REPORT OF THE JUDICIAL COUNCIL CHILD DEATH REVIEW BOARD ADVISORY COMMITTEE ON 2013 SB 77

In the last two legislative sessions, identical bills have been introduced that would amend K.S.A. 22a-243 to allow disclosure of Kansas State Child Death Review Board (SCDRB) records for research and public health purposes. 2012 SB 360 was heard in the Senate Judiciary Committee, but died in committee. The Senate Judiciary Committee held a hearing on 2013 SB 77, but the bill again did not make it out of committee. In May 2013, Senator Jeff King requested that the Judicial Council study the issue further.

The Judicial Council considered Senator King's request in June 2013. The Council agreed to form a new advisory committee to undertake the study.

COMMITTEE MEMBERSHIP

The members of the Judicial Council Child Death Review Board Advisory Committee are:

Hon. Maritza Segarra, Chair, District Court Judge in Geary County and member of the Kansas Judicial Council
Christie Appelhanz, Vice President of Public Affairs, Kansas Action for Children
Rebecca A. Ballard, Director for the Office of Research Integrity, Children's Mercy Hospital
Kristiane Bryant, Assistant Attorney General and Chairperson of the State Child Death Review Board
Jeffrey Colvin, MD, Physician at Children's Mercy Hospital
Greg Crawford, Director, Vital Statistics Data Analysis, Bureau of Epidemiology and Public Health Informatics, Kansas Department of health and Environment
Anne M. Kindling, Manager of Risk Management, Stormont-Vail Health*Care*, Inc.
M. Michele Mariscalco, MD, Associate Dean for Research, KU School of Medicine - Wichita
Mary McDonald, Attorney in private practice and member of State Child Death Review Board
Steve Montgomery, Chief Information Officer, Kansas Bureau of Investigation

BACKGROUND

The Kansas State Child Death Review Board was created by the Legislature in 1992 and is administered by the Office of the Kansas Attorney General. K.S.A. 22a-243. Board membership is established by the same statute and includes: one member each from the Office of the Attorney General (serves as Chairperson), the Kansas Bureau of Investigation, the Department for Children and Families, the Kansas Department of Health and Environment, and the Department of Education;

three members appointed by the Board of Healing Arts to include a district coroner, a pathologist, and a pediatrician; one representative of a child advocacy group appointed by the Attorney General; and one county or district attorney appointed by the Kansas County and District Attorneys Association. Board members serve as volunteers and receive no reimbursement for mileage or other expenses associated with attendance at the Board's monthly meetings.

The Board examines the circumstances surrounding the deaths of all children under the age of 18 who die in Kansas – whether or not the child is a Kansas resident – as well as the deaths of any Kansas children who die in another state. A review includes analysis of medical records, law enforcement reports, social service history, school history, and a variety of other pertinent information. Through these extensive and comprehensive reviews, the Board is able to develop a complete picture of all the circumstances that surrounded a child at the time of the child's death.

Analysis of its compiled data enables the Board to identify patterns, trends, and risk factors and use that information to fulfill the board's statutory duty to make "recommendations for improving child protection, including recommendations for modifying statutes, rules and regulations, policies and procedures." K.S.A. 22a-243(l). The Board is required by the statute to publish its recommendations in an annual report. The Board is also required to prepare a written report on each child death, but the report may only be sent to a county or district attorney in the child's county of residence or to a state's child protective services if the child resided in another state. K.S.A. 22a-244(a) and (e). All information acquired by the Board and all of its records are confidential and may be disclosed only to a member of the Legislature or a Legislative committee having "legislative responsibility of the enabling or appropriating legislation, carrying out such member's or committee's official functions." K.S.A. 22a-243(j). The Board may disclose its conclusions about a child's death, but may not disclose any information that is not subject to public disclosure by the agency from whom it was received by the Board. K.S.A. 22a-244(g). There is no other statutory authority for disclosures by the Board.

Bills were introduced in 2012 (SB 360) and 2013 (SB 77) that would expand the Board's ability to disclose information for research and public health purposes. Although hearings were held both years in the Senate Judiciary Committee, neither bill made it out of committee. At the conclusion of the 2013 session, Senator Jeff King requested that the Judicial Council study the issue. The Judicial Council granted Senator King's request, and this Committee was formed to undertake the study.

COMMITTEE STUDY

Before making a recommendation on 2013 SB 77 (See Attachment 1 at page 11), the Committee reviewed the applicable statutes; the minutes and testimony from the Senate Judiciary Committee hearings on 2012 SB 360 and 2013 SB 77; the Board's 2012 Annual Report; *Keeping Kids Alive: A Report on the Status of Child Death Review in the United States, 2011*, The National Center for the Review & Prevention of Child Deaths; materials from the National Center for the Review & Prevention of Child Deaths; and a draft guidance document for data and statistical requests from the Kansas Department of Health and Environment – Division of Public Health. The Committee also invited Angela Nordhus, the Executive Director of the Board, to speak to the Committee and conduct a demonstration of data entry in the database currently used by the Board.

The Committee met on August 22, September 25, and October 24 in person and on November 4, November 13, and November 21, 2013 via telephone conference to consider the issues presented.

DISCUSSION

The Committee carefully considered 2013 SB 77's expanded disclosure of de-identified data collected by the Board for research and public health purposes and whether such expanded disclosure is consistent with the Board's mission. The following three goals direct the Board's work:

1. To describe trends and patterns of child deaths (birth through 17 years of age) in Kansas and to identify risk factors in the population;

2. To improve sources of data and communication among agencies so that recommendations can be made regarding recording of the actual cause of death, investigation of suspicious deaths, and system responses to child deaths. This interagency communication should occur at the individual case level and at the local and state levels;

3. To develop prevention strategies including community education and mobilization, professional training, and needed changes in legislation, public policy, and/or agency practices.

Since its inception, the Board has achieved critical successes in effecting changes in public policy and legislation in such areas as graduated drivers licenses and mandatory seat belt and booster seat use. These policy changes were targeted as a result of the Board's review of its own data on the circumstances surrounding each child death in Kansas. The Board is not the only source of information regarding the cause of death in child fatalities, although the Board's annual report does include a report that details child deaths by county, broken down into seven categories for cause of death (See Attachment 2 at page 15). The Kansas Department of Health and Environment publishes mortality data regarding 39 selected causes of death (See Attachment 3 at page 19). The National Center for Child Death Review publishes on its website Kansas child death statistics culled from information available from the Centers for Disease Control and Prevention and the National Center for Health Statistics (See Attachment 4 at page 23).

However, the information contained in the Board's database is much broader than cause of death. The Board enters data into hundreds of fields in its database that relate to the factual circumstances surrounding each child fatality. The Committee unanimously agreed that the statutes governing the Board should be amended to allow the release to researchers and certain policy-makers of non-identifying data. Such a release is consistent with the Board's mission and could lead to research breakthroughs, which in turn could save children's lives. For example, the American Academy of Pediatrics in 1992 issued revised recommendations for reducing the risk of SIDS (Sudden Infant Death Syndrome). One of those recommendations was that babies be placed on their backs to sleep. This recommendation was issued after several studies had shown an increased risk of SIDS when infants were placed on their stomachs to sleep. Since those new recommendations

were issued, the incidence of SIDS has dropped by more than half. The saving of lives began with researchers being given access to child death data, specifically, the child's sleep position at the time of death. The Board's database contains many similar pieces of information connected with each child fatality that can be released under appropriate circumstances to aid in potentially life-saving research. Research is most accurate and credible when the researcher has a full and complete dataset from which to make projections and test hypotheses. Researchers would be very interested in studying data currently in the Board's possession concerning factors surrounding child fatalities. Researchers neither need nor want to obtain datasets that include identifying information about the child.

The benefit of releasing de-identified data goes beyond the benefits that might come from research that is limited to a statewide review. The Committee was unanimous in its belief that there is also important insight to be gleaned from the comparison of de-identified Kansas data with that of other states, whether the comparison is regional or nationwide. The ability to do comparative bench marking is a typical byproduct of comprehensive research, but researchers are currently not allowed access to the Board's data beyond that which is published in the annual report.

The Committee understands that there is a great deal of concern about the confidential and sensitive nature of the information that the Board collects. The Committee discussed at great length the topic of "de-identifying" data. It is possible to restrict which fields are extracted when sharing data from a database, and the fields containing name, address, and other "identifiers" are easily excluded from disclosure. The Committee unanimously agreed that allowing the Board to share its "de-identified" data to limited and proscribed persons or groups would be consistent with the Board's goals, and the resulting research projects could provide new insights that further the Board's mission to prevent child deaths.

The Committee reviewed the language proposed in 2013 SB 77. Although the language would accomplish the goal of allowing the Board to provide access to its data for research and public health purposes, the Committee unanimously agreed that the proposed language should be more specific. First, 2013 SB 77 would allow access to "information and records." This would appear to include the possibility of access to the Board's actual paper records and reports from which data is pulled to enter into the database. The Committee believes it would be preferable for the statute to be clear that the Board can grant access only to de-identified data extracted from the database.

The last issue addressed by the Committee was not part of 2013 SB 77 and was not covered in the testimony. However, it came to the Committee's attention in the course of this study that the Board may need to have statutory authority to deal with issues surrounding the database used for the entry of child death data. The Board currently extracts specific pieces of information from its files regarding each child death and enters the data into a database that was created for the Board many years ago by a third party vendor.

The Committee heard from Board members and staff that the database is aging and outdated in many respects. The Board is encountering backup difficulties, field limits, unsatisfactory support from the vendor, and a high cost for database hosting ($625 per month). The vendor also charges $150 per hour to make changes or add any new fields to the database.

The Committee learned that the Board would like to consider the possibility of abandoning the current expensive and problematic database and joining the 43 states who enter their child death data into a national database managed by the Michigan Public Health Institute (MPHI). MPHI is a non-profit private agency that has a cooperative agreement with the Maternal and Child Health Bureaus, Health Resources and Services Administration, U.S. Department of Health and Human Services, to manage the National Center for the Review and Prevention of Child Deaths. As part of this agreement, MPHI manages a standardized, web-based reporting system for state and local child death review teams. This national database is called the Child Death Review Case Reporting System (CDR-CRS) and is free of charge to participating local and state child death review boards. Currently, Kansas is one of only seven states that does not use the CDR-CRS to enter its child death data.

The Committee reviewed the way that MPHI would handle the Board's data if it were input into the CDR-CRS database. Under the data use agreement, any child death data submitted by the Board remains the sole property of the Board. Data housed at MPHI is not subject to the Freedom of Information Act, and MPHI releases no data that contains any identifying characteristics as defined under the federal HIPAA laws, nor does it release data with cell counts of less than six cases. MPHI has a comprehensive data request procedure in place that incorporates extensive restrictions on who may request de-identified datasets and what may be done with the data (See Attachment 5 at page 25). The Board has been advised by counsel that the current statute would not permit the Board to join the other 43 states that currently use the CDR-CRS for entry of child death data.

After discussion, the Committee unanimously agreed that if the Board desires to terminate use of its outdated database and contract with MPHI to enter child death data in the national database, the Board should have the authority to do so. MPHI has strict security protocols in place to protect the data, and the Board still has ownership of the data and will be given the opportunity to have Kansas data excluded from any research request that proposes to identify data by state in any published or publicly released analysis or results. The Committee's proposed legislation includes provisions that would grant the Board the necessary authority to make its own informed decisions about the proper database in which to house its data.

CONCLUSION AND RECOMMENDATION

The Committee recommends against the adoption of SB 77 because the language is broad enough to improperly include release of the Board's actual records, which the Committee does not believe should ever occur. In addition, the Committee believes the statute should contain more specific guidance for the Board that limits the circumstances under which release of de-identified data may be allowed. The Committee's recommended amendments to K.S.A. 22a-243 appear below, with additional comments regarding specific sections. The Committee recommends that the Judicial Council introduce legislation in the 2014 session to enact these amendments.

K.S.A. 22a-243. State child death review board; executive director; development of protocol; annual report; confidentiality of records; rules and regulations.

. . .

(j) Information acquired by, ~~and~~ records of and data extracted from records of, the ~~state review~~ board shall be confidential, shall not be disclosed and shall not be subject to subpoena, discovery or introduction into evidence in any civil or criminal proceeding, except pursuant to subsection (k) and that such information and records may be disclosed to any member of the legislature or any legislative committee which has legislative responsibility of the enabling or appropriating legislation, carrying out such member's or committee's official functions. The legislative committee, in accordance with K.S.A. 75-4319 and amendments thereto, shall recess for a closed or executive meeting to receive and discuss information received by the committee pursuant to this subsection.

Comment

"Data extracted from records of the board" was added to subsection (j) to clarify that the Board's database is also subject to the statute's mandates regarding confidentiality and disclosure. Adding "except pursuant to subsection (k)," the substance of which is new, allows for the new language to act as an exception to the general rule. Striking "state review" is a technical amendment consistent with amendments the Revisor's Office had made to SB 77.

(k) (1) The board may extract information from its records and enter the extracted information into a secure database which the board maintains or contracts to maintain.

Comment

New subsection (k) grants explicit authority to the Board to pull pieces of information from its records and enter them into a database. The language was specifically drafted to allow the Board to manage its own database or to contract with a third party to maintain the database. Although the Board currently is interested in pursuing a possible agreement with MPHI to house the data, the Committee avoided naming any particular third party as the Board should have the authority to make that decision or to select some other option. The Committee intentionally left the words "secure database" undefined. Technology evolves quickly, and the technical protocol for securing data today may be outdated in a matter of years.

(2) The board may disclose or authorize disclosure of information from the database pursuant to rules and regulations adopted by the board. Such rules and regulations shall include provisions that:

(a) prohibit disclosure of any identifiers that could be used to identify a child's death, including name, full date of birth or death, complete address of incident or child's residence, birth certificate number, death certificate number, medical record number, and full date of incident;

(b) allow disclosure only to an institution of higher education, a recognized research organization, or a non-profit or governmental agency, unless the disclosure is for the purpose of public health or education; and

(c) require that each person who is granted access to the disclosed information sign a confidentiality agreement.

Comment

New subsection (k)(2) grants to the Board the explicit authority to release data from its database. The words "or authorize disclosure" are intended to allow the Board to enter into an agreement such as with MPHI, which would include giving authorization for MPHI to include Kansas data in releases of de-identified datasets that do not identify the state. "Such rules and regulations shall include provisions that:" is intended to make clear that the three limitations that follow in subparagraphs (a), (b), and (c) are the minimum restrictions the Board may issue, but the Board may also issue any additional rules and regulations and may impose stricter limitations as the Board deems warranted.

New subsection (k)(2)(a) is intended to clarify that no data field can be disclosed that may identify a child death. The word "including" is intended to mean that the list is not exclusive and, depending on the circumstances, there may be other fields that also must be withheld. The fields listed are some that are certain to be withheld in every case.

New subsection (k)(2)(b) is intended to limit who can request the release of data from the Board. The exception for public health or education grants the Board the authority to release data on its own initiative, for example if the Board wanted to create a public service announcement or publish educational materials consistent with the Board's mission.

New subsection (k)(2)(c) is intended to further protect the de-identified data that is released by requiring the requester to sign a confidentiality agreement outlining the requester's acknowledgment of the conditions placed upon the allowed access to the data.

(3) Any disclosure by the board under paragraph (2) is discretionary and not mandatory.

Comment

New subsection (k)(3) makes clear that the Board is the final arbiter. Even if all of the requirements are met, the Board may decline a request for access to de-identified data from the Board's database. The Board may not be compelled to grant any request.

(~~k~~ l) The ~~state review~~ board ~~may~~ shall adopt rules and regulations as necessary to carry out the provisions of K.S.A. 22a-241 through 22a-244 and amendments thereto.

ATTACHMENTS

Session of 2013

SENATE BILL No. 77

By Committee on Judiciary

1-24

AN ACT concerning the state child death review board; amending K.S.A. 22a-243 and repealing the existing section.

Be it enacted by the Legislature of the State of Kansas:

Section 1. K.S.A. 22a-243 is hereby amended to read as follows: 22a-243. (a) There is hereby established a state child death review board, which shall be composed of:

(1) One member appointed by each of the following officers to represent the officer's agency: The attorney general, the director of the Kansas bureau of investigation, the secretary of social and rehabilitation services, the secretary of health and environment and the commissioner of education;

(2) three members appointed by the state board of healing arts, one of whom shall be a district coroner and two of whom shall be ~~physicians~~ *persons* licensed to practice medicine and surgery, one specializing in pathology and the other specializing in pediatrics;

(3) one person appointed by the attorney general to represent advocacy groups which focus attention on child abuse awareness and prevention; and

(4) one county or district attorney appointed by the Kansas county and district attorneys association.

(b) The chairperson of the ~~state review~~ board shall be the member appointed by the attorney general to represent the office of the attorney general.

(c) The ~~state child death review~~ board shall be within the office of the attorney general as a part thereof. All budgeting, purchasing and related management functions of the board shall be administered under the direction and supervision of the attorney general. All vouchers for expenditures and all payrolls of the board shall be approved by the chairperson of the board and by the attorney general. The ~~state review~~ board shall establish and maintain an office in Topeka.

(d) The ~~state review~~ board shall meet at least annually to review all reports submitted to the board. The chairperson of the ~~state review~~ board may call a special meeting of the board at any time to review any report of a child death.

(e) Within the limits of appropriations therefor, the ~~state review~~ board

shall appoint an executive director who shall be in the unclassified service of the Kansas civil service act and shall receive an annual salary fixed by the ~~state review~~ board.

(f) Within the limits of appropriations therefor, the ~~state review~~ board may employ other persons who shall be in the classified service of the Kansas civil service act.

(g) Members of the ~~state review~~ board shall not receive compensation, subsistence allowances, mileage and expenses as provided by K.S.A. 75-3223, and amendments thereto, for attending meetings or subcommittee meetings of the board.

(h) The ~~state review~~ board shall develop a protocol to be used by the ~~state review~~ board. The protocol shall include written guidelines for coroners to use in identifying any suspicious deaths, procedures to be used by the board in investigating child deaths, methods to ensure coordination and cooperation among all agencies involved in child deaths and procedures for facilitating prosecution of perpetrators when it appears the cause of a child's death was from abuse or neglect. The protocol shall be adopted by the ~~state review~~ board by rules and regulations.

(i) The ~~state review~~ board shall submit an annual report to the governor and the legislature on or before October 1 of each year, commencing October 1993. Such report shall include the findings of the board regarding reports of child deaths, the board's analysis and the board's recommendations for improving child protection, including recommendations for modifying statutes, rules and regulations, policies and procedures.

(j) *Except as provided further,* information acquired by, and records of, the ~~state review~~ board shall be confidential, shall not be disclosed and shall not be subject to subpoena, discovery or introduction into evidence in any civil or criminal proceeding~~, except that~~:

(1) Such information and records may be disclosed to any member of the legislature or any legislative committee which has legislative responsibility of the enabling or appropriating legislation, carrying out such member's or committee's official functions. The legislative committee, in accordance with K.S.A. 75-4319, and amendments thereto, shall recess for a closed or executive meeting to receive and discuss information received by the committee pursuant to this subsection.

(2) Such information and records may be disclosed for research and public health purposes when approved by the board, in accordance with rules and regulations adopted by the board.

(k) The ~~state review~~ board may adopt rules and regulations as necessary to carry out the provisions of K.S.A. 22a-241 through 22a-244, and amendments thereto.

Sec. 2. K.S.A. 22a-243 is hereby repealed.

Sec. 3. This act shall take effect and be in force from and after its publication in the statute book.

Appendix

CHILD DEATHS BY COUNTY OF RESIDENCE IN 2011

County	Population Age 0-17	Total Deaths	Natural - Except SIDS	Unintentional Injury - MVC	Unintentional Injury	Natural - SIDS	Undetermined	Homicide	Suicide
Allen	3,138	1	1	0	0	0	0	0	0
Anderson	2,044	1	0	1	0	0	0	0	0
Atchison	4,043	4	2	1	0	1	0	0	0
Barber	1,102	1	1	0	0	0	0	0	0
Barton	6,837	8	6	1	0	1	0	0	0
Bourbon	3,752	2	1	0	0	1	0	0	0
Brown	2,515	3	2	0	0	1	0	0	0
Butler	17,437	8	2	2	1	1	0	0	2
Chase	616	0	0	0	0	0	0	0	0
Chautauqua	739	1	0	0	0	1	0	0	0
Cherokee	5,265	3	1	0	1	0	0	0	1
Cheyenne	552	0	0	0	0	0	0	0	0
Clark	531	1	1	0	0	0	0	0	0
Clay	2,009	2	1	0	0	1	0	0	0
Cloud	2,056	2	2	0	0	0	0	0	0
Coffey	2,014	2	1	0	0	0	0	1	0
Comanche	442	0	0	0	0	0	0	0	0
Cowley	8,770	7	5	1	1	0	0	0	0
Crawford	8,612	3	0	1	0	1	0	1	0
Decatur	539	0	0	0	0	0	0	0	0
Dickinson	4,791	2	2	0	0	0	0	0	0
Doniphan	1,739	0	0	0	0	0	0	0	0
Douglas	20,672	3	2	1	0	0	0	0	0
Edwards	701	2	1	1	0	0	0	0	0
Elk	578	0	0	0	0	0	0	0	0
Ellis	5,967	5	5	0	0	0	0	0	0
Ellsworth	1,196	0	0	0	0	0	0	0	0
Finney	11,931	4	3	0	0	0	0	1	0
Ford	10,826	9	4	1	2	0	1	1	0
Franklin	6,556	4	0	1	3	0	0	0	0
Geary	10,901	8	4	0	2	1	0	1	0
Gove	618	0	0	0	0	0	0	0	0
Graham	520	0	0	0	0	0	0	0	0
Grant	2,533	0	0	0	0	0	0	0	0
Gray	1,854	1	1	0	0	0	0	0	0
Greeley	262	0	0	0	0	0	0	0	0
Greenwood	1,463	0	0	0	0	0	0	0	0

CHILD DEATHS BY COUNTY OF RESIDENCE IN 2011, CONTINUED

County	Population Age 0-17	Total Deaths	Natural - Except SIDS	Unintentional Injury - MVC	Unintentional Injury	Natural - SIDS	Undetermined	Homicide	Suicide
Hamilton	758	1	0	0	0	0	0	0	1
Harper	1,403	1	0	0	1	0	0	0	0
Harvey	8,716	5	2	1	1	0	1	0	0
Haskell	1,327	2	1	1	0	0	0	0	0
Hodgeman	455	0	0	0	0	0	0	0	0
Jackson	3,516	1	1	0	0	0	0	0	0
Jefferson	4,527	5	2	1	0	0	0	1	1
Jewell	564	0	0	0	0	0	0	0	0
Johnson	143,801	42	26	2	4	5	0	3	2
Kearny	1,216	1	1	0	0	0	0	0	0
Kingman	1,883	1	1	0	0	0	0	0	0
Kiowa	534	1	0	1	0	0	0	0	0
Labette	5,141	6	2	0	2	2	0	0	0
Lane	398	0	0	0	0	0	0	0	0
Leavenworth	18,938	3	2	1	0	0	0	0	0
Lincoln	764	0	0	0	0	0	0	0	0
Linn	2,213	1	0	1	0	0	0	0	0
Logan	623	0	0	0	0	0	0	0	0
Lyon	7,843	7	3	0	3	1	0	0	0
Marion	2,748	2	1	0	0	0	0	1	0
Marshall	2,255	4	4	0	0	0	0	0	0
McPherson	6,789	4	3	0	0	0	0	0	1
Meade	1,228	1	1	0	0	0	0	0	0
Miami	8,640	2	1	0	0	0	1	0	0
Mitchell	1,381	0	0	0	0	0	0	0	0
Montgomery	8,212	5	3	1	1	0	0	0	0
Morris	1,243	1	1	0	0	0	0	0	0
Morton	844	0	0	0	0	0	0	0	0
Nemaha	2,630	2	2	0	0	0	0	0	0
Neosho	4,022	0	0	0	0	0	0	0	0
Ness	698	1	0	0	1	0	0	0	0
Norton	1,120	2	1	0	0	0	0	0	1
Osage	4,014	3	1	0	1	1	0	0	0
Osborne	792	1	1	0	0	0	0	0	0
Ottawa	1,528	0	0	0	0	0	0	0	0

CHILD DEATHS BY COUNTY OF RESIDENCE IN 2011, CONTINUED

County	Population Age 0-17	Total Deaths	Natural - Except SIDS	Unintentional Injury - MVC	Unintentional Injury	Natural - SIDS	Undetermined	Homicide	Suicide
Pawnee	1,530	0	0	0	0	0	0	0	0
Phillips	1,317	1	1	0	0	0	0	0	0
Pottawatomi	6,406	1	1	0	0	0	0	0	0
Pratt	2,185	2	1	0	1	0	0	0	0
Rawlins	466	1	1	0	0	0	0	0	0
Reno	15,127	13	5	3	1	2	0	0	2
Republic	947	1	0	1	0	0	0	0	0
Rice	2,375	2	1	0	0	1	0	0	0
Riley	13,219	6	4	1	0	0	0	1	0
Rooks	1,220	0	0	0	0	0	0	0	0
Rush	607	2	1	0	1	0	0	0	0
Russell	1,473	0	0	0	0	0	0	0	0
Saline	13,896	6	5	0	0	0	0	1	0
Scott	1,231	2	0	0	2	0	0	0	0
Sedgwick	135,140	75	48	2	7	11	1	3	3
Seward	7,569	0	0	0	0	0	0	0	0
Shawnee	44,086	28	16	1	0	6	1	3	1
Sheridan	593	0	0	0	0	0	0	0	0
Sherman	1,329	1	1	0	0	0	0	0	0
Smith	729	0	0	0	0	0	0	0	0
Stafford	1,039	1	0	0	1	0	0	0	0
Stanton	650	1	1	0	0	0	0	0	0
Stevens	1,685	0	0	0	0	0	0	0	0
Sumner	6,135	5	3	0	0	0	1	1	0
Thomas	1,787	0	0	0	0	0	0	0	0
Trego	560	0	0	0	0	0	0	0	0
Wabaunsee	1,784	1	1	0	0	0	0	0	0
Wallace	398	0	0	0	0	0	0	0	0
Washington	1,335	0	0	0	0	0	0	0	0
Wichita	600	0	0	0	0	0	0	0	0
Wilson	2,205	2	1	0	1	0	0	0	0
Woodson	692	0	0	0	0	0	0	0	0
Wyandotte	44,722	26	16	2	5	1	1	1	0
Out of State		22	15	3	2	0	1	1	0
Total	723,922	391	230	33	45	39	8	21	15

Table 72
Deaths from 39 Selected Causes
by Age-Group and Sex of Decedent
Kansas, 2012

Cause of Death and Sex of Decedent (ICD-10 Code)	Total	Age-Group											
		Under 1	1-4	5-14	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85 & Over	n.s.
All Causes	25,084	254	42	53	301	408	610	1,603	2,978	3,991	6,111	8,733	0
Male	12,421	143	20	32	225	296	357	955	1,823	2,267	3,065	3,238	0
Female	12,663	111	22	21	76	112	253	648	1,155	1,724	3,046	5,495	0
Tuberculosis (A16-A19)	3	0	0	0	0	0	0	1	1	0	1	0	0
Male	3	0	0	0	0	0	0	1	1	0	1	0	0
Female	0	0	0	0	0	0	0	0	0	0	0	0	0
Syphilis (A50-A53)	0	0	0	0	0	0	0	0	0	0	0	0	0
Male	0	0	0	0	0	0	0	0	0	0	0	0	0
Female	0	0	0	0	0	0	0	0	0	0	0	0	0
HIV/AIDS (B20-B24)	24	0	0	0	0	1	3	12	5	3	0	0	0
Male	21	0	0	0	0	0	3	12	4	2	0	0	0
Female	3	0	0	0	0	1	0	0	1	1	0	0	0
Cancer of Stomach (C16)	69	0	0	0	0	1	2	8	13	25	12	8	0
Male	48	0	0	0	0	1	1	7	6	20	9	4	0
Female	21	0	0	0	0	0	1	1	7	5	3	4	0
Cancer of Colon, Rectum & Anus (C18-C21)	471	0	0	1	0	2	16	48	84	97	120	103	0
Male	232	0	0	1	0	2	9	29	53	52	54	32	0
Female	239	0	0	0	0	0	7	19	31	45	66	71	0
Cancer of Pancreas (C25)	374	0	0	0	0	0	5	25	70	106	105	63	0
Male	182	0	0	0	0	0	5	8	34	58	48	29	0
Female	192	0	0	0	0	0	0	17	36	48	57	34	0
Cancer of Trachea, Bronchus & Lung (C33-C34)	1,495	0	0	0	0	5	11	101	316	443	417	202	0
Male	798	0	0	0	0	3	6	53	180	243	216	97	0
Female	697	0	0	0	0	2	5	48	136	200	201	105	0
Cancer of Breast (C50)	400	0	0	0	0	1	18	58	69	84	103	67	0
Male	4	0	0	0	0	0	0	0	1	3	0	0	0
Female	396	0	0	0	0	1	18	58	68	81	103	67	0
Cancer of Cervix, Corpus & Ovary (C53-C56)	248	0	0	1	1	1	9	25	54	64	49	44	0
Male	0	0	0	0	0	0	0	0	0	0	0	0	0
Female	248	0	0	1	1	1	9	25	54	64	49	44	0
Cancer of Prostate (C61)	231	0	0	0	0	0	0	5	21	47	76	82	0
Male	231	0	0	0	0	0	0	5	21	47	76	82	0
Female	0	0	0	0	0	0	0	0	0	0	0	0	0

Table 72
Deaths from 39 Selected Causes
by Age-Group and Sex of Decedent
Kansas, 2012

Cause of Death and Sex of Decedent (ICD-10 Code)	Total	Age-Group											
		Under 1	1-4	5-14	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85 & Over	n.s.
Cancer of Urinary Tract													
(C64-C68)	287	0	0	0	1	0	4	18	43	75	76	70	0
Male	204	0	0	0	0	0	3	11	36	58	48	48	0
Female	83	0	0	0	1	0	1	7	7	17	28	22	0
Non-Hodgkin's Lymphoma													
(C82-C85)	185	0	0	2	1	1	4	9	18	29	65	56	0
Male	99	0	0	2	1	1	3	9	11	15	35	22	0
Female	86	0	0	0	0	0	1	0	7	14	30	34	0
Leukemia													
(C91-C95)	249	0	2	2	3	5	6	13	23	64	76	55	0
Male	148	0	0	2	1	2	5	8	16	42	44	28	0
Female	101	0	2	0	2	3	1	5	7	22	32	27	0
Other Malignant Neoplasms*	1,397	0	1	5	10	9	35	126	283	355	360	213	0
Male	841	0	0	4	6	6	18	86	204	220	202	95	0
Female	556	0	1	1	4	3	17	40	79	135	158	118	0
Diabetes mellitus													
(E10-E14)	633	0	0	0	3	5	21	53	97	134	148	172	0
Male	312	0	0	0	2	1	13	32	50	76	73	65	0
Female	321	0	0	0	1	4	8	21	47	58	75	107	0
Alzheimer's Disease													
(G30)	788	0	0	0	0	0	0	1	14	39	233	501	0
Male	264	0	0	0	0	0	0	1	6	22	99	136	0
Female	524	0	0	0	0	0	0	0	8	17	134	365	0
Hypertensive Heart Disease													
(I11, I13)	140	0	0	0	0	2	3	7	10	9	33	76	0
Male	51	0	0	0	0	2	1	4	8	6	13	17	0
Female	89	0	0	0	0	0	2	3	2	3	20	59	0
Ischemic Heart Disease													
(I20-I25)	2,990	0	0	0	0	14	36	188	390	485	735	1,142	0
Male	1,766	0	0	0	0	13	26	132	296	346	446	507	0
Female	1,224	0	0	0	0	1	10	56	94	139	289	635	0
Other Heart Disease													
(I00-I09, I26-I51)	2,184	4	2	0	8	10	37	91	180	274	503	1,075	0
Male	981	1	1	0	5	7	20	52	114	148	230	403	0
Female	1,203	3	1	0	3	3	17	39	66	126	273	672	0
Prim. Hypertension/ Hypertensive Renal Dis. & Sec. Hypertension													
(I10, I12, I15)	159	0	0	0	0	2	0	9	15	19	29	85	0
Male	60	0	0	0	0	2	0	6	11	8	12	21	0
Female	99	0	0	0	0	0	0	3	4	11	17	64	0

Table 72
Deaths from 39 Selected Causes
by Age-Group and Sex of Decedent
Kansas, 2012

Cause of Death and Sex of Decedent (ICD-10 Code)	Total	Age-Group											
		Under 1	1-4	5-14	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85 & Over	n.s.
Cerebrovascular Disease													
(I60-I69)	1,331	1	0	0	1	1	15	39	99	165	363	647	0
Male	520	1	0	0	1	1	9	26	52	86	155	189	0
Female	811	0	0	0	0	0	6	13	47	79	208	458	0
Atherosclerosis													
(I70)	459	0	0	0	0	0	1	5	22	39	118	274	0
Male	184	0	0	0	0	0	1	3	17	21	51	91	0
Female	275	0	0	0	0	0	0	2	5	18	67	183	0
Other Disease of Circulatory System													
(I71-I78)	195	0	0	0	0	0	8	15	15	28	53	76	0
Male	104	0	0	0	0	0	3	11	10	19	32	29	0
Female	91	0	0	0	0	0	5	4	5	9	21	47	0
Pneumonia & Influenza													
(J09-J18)	621	0	1	0	0	4	10	9	41	52	156	348	0
Male	282	0	0	0	0	1	5	5	28	31	70	142	0
Female	339	0	1	0	0	3	5	4	13	21	86	206	0
Chronic Lower Respiratory Disease													
(J40-J47)	1,680	0	0	0	1	4	9	61	192	371	576	466	0
Male	830	0	0	0	1	1	4	25	88	186	310	215	0
Female	850	0	0	0	0	3	5	36	104	185	266	251	0
Peptic Ulcer													
(K25-K28)	22	0	0	0	0	0	2	2	4	3	4	7	0
Male	17	0	0	0	0	0	2	2	4	2	4	3	0
Female	5	0	0	0	0	0	0	0	0	1	0	4	0
Chonic Liver Disease & Cirrhosis													
(K70, K73-K74)	245	0	0	0	0	8	16	56	83	44	24	14	0
Male	164	0	0	0	0	4	9	41	60	26	15	9	0
Female	81	0	0	0	0	4	7	15	23	18	9	5	0
Nephritis, Nephrotic Syndrome & Nephrosis													
(N00-N07,N17-N19, N25-N27)	599	1	0	0	1	3	3	16	46	93	168	268	0
Male	290	1	0	0	0	3	2	10	21	57	91	105	0
Female	309	0	0	0	1	0	1	6	25	36	77	163	0
Pregnancy, Childbirth, & the Puerperium													
(O00-O99)	6	0	0	0	2	3	1	0	0	0	0	0	0
Male	0	0	0	0	0	0	0	0	0	0	0	0	0
Female	6	0	0	0	2	3	1	0	0	0	0	0	0
Certain Conditons Originating In the Perinatal Period													
(P00-P96)	123	122	0	0	0	1	0	0	0	0	0	0	0
Male	71	70	0	0	0	1	0	0	0	0	0	0	0
Female	52	52	0	0	0	0	0	0	0	0	0	0	0

Table 72
Deaths from 39 Selected Causes
by Age-Group and Sex of Decedent
Kansas, 2012

Cause of Death and Sex of Decedent (ICD-10 Code)	Total	Age-Group											
		Under 1	1-4	5-14	15-24	25-34	35-44	45-54	55-64	65-74	75-84	85 & Over	n.s.
Congenital Anomalies													
(Q00-Q99)	88	51	2	3	4	3	1	8	10	3	3	0	0
Male	52	30	2	1	3	3	0	4	5	2	2	0	0
Female	36	21	0	2	1	0	1	4	5	1	1	0	0
Sudden Infant Death Syndrome													
(R95)	24	24	0	0	0	0	0	0	0	0	0	0	0
Male	13	13	0	0	0	0	0	0	0	0	0	0	0
Female	11	11	0	0	0	0	0	0	0	0	0	0	0
Symptoms and Abnormal Findings													
(R00-R94, R96-R99)	668	14	5	2	7	17	19	53	69	66	91	325	0
Male	269	8	1	2	4	11	9	28	48	36	41	81	0
Female	399	6	4	0	3	6	10	25	21	30	50	244	0
All Other Diseases[†]	4,740	24	9	10	28	52	70	238	479	618	1,202	2,010	0
Male	2,072	12	6	6	16	29	34	134	279	322	561	673	0
Female	2,668	12	3	4	12	23	36	104	200	296	641	1,337	0
Motor Vehicle Accidents[‡]	410	1	8	11	88	60	49	50	41	39	38	25	0
Male	294	0	4	6	63	47	35	38	35	26	29	11	0
Female	116	1	4	5	25	13	14	12	6	13	9	14	0
All Other Accidents and Adverse Effects[§]	894	9	10	9	34	77	88	117	86	76	145	243	0
Male	498	5	6	4	29	58	52	71	60	51	72	90	0
Female	396	4	4	5	5	19	36	46	26	25	73	153	0
Suicide													
U03, X60-X84, Y87.0	505	0	0	5	79	87	80	110	70	36	24	14	0
Male	413	0	0	4	69	72	60	85	55	32	23	13	0
Female	92	0	0	1	10	15	20	25	15	4	1	1	0
Homicide													
U01-U02, X85-Y09, Y87.1	110	2	2	2	25	25	26	17	4	3	3	1	0
Male	78	1	0	0	20	22	17	12	1	3	2	0	0
Female	32	1	2	2	5	3	9	5	3	0	1	1	0
All Other External Causes													
Y10-Y35, Y87.2, Y89	37	1	0	0	4	4	2	9	11	3	2	1	0
Male	25	1	0	0	4	3	2	4	8	1	1	1	0
Female	12	0	0	0	0	1	0	5	3	2	1	0	0

* C00-C15, C17, C22-C24, C26-C32, C37-C49, C51-C52, C57-C60, C62-C63, C69-C81, C88, C90, C96-C97

[†]A00-A09, A20-A49, A54-B19, B25-B99, D00-E07, E15-G25, G31-H93, I80-J06, J20-J39, J60-K22, K29-K66, K71-K72, K75-M99, N10-N15, N20-N23, N28-N98, U04

[‡]V02-V04, V09.0, V09.2, V12-V14, V19.0-V19.2, V19.4-V19.6, V20-V79, V80.3-V80.5, V81.0-V81.1, V82.0-V82.1, V83-V86, V87.0-V87.8, V88.0-V88.8, V89.0, V89.2

[§]V01, V05-V06, V09.1, V09.3-V09.9, V10-V11, V15-V18, V19.3, V19.8-V19.9, V80.0-V80.2, V80.6-V80.9, V81.2-V81.9, V82.2-V82.9, V87.9, V88.9, V89.1, V89.3, V89.9, V90-X59, Y40-Y86, Y88

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NATIONAL MCH CENTER FOR CHILD DEATH REVIEW
KEEPING KIDS ALIVE

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The Child Death Review Process
Technical Assistance & Resources
State Spotlights
Tools for Teams
Upcoming Events
Causes of Child Deaths
Preventing Child Deaths

Kansas

Child Mortality, 2010

Number and Rate of Child Deaths, per 100,000 Population (2010)

Total Child Population (Ages 0-19)	Number of Child Deaths	Child Mortality Rate
810,644	506	62.4

Infant Mortality Number and Rate, per 1,000 Live Births (2010)

Number of Live Births (Ages 0-1)	Number of Infant Deaths	Infant Mortality Rate
40,786	253	6.2

Selected Causes of Death, Ages 0-19, per 100,000 Population (2010)

Cause	Number of Deaths	Mortality Rate
Natural	**323**	**39.8**
Perinatal Conditions	116	14.3
Congenital Anomalies	74	9.1
Neoplasms	15	1.9
Respiratory Disease	15	1.9
Circulatory Disease	15	1.9
Nervous System Disease	20	2.5
SIDS	25	3.1
Unintentional Injury	**127**	**15.7**
Motor Vehicle	73	9.0
Drowning	12	1.5
Fire/Burn	*	*
Poisoning	*	*
Suffocation/Strangulation	12	1.5
Firearm	*	*
Homicide	**18**	**2.2**
Firearm	11	1.4
Suicide	**30**	**3.7**
Firearm	10	1.2
Suffocation/Strangulation	16	2.0
Poisoning	*	*

- Sources: Centers for Disease Control and Prevention, National Center for Health Statistics.
- CDC WONDER On-line Database, CDC WISQARS On-line Database. Data accessed on 12/4/2012.
- Rates based on 20 or fewer deaths may be unstable. Use with caution.
* denotes suppressed data due to confidentiality constraints (fewer than 10 children)

Links

Kids Count Key Facts for Kansas
March of Dimes Peristats
National Center for Health Statistics
National Center for Injury Prevention and Control

The National Center for the
REVIEW & PREVENTION
OF CHILD DEATHS

Application Packet

For Access to Data from the

National Child Death Review

Case Reporting System

This Application Packet contains:

NCRPCD 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 the Review and Prevention of Child Deaths (NCRPCD) 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 NCRPCD. 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 certificates, death certificates, law enforcement records, medical records, autopsy reports, child protective services reports, and Emergency Medical Services run reports.

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[1] Grant No. 1 U49 MC 00225-11-00 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 200-2012-M-51198 from the US Centers for Disease Control and Prevention.

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/NCRPCD). Requests for de-identified, individual case report data will be submitted to the NCPRCD Data Dissemination Committee, per guidelines contained in this document. NCRPCD 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 1,800 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 M of the Case Report form will only be released to researchers under special circumstances.

To further protect anonymity of states, NCRPCD 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. NCRPCD will retain the coding key.

Permitted Data Uses

The NCRPCD may report aggregated, de-identified data identified by state to requested parties without state permission. The NCRPCD 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 NCRPCD 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 NCRPCD 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. NCRPCD 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, NCRPCD 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. NCRPCD 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 NCRPCD 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 NCRPCD 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 NCRPCD.
2. The PI must obtain IRB approval for the proposed research. Letters of approval must be submitted to NCRPCD 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 NCRPCD 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 NCRPCD 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 NCRPCD mission, and to permit NCRPCD 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. NCRPCD 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 NCRPCD data.
10. All presentations and publications making use of this dataset must be provided to NCRPCD 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 NCRPCD. They must include the following language: "This dataset was provided by the NCRPCD, which is funded in part by Grant Number U49MC00225 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 NCRPCD, 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 NCRPCD, 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 NCRPCD will survey states on an annual basis to make this determination.

Application Process

To request a de-identified dataset from the NCRPCD, the PI must complete the Application for Data, including a detailed proposal to NCRPCD 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 NCRPCD National Center Steering 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 NCRPCD 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 NCRPCD mission.

At a minimum, the Committee will review applications on a quarterly basis. All applicants will be notified in writing by NCRPCD 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, NCRPCD 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 the Review and Prevention of Child Deaths
2455 Woodlake Circle
Okemos, MI 48864
Phone : (800) 656-2434
Fax : (517) 324-7365
Email : info@childdeathreview.org

NATIONAL CENTER FOR THE REVIEW AND PREVENTION OF CHILD DEATHS
CASE REPORTING SYSTEM
Application for De-identified Dataset

Please complete information electronically.

I. Data

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

2005 ___
2006 ___
2007 ___
2008 ___
2009 ___
2010 ___
2011 ___
2012 ___

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. NCRPCD will survey 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 NCRPCD.

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 response is expected to be at least one page long, and it 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 NCRPCD 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 NCRPCD 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 NCRPCD mission, and to permit NCRPCD to have advance notice of potential issues pertaining to the analysis and/or results.)

IV. Data Security

All users of the NCRPCD 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 NCRPCD 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

MICHIGAN PUBLIC HEALTH INSTITUTE
National Center for the Review and Prevention of Child Deaths

Contract for Access to and Use of Data

This contract specifies the conditions for release of National Center for the Review and Prevention of Child Deaths (NCRPCD) 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 [_____] (Investigators), and Michigan Public Health Institute/National Center for the Review and Prevention of Child Deaths (NCRPCD).

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. The Investigators are 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 NCRPCD 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 which performed the child death reviews that are the source of the data.

5. NCRPCD 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 relea

sed 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 NCRPCD 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 NCRPCD.

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 NCRPCD 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 NCRPCD.

14. All presentations and publications will include the following language: "This dataset was provided by the NCRPCD, which is funded in part by Grant Number U49MC00225 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 NCRPCD, HHS or the participating states. The following states contributed data from their child death

review (list states)."

15. All presentations and publications making use of this dataset shall be provided to NCRPCD 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, NCRPCD 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 NCRPCD 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. The fee for obtaining the data file is: [____], which must be paid in full to Michigan Public Health Institute prior to release of any data.

23. NCRPCD 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.

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, Suite 300, Okemos MI 48864

Email address: _____Phone: (___) _____

Signature: _____ Date: _____

Attachment 1

HIPAA Required Elements to De-identify Case Data*

These data elements will be removed for all persons accessing de-identified case data, per the Data Use Agreement. The source of these data elements is the National Center for *Child Death Review Case Reporting System: Case Report Tool.*

Introduction: Case Definition

Case number
County of review
Review team number
Sequence of review
Death certificate number
Birth certificate number
ME/Coroner number

Section A: Child Information

Child first name
Child middle name
Child last name
Child name: unknown
Date of birth: month, day, 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

Section N: Form Completed By

The names and contact information will be removed.

** Source: http://www.hhs.gov/ocr/combinedregtext.pdf, Section 164.514(b)(2)(i) of the rules.

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 NCRPCD 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 Review and Prevention of Child Deaths (NCRPCD) 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 the Review and Prevention of Child Deaths' 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 NCRPCD will not include the list of data elements found in Appendix B of the NCRPCD 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 Review and Prevention of Child Deaths for signature.

Attachment 3

Confidentiality Agreement to be Signed by All Researchers with Access to NCRPCD 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 NCRPCD 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: _____

The US National Child Death Review Case Reporting System

Theresa M Covington[1,2]

[1]National Center for Child Death Review, Washington, DC, USA
[2]Michigan Public Health Institute, Okemos, Michigan, USA

Correspondence to
Theresa M Covington, National Center for Child Death Review, 1115 Massachusetts Avenue, NW, Washington, DC 20005, USA; tcovingt@mphi.org

Accepted 9 December 2010

ABSTRACT

The National Child Death Review Case Reporting System (NCDR-CRS) was developed in the USA to provide child death review teams with a simple method for capturing, analysing, and reporting on the full set of information shared at a child death or serious injury review. The NCDR-CRS is a web based system currently being used by 35 of the 50 US states. This article describes the purpose, features, limitations, and strengths of the system. It describes current and planned efforts for the dissemination of the data to inform and catalyse local, state, and national efforts to keep children safe, healthy, and alive.

A comprehensive review of a child's death requires the sharing of case records from multiple sources on the wide ranging set of circumstances leading up to and causing a child's death. An effective review requires using this information to improve systems and prevent deaths. Capturing all of the information from review using reports from multiple sources and in a format useful for analysis and prevention is the purpose of the National Child Death Review Case Reporting System (NCDR-CRS). This is a passive epidemiologic surveillance system. It allows for the 'ongoing systematic collection, analysis, and interpretation of data essential to the planning, implementation, and evaluation of public health practice closely integrated with the timely dissemination of these data to those who need to know'.[1] Most importantly, the system can help to identify the aetiologic or causal factors in deaths of children so that communities can reduce or eliminate exposure to those factors as the basis for prevention.[2]

DEVELOPMENT OF THE NCDR-CRS

When the National Center for Child Death Review (NCCDR), based at the Michigan Public Health Institute (MPHI), was funded in 2002 by the US government[i], a major project objective was to explore the feasibility of building a standardised reporting tool for local and state child death review (CDR) teams. NCCDR found that 44 of 50 states had a case reporting tool for CDR; however, there was little consistency in the type of information that was being collected and analysed. Thirty CDR leaders from 19 states volunteered to design and test a case reporting system. NCCDR managed the system design and software development. It was originally proposed that the system would be a minimal dataset, capturing only the final outcomes of a case review. The 30 volunteer designers argued instead for a system that would capture the whole story of a child's death or serious injury, such that the version in use today contains over 1700 data elements.[3]

Thirty-five states are now enrolled in this web based system and have entered more than 84 000 reviewed child deaths. The database primarily reflects a period of review between 2005 and 2009. Table 1 provides a summary of the types of cases entered as of December 2010.

PURPOSE AND OBJECTIVES OF THE NCDR-CRS

The purpose of the system is to provide CDR teams with a simple method for capturing, analysing, and reporting on the full set of information shared at a child death or serious injury review, so that the information can be used at the local, state, and national levels to inform improvements in child safety and prevent deaths.

The objectives of the system are to:

1. Permit local and state CDR teams to systematically collect comprehensive information on every child death or serious injury reviewed including:
   - Child, family, supervisor, and perpetrator
   - Incident place, events, and emergency response
   - Investigation actions
   - Risk and protective factors by cause of death
   - Further detail on acts of omission or commission contributing to the deaths, on sleep related infant deaths and on consumer product related deaths
   - Services needed, provided or referred
   - Recommendations for and actions taken to prevent deaths
   - Factors affecting the quality of the case review
2. Enable local and state CDR teams to easily analyse and report on their CDR findings
3. Enable child health and safety advocates to access aggregated state and national CDR findings to inform child health and safety prevention policies and practices.

SYSTEM FEATURES

NCDR-CRS is a web based reporting structure, built using MS-ASP.net. Data entered into the system is stored on secure servers at MPHI.

The system is child based, and can capture identifiable data on the child, but not identifiable for others involved in the death incident. Extensive data

[i]The Center, including the development and management of the NCDR-CRS, is funded in large part by the Maternal and Child Health Bureau of the Health Resources and Services Administration of the US Department of Health and Human Services.

Table 1 Summary of cases entered into the National Child Death Review Case Reporting System; 1995–2010.* N=84 122

	Number	%
Age of child		
Under age 1	45 339	53.9
Ages 1–4	10 065	12.0
Ages 5–9	4 954	5.9
Ages 10–14	6 513	7.7
Ages 15–17	11 761	14.0
Over 17 years old	2 257	2.7
Missing	3 233	3.8
Total	84 122	100.0
Gender of child		
Male	49 579	58.9
Female	33 360	39.7
Missing	1 183	1.4
Total	84 122	100.0
Race of child		
White	52 047	61.9
African American	21 233	25.2
Native Hawaiian	452	0.5
Pacific Island	263	0.3
Asian	1 498	1.8
American Indian	1 232	1.5
Alaska native	2	0.0
Multiracial	1 318	1.6
Missing	6 077	7.2
Total	84 122	100.0
Ethnicity of child		
Yes, Hispanic/Latino	12 568	14.9
Not Hispanic/Latino	55 266	65.7
Missing	16 288	19.4
Total	84 122	100.0
Official manner of death		
Natural	44 362	52.7
Accident	19 682	23.4
Suicide	3 004	3.6
Homicide	5 555	6.6
Undetermined	5 511	6.6
Pending	907	1.1
Missing	5 101	6.1
Total	84 122	100.0
Official cause of death		
External—motor vehicle	10 849	12.9
External—fire, burn, electrocution	1 672	2.0
External—drowning	2 724	3.2
External—asphyxia	5 283	6.3
External—weapon	5 951	7.1
External—animal bite	46	0.0
External—fall or crush	655	0.8
External—poisoning	1 346	1.6
External—exposure	153	0.2
External—undetermined	642	0.8
External—other	1 381	1.6
External—unknown	151	0.2
Medical—prematurity	15 450	18.4
Medical—congenital anomaly	6 597	7.8
Medical—SIDS	4 873	5.8
Medical—cancer	2 064	2.5
Medical—cardiovascular	2 036	2.4
Medical—other	14 419	17.1
Medical—undetermined and unknown	1 413	1.7
Undetermined if medical or external injury	2 207	2.6
Missing	4 210	5.0
Total	84 122	100.0

*22 596 cases (26.9%) were migrated from prior state reporting systems. Majority of cases (76%) were entered after 2004.

elements are included that address risk factors for most major causes of injury death.

Access to the system is allowed upon the signing of a data use agreement between a state and MPHI and confidentiality statements for all registered users in a state. Users log into and have access to the secure system via passcodes, depending upon one of three levels:

- Level 1: individual team users can enter, edit, print, and delete cases and download identifiable data only for the cases reviewed by their team
- Level 2: state level users can enter, edit, print, and delete cases and download identifiable data for cases reviewed by teams in the state[ii].
- Level 3: NCCDR staff can print and download de-identified data for all cases in the system by state

There is a paper form available that mimics the web system, but the web system was developed using a complex system of skip patterns to speed the data entry process. A data dictionary is available via paper and is also linked as a help feature to every data element in the web system.

Thirty-two standardised reports are available for downloading and/or printing at the local and state level. These reports are created using real time data. The reports cover all major causes of deaths and serious injuries. Local and state users are able to download local data at any time into their own software for further analysis. A data code book accompanies the system.

States are able to migrate case reports from archived CDR databases into the NCDR-CRS. A number of states have already done this. Some customisation is available at minimal costs for states. For example, users in Georgia are presented with an additional screen to help them track the state agencies involved in the case and recommended systems improvements.

The system is free to all users. The NCCDR staff enrols users and provides training and help desk support. MPHI programmers and IT staff maintain the system's functionality and servers.

LIMITATIONS OF THE DATA

There are a number of ways in which this system is unlike typical public health surveillance or vital statistics data. Most obvious is that the case reporting system does not usually include all child deaths occurring in specific jurisdiction and thus cannot be compared one to one with vital statistics data; rates cannot be calculated nor can the data be assumed to be a representative sample of all deaths without detailed analysis. Secondly, the data cannot be compared state to state, and sometimes even team to team within a state, because of variation among teams in the types and timing of death reviews. Third, there can be large differences in the quality of data between teams and states, especially for states new to the system. At first many users leave a large proportion of questions unanswered and data fields blank. We have found that this improves with time. CDR teams can use the form as a quality

[ii] A few states have elected not to have access to case identifiers from local reviews.

improvement tool. They find that not knowing the answer to an important question such as 'were there working smoke detectors in a fire death' has them gathering this information for their next fire death review.

Some teams also do not routinely access the data dictionary to ensure consistent meaning. NCCDR attempts to work with users to encourage compliance with the data dictionary, but is aware that some states have developed their 'own' definitions for a term. There are also a number of relatively subjective data elements, such as 'was this death preventable?' or 'did an act of omission contribute to the death?'. These questions were intentionally included in the tool to encourage discussion, but may be problematic for certain types of analysis. Fourth, the original reporting source for specific data elements is not specified—so that it is not known which agencies contributed information, although the types of agencies participating at the review can be entered for each case. As such the system does not have a primacy rule for selecting the best answer to a question and instead relies on the CDR teams to determine primacy when there is dispute among agencies. The system cannot determine if the team or the person entering the data selected an answer.

STRENGTHS OF THE DATA

Despite the limitations, the case information provided by local and state CDR teams provides valuable information on the complexities involved in many child deaths, and much of this information is not available from any other single source. For example, data entered on infant sleep related suffocations describe with whom, on what surface, and where the child was sleeping at the time of the death. This can be cross matched with detailed information on the child's supervisor to better understand the circumstances of these deaths. With pool drowning deaths, data record how the child entered the pool area, what barriers they may have breached, and why those barriers were not working. Box 1 describes the type of data that could be entered for a teen motor vehicle crash. For all deaths, comprehensive information on caregivers, supervisors, and perpetrators can help describe specific risks to children and improvements to help persons acquire resources to better protect their children.

DISSEMINATION OF THE DATA

Ideally, any review findings should be easily disseminated for use by government, organisations, and the public to keep children alive. However, the NCDR-CRS is first and foremost a system for use by local and state CDR teams and programmes. This is in keeping with the fact that CDR is best as a local process—people closest to the death event coming together to share the story of the death in order to keep other children safe from harm. In fact, according to the terms of the data use agreements with participating states, the data entered into the system is the property of these states. NCCDR only serves as the custodian of the data.

Most local teams are not accessing the data download feature, relying instead on the standardised reports. They are able to generate up to 32 of these, incorporate them into an annual report template, and thereby produce a report on their CDR findings and process to share with their community.

Most states participating in the system are downloading their data on an annual basis and generating extensive annual reports on all deaths reviewed or specialised reports on specific types of deaths such as suicides or drownings[iii]. Most states have legislation requiring that reports on state CDR be presented annually to state agencies, legislators and/or governors. Some states are now linking their CDR data to their birth, death, and other records for more enhanced analysis.

Box 1 What the case reporting system can tell us about a teen motor vehicle death

Child's demographic information
Age; sex; education and employment; disabilities, health, substance abuse, mental health, delinquency, and child maltreatment and family violence histories.

Child's primary caregivers (up to two)
Age; sex; income; education and employment; primary language spoken; on active military duty; disabilities, health, substance abuse, mental health, delinquency, and child maltreatment and family violence histories; prior child deaths.

Supervision
If needed and for person responsible for supervision: age; sex; income; education and employment; primary language spoken; on active duty in military; disabilities, health, substance abuse, mental health, delinquency, and child maltreatment and family violence histories; prior child deaths; specific impairments at time of supervision.

Incident
Time, place, emergency response, child's activity at time, number of other deaths.

Investigation
Types of investigators, persons declaring cause of death, types of forensic tests conducted, reviews of child protective services records.

Manner and primary cause of death

Information on crash circumstances
Number and types of vehicles involved in crash, position of child, collision type, primary causes of crash, driving conditions, location of crash.

Information on drivers, occupants, pedestrians
For child, child's driver and other drivers involved in crash: licence status and violations to graduated licensing regulations; for all vehicles in crash: number of total occupants, teen occupants and teen deaths; protective measures—for example, seat belts needed, present, used, used incorrectly or not used.

Information on acts of omission or commission
Types of acts contributing to the death and information on the perpetrators of these acts (same as for supervisor).

Services used, needed, referred or recommended as a result of the death

Recommendations on actions to prevent other deaths
Includes a wide range of options—including education, environmental modifications, legislation, product safety; status of implementation of recommendations.

Information on the case review
Attendees, issues preventing a comprehensive review, summary of outcomes.

[iii]Annual reports from most states can be accessed at http://www.childdeathreview.org/

Aggregated multi-state, de-identified data analysis generated by NCCDR staff is available to federal agencies and other researchers in accordance with the NCCDR data dissemination policy. Recently a number of agencies in the US government have shown interest in accessing the data to inform national policy. For example, a request has been made to generate data on the circumstances in child passenger deaths which may explain why caregivers fail to use child passenger seats. One federal agency is interested in comparing the number of child maltreatment deaths identified through this reporting system to the number generated in the federal child abuse reporting system. Mental health agencies are interested in access and compliance issues for prior and current mental health services in suicide deaths. A federal childcare licensing agency is interested in analysing unintentional deaths occurring in licensed day care centres. Federal child welfare has requested data on the quality of supervision in all injury deaths to understand the role of supervision and caregiver neglect in these deaths.

The US Centers for Disease Control and Prevention (CDC) are funding two projects to utilise the case reporting system as a means to better understand sudden unexplained infant deaths (SUID) and violent deaths. In the former, an expanded version of the case report tool that includes additional questions on SUID deaths is being piloted in seven states with support to ensure the review of 100% of all SUID deaths. Their data are being shared with the CDC as the pilot for a national SUID Case Registry. Data on violent deaths is being matched with data from states participating in the CDC's National Violent Death Reporting System.[4] This probabilistic match will inform both the National Violent Death Reporting System and CDR as to the completeness of their violent death data and enrich understanding of these deaths. The US Maternal and Child Health Bureau is funding a secondary data analysis of infant sleep related deaths, using NCDR-CRS data from over 3000 SUID deaths in nine states, to understand the risk factors in these deaths.

A number of non-federal researchers have also made enquiries as to the availability of the data for research purposes. A formal application must be submitted and approved by the NCCDR Data Dissemination Committee for access to the de-identified database. Part of the application is agreement on the limitations of the data for surveillance purposes. The committee includes representatives from participating states and members of the NCCDR National Steering Committee. Data are not available from NCCDR that counts specific data elements by an individual state—for example, '100 of the 1000 deaths are from New York'. Requests for state identified data are rarely approved and if so must be approved by the participating states through a separate process.

FUTURE DIRECTIONS

Efforts will continue to enrol the remaining 16 states into the NCDR-CRS and to improve data quality. Especially important are: increasing the completeness of information, reducing inconsistencies in interpreting definitions, providing training and technical assistance for all users, and enhancements to the software to allow for customisation and automatic pre-population of data from agency case records. Most importantly, efforts will continue to assist child death review teams to interpret and use their data to prevent child deaths and to keep all children safe and healthy.

Acknowledgements The author would like to thank and acknowledge the senior data analysts at the NCCDR, Heather Dykstra, MPA and Esther Shaw, MSIS, for their contributions to NCDR-CRS and review of this document; and to the 30 state CDR leaders who worked tirelessly to design the three versions of the case reporting tool.

Funding Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services (grant 5 U49MC00225-09-00) and the US Centers for Disease Control and Prevention.

Provenance and peer review Not commissioned; externally peer reviewed.

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