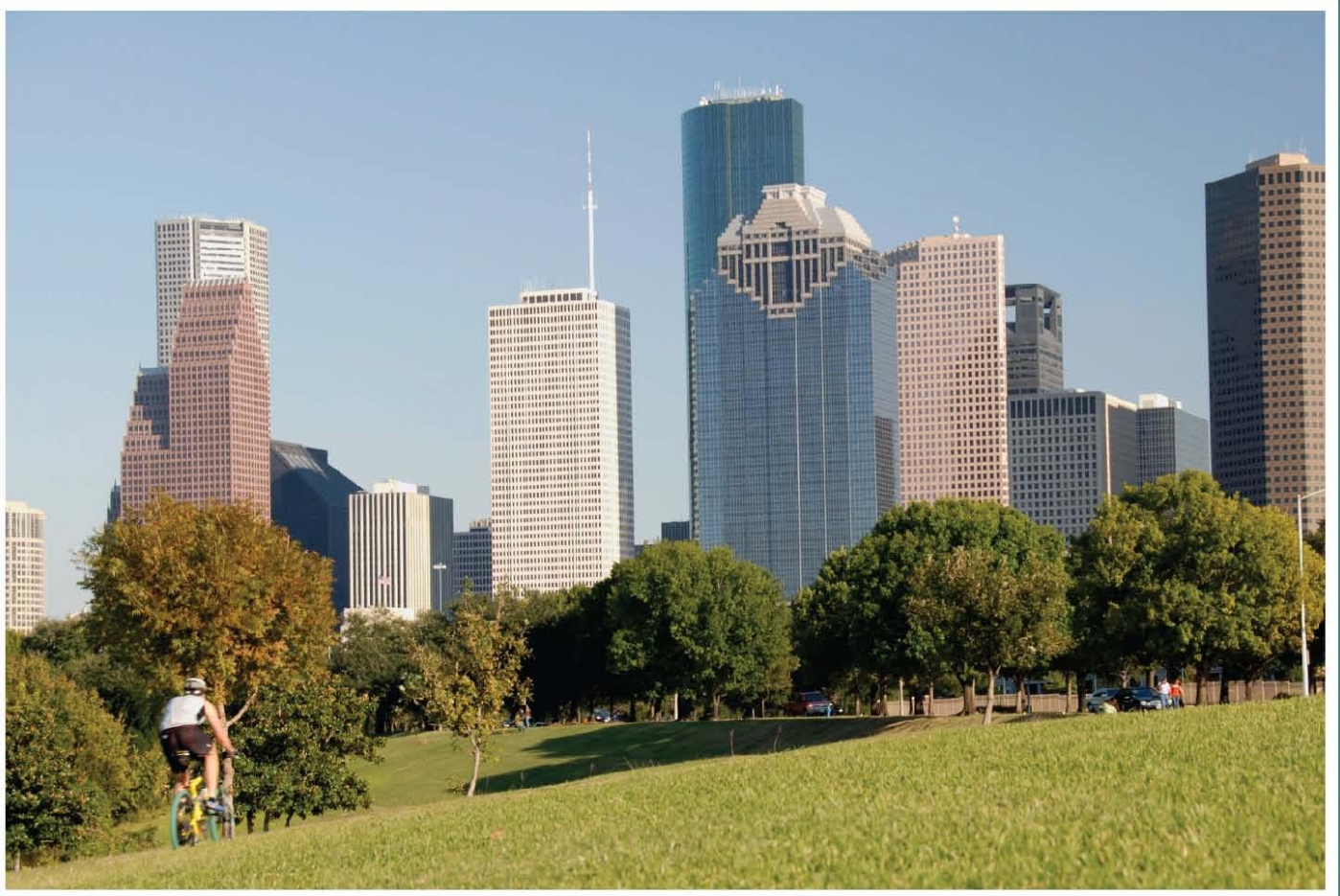




National Violent Death Reporting System (NVDRS) Roundtable Meeting: Summary of Discussions and Next Steps

*September 12-13, 2011
Atlanta, GA*

TABLE OF CONTENTS

Executive Summary	2
Background: Meeting Purpose, Participants, and Scope	5
Examples from Other National Surveillance Systems	6
Critical Elements of NVDRS: State/Local and National Perspectives	8
Barriers to NVDRS Participation and Implementation.....	10
Capacity Issues, Including Information Technology (IT)	10
Funding	10
Data Elements and Quality.....	11
Data Sources	11
Application Process and Requirements; Planning for an NVDRS System	11
Making the Case.....	12
A National System; Dealing with Variability	12
Criteria for Effective Solutions.....	13
Suggested Solutions and Next Steps.....	14
Should NVDRS transition from a “shoe-leather” to a more electronic system?	14
How can adequate funds be secured for (and within) each state, tribe, and territory?	15
How can the requirement to secure MOUs from data partners before applying be made less restrictive?	16
What are the implications for confidentiality agreements in terms of states sharing data that includes personally identifiable information (PII)?	16
How can NVDRS programs obtain legal access to data on open homicide cases?	16
What are the options for reducing the number of data elements collected?	17
How can data quality be improved?	17
What’s the NVDRS “wow” factor and how can it be communicated more effectively?	18
How can more statewide participation be encouraged?	18
Recommended Next Steps:	19
Appendix A: List of NVDRS Roundtable Participants.....	21
Appendix B: NVDRS Roundtable Agenda	23

EXECUTIVE SUMMARY

The National Violent Death Reporting System (NVDRS) was first launched in 2003 to compile more detailed and comprehensive data about the estimated 50,000 violent deaths that occur annually in the United States. By understanding more about the circumstances surrounding homicides and suicides, the Centers for Disease Control and Prevention (CDC) National Center for Injury Prevention and Control (NCIPC) and participating states hope to shed light on opportunities for prevention at the local, state and national levels.

Because the system draws upon data from multiple sources — death certificates, medical examiner (me)/coroner reports, and law enforcement reports — it has the potential to reveal much more about the circumstances surrounding violent deaths than any single data source alone could offer. However, collecting data from each of these sources in a timely and cost-effective manner has proven to be challenging in some states.

To think through barriers and solutions to broader NVDRS implementation, the Safe States Alliance convened a roundtable discussion in Atlanta in September 2011. Participants included representatives from the CDC/NCIPC Division of Violence Prevention who helped design and implement NVDRS, states already participating in the program, those who had applied but not succeeded in meeting the requirements, and several states interested in applying in the future.

After hearing from representatives of several other national surveillance systems, meeting participants identified some specific challenges related to continued and expanded NVDRS implementation, as well as potential solutions and next steps.

BARRIERS

Barriers identified by participants included basic **capacity** issues (especially regarding **information technology**), insufficient and variable **funding**, problems with required **data elements** and **data quality** (particularly from medical examiner (ME)/coroner and law enforcement data partners), **data sources**, the **application process and requirements** for states, **communicating** NVDRS's value, and the system's **scope** (within states, and nationally).

POTENTIAL SOLUTIONS

Discussions about potential solutions were framed by the following questions:

- Should NVDRS transition from a “shoe-leather” to a more electronic system?
- How can adequate funds be secured for (and within) each state, tribe, and territory?
- How can the requirement to secure MOUs from data partners before applying be made less restrictive?
- What are the implications for confidentiality agreements in terms of states sharing data that includes personally identifiable information (PII)?

- How can NVDRS programs obtain legal access to data on open homicide cases?
- What are the options for reducing the number of data elements collected?
- How can data quality be improved?
- What's the NVDRS "wow" factor and how can it be communicated more effectively?
- How can more statewide participation be encouraged?

RECOMMENDED NEXT STEPS

Although the group did not have time to explore each of these questions in detail, they did offer several specific suggestions for next steps. These included:

1. Convene a standing Technical Consultation Group for NVDRS mediated through Safe States Alliance and CSTE modeled on the Injury Surveillance Workgroup (ISW), to promote more state ownership and participation in the program. Use this venue to:
 - Review CDC's shortened data elements list.
 - Identify and share best practices about the best staff configurations for an NVDRS program.
 - Solve other technical issues.
2. Promote adoption of a web-based data collection system for NVDRS, with attention to potential barriers and issues:
 - Assess state capacity to draw NVDRS data from electronic data sets, and incorporate this in planning for the NVDRS web-based data collection system. This could be accomplished through planned CDC Core Violence and Injury Prevention Program Regional Network Leader needs assessments.
 - Partner with CDC's Public Health Law Program to assess the potential of the NVDRS web-based data system to conflict with state confidentiality laws, to communicate findings to legal counsel in states as appropriate through each state's injury prevention program, and to integrate findings into planning for the web-based system.
 - Ensure that the web-based data collections system will allow states to include state-specific data elements and to have full and immediate access to their state's data.
3. Support advocacy for expansion and enhancement of NVDRS
 - Make clear and continually reinforce the vision of a nationwide NVDRS that includes all states, territories and tribes.
 - Work with experts in communications to create a feasible strategy for communicating the unique contributions of NVDRS to policymakers, funders, and advocates working on violence-related issues including suicide and domestic violence.
 - Engage the National Violence Prevention Network, Association of State and Territorial Health (ASTHO), Council of State and Territorial Epidemiologists (CSTE),

Action Alliance for Suicide Prevention, Safe States Alliance and other related national organizations to promote NVDRS with their members as a core building block for prevention violent-related deaths and injuries, and work to align these organizations around advocacy for NVDRS with policymakers.

4. Enhance data quality and timeliness

- Lead efforts at CDC to improve ME/Coroner and Law Enforcement data systems.
 - Encourage adoption of laws, rules, policies, and/or incentives at the state and federal levels to achieve standardization of ME/coroner data collection, and overcome fears that data sharing will impede prosecution.
 - Partner with CDC's Center for Emergency Preparedness and Response to promote collaboration with Public Health Emergency Response grants to improve data systems so that they will be highly functional in a public health emergency.
 - Work with the Department of Justice, the Department of Homeland Security, and other federal agencies to identify and advocate for funding incentives to drive improvements in ME/coroner and LE data systems.
- Consider providing one-year planning grants and technical assistance to states interested in applying for NVDRS to plan and conduct activities related to adopting laws, rules or policies that require and/or incentivize submission of data to NVDRS.
- Work with the National Association for Public Health Statistics and Information Systems (NAPHSIS) and the National Center for Health Statistics (NCHS) to analyze the data collection process for vital records using Lean Six Sigma or other widely used methodologies for process improvement, and to implement the recommendations for improvement that come out of such an analysis.
- Issue two NVDRS data sets for analysis: a provisional data set that includes data elements that can be gathered in a timelier manner, and a final data set that includes the full complement of NVDRS variables.

5. Analyze the feasibility and cost/benefits of other models for data collection, including:

- State developed violent death reporting systems, such as California's Electronic Death Registration System (CA-EDRS), a web-based electronic violent death reporting system based around the NVDRS data specifications;
- Use of sampling rather than census approaches;
- Regional data collection for large states; and
- Approaches used by other national surveillance systems such as CFOI, FARS and Cancer Registries.

BACKGROUND: MEETING PURPOSE, PARTICIPANTS, AND SCOPE

The National Violent Death Reporting System (NVDRS) was first launched in 2003 to compile more detailed and comprehensive data about the estimated 50,000 violent deaths that occur annually in the United States. By understanding more about the circumstances surrounding homicides and suicides, the Centers for Disease Control and Prevention (CDC) National Center for Injury Prevention and Control (NCIPC) and participating states hope to shed light on opportunities for prevention at the local, state and national levels.

Because the system draws upon data from multiple sources — death certificates, ME/coroner reports, and law enforcement reports — it has the potential to reveal much more about the circumstances surrounding violent deaths than any single data source alone could offer. However, collecting data from each of these sources in a timely and cost-effective manner has proven to be challenging in some states. In 2003, NVDRS began with seven states participating, gradually increasing to 18 in 2010 as additional funds were allocated by Congress. At the state and national levels, budget pressures have made it difficult to expand the program, but the obstacles have not all been financial. In order to become a truly national surveillance system with participation from all or most states, both CDC/NCIPC and states (those already participating as well as those interested in becoming part of NVDRS in the future) recognize that the barriers relate to the processes for applying for funding and implementation of the system need to be understood and overcome.

To think through barriers and solutions to broader NVDRS implementation, the Safe States Alliance convened a roundtable discussion in Atlanta in September 2011. Participants included representatives from the CDC/NCIPC Division of Violence Prevention who helped design and implement NVDRS, states already participating in the program, states who had applied but not succeeded in meeting the requirements, and several states interested in applying in the future. A list of meeting participants is provided in Appendix A.

After a brief update about upcoming technological changes affecting NVDRS as it moves to a Web-based architecture, participants heard from presenters who had been involved in the design and implementation of two other national surveillance systems that rely on state participation and data: the Census of Fatal Occupational Injuries (CFOI) maintained by the Bureau of Labor Statistics and CDC's National Program of Cancer Registries (NPCR).

Roundtable meeting participants then discussed **what's critical** about NVDRS for national and state or local purposes, as well as the **barriers** that hinder implementation or full participation. Meeting participants generated a list of criteria for solutions, and then turned to a discussion of **possible solutions** and specific **next steps**.

Highlights from each of these discussions are summarized below. A meeting agenda is provided in Appendix B.

EXAMPLES FROM OTHER NATIONAL SURVEILLANCE SYSTEMS

Joining the meeting by telephone, Steve Pegula provided an overview of the Bureau of Labor Statistics CFOI, which attempts to count and describe all the fatal occupational injuries that occur across the United States in a calendar year. In 2010, 18,000 source documents were reviewed to compile information on a preliminary total of 4,547 fatal occupational injuries, ranging from a handful in small states like New Hampshire to hundreds in larger states like Texas.

The current system relies on a state representative (in most cases) who acts as a liaison to the various data sources in each state, customizing the approach to each state's situation. A new web-based system is being used for the first time this year to collect additional data elements and enhance the user experience.

Mr. Pegula shared some lessons learned since the program began in 1992:

- It has been important to educate the owners of the data sources for CFOI about the surveillance system's benefits. This helps engage them in providing high quality data to the system on a timely basis.
- It's easier to persuade people rather than organizations to provide data to the surveillance system, so find a sympathetic champion in the organization that is supplying data at the outset. However, turnover is an issue — so once a champion has been identified, more formal MOUs may be needed to keep the data flowing.
- Paying a flat fee for access to medical examiner, vital statistics, and police reports has worked wonders.
- CFOI tries to make it as easy as possible for partners to give them data. Flexibility is paramount; CFOI's philosophy is that anything is better than nothing when it comes to data.
- In some cases when establishing a relationship between a data provider and CFOI, CFOI begins in an initial probationary period, followed by targeted outreach aimed at receiving more data (and more accurate, comprehensive data) in the future.
- States are funded via a CFOI cooperative agreement, which is renewed annually and varies depending on the state's size and volume.
- Regional CFOI staff review the data collection and coding of state-level staff and augment the state-level staff when needed. Regional staff negotiate cooperative agreements between the States and CFOI and monitor State programs.

Jean Ewing from CDC's National Program of Cancer Registries (NPCR) explained the program's evolution since it began as a state-based program in Vermont in the early 1990s. Early activism supporting cancer registries came from the families of women who had died of breast cancer, who wanted each of these deaths counted and not forgotten. The approach was intended to

build on existing surveillance systems such as the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) program and individual hospital registries.

The emotional “hook” of making every death count garnered Congressional support, which led to the Cancer Registries Amendment Act of 1992, which mandated reporting. To create the political will for the system, it was critical to define for politicians why these data are important to address their needs and concerns, such as highlighting disparities in cancer rates that affect major constituent groups, and responding to community concerns about cancer clusters. Creating state cancer profiles was also useful in enlisting support.

Since the passage of the federal legislation, NPCR (administered by CDC) has expanded to 45 states as well as the District of Columbia and Puerto Rico, covering 96% of the U.S. population. In participating states, medical facilities (including hospitals and physicians’ offices) report cases, initial treatment, and deaths to a central cancer registry.

CDC has required that states have a law mandating reporting cancer diagnoses to the state in order to receive funding. CDC promoted a model state law, which included penalties for non-reporters.

Although the program relies on comprehensive and rigorous data quality standards (articulated through manuals, coding books, and training), variations in how data are collected and reported are tolerated as long as reporting entities meet the data quality standards. In some states, there are regional registries that aggregate data for their region, and feed it into the state data system.

Staffing for cancer registries is robust compared to current staffing for NVDRS. For example, in Colorado, NVDRS supports two staff members, and the Cancer Registry supports 12 staff.

Mel Kohn shared information he received from Ann Dellinger at NCIPC about the Fatality Analysis Reporting System (FARS), which collects data on fatal motor vehicle crashes. Dr. Dellinger noted that FARS has been around since the 1970s, so there has been much more time than NVDRS has had to “work out the kinks” in the system. There is a paid FARS coordinator in every state. Although FARS combines data from several sources, in practice most of the data comes from the Police Accident Report. This report has a recommended minimum data set with about 70 elements, and this helps standardize reporting across jurisdictions. The Department of Transportation has provided incentives (either ongoing or one-time funding opportunities) to states that meet the minimal data set requirements.

CRITICAL ELEMENTS OF NVDRS: STATE/LOCAL AND NATIONAL PERSPECTIVES

Meeting participants shared their views about what is most critical in terms of promoting and sustaining NVDRS with partners and other audiences.

Building the “case” for NVDRS is critical to develop the political will and funding to sustain and expand NVDRS. The “case” needs to clearly explain the unique additional value that NVDRS adds beyond existing data streams. In addition, the “case” will need to demonstrate how the system is useful at the local level (e.g., in designing community safety programs or interventions, or providing a rationale for grant or other funding) as well as at the state and national levels. The primary contribution of NVDRS is that it provides rich circumstantial data, particularly in the narrative section. These circumstances provide the “why” rather than just the “who, what, when and where,” and this is critical for designing and implementing prevention programs and policies.

Timeliness has been a challenge for NVDRS. Two substantial barriers to providing data in a more timely way are the slow pace at which vital statistics data are finalized and the reluctance of law enforcement to release data until cases have been adjudicated. It’s not realistic to expect that these barriers can be overcome in the short term, and even in the long term without substantial efforts at the national level. One way to address this might be to agree with grantees on a smaller database without the narrative that can be made accessible more quickly through a query-able website. The complete database could then be released when available.

Engaging partners (as more than simply providers of data) was another theme. Examples included providing technical assistance and support to child death review or domestic violence programs to make data sharing easier and more efficient, such as through web-based query systems, or to promote joint uses of common data. Working within public health to connect the dots between chronic disease burden and violence prevention or providing a query Website accessible by partners were other suggestions. If partners see value from their participation in NVDRS, they are likely to become not only reliable data sources but promoters of the programs.

Creating and maintaining internal support for NVDRS within the health department has been a challenge in many states, and this makes it difficult for state injury programs to maintain momentum and enthusiasm — particularly in light of budget pressures or turnover among partners that requires rebuilding relationships over and over. Enlisting high-level, state agency support from partner organizations, such as ASTHO and CSTE, was suggested as one way to help address this. State Epidemiologists and State Health Officials have many programs and needs competing for their attention and support. NVDRS should be promoted to these leaders through their professional organizations as a core building block for injury prevention and the

nucleus around which their injury program should be built, and therefore meriting substantial attention and support from them.

BARRIERS TO NVDRS PARTICIPATION AND IMPLEMENTATION

Participants broke into small groups to discuss some of the barriers to participation in NVDRS and its implementation. After reporting back to the larger group, the list of barriers was categorized as follows:

CAPACITY ISSUES, INCLUDING INFORMATION TECHNOLOGY (IT)

Several items in this category centered around staff and staff training, such as difficulties with hiring and training staff. Given the limited funds available for staff support, state programs spend a great deal of energy finding the right configuration of staff to provide the necessary skills, such as data abstraction, data analysis, and relationship building with partners. It might help new states as they develop their programs to have some models or examples about how these staffing issues have been juggled in different states. In addition, it might help all funded states to brainstorm about best practices for retaining staff, improving morale, addressing the stress which staff experience when they are exposed repeatedly to stories of violence and death, and dealing with staff turnover when it occurs. Staff turnover is particularly difficult with a small project staff, since there is little redundancy to “take up the slack” when someone leaves.

Although electronic systems were generally felt to be more efficient in the long run, several participants voiced concerns about problematic transitions from paper-based to electronic systems, and about the inevitable “bugs” that need to be fixed in any electronic systems. Participants were also very concerned about how the Web-based data system that CDC is developing for NVDRS may conflict with state laws about disclosure; when the data reside at the federal level there may not be protection against public records requests, and so the data become public record, even if they are not public under state law. In addition, states want to be sure that they will have full access to all data they input into a Web-based system that CDC would develop, and not just be the “data gnomes” entering data into a system to which they do not have immediate access. Finally, states want to be sure that the new Web-based system will continue to allow them to collect state-specific variables; the Web-based system should facilitate states being able to do this at least to some extent. Some barriers were related to implementing “shoe-leather” or paper-based systems as opposed to electronic ones, and to the time and resources related to cleaning and editing data. IT transitions and bugs were also cited as barriers.

FUNDING

While acknowledging the overall constrained budget climate at the federal and state levels, participants did point to a lack of funding as a barrier. This included insufficient funds to support a truly national system that encompasses all the state, tribes, and territories, as well as providing adequate funds within each state. Variations or disparities across states — in terms of

funding per case, the personnel time needed for developing, maintaining and rebuilding relationships across the state to maintain data access, or the costs incurred for NVDRS implementation in large and/or geographically dispersed states — also were listed as barriers.

There was also discussion about the value of having two tiers of funding — planning and implementation — that would recognize the substantial investment in relationship building and partnership development required to start an NVDRS system, and also recognize that it takes time to do this, particularly for larger states and states with more decentralized data systems.

DATA ELEMENTS AND QUALITY

These barriers included the number of elements to be collected (and whether all were necessary), data quality issues (especially ME/coroner and law enforcement data), and dealing with the problem of unknown or missing data. Participants questioned whether sampling cases might be appropriate or whether NVDRS should follow a registry or surveillance system approach. Difficulties and expenses related to collecting data from narratives were also cited as barriers, as was a lack of flexibility regarding how core data elements are collected.

DATA SOURCES

Barriers related to data sources included the turnover and constant change among contacts for various sources and accessing the police investigative report and Medical Examiner's report. Participants also questioned whether all three main sources were always needed, whether local sources were always needed (e.g., accessing the Department of Justice's data instead), and whether other data sources (such as emergency medical services data) might be relevant or useful in the future. The lack of standardization of law enforcement and ME/coroner data across the country is a major barrier to data collection for NVDRS; participants opined that CDC's leadership at a national level could help address this.

APPLICATION PROCESS AND REQUIREMENTS; PLANNING FOR AN NVDRS SYSTEM

Barriers in this category included the lack of a planning phase, lack of clarity about what states need to have in place in order to write a successful application, short timelines for obtaining required MOUs/MOAs, and lack of authority to enforce MOUs once they are in place. A lack of state contingency plans to cover interruptions in staffing or data flow also was mentioned as a barrier.

MAKING THE CASE

Participants noted a number of barriers related to how difficult it is to communicate the NVDRS program's value or "wow" factor and to promote the usefulness of its results or products (e.g., in making the public health case for violence prevention). Some of the barriers included a lack of timeliness of data availability, an initial selling point that distinguished NVDRS from other data sources was the potential for having more timely and robust information about violence deaths and differing priorities for data analyses.

A NATIONAL SYSTEM; DEALING WITH VARIABILITY

A final set of barriers concerned various aspects of the system's scope. Some questioned whether the "all-or-nothing" requirement for a statewide system is serving the program. If some states can obtain data from regions and/or large population centers, would this support the national system goals more than not participating at all?

A related issue is local variability (within and across states) in system elements such as data capacity and data quality for law enforcement and ME/coroner data sets. Some participants noted that the current system requirements are often incompatible with the wide range of state and local agency structures, data systems, laws, and cultures — and that it is not realistic to expect these to change to accommodate a surveillance program. Finally, state participants thought it would be helpful for CDC to emphasize on its Website and when staff talk about NVDRS or use NVDRS data that CDC is committed to a nationwide state-based system with participation from all states.

CRITERIA FOR EFFECTIVE SOLUTIONS

Before turning to potential solutions to address these barriers, the group considered criteria that could be used to ensure that potential solutions serve the shared interests of CDC/NCIPC and state participants to develop a viable, useful and sustainable system.

Ideally, potential solutions should:

- Be feasible or achievable and work for all states
- Minimize the burden on local (sub-state) agencies
- Produce data that are timely and useful at both state and national levels
- Generates “Wow!” or marketability for the program
- Maximize circumstance data
- Offer a clear process (including standards and minimum steps) while remaining flexible
- Be cheap, fast and good
- Be sustainable in the long term
- Offer clarity regarding who takes on the next step(s)
- Be scalable (i.e., even if they start small, still offer potential for a larger scale effort)
- Build capacity and where possible improve other data systems (such as vital records or medical examiner systems) within states
- Be defensible so that CDC can provide a rationale for continued funding (e.g., outcomes/results, cost-effectiveness, doesn’t duplicate other efforts)
- Meet data quality standards/thresholds
- Yield output that advances and aligns with emerging meaningful use/national data systems and informatics goals.

SUGGESTED SOLUTIONS AND NEXT STEPS

Although the face-to-face meeting time didn't allow for addressing all of the barriers listed above, the group did suggest some specific strategies and potential solutions designed to address nine high-priority topics. These are summarized below.

SHOULD NVDRS TRANSITION FROM A “SHOE-LEATHER” TO A MORE ELECTRONIC SYSTEM?

The presentations about other national surveillance systems generated ideas about how NVDRS could balance comprehensive data requirements with the need for fuller participation and a more sustainable system.

One suggestion was to conduct a scan or inventory of what states currently can obtain electronically. This, in turn, could yield information on commonalities across states and a set of core elements that most states could gather (beyond vital statistics and still yielding valuable insights, but short of the current list of required data elements). There was interest in exploring a multi-tiered approach similar to how the NPCR is organized, with a required core set of data that would be required of all states that wished to participate paired with an enhanced but optional set for states that receive federal funding (or perhaps with tiered funding as well).

Another suggestion was to define a minimum set of core data elements, and then develop a sampling strategy (with the help of statisticians and epidemiologists) that would be used for abstracting records and collecting qualitative information from narratives. It was noted that this needs to be balanced with the potential loss of information and potential political support of “counting every case.”

In addition to NPCR, the Traumatic Brain Injury (TBI) surveillance system was offered as a possible model of a system that enumerates all cases with one data source and then collects more detailed information on a sample of cases. In the TBI surveillance, hospital discharge data are used to identify the entire population of people hospitalized with a TBI. Sampling strata are used to identify cases for medical record review. The results are then weighted back to generate population estimates.

It was noted that determining the sampling strata for NVDRS would be very difficult. Additionally, there are types of cases with small numbers (e.g., suicide by cop, violent deaths of women who are pregnant at the time of death) where one would want detailed information on every case.

Securing other resources for infrastructure and data system development was another suggested strategy, as well as exploring what could be done at both national and state levels to institutionalize this type of data collection (e.g., through state laws, federal incentives, or other means).

HOW CAN ADEQUATE FUNDS BE SECURED FOR (AND WITHIN) EACH STATE, TRIBE, AND TERRITORY?

Echoing an earlier discussion, participants noted the high degree of variability across states — and how little this variability is reflected in differences in funding levels. For example, a large state such as Texas, with many sparsely populated and geographically distant areas, would need several staffed centers across the state in order to maintain frequent contact with data partners, as well as ongoing IT support. Other states (such as North Carolina) have a centralized medical examiner data system that greatly simplifies data collection. North Carolina also has managed to keep their NVDRS programs going only with significant supplemental funding from other sources (in their case, the CDC’s Preventive Health and Health Services Block Grant), but as these additional funding sources are cut, the program’s scope and viability are threatened.

One question the NVDRS program could explore is how close state-based systems, such as California’s Electronic Violent Death Reporting System (CalEVDRS), would be to delivering at least some of the data NVDRS seeks on a national scale. If all states could be funded at modest levels to deliver what California does, what are the potential benefits and trade-offs? Could a more national program begin with a minimum core available electronically, and then increase to more comprehensive or resource-intensive systems?

Regardless of which model is pursued, participants felt NVDRS needs to clarify the questions it is trying to answer (and be cautious about over-promising impact in areas like prevention given the limitations of the injury and violence prevention infrastructure across the United States). A clear, compelling message is needed about what it would take to adequately fund such a system.

Once that is accomplished, other partners should be engaged to help champion the cause (such as Safe States Alliance, the Action Alliance for Suicide Prevention, the Armed Forces, and state and national domestic violence coalitions). Just as breast cancer victims and advocates made the cancer registry system possible, suicide survivors should be mobilized as an advocacy force for full implementation of NVDRS across the country. Part of the context for the funding pitch should be state injury and violence prevention funding, which is not in place nationwide.

Finally, some participants thought CDC’s state grants for Public Health Emergency Response (PHER) might be worth exploring as a potential source of funding from the vantage point of building up ME/coroner data systems and reporting capacity that would be useful in a variety of crisis situations. Some states have used PHER funding for this, but additional work within CDC to encourage this kind of “dual use” for preparedness funding would help open the door for this kind of innovation.

HOW CAN THE REQUIREMENT TO SECURE MOUS FROM DATA PARTNERS BEFORE APPLYING BE MADE LESS RESTRICTIVE?

One suggestion was to consider planning grants specifically for the purpose of obtaining signed MOUs. Another was to relax the requirement altogether — e.g., to accept letters of support instead. A third option raised would be to accept letters of support for the grant application with the requirement for having MOUs in place by the end of the first grant year.

WHAT ARE THE IMPLICATIONS FOR CONFIDENTIALITY AGREEMENTS IN TERMS OF STATES SHARING DATA THAT INCLUDES PERSONALLY IDENTIFIABLE INFORMATION (PII)?

The plan to transition to a CDC-hosted Web-based architecture in which state data are sent to CDC raises legal questions for some states about whether CDC can possess state data that includes PII. The backdrop is not only overall concerns about confidentiality, but also a national movement demanding greater protection for death data. For many, sending confidential data out of state would be an automatic deal breaker — although others with existing strong relationships with data partners thought they might be able to convince them to continue participating, based on trust and history.

Transferring data without PII is one option. Another might be to create a unique identifier for state use and for linking to the CDC server.

If CDC is able to host data with PII, a statement from CDC's legal team would be helpful — as would a mechanism for sharing this information with state (and possibly local) legal teams as well. CDC Public Health Law Program might be able to serve as a resource for these questions and/or develop a white paper for state lawyers concerned about risks and breaches of confidentiality.

Again, other models might be instructive. For example, CFI data are shared with protections that may serve as models. An analysis of the extent of the problem and the degree to which federal legislation would address it would be useful; if appropriate, working with partners to have such legislation passed could be helpful.

HOW CAN NVDRS PROGRAMS OBTAIN LEGAL ACCESS TO DATA ON OPEN HOMICIDE CASES?

For a variety of reasons, data on open homicide cases pose additional hurdles. Perpetrator data are more sensitive; in some states (e.g., Florida), public health can't even obtain the mechanism of death for open cases because the medical examiner's office is under law enforcement, rather than the health agency.

Suggestions included conducting different analyses of state data based on whether or not perpetrator data are available (or including partial information from some cases and records),

and trying to engage national groups (law enforcement, Governors' offices) in resolving this and exploring how to reduce fears that releasing the data impedes prosecution of cases. Ohio found a workaround to obtain at least some case information (by obtaining IRB clearance) and is now exploring legislative options; in Oregon, efforts are underway to make more explicit the health department's legal authority to have access to injury and violence prevention data.

WHAT ARE THE OPTIONS FOR REDUCING THE NUMBER OF DATA ELEMENTS COLLECTED?

As part of the transition to the new Web-based architecture, CDC has analyzed the list of existing variables and whittled it down from over 800 to 300-350 by removing redundant, consistently missing or uncollectable, or other less crucial elements. The list, which should be finalized this fall, will be shared with states for their input. Roll-out is planned for 2014.

Because of the overall reductions, it may be possible to add some data elements —e.g., those that would be particularly relevant for advocacy partners (suicide, domestic violence, firearms). However, all agree that additions (and subtractions) should be made with caution.

Another issue raised by participants is how narrow definitions may restrict categories to the degree that they are not yielding useful information or entirely miss the point of an event. One example was overly narrow distinctions between bystander and gang-related violence which may results in bystander related deaths becoming excluded from reported deaths from gang-related violence.

HOW CAN DATA QUALITY BE IMPROVED?

Improving coroner and medical examiner data will require national leadership. Opportunities include the advent of more widely used (and linked) electronic health records, using PHER resources available to states for emergency preparedness and response, and enlisting the help of other allies interested in quality state-level coroner data (e.g., trauma system funders, departments of transportation interested in fatal crashes).

Another suggestion was to work with the American Board of Medical Death Investigators to highlight the value of investigations (yielding much more than an autopsy alone) and to incorporate data quality issues into their training. Standardizing a list of 10 or so questions to be asked in the event of a suicide, homicide or domestic violence case would be useful, reducing the need for abstraction (similar to how FARS works).

Education alone will not solve the problem of incomplete or poor quality data in these systems. CDC should explore the possibility of financial or policy incentives or penalties to drive improvements to these data systems, as has been done for FARS and Cancer Registries.

Overall, it will continue to be important to demonstrate the value of NVDRS to these partners and thus demonstrate the role that coroner and medical examiner data play in generating that value.

WHAT IS THE NVDRS “WOW” FACTOR AND HOW CAN IT BE COMMUNICATED MORE EFFECTIVELY?

Participants agreed that messages about NVDRS’s unique value and contributions are not getting through — in part, because many “wows” are local and it takes time and effort to collect them. Suggestions for improvement included cultivating relationships with reporters (possibly with technical assistance and support from CDC), tapping prevention and other expertise on Advisory Boards, and linking more closely to advocacy groups and partners (especially as vehicles for press releases and other direct media contact).

To document the benefits and returns on investment for data partners, programs could more systematically collect stories of tangible ways NVDRS data have been used. Another suggestion was to contribute stories to (or draw ideas from) the Veto Violence web site (www.vetoviolence.org).

Communications is a professional discipline of its own, and public health practitioners are not usually experts in this area. CDC should work with a team of communications professionals to identify the key audiences for these messages and to design appropriate communications tools and strategies to disseminate these messages.

HOW CAN MORE STATEWIDE PARTICIPATION BE ENCOURAGED?

Several states feel they could or would participate, if they could do so on the basis of including some but not all of their state’s jurisdictions. Focusing on high-population/high-yield counties, they suggested, might yield enough useful and relevant data, without sacrificing too many cases. In many states, large urban settings could be brought on board relatively quickly.

If this becomes possible, meeting participants offered several cautions. The first is to ensure that states are still involved as an entity (i.e., CDC shouldn’t work directly with cities without state-level involvement, or set up a situation in which cities within states are competing for funding against each other or the state overall). The second is to make sure that rural issues and populations are still captured — possibly via sampling strategies. A number of violent death-related issues are qualitatively different in urban and rural areas in some parts of the country (e.g., suicide, methamphetamine abuse) and thus high-population/high-yield strategies should be careful not to overlook these.

A truly national picture of violent deaths, some noted, should include all states or as many as possible, even if their data are incomplete (or, for now, nonexistent). Letting states join in as they are able, in a tiered or phased system, might be one way to reach this goal. Another would

be to follow the cancer registries' approach of allowing some regional registries, instead of focusing exclusively on states.

RECOMMENDED NEXT STEPS:

Although the group did not have time to explore each of these questions in detail, they did offer several specific suggestions for next steps. These included:

1. Convene a standing Technical Consultation Group for NVDRS mediated through Safe States Alliance and CSTE modeled on the Injury Surveillance Workgroup (ISW), to promote more state ownership and participation in the program. Use this venue to:
 - Review CDC's shortened data elements list.
 - Identify and share best practices about the best staff configurations for an NVDRS program.
 - Solve other technical issues.
2. Promote adoption of a web-based data collection system for NVDRS, with attention to potential barriers and issues:
 - Assess state capacity to draw NVDRS data from electronic data sets, and incorporate this in planning for the NVDRS web-based data collection system. This could be accomplished through planned CDC Core Violence and Injury Prevention Program Regional Network Leader needs assessments.
 - Partner with CDC's Public Health Law Program to assess the potential of the NVDRS web-based data system to conflict with state confidentiality laws, to communicate findings to legal counsel in states as appropriate through each state's injury prevention program, and to integrate findings into planning for the web-based system.
 - Ensure that the web-based data collections system will allow states to include state-specific data elements and to have full and immediate access to their state's data.
3. Support advocacy for expansion and enhancement of NVDRS
 - Make clear and continually reinforce the vision of a nationwide NVDRS that includes all states, territories and tribes.
 - Work with experts in communications to create a feasible strategy for communicating the unique contributions of NVDRS to policymakers, funders, and advocates working on violence-related issues including suicide and domestic violence.
 - Engage the National Violence Prevention Network, Association of State and Territorial Health (ASTHO), Council of State and Territorial Epidemiologists (CSTE), Action Alliance for Suicide Prevention, Safe States Alliance and other related

national organizations to promote NVDRS with their members as a core building block for prevention violent-related deaths and injuries, and work to align these organizations around advocacy for NVDRS with policymakers.

4. Enhance data quality and timeliness

- Lead efforts at CDC to improve ME/Coroner and Law Enforcement data systems.
 - Encourage adoption of laws, rules, policies, and/or incentives at the state and federal levels to achieve standardization of ME/coroner data collection, and overcome fears that data sharing will impede prosecution.
 - Partner with CDC's Center for Emergency Preparedness and Response to promote collaboration with Public Health Emergency Response grants to improve data systems so that they will be highly functional in a public health emergency.
 - Work with the Department of Justice, the Department of Homeland Security, and other federal agencies to identify and advocate for funding incentives to drive improvements in ME/coroner and LE data systems.
- Consider providing one-year planning grants and technical assistance to states interested in applying for NVDRS to plan and conduct activities related to adopting laws, rules or policies that require and/or incentivize submission of data to NVDRS.
- Work with the National Association for Public Health Statistics and Information Systems (NAPHSIS) and the National Center for Health Statistics (NCHS) to analyze the data collection process for vital records using Lean Six Sigma or other widely used methodologies for process improvement, and to implement the recommendations for improvement that come out of such an analysis.
- Issue two NVDRS data sets for analysis: a provisional data set that includes data elements that can be gathered in a timelier manner, and a final data set that includes the full complement of NVDRS variables.

5. Analyze the feasibility and cost/benefits of other models for data collection, including:

- State developed violent death reporting systems, such as California's Electronic Death Registration System (CA-EDRS), a web-based electronic violent death reporting system based around the NVDRS data specifications;
- Use of sampling rather than census approaches;
- Regional data collection for large states; and
- Approaches used by other national surveillance systems such as CFOI, FARS and Cancer Registries.

APPENDIX A: LIST OF NVDRS ROUNDTABLE PARTICIPANTS

Michael Bauer

Director
Injury Prevention Program
New York State Department of Health
Riverview Center 150 Broadway, Suite 302
Albany, NY 12204
(518) 473-1143
mjb13@health.state.ny.us

Rana Bayakly

Chief Epidemiologist
Georgia Department of Public Health
Chronic Diseases, Health Behaviors, and Injury
Epidemiology Section
2 Peachtree Street, NW
Suite 14-440
Atlanta, GA 30303-3142
(404) 657-2617
arbayakly@dhr.state.ga.us

Jenifer Cartland

Research Associate Professor
Department of Pediatrics
Feinberg School of Medicine
Director, Child Health Data Lab
Co-Director, Center for Community Partnerships
and Health Promotion
Children's Memorial Research Center
2300 Children's Plaza, Box 157
Chicago, IL 60614
(312) 573-7772
jcartland@childrensmemorial.org

Steve Dearwater

Injury Epidemiologist
Holtz Children's Hospital
Jackson Health Systems
794 NW 18th St., 2nd Floor
Miami, FL 33136
(305) 804-7212
stephen.dearwater@jhsmiami.org

Jolene DeFiore-Hyrmer

Program Manager
Ohio Violent Death Reporting System
Ohio Department of Health
246 N. High Street, 8th Floor
Columbus, Ohio 43215
(614) 644-0135
jolene.dhyrmer@odh.ohio.gov

Dylan Ellis

Statistical Analyst for Injury Program
Pennsylvania Department of Health
555 Walnut Street
Harrisburg, PA 17101
(717) 783-2548
dyellis@pa.gov

Leroy Frazier, Jr.

Health Scientist
Division of Violence Prevention, National Center
for Injury Prevention and Control, Centers for
Disease Control and Prevention
4770 Buford Hwy, NE (F64)
Atlanta, GA 30341
(770) 488-1507
LFrazier1@cdc.gov

Holly Hedegaard

Colorado Department of Public Health and
Environment
4300 Cherry Creek Drive South
Denver, CO 80246
(303) 692-3005
holly.hedegaard@state.co.us

E. Lynn Jenkins

Chief, Etiology and Surveillance Branch
CDC/NCIPC/DVP
4770 Buford Highway NE, Mailstop F63
Atlanta, Georgia 30341
(770) 488-3931
LJenkins@cdc.gov

Deb Karch

Lead Behavioral Scientist
CDC/NCIPC/DVP/ESB
4770 Buford Hwy, NE
Atlanta, GA 30341
(770) 488-1307
debra.karch@cdc.hhs.gov

Mark Kinde

Unit Leader/Research Scientist Supervisor 2
Minnesota Department of Health
Injury and Violence Prevention Unit
85 East Seventh Place, Suite 220
P.O. Box 64882
St. Paul, MN 55164-0882
(651) 201-5447
mark.kinde@state.mn.us

Mel Kohn

3035 NE 21st Ave
Portland, OR 97212
(503) 314-7282
melster@teleport.com

Nicole Lezin

Consultant to Safe States
Cole Communications, Inc.
6164 Sheraton Place
Aptos, CA 95003
(831) 479-1786
lezin@mindspring.com

Lloyd B. Potter

State Demographer of Texas
Director, Institute for Demographic and
Socioeconomic Research, and
Texas State Data Center
Professor, Department of Demography and
Organization Studies
University of Texas at San Antonio
501 Cesar Chavez Blvd.
Monterey Bldg., 4th Floor
San Antonio, TX 78207-4415
(210) 458-6530
Lloyd.Potter@osd.state.tx.us

Scott Proescholdbell

North Carolina Division of Public Health
1915 Mail Service Center
Raleigh, NC 27699
(919) 707-5442
scott.proescholdbell@dhhs.nc.gov

Tammy Sajak

Manager
Epidemiology Studies & Initiatives Branch
Texas Department of State Health Services
PO Box 149347 MC1964
Austin, TX 78714-9347
(512) 458-7220
Tammy.sajak@dshs.state.tx.us

Linda Scarpetta

Manager, Childhood & Unintentional Injury
Prevention Section
Michigan Department of Community Health
3423 N. Martin Luther King, Jr. Blvd.
P.O. Box 30195
Lansing, MI 48909
(517) 335-8397
scarpetta@michigan.gov

Kyla Shelton

Injury Epidemiologist
Office of Injury Prevention
Florida Department of Health
4052 Bald Cypress Way Bin # C15
Tallahassee, FL 32399-1735
(850) 245-4440 X 2729
Kyla_Shelton@doh.state.fl.us

Roger Trent

Chief, Injury Surveillance & Epi Section
California Department of Public Health
MS 7214, P.O. Box 997377
Sacramento, CA 95899-7377
(916) 552-9858
Roger.trent@cdph.ca.gov

Amber Williams

Executive Director
Safe States Alliance
2200 Century Parkway, Suite 700
Atlanta, GA 30345
(770) 690-9000
amber.williams@safestates.org

APPENDIX B: NVDRS ROUNDTABLE AGENDA



Safe States Alliance and National Center for Injury Prevention and Control (NCIPC),
Centers for Disease Control and Prevention (CDC)

National Violent Death Reporting System (NVDRS) Roundtable Agenda
Atlanta, GA
September 12-13, 2011

Purpose: To better understand barriers states face in implementing NVDRS and brainstorm possible ways to help resolve them so that states and CDC can move forward on achieving shared NVDRS implementation goals.

Monday, September 12, 2011 (Phoenix III Room)

12:30 – 12:45	Introductions and Review of Agenda
12:45 – 1:00	CDC Welcome (Lynn Jenkins)
1:00 – 1:15	Shared Vision/Interests for States and CDC (Mel Kohn)
1:15 – 1:30	CDC Updates NVDRS Web-based Architecture (Craig Bryant)
1:30 – 2:30	Setting the Stage: Example(s) from Other National Surveillance Systems - Illustration of other systems (e.g., FARS, CFI, CDC Cancer Registries), noting initial barriers and how they were resolved - Q&A/Discussion
2:30 – 2:45	Break
2:45 – 2:55	Group Agreements/Ground Rules (Nicole Lezin)
2:55 – 3:30	NVDRS: What's Critical for National and State/Local Purposes (Nicole and Mel) - Discussion
3:30 – 4:30	Barriers - Small group discussions to identify implementation and application barriers in major categories (e.g., centralized data systems, electronic/linked data systems, data source-specific issues, legal barriers, small state/large state, partnerships, IT, data coding, staff training/turnover) - Report-outs - Discussion

4:30 – 4:50	Transition to Solutions – Developing criteria for effective solutions
4:50 – 5:15	Success Stories
5:15 – 5:30	Overview of Day 2; Adjourn

Tuesday, September 13, 2011 (Orleans Room)

8:30 – 8:45	Reflections on Day 1; Game Plan
8:45 – 10:00	Solutions, Part I For barriers identified on Day 1 — ideas and potential solutions from states and CDC
10:00 – 10:15	Break
10:15 – 10:45	Solutions, Part II For barriers identified on Day 1 — ideas and potential solutions from states and CDC
10:45 – 11:15	Applying criteria for effective solutions (from Day 1) - Which solutions meet the criteria? - What modifications would help them meet the criteria?
11:15 – 12:00	Agreements on next steps “Gives and Gets” exercise (what I can contribute to solutions; what I need from others to be effective)
12:00	Wrap-up and Adjourn