

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), and local law enforcement (LLE) 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 <https://www.cdc.gov/violenceprevention/nvdrs/datacollectionaccess.html>; unrestricted violent death data are also available through the WISQARS Violent Death Module located at the same address).

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 releases: 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.

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

¹ NVDRS Data Re-Release Plan, Version 9, Draft, 06-22-2004- revised 8/20/2011 and 5/30/2017

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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 consistent 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 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.

Data sharing requests for access to the NC-VDRS data that include any identifiable data elements 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.

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.

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

- Maintain secure storage of the data and 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;
- Abide by the terms of the publications policy detailed below if data are to be used for a scientific publication or presentation;
- Acknowledge the OCME, SCHS, SBI, and LLE 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.

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3. Data Storage

Data recipient(s) must limit access to NC-VDRS data to only those described and authorized within their data release agreement. Appropriate safeguards must be taken to prevent the use or disclosure of these data for any other purposes than that outlined in the data sharing agreement. Data must be password-protected and stored on a secure server at all times. Person(s) requesting the data will be asked to describe how they will store and maintain these data throughout the duration of their agreement. Once the project is complete, all original and copies of the data must be destroyed.

4. Publications Policy:

The NC-VDRS Director will review and approve all publication of the results of projects using NC-VDRS data 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 the standardized data sharing agreement form at the end of this document. The agreement 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 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). The data recipient(s) assume full responsibility for the analysis and interpretation of the data. To the extent that the data recipient(s) require technical assistance in analyzing or interpreting the data that goes above and beyond providing non-manipulated data, the NC-VDRS reserves the right to request that these activities be considered a substantial contribution to the research that may warrant consideration as a research collaborator or co-author in any resulting publications or presentations.

Data recipients must acknowledge the OCME, SCHS, SBI, and LLE as the source of the NC-VDRS data in all publications, press releases, website releases, and public statements using the NC-VDRS data.

At 6 month intervals, the person(s) with whom the data has been shared must provide a progress report to the Director. 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

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 (where applicable)
- 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 stored on a secure server at all times.

Name

Signature

Date