

Policy on Data Release and Publication of NC-VDRS Data

Introduction

The North Carolina – Violent Death Reporting System (NC-VDRS) policy on data release and publication of data reflects the collaborative nature of the NC-VDRS data and the desire to **“provide data for public health purposes without compromising the privacy concerns, federal and state confidentiality concerns, proprietary interests, national security interests, or law enforcement activities”**¹.

NC-VDRS database is a relational, incident-based system that includes secondary data from the Vital Records (VR), the Office of the Chief Medical Examiner (OCME), State Bureau of Investigation (SBI), local law enforcement (LLE), and crime laboratories (for firearms) on every reported incident of violence in North Carolina that results in a fatality as of January 1, 2004. Death Certificate and Medical Examiner data in the NC-VDRS are public record. In contrast, the law enforcement and type of weapon recorded on a crime laboratory report that are entered into NC-VDRS are not public record. Therefore the data in NC-VDRS require special confidentiality and data release policies.

The NC-VDRS policy on data release incorporates the major data release tenets of each agency that contributes data (acknowledging that each of these groups has different procedures and policies on data release) and the data release and publication policies of the National Violent Death Reporting System (see excerpt below; the full National Violent Death Reporting System data release policy is available from the NC-VDRS Director).

The CDC receives information about violent deaths from the state health departments pursuant to Cooperative Agreements for Development of the NVDRS. [North Carolina was funded to begin collecting data as of January 1, 2004.] These data do not contain obvious identifiers such as a name and street address (Table 1), but they do include fields that could potentially be identifying when used in the aggregate, such as the variables in Table 2. Some of the data [in the National and the North Carolina databases] will pertain to open investigations and will include sensitive information such as substance abuse and mental illness history.

The CDC's Office of the General Counsel and the CDC's Freedom of Information Act (FOIA) Officer have been consulted regarding the legal basis for the protection of NVDRS data. They have informed NVDRS staff that the CDC has mechanisms to protect these data from disclosure if allowable under federal law. CDC may be asked to disclose data through such means as a FOIA request or a subpoena, both of which are discussed below.

The FOIA applies to these data, just as it does to all other records in the control of the CDC at the time a FOIA request is received. Pursuant to exemption 6 of the Act, however, the CDC protects material, the release of which would be a clearly unwarranted invasion of personal privacy. The CDC would argue that the release of any details about individual records provided by the states could lead to the identification of an individual and would therefore constitute such an invasion of privacy.

CDC could potentially receive a subpoena requesting the NVDRS data. CDC's response to the subpoena would depend on such factors as whether the issuing court has jurisdiction over the federal government. If the subpoena is determined to be from a tribunal or court not having jurisdiction, such as a subpoena originating from a state court, the subpoena will be deemed to be a request for records under FOIA and will be protected in accordance with the act, as described above.

If, however, the subpoena originates from a court having jurisdiction over the federal government, such as a federal court, CDC will utilize all available legal mechanisms to protect the confidentiality of data that could potentially lead to the identification of any individual. CDC has been successful in protecting such sensitive data in other instances.¹

The NC-DHHS Division of Public Health has a CDC Certificate of Confidentiality to protect the data in the NC-VDRS from subpoena.

Table 1: NVDRS variables that are not sent to the CDC

Variable Label	Variable Name(s)
Source agency requested from	SrAgen
Source agency's internal record no.	AgenNum
Document notes field	DocTxt
Last name	CME_Lname, DC_Lname, PR_Lname
First name	CME_Fname, DC_Fname, PR_Fname
Middle name	CME_Mname, DC_Mname, PR_Mname
Social Security #	CME_SSN, DC_SSN
Date of birth	CME_DOB, DC_DOB
Address (residence)	CME_ResAddress, DC_ResAddress, PR_ResAddress
US Census tract (residence)	DC_CensSt
US Census block group (res.)	DC_CensBl

¹ NVDRS Data Re-Release Plan, Version 9, Draft, 06-22-2004- revised 8/20/2011

Variable Label	Variable Name(s)
Zip code (residence)	CME_ResZip, DC_ResZip, PR_ResZip
Death Certificate number	DthCrtNum
Street and number of injury site	CME_InjAddress, DC_InjAddress, PR_InjAddress
US Census block group of injury	DC_CnsBlk
US Census tract of injury	DC_CnsTrt
Zip code of injury	CME_Zip, PR_Zip
Date specimens were collected	CME_SpcDt
Firearm serial number	CME_Serial, LAB_Serial, PR_Serial

Table 2: NVDRS variables that could potentially be personal identifiers and are sent to the CDC

Variable Label	Variable Name(s)
Date of injury	CME_Idate, DC_Idate, PR_Idate
Time of injury	CME_Itime, DC_Itime, PR_Itime
Date of death	CME_DthDt, DC_DthDt
City (residence)	CME_Place, DC_Place, PR_Place
County (residence)	CME_ResCounty, DC_ResCounty, PR_ResCounty
City of injury FIPS code	CME_InjPlace, DC_InjPlace, PR_InjPlace
County of injury	CME_County, PR_County
Narrative of the incident	CME_IncNarr, PR_IncNarr
CFR additional information	CFRTxt

The purpose of the NC-VDRS is to provide accurate and timely data on violence that leads to fatalities in North Carolina as the basis for conducting injury surveillance and for developing and evaluating injury and violence prevention programs. NC-VDRS data is not designed to support criminal investigations.

The NC-VDRS provides for two types of data release: Aggregate Statistical Tables and Data Sharing. Aggregate Statistical Tables are aggregate counts of data in tables that the NC-VDRS distributes, either in routine reports or in response to requests from data users. These reports are available in both electronic or hardcopy format.

Data Sharing occurs when the NC-VDRS provides an electronic file containing data records (observations) at the level of the incident, person, or weapon. De-identified data from North Carolina, and all other states that are participating the National Violent Death Reporting System (NVDRS), are routinely sent to the CDC National Center for Injury Prevention and Control where the NVDRS is housed. The variables that constitute personal identifiers in the NC-VDRS are listed in Table 1.

Shared files would generally be electronic, but could be hardcopy. A shared file could be incident-based, person-based, or weapon-based.

1. Aggregate Statistical Tables:

Provisional data are not released in the form of Aggregate Statistical Tables until at least 6 months after the date of the incident. This is to allow sufficient time for useful information on the incident from all of the routine sources to be accumulated in the NC-VDRS database. These interim tables are identified as PROVISIONAL COUNTS that are subject to change.

Final data tables are not released until the VR records that pertain to each case or incident are closed. In general, the VR file for death certificates for any calendar year is closed during August or September of the next calendar year.

The OCME, SCHS, SBI, and LLE must be acknowledged as the source of the NC-VDRS data in both provisional and final tables.

2. Data Sharing:

Data sharing requests must be made in writing to the director(s) of the NC-VDRS using a standardized form that requests information about the people requesting the data, the institutions they represent, their purpose in requesting the data, and a list of the data fields they require. To be eligible for shared data, the requestor must intend to use the data for a public health purpose, a requirement that is consonant with the CDC's standard for data release, as described on page 1 of this document.

Data sharing requests for access to the NC-VDRS data without the variables listed in Tables 1 and 2 will be reviewed by the Director. The expectation is that all information data sharing releases will be discussed with at least one additional staff member.

The NC-VDRS maintains a Data Sharing Committee. The purpose of the committee is to facilitate access to the NC-VDRS data. The expectation is that the Director will use this committee to review pertinent requests for access to the data. However, in unusual circumstances, the Director may expedite the review without recourse to the Committee. Additionally, the Chair of the Data Sharing Committee may occasionally act on the Director's behalf in unusual circumstances, e.g., when the Director is unavailable for a protracted period due to travel. Typically this Data Sharing Committee Chair would have been authorized in advance by the Director to act on his/her behalf.

Data sharing requests for access to the NC-VDRS data that include any elements from Tables 1 or 2 must be approved by an Institutional Review Board

prior to submission to the director(s) of the NC-VDRS. Once IRB approval is obtained, these requests for sensitive data elements from the NC-VDRS will then be processed in the same fashion as requests for non-sensitive data (see previous paragraph).

Data sharing requests that require data that are wholly and completely available from the OCME, VR, SBI, or a LLE agency will be referred to those entities and will not be processed further.

The chairs of the NC-VDRS Advisory Boards are notified of all data sharing releases, typically via the Board Leadership and Evaluation Team meetings/or minutes. The members of the Technical Advisory Board are notified of all data sharing releases, typically via the meetings and/or minutes of that Board.

A written data sharing agreement is signed by the person(s) with whom the data is shared. The agreement stipulates that the person(s) with whom the data is shared must:

- Destroy the data once the project is complete;
- Not make a website release, press release, or other public statement using the NC-VDRS data without the express prior approval of NC-VDRS Director;
- If data are to be used for a scientific publication or presentation, abide by the terms of the publications policy detailed below;
- The OCME, SCHS, SBI, and LLE must be acknowledged as the source of the NC-VDRS data in all publications, press releases, website releases, and public statements using the NC-VDRS data;
- The Director reserves the right to withdraw access to the data and cancel the data sharing agreement. In this case, all data that have been shared must be destroyed and the project terminated.

3. Publications Policy:

The NC-VDRS Director will review and approve all publication of the results in scientific forums, such as journals or professional meetings. They will maintain a list of proposed publications and presentations which identifies lead authors associated with each area.

Person(s) wishing to use the NC-VDRS data for scientific publications or presentations must request access to the data using a standardized form at the end of this document that requests information about the person(s) requesting the data, the institutions they represent, their purpose in requesting the data, and a list of the data fields they require. In addition, a brief outline of the proposed project detailing background and significance, the research questions or hypotheses, and scientific and analytic methods to be used, is required. The restrictions and processes that apply for obtaining a shared data set apply to data to be used for publication purposes. The Director (typically in consultation

with the Data Sharing Committee) reviews these requests and may send them to colleagues for anonymous (double-blinded) review. They then make a decision regarding access to the data within 30 days of the date the request is submitted.

A written data sharing agreement (at the end of this document) is signed by the person(s) with whom the data is shared. The agreement stipulates that the person(s) with whom the data is shared must:

- Destroy their data once their project is complete
- Not make a website release, press release, or other public statement using the NC-VDRS data without the express prior approval of NC-VDRS Director
- The OCME, SCHS, SBI, and LLE must be acknowledged as the source of the NC-VDRS data in all publications, press release, website release, and public statements using the NC-VDRS data.
- The Director reserves the right to withdraw access to the data and cancel the data sharing agreement. In this case, all data that has been shared must be destroyed and the project terminated.

The person(s) with whom the data is shared must submit a draft of any conference abstract, conference presentation or journal paper to the Director at least 2 weeks before submitting or presenting, unless they have a prior arrangement with the Director exempting them from the rule (e.g., in the case of an abstract deadline).

At a 6 monthly interval, the person(s) with whom the data has been shared must provide a progress report to the Director and the NC-VDRS Data Sharing Committee. Person(s) who fail to generate their identified product(s) within 2 years of receiving the data lose access to the data. In that situation, the data sharing agreement is canceled and the project must be terminated. An extension may be granted by the Director at his/her discretion, following consultation with the Data Sharing Committee.

NC-VDRS Data Sharing Request: Instructions for Completing this Form

The purpose of this form is to file a request with the NC-VDRS for permission to access the NC-VDRS data. Anyone who wishes to access the NC-VDRS data should file this form with the NC-VDRS using the procedures described below.

You should complete this form BEFORE you begin work in your project. The NC-VDRS will review your project to ensure it confidentiality of the data will be maintained and that it does not overlap with existing planned analyses of the data by others. All requests will receive a response within 4 weeks from the date they are received. The form will typically be reviewed by the NC-VDRS Director in consultation with the NC-VDRS Data Sharing Committee.

To file this request, send it via email to Tammy.Norwood@dhhs.nc.gov or Scott Proescholdbell@dhhs.nc.gov . It must be in an electronic format readable by MS-Word. Hardcopy requests can be sent to:

Tammy Norwood
Program Manager, NC-Violent Death Reporting System
1915 Mail Service Center
Raleigh, North Carolina 27699-1915

You should make sure you carefully review Policy on Data Release and Publication of NC-VDRS Data. A copy can be obtained by emailing or writing to Mr. Proescholdbell. In particular, note the following:

- You must destroy the data once your project is complete, e.g., 2 years following publication of a paper (NC-VDRS will archive your data free of charge upon request).
- You must not release the data to others, or make a public statement (e.g. press release, website release) based on the data, without the express permission of NC-VDRS Director or Program Manager.
- Your project must have IRB approval
- You must treat the data as confidential
- You must sign the data sharing agreement

NC-VDRS Data Sharing Request

<p><i>If you are requesting access to the NC-VDRS data for ANY purpose, answer the questions below:</i></p>	
1. Title of Your Project:	
2. Your Name:	
3. Address:	
4. Institutional Affiliation:	
5. Phone:	
6. Email:	
7. Collaborators (name and institution):	
8. Is this a student project? a. Yes / No b. If yes, name your mentor for this project (if applicable):	
9. Brief outline of your project:	
10. IRB status (check one)	<input type="checkbox"/> Will file IRB on : _____ (date) <input type="checkbox"/> Under review by IRB <input type="checkbox"/> Approved by IRB : ○ Name of IRB: _____ ○ approval expires: _____ (date)

NC-VDRS Data Sharing Request

<i>In addition, if you are requesting data for the purpose of scientific presentation or publication, you must answer the questions below:</i>	
1. What are the specific aims of your project?	
2. Briefly describe the significance of your project.	
3. Describe the statistical methods and/or data analysis to be used.	
4. Describe the data files you will need for this project.	
5. What data fields (variables) do you need? (attach a list if there is insufficient space on this page)	
6. In what software (SAS, STATA, etc) do you need the data?	

NC-VDRS Data Sharing Agreement

I HEREBY AGREE TO THE FOLLOWING TERMS REGARDING MY USE OF THE NC-VDRS DATA

- I will destroy the data once my project is complete, e.g., 2 years after publication of a scientific paper. I understand that NC-VDRS will archive my data free of charge if I so request.
- I will not make a website release, press release, or other public statement using the NC-VDRS data without the express prior approval of NC-VDRS Director.
- I agree to acknowledge the OCME, SCHS, & Law Enforcement Agencies as the source of the NC-VDRS data in all publications, press release, website release, and public statements using the NC-VDRS data.
- I understand that the Director reserves the right to withdraw access to the data and cancel the data sharing agreement. In that case, all data that has been shared must be destroyed and the project terminated.
- I understand that I must maintain IRB approval for my project throughout the entire project
- I have reviewed the Policy on Data Release and Publication of NC-VDRS Data and I agree to abide by the policy.

Name:	Signature:	Date:

DATA CONFIDENTIALITY

I will treat the data as confidential and will not disclose the identity of anyone, living or dead, on the data file. I will report data in an aggregated fashion only. I have reviewed the Policy on Data Release and Publication of NC-VDRS Data and I agree to abide by the policy. Data will be password-protected and/or stored on secure servers at all times.

Name:	Signature:	Date: