Application Packet

For Access to Data from the

National Child Death Review

Case Reporting System

National Center for Fatality Review & Prevention
2479 Woodlake Circle, Suite 380
Okemos MI 48864
800-656-2434 www.ncfrp.org

This Application Packet contains:

NCFRP Data Dissemination Policy & Guidelines for Requesting De-identified Dataset

DATA DISSEMINATION POLICY

Mission

The purpose of the Child Death Review (CDR) Case Reporting System of the National Center for Fatality Review and Prevention (NCFRP) is to systematically collect, analyze, and report on information surrounding deaths of individual children around the country. The information can then be used at the local, state, and national levels to inform improvement in child health and safety and to prevent deaths. The data collected with the System includes the following:

- information about the child, family, supervisor and perpetrator;
- the types of action taken during the investigation;
- the scene, incident, and background information on the cause of death, including the risk and protective factors;
- the services provided or needed as a result of the death;
- a descriptions of the teams' recommendations, as well as the policies, practices, and other actions taken to prevent other child deaths; and
- factors affecting the quality of the case review.

The web-based CDR Case Reporting System was first implemented in May 2004 in 14 pilot states. Version 1 was made available for widespread use in January 2007, and Version 2 was released in January 2008. Updated information on the number of participating states, number of entered cases and number of cases migrated into the system from older state reporting systems is available from NCFRP. The CDR Case Reporting System is supported primarily by the HRSA Maternal and Child Health Bureau[1] and secondarily by the US Centers for Disease Control and Prevention[2]. Data submitted by states resides on servers at the Michigan Public Health Institute (MPHI).

Data Sources

Data collected by the CDR Case Reporting System are the result of multi-disciplinary processes that bring together state and/or community agencies to share information on child death events and to identify the risk factors in these deaths. Data entered into the System may include, but are not limited to, information gathered from the following data sources: birth

[1] Grant No. 1 UG7 MC 28482 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

[2] Number 200-2013-57324 and 200-2013-57324 from the US Centers for Disease Control and Prevention.

certificates, death certificates, law enforcement records, medical records, autopsy reports, child protective services reports, and Emergency Medical Services run reports.

Child Death Review Programs in States

Child death review programs vary by state with respect to the types of death reviewed (all deaths, non-natural deaths, all injuries, abuse and neglect, and/or near-deaths, etc.); the maximum age of children whose deaths are reviewed (0-14, 0-17, 0-25, etc.); and the average time between review and death (ranges from 1 to 36 months). Due to these variances, the data are not universally consistent from state to state.

Because most states do not review or enter every child fatality into the System, the CDR Case Reporting System should not be directly compared with vital statistics data nor should it be used to compute incidence rates. All of these distinctions among states and limitations must be accounted for and noted in any analysis of the data. More information about child death review programs and selection of cases by states for review can be found at http://www.childdeathreview.org/state.htm.

Data Ownership

Child death review data entered into the System are owned by the individual state that entered it (per the data use agreement executed between each state and MPHI/NCFRP). Requests for de-identified, individual case report data will be submitted to the NCFRP Data Dissemination Committee, per guidelines contained in this document. NCFRP will inform states participating in the CDR Case Reporting System of all approved applications. For any research request that proposes to identify data by state in any published or publicly released analysis or results, states will be provided an opportunity to have their state's data excluded from the study.

Removal of Identifiable Data Elements for Dataset

No data file that includes HIPAA-defined personally identifiable elements is available to researchers. The complete Case Report tool contains more than 275 questions (approximately 2,200 data elements) about an individual fatality. (The Case Report form can be viewed and downloaded at www.childdeathreview.org.) Although states often enter HIPPA-defined personally identifiable data elements (child's name, address, date of birth, date of death, date and time of incident, and incident county) into the System, all personally identifiable data elements will be removed from any dataset made available to researchers. The data elements that will be removed from the dataset are listed in Attachment 1 of the Application for Access to De-identified Dataset (Application for Data). The "Narrative" field contained in Section O of the Case Report form will only be released to researchers under special circumstances.

To further protect anonymity of states, NCFRP will create and provide a unique code for each state for each approved research project so that researchers can evaluate variation and control for potential bias in the dataset without identifying the individual states. NCFRP will retain the coding key.

Permitted Data Uses
The NCFRP may report aggregated, de-identified data identified by state to requested parties without state permission. The NCFRP will only report aggregated data with cell counts of six or more cases. Requests by researchers for de-identified datasets must be made in accordance with the Guidelines for Requesting De-identified Dataset (Guidelines), below, and NCFRP will only release de-identified datasets in accordance with the Guidelines.

Required Fees
A fee will be charged to each applicant for preparation of the requested dataset. The amount of the fee will be determined by NCFRP staff. An estimate of this fee will be provided to the applicant upon a preliminary review of the proposal by staff. Fees will be determined based on a price equal to the number of staffing hours estimated to prepare the dataset using the federally approved MPHI MOBUS rates. Fees must be paid in full prior to the release of the dataset to the applicant. NCFRP reserves the right to waive fees in certain situations.

Data Quality
In order to standardize the collection and interpretation of data elements, the CDR Case Reporting System contains a comprehensive Data Dictionary that is readily available online when entering cases into the System or as a standalone PDF document that can be used by child death review teams during review meetings. Additionally, NCFRP is readily available to provide technical assistance about the Case Report tool and is in constant communication with states about data and reporting questions. Since the data are owned by the individual participating states, states are responsible for cleaning data records, and states vary in the degree to which they review data for inconsistencies, incompleteness, or inaccuracies. NCFRP has found that data quality appears to improve with increased time and training on the System. The Case Report tool contains by design some subjective questions to engage team discussion (e.g., “Was the death preventable?” or “Did an act of omission contribute to the death?”). The subjective nature of some of the questions can, however, make data analysis more problematic. Finally, although teams record in the System which agencies participated in the child death review, the primary data source for each data element is not collected as part of the Case Report tool. If there is a discrepancy in information shared by the different agencies at the review meeting, it is up to the CDR teams to determine the best answer and there is no set primacy rule for data sources.

More information about the CDR Case Reporting System and limitations on the use of the data can be found in the February 2011 Supplement to *Injury Prevention* (Covington TM. The US national child death review case reporting system. *Injury Prevention* 2011; 17 Suppl 1:i34-i37).

GUIDELINES FOR REQUESTING DE-IDENTIFIED DATASET

Researchers affiliated with eligible Receiving Institutions may apply for access to a de-identified dataset. The Receiving Institution must be an institution of higher education, research organization, non-profit agency or government agency that either employs or contracts with the Investigator. The Institution must be registered with the U.S. Office for Human Research Protections. Any release of data will be subject to a signed Contract for Access to and Use of Data (Contract for Data) between NCFRP and an authorized representative of the Receiving Institution. The Contract for Data is set out after these Guidelines.

An Application for De-identified Dataset (Application for Data) must identify a principal investigator (PI). The PI serves as the primary point of contact for all communications involving the Contract for Data. The PI must sign the Contract for Data, by which the PI assumes responsibility for compliance with all terms of the Contract for Data by employees of the Receiving Institution, including the day-to-day security of the electronic data and all printed output derived from the files.

Each additional researcher who will have access to the NCFRP dataset must be identified on the Application for Data and must sign the Confidentiality Agreement attached (Attachment 3). The applicants may not release or permit others to release the dataset in whole or in part to any persons other than those identified in the Application for Data.

Access to the dataset is also subject to the following requirements:

1. The researchers given access to the Center's dataset may not conduct analyses of the data for purposes other than those described in the approved Application for Data. Applicants will not alter the approved use of the data in the research design unless they have notified and obtained written permission for the alteration from NCFRP.
2. The PI must obtain IRB approval for the proposed research. Letters of approval must be submitted to NCFRP prior to release of data for approved analyses.
3. All data shared are and shall at all times remain the sole property of the state and local county teams which performed the child death reviews that are the source of the data. States have the right of first refusal to participate in this research project if the PI plans to publish or publicly release any analysis or results that identifies individual states. It is permissible, however, to list the states included in the dataset, as long as no data are attributed to specific states, and the states have authorized this acknowledgement. States will be asked whether they wish to be specifically acknowledged in any project publication or presentation.
4. The researchers must not attempt nor permit others to attempt to use the dataset to learn the identity of any decedent. If the identity of a decedent should be inadvertently discovered by the PI or any other individual, the PI must make no use of this knowledge, permit others to use the knowledge, or inform anyone else of this knowledge, and must inform NCFRP of the discovery so it can prevent future discoveries of this nature.
5. No data will be released that identifies data by state jurisdiction without the explicit approval of the state(s).

6. Only aggregated data with cell counts of six or more cases will be released and reported in any analysis. Cells less than six cases will be aggregated with other like cells.
7. All oral and written presentations or other distribution of information resulting from the use of this dataset must be developed with adequate provision for the accuracy, reliability and integrity of the data.
8. All oral and written presentations or other distribution of information resulting from the use of the requested data must be submitted to NCFRP for review at least two weeks prior to presentation or submission to a journal or other source of publication. The purpose of this review is to determine whether the research was completed in the manner specified in the Application and whether the analysis is in the spirit of Child Death Review and the NCFRP mission, and to permit NCFRP to have advance notice of potential issues pertaining to the analysis and/or results. Any additional or other use of these data will be considered a breach of the Contract for Data, unless agreed upon in writing by both parties beforehand.
9. NCFRP may terminate its contract with the recipient if the recipient is in violation of any condition of the contract and such violation is not remedied within 30 days after the date of written notice of the violation. Furthermore, failure to comply with the contract terms will result in the disqualification of the PI, along with any collaborators implicated in the violation, from receiving additional NCFRP data.
10. All presentations and publications making use of this dataset must be provided to NCFRP in a timely manner so that it is a repository of the various uses of the data.
11. All presentations or other distribution resulting from use of the requested dataset must include an acknowledgement of the participating states and NCFRP. They must include the following language: "This dataset was provided by the NCFRP, which is funded in part by Grant Number UG7MC28482 from the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA) and in part by the US Centers for Disease Control and Prevention Division of Reproductive Health. The contents are solely the responsibility of the authors and do not necessarily represent the official views of NCFRP, HHS or the participating states. The following states contributed data from their child death review: (list states)."
12. Within three years of completion of the project, all hard copies of the dataset generated by the researchers must be destroyed with a cross-cut shredder or returned to NCFRP, and all electronic data must be destroyed/deleted within the same time frame. Written confirmation that the dataset has been destroyed is required.
13. All installations of the data must have electronic security measures in place to prevent unauthorized access, by electronic or physical means, to the confidential data provided or to output from that data.

Data Quality

Only cases that have been identified and approved by the states as being complete and clean will be included in the de-identified dataset. The NCFRP will survey states on an annual basis to make this determination.

Application Process

To request a de-identified dataset from the NCFRP, the PI must complete the Application for Data, including a detailed proposal to NCFRP describing the purpose of the data request, methods for study, and mechanisms that will be used to keep the data secure (see Application form). Upon receipt, the Data Dissemination Committee (consisting of representatives of participating states, scientists, members of the NCFRP National Center Advisory Committee, and other relevant individuals) will evaluate the application on the basis of the following criteria:

- Quality of the research question(s) and objectives for use of the dataset;
- Whether the requested data elements are clearly described and whether access to those elements is necessary for the research questions;
- Applicant's understanding of the strengths and limitations of the database and analysis plan that is appropriate for this type of dataset;
- Qualifications of researchers who will have access to the dataset;
- Sufficiency of safeguards in place to maintain the data security, confidentiality, and prevent unauthorized access to data and evidence that the institution is registered with the U.S. Office for Human Research Protections;
- Extent to which the proposal is in accordance with the mission of Child Death Review, which is to better understand how and why children die and use the findings to take action that can prevent other deaths and improve the health and safety of children;
- Whether NCFRP is conducting similar research or has plans to do so; and
- Whether anticipated presentations, publications, or other dissemination of results from the research is consistent with the NCFRP mission.

At a minimum, the Committee will review applications on a quarterly basis. All applicants will be notified in writing by NCFRP of the Committee's decision. Proposals will be scored using the above criteria and given one of three grades:

1. Rejected for not meeting the criteria
2. Preliminary approval but requesting revision
3. Approved

After approval by the Committee, NCFRP will inform the states participating in the CDR Case Reporting System of the Committee's decision. For any research request that proposes to identify data by state in any published or publicly released analysis or results, states will be notified and given the opportunity to have their state's data excluded from the study (Attachment 2). States will also be asked whether they wish to be specifically acknowledged in any project publication or presentation.

Requests for more information about the data file and the process for obtaining permission to access the dataset should be directed to:

Heather Dykstra, MPA
Senior Data Analyst
National Center for Fatality Review and Prevention
2479 Woodlake Circle, Suite 380
Okemos, MI 48864
Phone : (800) 656-2434
Fax : (517) 324-7365
Email : info@ncfrp.org

NATIONAL CENTER FOR FATALITY REVIEW & PREVENTION
CASE REPORTING SYSTEM
Application for De-identified Dataset

Please complete information electronically.

I. Data

A. For what year or years of the NCFRP Case Reporting System are data requested?

2004 ___
2005 ___
2006 ___
2007 ___
2008 ___
2009 ___
2010 ___
2011 ___
2012 ___
2013 ___
2014 ___
2015 ___

Note: States have different timeframes for when cases are reviewed and entered into the CDR Case Reporting System. Only cases that have been identified and approved by the states as being complete and clean will be included in the de-identified dataset. NCFRP surveys states on an annual basis to make this determination.

Cases migrated from previous child death review reporting systems into the CDR Case Reporting System will not be included in a standard dataset, but may be provided upon further consultation between the researcher and NCFRP.

II. Investigator/researchers

A. Identify the Principal Investigator who will carry out the duties described in the Guidelines and provide his/her curriculum vitae as an attachment:

Name:
Title:
Institution:
Department:
Street address:
City:
State:
Zip:
Phone:

Email address:

B. Identify each additional researcher/collaborator/co-investigator that will have access to the dataset and provide the curriculum vitae for each:

Name:
Title:
Institution:
Department:
Street address:
City:
State:
Zip:
Phone:
Email address:

C. Describe the specific responsibilities the PI and other investigator(s) will have in conducting and completing the proposed research:

PI role: _____

Investigator 2:_____

Investigator 3:_____

[Add additional description for additional investigators.]

III. Description of proposed research project

In no more than five pages (excluding the list of variables), provide a detailed study protocol that includes the following:

A. Title of project.

B. Describe the research question(s) and objectives for the study.

C. Describe the significance and rationale for the research.

D. Describe the funding source(s) for the research.

E. Describe the study design and methods.

The response should be a coherent narrative that links the sample, the variables requested, and the analysis plan to the research questions. The narrative response is expected to be at least one page long, and, in addition to the narrative description, the response must include the following:

1. Description of the sample set requested using the Case Report form as a guide (for example, "infants only," or "children ages 0-4 with motor vehicle as cause of death").

2. List of variables needed to carry out the study using the Case Report form (attached to Application Packet) as the guide.

3. Analysis plan and software that will be used.

4. Discussion of how limitations of the data and data quality issues will be addressed and will likely impact the study and your conclusions. **The NCFRP database is a unique set of information, and researchers are urged to read the attached article from *Injury Prevention*, in particular the sections that describe in detail the "Limitations" and "Strengths" of the data.**

5. Discussion of how the study will handle small data numbers and missing and incomplete data.

F. Estimated timeframe for study start and completion.

G. Anticipated presentations, publications, or other dissemination of results. Please be as specific as possible. Reminder: Per the Guidelines for Use of Data, all oral and written presentations or other distribution of information resulting from the use of the requested data must be submitted to NCFRP for review at least two weeks prior to presentation or submission to a journal or other source of publication to determine whether the research was completed in the manner specified in the Application, whether the analysis is in the spirit of Child Death Review and the NCFRP mission, and to permit NCFRP to have advance notice of potential issues pertaining to the analysis and/or results.

IV. Data Security

All users of the NCFRP dataset must have electronic security measures in place to prevent access to the confidential dataset from unauthorized individuals.

A. Where will the data reside and how will data be shared among researchers? Describe the physical transmission.

B. Security details: In the table below, provide a comprehensive list of all devices on which the dataset will be installed and indicate the electronic security measures that will be applied to each device. For those devices that have access to the Internet, all four of the electronic security measures must be in place for this data request to be approved. For non-Internet devices, firewall protection is not required.

If co-investigators at different institutions from the PI will also have physical control of the data, complete a table for each such co-investigator's institution.

ID	**Device type** Indicate workstation, laptop, server, portable media, or other device	**Internet** Does the device have access to the Internet?(Y/N)	**Electronic security measures**			
			Password login The device requires a login ID and password at startup and after a period of inactivity. (Y/N)	Restricted directory access The directories containing the data are restricted to authorized users who have logged in to the device. (Y/N)	Virus protection Anti-virus software is installed on the device. (Y/N)	Firewall protection Firewall technology is in place for devices that are connected to the Internet. (Y/N)
1						
2						
3						
4						

C. Physical security: In addition to electronic security, the devices on which the dataset have been copied must be physically secured to prevent theft of the device. Describe below the physical security measure in place for each device.

If co-investigators at different institutions from the PI will also have physical control of the data, complete the table for each such co-investigator's institution and describe how data will be securely transferred between institutions.

ID	**Location of Device** Indicate building name and office number	**Description of physical security** Examples are offices are locked when unoccupied; storage in secure cabinets when the device is not in use; and monitored access to the building where the data are stored.
1		
2		
3		
4		

V. Receiving Institution

A. Identify the Receiving Institution, as that term is described in the Guidelines.

B. Provide the IRB assurance number.

C. Describe your Institution in detail. What kind of work does it do? Include the type of organization, its profit/non-profit status, and primary sources of revenue.

D. Provide evidence in an attachment that your institution is registered with the U.S. Office for Human Research Protections.

E. Describe your plans to obtain IRB approval for this study using the NCFRP data.

F. Describe your Institution's experience in overseeing the use of sensitive research data by its staff. Please give specific examples.

G. Describe any known breaches of sensitive research data by your organization and the steps taken to remedy the breach.

Application signatures:

_____ _____

Signature of Principal Investigator Date

_____ _____

Signature of Representative of Receiving Institution Date

_____

Title

TEMPLATE ONLY: CONTRACT NEED NOT BE COMPLETED OR SIGNED AT TIME OF APPLICATION OF APPLICATION

MICHIGAN PUBLIC HEALTH INSTITUTE
National Center for Fatality Review and Prevention

Contract for Access to and Use of Data

This contract specifies the conditions for release of National Center for Fatality Review and Prevention (NCFRP) CDR Case Reporting System data, research, and reports for legitimate public health or related research. The intent of this contract is to foster such research and to prevent misrepresentation of the data. This Contract for Access to and Use of Data (Contract for Data) is between [_____] (Institution), and Michigan Public Health Institute/National Center for Fatality Review and Prevention (NCFRP).

This Contract for Data is for the study entitled [_____], as described in the Application for De-identified Dataset, dated [_____], which is attached hereto and made part of this contract as Appendix A. Institution's employee, _____, is intended to be the Principal Investigator for said study. Collectively, Institution and Principal Investigator shall be referred to as "Investigators." The Institution is responsible for ensuring that all work under this study including the work of additional researchers, collaborators, and co-investigators complies with all applicable federal, state, local and international laws and regulations; and that the work is performed in a professional manner to the highest academic standards.

Investigators agree to the following requirements for the use of the dataset and assure compliance with the requirements.

1. This agreement applies to all activities occurring between the date of signing and 18 months after that date.

2. No one will be permitted to use this dataset to conduct analyses other than those described in the Application for Access to and Use of Data that accompanies this statement.

3. IRB approval of the Receiving Institution will be obtained, and documentation of that approval will be provided to NCFRP prior to release of any dataset.

4. Investigators understand that all data shared are and shall at all times remain the sole property of the state and local teams that performed the child death reviews that are the source of the data.

5. NCFRP will seek permission from the participating states for release of the data for the project described in the Application for Data if said states are to be named in the analysis or results. States have the right of first refusal to participate in this research project if

applicant intends to identify state jurisdiction in any published or publicly released analysis or results.

6. Neither the dataset nor any part of it will be released to any persons other than those identified in the approved Application for Data.

7. Investigators and all other researchers with access to the dataset will not attempt nor permit others to attempt to use the dataset to learn the identity of any decedent. If the identity of a decedent should be inadvertently discovered, Investigators will make no use of this knowledge, nor will they permit others to use the knowledge. Investigators will inform NCFRP of the discovery so it can prevent future discoveries. Investigators will not inform anyone else of the discovery of identity.

8. Investigators understand that not all deaths of children in the states have been reviewed by child death review teams and that not every child death review team in the country participates in the CDR Case Reporting System.

9. Investigators understand that data will only be reported at an aggregated level and no data will be released that identifies data by state jurisdiction without explicit state permission. Aggregated data must have cell counts of six or more cases in order to be reported.

10. Investigators will not alter the approved research design without written permission from NCFRP.

11. All oral and written presentations or other distribution of information resulting from the use of this dataset shall be developed with adequate provision for the accuracy, reliability and integrity of the data.

12. All oral and written presentations or other distribution of information resulting from the use of the requested dataset will be submitted to the NCFRP for review at least two weeks prior to presentation or submission to a journal or other source of publication.

13. All oral and written presentations or other distribution of information resulting from use of the requested dataset will include an acknowledgement of the participating states and NCFRP.

14. All presentations and publications will include the following language: "This dataset was provided by the NCFRP, which is funded in part by Grant Number UG7mc28482 from the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA) and in part by the US Centers for Disease Control and Prevention Division of Reproductive Health. The contents are solely the responsibility of the authors and do not necessarily represent the official views of NCFRP, HHS or the participating states. The following states contributed data from their child death review (list states)."

TEMPLATE ONLY: CONTRACT NEED NOT BE COMPLETED OR SIGNED AT TIME OF APPLICATION

15. All presentations and publications making use of this dataset shall be provided to NCFRP in a timely manner so that it is a repository of the various uses of the data.

16. Investigators understand that once a proposal for use of the dataset is approved, NCFRP may acknowledge publicly the investigators' names, institution, and name of the study as partners working with the CDR Case Reporting System data.

17. The sharing of this dataset for the purposes stated in the approved project does not imply, in whole or in part, that the topic of the approved project has not been investigated before, or will not be investigated now or in the future, by other investigators interested in this topic.

18. Any additional or other use of this dataset except as described in Investigators' Application for Data will be considered a breach of this contract, unless agreed upon in writing by both parties beforehand.

19. Investigators will assure compliance with the security measures described in the Application for Data.

20. When the proposed analyses are completed, all copies of the dataset will be destroyed with a cross-cut shredder or returned to the NCFRP upon completion of project plus three years. All electronic versions of the dataset will be deleted. Written confirmation that the dataset has been destroyed or deleted is required.

21. By signing this document, Investigators agree to be responsible for compliance with the conditions of this agreement and agree to these conditions by their signatures below.

22. Cost-reimbursement for the time and expenses spent by MPHI staff to compile the data file requested by Investigators will be invoiced to Investigators after the work is complete. The invoice must be paid in full to Michigan Public Health Institute prior to release of the data file.

23. NCFRP may terminate the Contract for Data if the Investigator is in violation of any condition of the agreement and such violation is not remedied within 30 days after the date of written notice of the violation.

TEMPLATE ONLY: CONTRACT NEED NOT BE COMPLETED OR SIGNED AT TIME OF APPLICATION

Principal Investigator:

Name: _____ Title: _____

Organization: _____

Address: _____

Email address: _____Phone: _____

Signature: _____ Date: _____

For Receiving Institution:

Name: _____ Title: _____

Organization: _____

Address: _____

Email address: _____Phone: (___) _____

Signature: _____ Date: _____

For MPHI:

Name: _____ Title: _____

Organization: ____Michigan Public Health Institute_____

Address: __2436 Woodlake Circle, Okemos MI 48864_____

Email address: _____Phone: (___) _____

Signature: _____ Date: _____

Appendix B

HIPAA Required Elements to De-Identify Case Data*

The CDR-CRS supports two types of data downloads: identified and de-identified. NCFRP staff and researchers who have been approved by the NCFRP will receive only de-identified data. The CDR-CRS variables that will be removed in de-identified downloads are listed below.

The CDR-CRS contains many free text fields (most often in the 'specify' or 'describe' text fields). The CDR-CRS also provides users the opportunity to provide more detail surrounding the circumstances of the death in Section N: Narrative text field. **When the Narrative, 'specify,' and/or 'describe' text fields are included in a de-identified download, the Narrative, 'describe,' and 'specify' text fields SHOULD NOT contain any HIPAA Identifiers.**

HIPAA Identifiers include names; all geographical subdivisions smaller than a state; all elements of dates (except year) for dates directly related to an individual; phone numbers; fax numbers; electronic mail addresses; social security numbers; medical record numbers; health plan beneficiary numbers; account numbers; certificate/license numbers; vehicle identifiers and serial numbers; device identifiers and serial numbers; web universal resource locators; internet protocol address numbers; biometric identifiers; full face photographic images; and any other unique identifying number, characteristic or code.

Identifying information can be entered into the CDR-CRS element fields in the list below, including free text fields associated with the listed fields, because all the listed fields and their related text fields will be removed from every de-identified download. **However, Users should be instructed by the Holder not to enter any identifying information in other free text fields, including Section N: Narrative text field, because these text fields may be included in de-identified downloads. NCFRP cannot review free text fields in de-identified downloads to assure that they contain no HIPAA Identifiers.**

HIPAA Required Elements to De-Identify Case Data

The CDR-CRS elements listed below will be removed for all persons accessing de-identified case data:

Introduction: Case Definition
Case number
County of review
Review team number
Sequence of review
Death certificate number
Birth certificate number
Medical examiner/Coroner number

* Source: Code of Federal Regulations Section 164.514(b)(2)(i).

Date CDR team notified of death

Section A: Child Information
Child first name
Child middle name
Child last name
Child name: unknown
Date of birth: month, day, and year
Date of birth: unknown
Date of death: month and day
Date of death: unknown
Residential address: unknown
Residential address: street
Residential address: apartment
Residential address: city
Residential address: county
Residential address: zip

Section D: Incident Information
Date of incident
Date of incident: same
Date of incident: unknown
Time of incident
Time of incident: am or pm
Time of incident: unknown
Incident county
Death county

Section L: Review Meeting Process
Date of first CDR meeting

Section M: SUID and SDY Case Registry
Date of first Advanced Review meeting
Date of SUID Case Registry data entry complete

Section O: Form Completed By
Form completed by – Person's name
Form completed by – Title
Form completed by – Agency
Form completed by – Phone
Form completed by – Phone extension
Form completed by – Email
Form completed by - Date
Date of quality assurance completed by State

My CDR Outcomes
My CDR Outcomes – Person's name
My CDR Outcomes - Team of review

* Source: Code of Federal Regulation Section 164.514(b)(2)(i).

Attachment 2

A Request for the Release of CDR Case Report Data when Research Applicant Intends to Identify State(s) in Proposed Published Analysis or Results

The following template will be used by NCFRP to request written authorization from states participating with the CDR Case Reporting System for permission to release individual case report data to research applicants that intend to identify state jurisdiction in published analysis or results. State permission will be sought once the Data Dissemination Committee has approved the project.

Dear State of (insert state) Data Holder:

This letter is to inform you that the National Center for Fatality Review and Prevention (NCFRP) has received a request to release de-identified individual case report data. The request was submitted by (insert name of requestor and organization) on (insert date).

The requester will be using the data for the purpose of (insert purpose). If the requester intends to use the data for a purpose other than what is stated here, they must submit a new request.

Per the National Center for Fatality Review and Prevention's Guidelines for Requesting De-identified Dataset, written permission is necessary from each state where the research applicant intends to identify state jurisdictions in published or publicly released analysis or results of CDR data.

As a reminder, de-identified individual case report data released by the NCFRP will not include the list of data elements found in Appendix B of the NCFRP Data Dissemination Policy and Guidelines.

Please verify that your state is not precluded from releasing this data by any rules or statutes before signing this agreement.

If you approve this data request, please sign both copies of the attached contract. Mail both copies to the National Center for Fatality Review and Prevention for signature.

Attachment 3

Confidentiality Agreement to be Signed by All Researchers with Access to NCFRP Data

By signing this Agreement, I agree to the following:

1. I will safeguard the confidentiality of all confidential information contained in the National CDR dataset to which I have been given access. I will not carelessly handle confidential information. I will not in any way divulge copy, release, sell, loan, review, or alter any confidential information except as within the scope of my duties.
2. I will only access confidential information for which I have a need to know and I will use that information only as needed to perform my duties.
3. I will not attempt nor permit others to attempt to use the dataset to learn the identity of any decedent. If I inadvertently discover the identity of a decedent, I will make no use of this knowledge, will not permit others to use the knowledge, will not inform anyone else of this knowledge, and will inform NCFRP of the discovery so it can prevent future discoveries.
4. I will transmit and store all electronic and hard copy data in a secure and confidential manner and location at all times.
5. Upon completion of the performance of my duties, the identifiable dataset will be destroyed and no opportunities will be available to access that data on the network or computer systems.
6. I will promptly report activities by any individual or entity that I suspect may compromise the availability, integrity, security, or privacy of confidential information.
7. I understand that the ownership of any confidential information referred to in this Agreement is defined by State statutes.
8. I understand that violating applicable laws and regulations may lead to other legal penalties imposed by the judicial system.

Signature: _____ Date: _____

Print Name: _____

Attachment 4

SELECTED JOURNAL ARTICLES AND REPORTS USING CDR-CRS DATA

Classification of Maltreatment-Related Mortality by Child Death Review Teams: How reliable are they?

Parrish J, Schnitzer PG, Lanier P, Shanahan ME, Daniels JL, Marshall SW. 2017. Child Abuse & Neglect Final version published online: 30-Mar-2017 DOI information: 10.1016/j.chiabu.2017.03.003. http://www.sciencedirect.com/science/article/pii/S0145213417300959

The Sudden Death in the Young Case Registry: Collaborating to Understand and Reduce Mortality

Burns KM, Bienemann L, Camperlengo L, Cottengim C, Covington TM, Dykstra H, Faulkner M, Kobau R, Erck Lambert E, MacLeod H, Parks SE, Rosenberg E, Russell MW, Shapiro-Mendoza CK, Shaw E, Tian N, Whittemore V, Kaltman JR., Sudden Death in the Young Case Registry Steering Committee. 2017. Available first online: http://pediatrics.aappublications.org/content/early/2017/02/20/peds.2016-2757.

Dangerous Waters: Profiles of Fatal Child Drowning in the U.S. 2005-2014

MacKay JM, Steel A, Dykstra H. 2016. Safe Kids Worldwide. https://www.safekids.org/sites/default/files/dangerous_waters_research_report.pdf

Keeping Kids Safe In and Around Water: Exploring Misconceptions that Lead to Drowning

MacKay JM, Steel A, Dykstra H, Wheeler T, Samuel E, Green A. 2016. Safe Kids Worldwide. https://www.safekids.org/sites/default/files/small_water_safety_study_2016.pdf

Death Scene Investigation and Autopsy Practices in Sudden Unexpected Infant Deaths

Erck AB, Parks SE, Camperlengo L, Cottengim C, Anderson RL, Covington TM, Shapiro-Mendoza CK. 2016. J Pediatr2016; 174:84-90. https://www.researchgate.net/publication/301671583_Death_Scene_Investigation_and_Autopsy_Practices_in_Sudden_Unexpected_Infant_Deaths. Abstract only.

Pediatric Suicide in the United States: Analysis of the National Child Death Case Reporting System

Triglylidas T, Reynolds E, Teshome G, Dykstra H, Lichenstein R. 2016. I*njury Prevention* 2016; 0:1–6. Published first online.doi:10.1136/injuryprev-2015-041796. http://injuryprevention.bmj.com/content/early/2016/01/18/injuryprev-2015-041796.abstract. Abstract only.

Crib bumpers continue to cause infant deaths: A need for a new preventive approach

Scheers N.J., Woodard D.W, Thach, B.T. 2015. Pediatrics, DOI: http://dx.doi.org/10.1016/j.jpeds.2015.10.050. Published online 11/24/2015. http://www.jpeds.com/article/S0022-3476(15)01284-6/pdf.

Cause-specific mortality among children and young adults with epilepsy: Results from the U.S. National Child Death Review Case Reporting System

Tian N, Shaw EC, Zack M, Kobau R, Dykstra H, Covington TM. 2015. Epilepsy Behav. 2015. Apr; 45:31-4. doi: 10.1016/j.yebeh.2015.02.006. Epub 2015 Mar 18. http://www.epilepsybehavior.com/article/S1525-5050(15)00054-2/pdf

Development of a dataset of national cardiovascular deaths in the young

Vetter VL, Dugan NP, Haley DM, Covington TM, Dykstra H, Overpeck M, Iyer VR, Shults J. 2014. DOI: doi: 10.1016/j.ahj.2014.06.015. *American Heart Journal. http://www.ahjonline.com/article/S0002-8703(14)00365-2/pdf*

Sofas and Infant Mortality

Rechtman LR, Colvin JD, Blair PS, & Moon RY. 2014. Pediatrics 2014. 134:e1292. http://pediatrics.aappublications.org/content/pediatrics/early/2014/10/08/peds.2014-1543.full.pdf.

Sleep Environment Risks for Younger and Older Infants

Colvin J, et al. 2014. Pediatrics 134(2):e406-e412. http://pediatrics.aappublications.org/content/pediatrics/early/2014/07/09/peds.2014-0401.full.pdf

Classification System for the Sudden Unexpected Infant Death Case Registry and its Application

Shapiro-Mendoza C, Camperlengo L, Ludvigsen R, Cottengim C, Anderson R, Andrew T, Covington T, Hauck F, Kemp J, MacDorman M. 2014. *Pediatrics* 2014; 134(1): 1-10. http://pediatrics.aappublications.org/content/pediatrics/early/2014/06/03/peds.2014-0180.full.pdf

Child maltreatment deaths in the U.S. National Child Death Review Case Reporting System

Palusci V, Covington T. 2013. *Child Abuse Neglect.* S0145-2134(13)00245-7. doi: 10.1016/j.chiabu.2013.08.014. [Epub ahead of print] PubMed PMID: 24094272. https://www.ncbi.nlm.nih.gov/pubmed/24094272 Abstract only.

Sudden Unexpected Infant Deaths: Sleep Environment and Circumstances

Schnitzer P, Covington T, Dykstra H. 2012. *American Journal of Public Health 2012;* 102(6): 1204-1212. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3483961/

Public Health Surveillance of Fatal Child Maltreatment: Analysis of Three State Programs

Schnitzer P, Covington T, et al. 2008. *American Journal of Public Health*; 98:296-303. http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2006.087783?journalCode=ajph