse to release any such information, documents, records, and other materials, unless and until authorized to do so by the CDC; and (3) work in collaboration with CDC legal counsel to take whatever legal action is necessary to maintain confidentiality of the data. (The NVDRS Data Re-release Plan calls for expedited review and fast-track processing in the event of selected public health emergencies).

d. Non-Identification of Subjects

The recipient of NVDRS RAD agrees to the following confidentiality restrictions:

- NVDRS data will be used solely for statistical analyses related to the approved project. No attempt will be made to identify specific individuals, households, or institutions. Data lists at the individual level will not be published or distributed.
- In the event of inadvertent discovery of the identity of any person during the course of the proposed project, the recipient will (1) notify the NCIPC Associate Director for Science; (2) safeguard or destroy the identifying information as directed by the CDC; and (3) make no use of knowledge of the discovery. The identifying information must not be disclosed to any other individual or party.
- The inadvertent disclosure of potentially identifying information is to be avoided by using the following guidelines for the release of statistics derived from the requested dataset. For any data release format:
 - i. Annual counts and rates must be suppressed for cities or counties of fewer than 100,000 people.
 - ii. Cells showing or derived from fewer than 5 deaths must be suppressed, but “zero” cells may be shown. Cell “suppression” will take one of two approaches: 1) combining row or column categories so as to eliminate the small cells, or 2) suppressing the small cell, another cell in the same row, another cell in the same column, and a fourth cell at the intersection of the row and column containing the second and third suppressed cells. Suppression of the second and third additional cells is necessary to prevent derivation of the small cell by subtraction from the row or column totals. Suppression of the fourth cell is necessary to prevent derivation of the second or third cells by subtraction. Beyond these specific guidelines, it must not otherwise be possible to derive identifying information by subtraction or other calculation from a table, or combination of tables, in any release format.
 - iii. Rates are not to be computed for cells containing fewer than 20 deaths (or cases) or with a coefficient of variation that is equal to or greater than 23%, based on the assumptions of a Poisson distribution.
 - iv. The disclosed data should never permit identification when used in combination with other known data.

e. Maintenance of Data Security and Oversight

The recipient must ensure that the data security measures described in the project proposal are enforced and maintained at all times during possession of NVDRS RAD. No unauthorized person should be permitted access to the contents of NVDRS RAD files or to any files derived from RAD. Upon request, the recipient agrees to permit the inspection by the CDC of the physical storage, management, and handling of RAD files (at reasonable hours) and any other information relating to the DSA.

f. Notification of the CDC of Pending Publications

The recipient agrees to notify the CDC in advance as to when and where a publication of a report (or other public disclosure) from the project will appear. In addition, the recipient agrees to provide the CDC, in advance of its appearance, a copy of any manuscript or other public disclosure document.

g. Non-Endorsement Liability

The recipient agrees not to claim, infer, or imply Governmental endorsement of the research project, the entity, or personnel conducting the research project. Any published material derived from NVDRS data must acknowledge the CDC as the provider of the data and participating NVDRS states as the sources of the data. Published materials must also include a disclaimer that credits any analyses, interpretations, or conclusions reached by the author (recipient of the data) to that author and not to the original sources of the data (i.e., NVDRS participating states) or to the CDC. The disclaimer should take the following form: “The findings and conclusions of this study are those of the authors alone and do not necessarily represent the views of the Centers for Disease Control and Prevention or of participating NVDRS states.”

h. Termination and Disqualification

The CDC may terminate the DSA if the recipient is in violation of any condition of the DSA and such violation is not remedied within 30 days after the date of written notice of the violation. Furthermore, failure to comply with the DSA will result in the disqualification of the principal investigator/recipient, along with any collaborators implicated in the violation, from any future funding from NCIPC, and may result in the disqualification of the recipient from receiving additional data.

i. Duplication of Research

The recipient of NVDRS RAD acknowledges that other researchers have access to NVDRS data in the form of public-use datasets and RAD and that duplication of research is a distinct possibility.

j. Return or Destruction of All Sensitive Files at Project Completion

The recipient agrees to return or destroy all NVDRS RAD files, and all derived files, when the approved use of the data will have been completed (i.e., on the agreed upon date scheduled by the CDC).

k. Signatures:

Recipient Principal Investigator

Printed Name

Signature

Recipient Co-Principal Investigator (if applicable)

Printed Name

Signature

Recipient's Authorized Institutional Business Official

Printed Name and Title

Signature

All other individuals who will have access to the data (e.g., research assistants, statisticians):

Printed Name

Signature

Printed Name

Signature

Printed Name

Signature

2. NVDRS Science Officer Contact Information

All requests for NVDRS RAD, or questions pertaining to NVDRS RAD, should be forwarded to:

NVDRS Science Officer
Etiology and Surveillance Branch
Division of Violence Prevention

National Center for Injury Prevention and Control
Centers for Disease Control and Prevention
4770 Buford Highway, MS F-63
Atlanta, GA 30341-3724

A complete request for NVDRS RAD includes a description of the project proposal and a signed copy of this Data Sharing Agreement.