



SUICIDE PREVENTION ACTION NETWORK USA

**Strategies to Improve
Non-fatal Suicide Attempt Surveillance:
Recommendations from an Expert Roundtable**

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Executive Summary

At least 30,000 Americans die by suicide each year. For every person who completes the act, it is thought that 8 - 25 more people attempt. Even using conservative estimates, the number of suicides and attempted suicides clearly indicates a public health crisis.

But why is there such disparity in the number of attempted suicides? What can be done to provide more precise and reliable information to guide suicide prevention policies and programs?

In April 2006, the Suicide Prevention Action Network USA (SPAN USA) hosted a roundtable discussion to tackle these challenging questions. Experts involved with state and national public health surveillance systems and academia discussed current public health surveillance activities and recommended ways to strengthen non-fatal suicide attempt surveillance systems.

Currently, non-fatal suicide attempt data are gathered from (1) hospital discharge data for inpatients, (2) emergency department data, and (3) population-based randomized phone surveys and self-administered questionnaires. These data sources were not developed specifically for capturing information about suicide attempts, so each provides a partial look at the incidence and circumstances surrounding attempts. Together, the data sources offer an incomplete, and likely understated, account of the problem. However, policy makers and planners need more specific data to better assess and respond to the needs of at-risk individuals, particularly as those who survive a suicide attempt are at increased risk for subsequent attempts.

In their review of current public health surveillance activities, roundtable experts noted the limitations of current systems. One over-arching problem is the lack of infrastructure. The experts expressed great concern about the lack of resources and infrastructure within state and local health departments to conduct surveillance, conduct epidemiologic analysis and disseminate data. Five states do not have systems to collect hospital discharge data, while twenty-five states lack hospital emergency department data systems.

Another significant shortcoming is data variability. There is no standard set of uniform definitions or coding schemes for key variables relevant to suicide and suicide attempt surveillance. For example, states that collect hospital discharge and emergency department data use a variety of fields to record external-cause-of-injury codes (used to identify cases of suicide and non-fatal intentional self harm in hospital records). This lack of standardization makes it difficult to aggregate and compare data across states.

To frame their recommendations, the expert group first agreed upon general principles to guide decision-making about public health surveillance. The principles were:

- Public health surveillance is necessary as a foundation for addressing suicide.
- Healthcare providers need to identify and report suicide attempts.
- Public health professionals need to track and analyze the data.

- A national data clearing house needs to aggregate the data and identify available data sources for suicide and suicide attempts.
- National and state-based data on the incidence and characteristics of suicide and suicide attempt events should inform policy and program decisions.

The group then went on to recommend specific strategies for putting these principles into action. The experts came up with a series of seven steps aimed at strengthening non-fatal suicide attempt surveillance over the short- and long-term. Their recommendations were to:

- (1) Mandate external-cause-of-injury coding for all inpatient hospitalizations and outpatient visits reimbursed by Medicaid and Medicare
- (2) Improve charting and other systems used in external-cause-of-injury coding
- (3) Educate others about suicide and suicide attempts as a public health concern, including the importance of reliable national and state-based non-fatal surveillance systems to monitor suicides and suicide attempts
- (4) Address ethical issues associated with suicide surveillance (e.g., privacy concerns)
- (5) Build upon existing public health surveillance systems
- (6) Hold joint meetings with the epidemiology and suicidology fields to discuss surveillance
- (7) Provide decision makers with the best data on suicide attempt that are currently available

The experts elaborated on these recommendations, providing background information and suggesting implementation strategies. The group agreed that an initial first step would be to coordinate information produced by current public health surveillance systems and put forth an expert consensus opinion on which estimate is most accurate.

In the end, the expert roundtable discussion affirmed the value of a national, uniform public health surveillance system for collecting data on suicide attempts. Participants called for a more standardized and cohesive approach to public health surveillance that would produce high quality data to better inform prevention policies and interventions.

Introduction

Policy makers know that at least 30,000 Americans die by suicide each year.

The CDC's National Center for Health Statistics compiles that information from state-level death records for its National Vital Statistics System. CDC's National Center for Injury Prevention and Control then uses that data for the Web-based Injury Statistics Query and Reporting System (WISQARS), an interactive system which allows users to obtain annual national mortality data, as well as customized demographic and state-by-state reports. In addition, CDC is building a National Violent Death Surveillance System to better understand suicide deaths. With data from seventeen, currently-funded states, the system provides a rich source of circumstantial data that sheds more light on completed suicides.

However, much less is known about those people who survive suicide attempts (and are at increased risk for subsequent suicide attempts as a result).

It is thought that 8 - 25 people attempt suicide for every person who completes the act.¹ Why is there such disparity in those numbers? Existing suicide attempt data comes from data systems that were not developed specifically for capturing information about suicide attempts. As a result, suicide attempt morbidity data that are available give an incomplete, and likely understated, account of the problem.

However, more precise and reliable information is needed to guide suicide prevention policies and programs. Wide-ranging estimates make it extremely difficult for planners to assess and respond to the needs of attempt survivors and to advance effective suicide prevention strategies.

Surveillance is an essential and powerful tool to better understand public health problems such as suicide and suicide attempts. Public health surveillance systematically collects, analyzes, interprets, and disseminates health data on an ongoing basis. Planners use the data to detect occurrence patterns and take steps to control and prevent health problems in the community.

Thus, public health surveillance has a critical role in suicide prevention efforts at the societal-, community- and individual-levels. Data should be able to galvanize communities to adopt policies that save lives. In addition, good surveillance data helps to evaluate the effectiveness of prevention and intervention efforts. Regional and community prevention programs depend upon public health surveillance data to demonstrate need, monitor outcomes and secure ongoing funding. And, in some places, public health surveillance is used to identify and refer those individuals needing services (case finding).

The *National Strategy for Suicide Prevention* (NSSP) recognized the power of public health surveillance to affect change. Released in 2001, the comprehensive national plan includes a goal to "improve and expand surveillance systems" (NSSP, Goal 11). The NSSP puts forth four objectives to advance that broad goal of non-fatal suicide attempt surveillance:

¹ National Institute of Mental Health. (2003). *In Harm's Way: Suicide in America*. NIH Publication No. 03-4594. Available at <http://www.nimh.nih.gov/publicat/harmsway.cfm>

- increase the proportion of hospitals (including emergency departments) that collect uniform and reliable data on suicidal behavior by coding external cause of injuries, utilizing the categories included in the International Classification of Diseases (NSSP, Objective 11.3)
- increase the number of states that produce annual reports on suicide and suicide attempts, integrating data from multiple state data management systems (NSSP, Objective 11.5)
- increase the number of national representative surveys that include questions on suicidal behavior (NSSP, Objective 11.6).
- implement pilot projects in several states that link and analyze information related to self-destructive behavior derived from separate data systems, including for example law enforcement, emergency medical services, and hospitals (NSSP, Objective 11.7).

These objectives were the starting point for a roundtable discussion hosted by the Suicide Prevention Action Network USA (SPAN USA) in April 2006. Experts involved with state and national public health surveillance systems and academia (see List of Roundtable Participants) were asked to give input on how CDC's National Center for Injury Prevention and Control should move forward on these objectives and strengthen non-fatal suicide attempt surveillance. The experts were given background material to read and participated in an electronic dialogue prior to the April 10th meeting.

In addition to requesting concrete and achievable next steps, SPAN USA invited the experts to offer their vision for a more ideal public health surveillance system. During the day-long discussion facilitated by Lloyd Potter, PhD, MPH, Director of the Suicide Prevention Resource Center, the experts responded to both requests.

Early on, expert group members outlined a set of principles to guide decision-making about surveillance activities. They believed that:

- Public health surveillance is necessary as a foundation for addressing suicide.
- Healthcare providers need to identify and report suicide attempts.
- Public health professionals need to track and analyze the data.
- A national data clearing house needs to aggregate the data and identify available data sources for suicide and suicide attempts.
- National and state-based data on the incidence and characteristics of suicide and suicide attempt events should inform policy and program decisions.

The experts acknowledged that CDC and others could implement these principles in any number of ways. To jump start that discussion, the expert group went on to recommend specific steps to

put these principles into action and strengthen non-fatal suicide attempt surveillance over the short- and long-term. This white paper reflects the essence of the roundtable discussion, including the experts' brief review of current surveillance activities, agreement on system shortcomings and recommendations for next steps.

Current Surveillance Systems

The Council of State and Territorial Epidemiologists, STIPDA and the CDC have outlined different methods and sources for the collection and analysis of injury information, including data on non-fatal suicidal behavior.^{2 3} There are three data sources used for non-fatal suicide attempt surveillance:

- Hospital discharge data is collected on cases that require inpatient stays.
- Emergency department data is collected on people who are transported to or walk into hospitals for emergency care.
- Population-based randomized phone surveys and self-administered questionnaires collect self-reported data on suicidal ideation and behavior.

Hospital discharge data

Hospitals generate electronic datasets for billing purposes that include data on patient demographics, diagnoses, treatments, discharge status and cost of care. Medical record coders review the records of discharged patients and assign multiple diagnosis codes, procedure codes, and external-cause-of-injury codes. External-cause-of-injury codes indicate the intent (unintentional, suicide, assault, undetermined) and mechanism (e.g. "intentional self-inflicted poisoning with car exhaust") of injuries. Using hospital discharge data (HDD), states can identify cases of suicide and non-fatal intentional self harm and associated mechanisms of injury by using the external-cause-of-injury codes. Once cases are identified, analysts then can explore many variables within these data sets. Presently, 45 states have HDD systems. Of these, 42 states routinely collect external-cause-of-injury codes.

However, HDD systems have limitations, as pointed out in a recent report on state collection and use of injury data.⁴ The frequency of external-cause-of-injury coding varies greatly within these systems, which affects analysts' ability to find non-fatal self-harm cases. In states that have evaluated their systems, only 43.8 percent of HDD systems have external-cause-of-injury codes in more than 90 percent of their injury records. In addition, the number and type of fields

² State and Territorial Injury Prevention Director's Association. (1999). *Consensus Recommendations for Injury Surveillance in State Health Departments*. Atlanta, GA. Online at <http://www.stipda.org/displaycommon.cfm?an=8> [2006, June 20].

³ Injury Surveillance Workgroup. (2003). *Consensus Recommendations for Using Hospital Discharge Data for Injury Surveillance*. Marietta, GA: State and Territorial Injury Prevention Directors Association. Online at <http://www.stipda.org/displaycommon.cfm?an=8> [2006, June 20].

⁴ Council of State and Territorial Epidemiologists Data Committee Injury Control and Emergency Health Services Section, American Public Health Association, and State and Territorial Injury Prevention Directors Association. (2005). *How States are Collecting and Using Cause of Injury Data: 2004 Update to the 1997 Report*. Atlanta, GA. Online at <http://www.cste.org/pdffiles/newpdffiles/ECodeFinal3705.pdf> [2006, June 21].

available for external-cause-of-injury codes vary greatly across states, making it challenging to aggregate and compare multi-state data.

As a result, analysts must be cautious in their interpretation and dissemination of incomplete data when state-level HDD is used to analyze non-fatal hospitalized suicide attempts. And, since HDD only reflects people admitted for treatment after a suicide attempt, additional data sets are necessary to capture the true magnitude of the problem of non-fatal attempts.

Emergency department data

At the national, state and local levels, epidemiologists routinely analyze emergency department (ED) data to identify suicide attempts. Hospital emergency department data system (HEDDS) can be used to identify less severe injuries that were treated and released. The system provides information on patient demographics, external-cause-of-injury, treatment, cost and discharge status.

Twenty-five states have HEDDS, and 23 of those 25 state systems routinely collect some level of external-cause-of-injury codes. It is these codes that are used to identify cases with non-fatal self-harm injuries treated in emergency departments.

While helpful, ED data also have limitations. For one, HEDSS are not available in all 50 states. Of the states with these systems, only six states have evaluated their systems to determine rates of external-cause-of-injury coding and other important system characteristics. And, as with state HDD systems, state HEDSS use a variety of fields to record external-cause-of-injury codes, making it difficult to aggregate and compare data across states.

Surveillance systems that rely upon ED data include:

- *National Electronic Injury Surveillance System All Injury Program (NEISS-AIP)*. The Consumer Product Safety Commission operates the NEISS-AIP, which collects data on types and causes of non-fatal injuries (including intentional self-harm injuries) from a nationally representative, stratified probability sample of all U.S. hospital EDs. The NEISS-AIP database includes narratives from the ED patient charts that allow self-inflicted injuries to be classified as probable suicide attempt, possible suicide attempt, unlikely suicide attempt or unclear. The non-fatal injury data that appears on CDC-run WISQARS also comes from the NEISS-AIP dataset.⁵
- *Drug Abuse Warning Network (DAWN)*. Operated by SAMHSA, DAWN collects national data on all ED visits related to recent drug use. DAWN data are classified as suicide attempts when the medical record suggests that drug-related ED visits are the result of patients trying to end their lives. Hospitals submit their ED data electronically on a monthly basis, and can continually access their own data from the database. SAMHSA releases annual suicide attempt estimates for the country and for a number of

⁵ See <http://www.cpsc.gov/library/neiss.html> and <http://www.cdc.gov/ncipc/wisqars>

metropolitan areas; the data also can be broken down by age group, gender, drugs involved, disposition; and diagnosis.⁶

- National Hospital Ambulatory Medical Care Survey – ED Component (NHAMCS-ED). The CDC’s National Center for Health Statistics conducts the NHAMCS-ED, an annual national survey of ambulatory services delivered in a sample of hospital emergency departments. This survey captures suicide attempts when the patient’s record contains verbatim text describing the injury circumstances and that verbatim text is coded as self-inflicted injury in the patient’s record form.⁷
- *Adolescent Suicide Attempt Data System (ASADS)*. ASADS is an example of a state-level surveillance initiative using ED data. In 1987, the Oregon state legislature mandated reporting of suicide attempts by those under age 18, and the state health department maintains that data system. While the database is not a registry (names are not collected), comprehensive information is gathered, including demographics, place of attempt, psychological history and drug/alcohol use.⁸

Population-based surveys

National, population-based surveys pose a myriad of health-related questions (including injury-related questions) to a sample population; some surveys ask more targeted questions, such as questions about self-inflicted injury and mental health. National surveys that elicit suicide attempt information include:

- *National Health Interview Survey (NHIS)*. The CDC’s National Center for Health Statistics conducts the NHIS, a cross-sectional household interview survey that collects and analyzes data on a broad range of health topics. Interviewers meet with household members throughout the year to ask health questions, including questions about injuries to any member of the family over the most recent three-month period. While the NHIS aims to capture intentional injuries, respondents often do not discuss those injuries with interviewers. NHIS is thought to underestimate the incidence of injuries because these intentional injuries (assault or self-inflicted) are not reported.⁹
- *National Survey on Drug Use and Health (NSDUH)*. The Substance Abuse and Mental Health Services Administration (SAMHSA) oversees the NSDUH, a survey directed at the civilian, non-institutional population over age twelve. Respondents who indicate they have had a major depressive episode are asked if they had suicide ideation or attempts

⁶ See <http://DAWNinfo.samhsa.gov>

⁷ See <http://www.cdc.gov/nchs/about/major/ahcd/nhamcsds.htm>

⁸ See <http://www.oregon.gov/DHS/ph/ah/datasources.shtml>

⁹ See <http://www.cdc.gov/nchs/nhis.htm>

during their lifetime. No follow-up questions are asked, so interviewers cannot determine when the attempt occurred or the method.¹⁰

- *Behavioral Risk Factor Surveillance System (BRFSS)*. Administered by the CDC, the BRFSS is a state-based surveillance system that uses telephone surveys throughout the country to collect data on major behavioral risks and health practices among non-institutional adults. State health departments conduct the monthly survey, and some include an optional module with suicide questions.¹¹
- *Youth Risk Behavior Survey (YRBS)*. The YRBS is managed by CDC and encompasses national, state and local school-based surveys. Representative samples of students in grade 9-12 are asked questions about a range of health-risk behaviors (e.g., tobacco use, sexual behavior and injury). The bi-annual survey is also administered by health and education departments, and does not always include questions about suicide.¹²
- *National Comorbidity Survey (NCS) and National Comorbidity Survey Replication (NCS-Replication)*. Conducted from 1990 - 1992, the NCS was the first nationally representative mental health survey in the U.S. to use a diagnostic interview to assess the prevalence of mental disorders according to DSM-III-R classifications. In 2001 - 2003, the NCS Replication collected data from a new national sample of 10,000 respondents using many of the original NCS questions and updated disease assessment criteria based on the DSM-IV. Respondents from both studies provided information on suicidal ideation, plans, gestures, and attempts.¹³

A benefit of population-based surveys is that they can provide estimates of the number of people who experience suicidal ideation. The health profiles of these individual can be compared to others in the survey to determine who is at increased risk for suicidal thoughts and behavior. In addition, surveys provide a vital resource to estimate the incidence of known risk factors (such as mental illness, access to firearms, previous attempts), as well as demographic information.

Yet, population-based surveys also present challenges. It is expensive to use the over-sampling techniques needed to collect sufficient data that provides information on minority populations and geographic localities. Also, there is increasing concern about significant portions of the population who are excluded due to lack of phone service or exclusive use of cellular phones.

Clearly, each of the three data collection methods – hospital discharge data, emergency department data and population-based surveys/self-administered questionnaires – offers a partial look at the incidence and circumstances surrounding suicide attempts.

¹⁰ See <http://oas.samhsa.gov/nhsda.htm>

¹¹ See www.cdc.gov/brfss/

¹² See www.cdc.gov/HealthyYouth/yrbs/index.htm

¹³ See www.hcp.med.harvard.edu/ncs/

System Shortcomings

The expert group reviewed the limitations of the current public health surveillance systems. These limitations fell into two categories: how data are collected and the type of data collected. The over-arching problems are a lack of infrastructure to support data systems and no standard set of uniform definitions or coding schemes for key variables relevant to suicide and suicide attempt surveillance.

Data collection methods

The expert group pointed out several layers of problems with existing data collection methods, such as the lack of surveillance infrastructure, challenges of conducting any large-scale survey and interviewer unease when asking suicide-related questions.

The experts expressed great concern about the lack of resources and infrastructure within state and local health departments to conduct surveillance, conduct epidemiologic analysis and disseminate data. Currently, 30 states are funded to conduct basic injury surveillance and report their data through CDC's Public Health Injury Surveillance and Prevention Program. These CDC-funded programs support state health department activities in planning, implementation and integration of comprehensive injury prevention and control activities with basic injury surveillance. The programs establish a solid infrastructure for states to conduct injury prevention and control. While the remaining 20 states can voluntarily participate in this surveillance effort, some experts suggested that additional funding is needed to help those states develop their capacity.

For population-based surveys, the experts raised a number of data collection issues. The experts noted that response rates for random-digit-dialing telephone interview surveys have declined dramatically in recent years, and that in-person interviews are expensive. Both survey methods have difficulty with reaching certain segments of the population due to language and other barriers; as a result, they end up under-sampling at-risk populations and under-reporting the count. In addition, in-person interviews may be conducted with multiple family members present, which could possibly reduce the likelihood of a respondent mentioning a suicide attempt.

There is a different set of problems for data collection within healthcare settings. There is great variability in the completeness of external-cause-of-injury coding from state to state and within a state from year to year. The expert group had a thorough discussion about where the data collection process can break down within healthcare settings. They identified several vulnerable information-transfer points, including a patient's willingness to disclose the attempt; provider's role in obtaining and recording patient information; coder's ability to abstract the information from the record; system programming that establishes external-cause-of-injury codes and system policies on coding. They went into detail about how the system falters at each of these points.

Patient willingness

Patients may be unwilling or unable to report suicidal behaviors for a variety of reasons. Self-reported behavior may be minimized, overstated, or denied, particularly if other family members are present. Individuals, particularly youth, may not understand suicide-related terms or questions used in the interview. (For example, respondents need to understand what constitutes a prior attempt if they are to give accurate self-reports about any prior attempts.) The stigma still associated with suicide is a powerful disincentive for people to reveal their suicidal thoughts and behavior.

Provider role

Providers have a key role in ensuring the flow of patient information. If providers do not consistently determine the presence of intentional, self-inflicted injuries and record information on injury circumstances, then the morbidity data systems will underestimate the number of suicide attempts.

The expert group noted there are inadequate standards for assessing intention of self-inflicted injury/poisoning. Additionally, providers may experience other barriers, such as lack of knowledge/skill about how to respond to a patient who expresses suicidal intent and a limited amount of time to assess patients.

Another factor is that healthcare professionals may be unwilling to document a highly stigmatized behavior in patients' permanent medical records. They may be reluctant due to outdated beliefs about suicide and/or uncertainty about what happens to patients once they are identified as suicidal risks, including the availability of treatment.

Coder ability

Coders abstract information from patient records and assign codes for the data sets. To do their job, they must rely upon the quality and completeness of the patient record; the lack of codable information in patient records is a primary reason for inaccurate or missing codes. Another problem is that coding rules may inadvertently interfere with coders' ability to abstract information; for example, coders can only assign codes based upon physician notes and must ignore notes made by any other health professional, even if those notes indicate a suicide attempt.

System capacity

Finally, system issues can cloud the data collection process. Currently, the International Classification of Diseases, Ninth Revision, Clinical Modifications (ICD-9-CM) is used by the field for coding purposes. However, the International Classification of Diseases, Tenth Revision, Clinical Modifications (ICD-10-CM) has been developed (and includes categories for suspected suicide), but has not yet been implemented by the U.S. Department of Health and Human Services. While ICD-10-CM codes are preferable to the earlier version, the experts agreed that

using either set of external-case-of-injury codes consistently would greatly increase the quality and reliability of the data.

Type of data collected

The expert group indicated that a significant shortcoming of current surveillance systems is data variability. Specific problems include:

- *Lack of uniform terms and definitions.* While all agree that standardization is needed to produce meaningful data, the process of changing complex data systems seems overwhelming to most. The American Association of Suicidology is trying to move in that direction with its proposed standard nomenclature for the field. However, this terminology is less useful for medical settings or for self-reports from lay people in population-based surveys. The experts commented that, for standardization to have the maximum impact, uniform terms must be relevant and useful for medical settings and for surveillance activities.
- *Vague and unclear questions.* The group observed that questions currently used in suicide surveys and screening have not been tested to determine if they are the best questions to elicit that information. Asking the often-used question, “Did you attempt suicide in the last 30 days?” probably produces less helpful information than concrete questions such as “Have you hurt yourself seriously enough to be seen by a nurse or doctor?”

Also, the context for posing these questions has an important impact on the data. In surveys, does the suicide question occur only in the depression section or does it come up during questions about other injuries? During interviews, who is in the room when the questions are asked, and are outside assistance or proxy responses allowed? These varying approaches contribute to the lack of reliable, valid and comparable data.

- *Confusion about assessing intention.* Determining intention in self-harm cases is difficult, yet crucial. Practitioners are asked to make distinctions between self-harm behaviors (e.g., poisoning incidents where there is no intent to die) and suicidal behaviors. They need parameters for understanding and establishing suicidal intent (e.g., patient’s expectation of discovery and patient’s understanding about the lethality of the self-harm means). Assessing intention is very challenging for drug-related overdoses in general, and opioid-related overdoses in particular.
- *Undetermined and misclassified cases.* Too often in emergency rooms, intentional, self-harm injuries are called something else (including undetermined), which further masks the extent of the problem.

Suggested Next Steps

Different approaches are needed to improve data supplied by healthcare practitioners versus information provided by the general public. The experts came up with a series of seven action steps aimed at improving data collection methods and the type of data collected. The surveillance recommendations require leveraging additional resources (not just reallocating existing resources). However, not all of the recommendations require new monies; some involve the additional resources of time and attention dedicated to systems already in place.

The expert group recommended:

- Mandate external-cause-of-injury coding for all inpatient hospitalizations and outpatient visits reimbursed by Medicaid and Medicare
- Improve charting and other systems used in external-cause-of-injury coding
- Educate others about suicide and suicide attempts as a public health concern, including the importance of reliable national and state-based non-fatal surveillance systems to monitor suicides and suicide attempts
- Address ethical issues associated with suicide surveillance (e.g., privacy concerns)
- Build upon existing public health surveillance systems
- Hold joint meetings with the epidemiology and suicidology fields to discuss surveillance
- Provide decision makers with the best data on suicide attempt that are currently available

(1) Mandate external-cause-of-injury coding for all inpatient hospitalizations and outpatient visits reimbursed by Medicaid and Medicare

One expert observed, “If we did nothing else but came out with a plan for improving external-cause-of-injury coding, our surveillance systems would be quantum leaps ahead.” The expert group believed that mandating external-cause-of-injury coding is the most effective step toward improving external-cause-of-injury coding and establishing state- and national-level census of all hospital-treated suicide attempts.

To assure compliance, the experts recommended that the Centers for Medicaid and Medicare Services (CMS) require external-cause-of-injury codes for patients with injury or poisoning diagnoses, and make the external-cause-of-injury code an audited field. One expert reported that at least one state has adopted a similar practice to ensure complete and accurate data; that is, California hospitals are not reimbursed if they submit poor quality data (including external-cause-of-injury codes) to their statewide HDD system.

Instituting the external-cause-of-injury code requirement would drive nationwide system change. To respond, hospitals would have to better train their staff, improve their chart review process and complete a high percentage of external-cause-of-injury codes for their discharge data.

Why should CMS consider adding another rule to its record-keeping requirements? In addition to providing a better understanding of the incidence of suicide attempts, improved external-cause-of-injury coding helps planners identify and address issues involving elderly falls, motor vehicle accidents and other injuries that present a huge economic burden to the healthcare system.

(2) Improve charting and other systems used in external-cause-of-injury coding

In the discussion about surveillance shortcomings, the experts identified numerous problems that occur during charting and external-cause-of-injury coding. The expert group generated recommendations aimed at each of these junctures.

Initial interview/screening

- Give staff protocol (e.g., scale or other tool) and train them so that they are comfortable, competent and confident when they ask patients about suicidal intention and make appropriate referrals. For example, Oregon EDs have plans to use practice guidelines from British Columbia for assessing suicidality.
- Incorporate standard suicide screening questions for all patients (such as those used for inquiries about blood pressure or domestic violence) to reduce stigma around suicide
- Educate staff about suicide to help change negative feelings and attitudes that may affect their clinical interactions and record-keeping
- Make training available at professional conferences to help triage nurses and other health professionals understand their role in preventing further injuries through screening and documenting.

Documentation

- Make the documentation system convenient or routinized (e.g., check list)
- Advise providers of the benefits to patients as a result of screening and record-keeping (even for conditions that are highly stigmatized) to help them see that their efforts do make a difference
- Package and disseminate aggregate hospital data for use by local communities, further underscoring the value of data collection for providers
- Train professionals who write narratives of the circumstances of the injury incident in the patient's medical record so that they know what is necessary for coding purposes

- Expect hospital staff to complete good documentation and hold them accountable
- Encourage schools that train health providers to incorporate the importance of screening and charting into their curricula.

Coding

- Train coders to know what to look for in narratives to classify an injury as a suicide attempt
- Review coding rules to make sure they allow coders to classify suicide attempts when indicated in the record
- Talk with coders about what factors lead to their using the “undetermined intent” code and address those factors through training.

System improvements

- Work on standardizing forms that capture patient information, and still keep the forms user-friendly
- Ensure that forms encourage healthcare professionals to provide detailed enough information and descriptions so that more specific external-cause-of-injury codes can be assigned
- Institute quality assurance processes to support consistency when charting records and coding forms
- Examine other data systems (e.g., reimbursement systems) that interact with hospital datasets. Some experts noted that third-party payer systems reject external-cause-of-injury codes or slow down payment for certain external-cause-of-injury codes, creating a disincentive for hospitals to code.

(3) Educate others about suicide and suicide attempts as a public health concern, including the importance of reliable national and state-based non-fatal surveillance systems to monitor suicides and suicide attempts.

The expert group suggested that the suicide field make a more convincing public health case for suicide prevention and surveillance. In order to understand the public health implications, the general public and decision makers should understand risk and protective factors for suicide and suicidal behavior, promising and effective prevention strategies, and the costs and consequences of suicide. The experts offered a range of recommendations aimed at three target audiences they thought most needed to hear the public health case: policy makers, federal agencies and employers.

Policy makers

- Ensure policy makers have information on the need for surveillance and its value to suicide prevention practice. In particular, share information on the costs of suicide and the benefits that could be reaped by national and statewide surveillance. Educate policy makers about how high quality data is useful for monitoring and evaluating the effectiveness of suicide prevention programs.
- Evaluate surveillance policies and activities aimed at those under age 18, an age group that is currently a priority population for prevention efforts. Then expand effective public health surveillance activities to other age groups.
- Engage the Action Alliance for Suicide Prevention, a national public-private collaborative working together on suicide prevention, to prioritize action on the NSSP surveillance goal and raise the visibility of the importance of data collection and monitoring.
- Encourage states to use their existing statutes and programs to institute surveillance of suicide attempts. For example, many states have a Traumatic Brain Injury (TBI) Registry that records specific injury-related data. Using the TBI Registry model, communities can use a similar approach to develop a registry for people with intentional, self-harm injuries.
- Consult with experts to help frame suicide prevention as a public health concern that affects the health of the entire community.

Federal agencies

Suicide prevention is often considered the domain of mental health, but collaboration must take place between the mental health and public health if prevention and surveillance activities are to be successful. The federal government can lead the way by motivating the public sector and exhibiting collaboration in the following ways:

- Develop and release more joint RFA's and program announcements. One recent example is the collaboration between SAMHSA and CDC on the evaluation of suicide prevention programs funded by the Garrett Lee Smith Memorial Act announcements.
- Require applicants seeking federal funding to demonstrate mental health and public health collaboration and instruct reviewers to consider the degree of collaboration when awarding funds.
- Attach funding to mental health/public health collaborative activities to send a strong message that such collaboration is valued.
- Maintain and expand national and state-based injury surveillance efforts that capture information on attempted suicide.

- Support efforts to advance standardized data collection of attempted suicide information across surveillance systems and population-based surveys.
- Promote inclusion of standardized suicide attempt variables on population-based surveys.

Employers

Employers will understand the need for prevention and surveillance activities when they learn the tremendous impact of suicide on employees, even those not directly connected to the person who died. There's also the resulting loss of productivity as suicide's ripple effects continue to be felt. Employers can be important agents of change when they institute programs aimed at the risk factors (job-related and otherwise) associated with suicide, as evidenced by the results of the United States Air Force's suicide prevention efforts over the last decade.

(4) Address ethical issues associated with suicide surveillance

Confidentiality is the often-cited concern during discussions about surveillance and suicide prevention. However, in addition to a patient's right to privacy, there are other ethical issues involved: availability of follow-up services once a person is identified as suicidal, responsibility/liability of professionals working with suicidal individuals and the impact of referencing suicidality in treatment records on the patient's insurance coverage. The expert group recommended several steps to begin untangling these ethical issues:

Privacy

An unintended consequence of privacy concerns and protections is additional stigma for people who are suicidal. While few would argue against the need for confidentiality, participants observed that the mental health and public health fields have different understandings and practices around privacy. They also noted that privacy concerns had begun to bog down some surveillance activities, including the release of national aggregate data. They suggested the following:

- Hold national discussions on the role of public health surveillance, the statutory authority to have access to protected health information, and the Health Insurance Portability and Accountability Act (HIPAA) exclusion that allows public health surveillance activities without patient consent. Some of the ethical points to discuss include the stigma of identifying suicidal individuals and using suicide attempts as trigger events for intervention.
- Examine current state surveillance statutes, many of which may already permit suicide attempt surveillance activity. Some healthcare professionals who do not understand surveillance believe that HIPAA's privacy provisions limit the ability to collect and disseminate this type of information. However, surveillance is a long-established public health practice that is supported by state and federal statutes

Availability of Follow-up Services

Ethical concerns arise when providers do not refer suicidal or at-risk individuals to treatment, sometimes due to the lack of available treatment options. However, as one participant pointed out, the need for services still exists even if a professional does not identify and refer that person. Some suggestions were:

- Identify or develop a mental health service network within the hospital and local community.
- Underscore how better surveillance can lead to more services. Currently, the mental and public health systems do not know what happens after suicidal individuals leave the ED. Decision makers will truly understand the gaps in the mental health system if surveillance data reveal the number of attempters who leave the ED but are unable to obtain follow-up treatment.

Responsibility/Liability

A real barrier to collecting suicide-related information is perceived liability; too often, suicide assessment questions are not even posed due to concerns that interviewers then become responsible for follow-up action (and liable if such action does not occur). Or, as they assess risk factors for suicide, professionals may uncover illegal and reportable behaviors (e.g., when child abuse or partner violence is involved). While groups address these concerns in different ways (e.g., disclaimers), the field needs to agree on the best way to handle these real and perceived liability issues. Recommended activities included:

- Discuss the ethical and legal responsibilities of people who elicit information about suicidal or at-risk persons, including surveyors who go into homes.
- Consult with the National Institute on Drug Abuse, which is about to issue a publication on its ethical workshop addressing many of these same issues.
- Consult with the Council of State and Territorial Epidemiologists regarding its principle of confidentiality outlined in the *Blueprint for a National Public Health Surveillance System for the 21st Century*.¹⁴

Insurance coverage

When a patient discloses suicidal intention and the provider notes that in the record, the patient's ability to maintain insurance coverage or obtain it in the future may be jeopardized. This is true for both medical coverage and life insurance. As a result, both providers and patients are wary of creating a permanent record that includes references to a purposeful, self-inflicted injury. While

¹⁴ Meriwether, R. (1996). *Blueprint for a National Public Health Surveillance System for the 21st Century*. New Orleans, LA: Office of Public Health, Louisiana Department of Health and Hospitals. Online at <http://www.cste.org/pdffiles/Blueprint.pdf> [2006, June 21].

members of the expert group offered no recommendation to address this dilemma, they noted the ethical considerations and chilling effect of these consequences.

(5) Build upon existing public health surveillance systems

There are a number of surveillance vehicles in place, albeit not designed or optimal for the task of suicide attempt surveillance. The expert group discussed ways to enhance these current systems and convince more individuals to use the systems.

The most promising idea discussed was to make better use of the National Survey on Drug Use and Health (NSDUH) administered by SAMHSA annually. Currently, the survey asks people who report a current or past depressive episode whether they had suicide ideation or attempt(s) during their lifetime. The group recommended moving questions about suicide out from the subset of depression questions and posing more detailed questions than just lifetime occurrence. Perhaps the survey could include a special suicide module to be used every few years. While adding questions to any national survey instrument is difficult given the limits on the number of survey questions, participants believed that this one step would produce uniform, state and national estimates of self-reported suicide attempts in the very short-term.

Other steps to build on existing systems include:

- Expand the Garrett Lee Smith Memorial Act (GLSMA) initiative. Since GLSMA provides funding to adolescent suicide prevention programs serving individuals up to age 24, Congress may be willing to institute surveillance activities that complement GLSMA-funded prevention efforts. Or, states that apply for future GLSMA funding could be encouraged to incorporate surveillance into their activities. Oregon officials could provide model language for collecting data on those under 18 from its Adolescent Suicide Attempt Data System.
- Increase the number of states that participate in the *State Injury Indicators Report*. The CDC's National Injury Center for Prevention and Control, the Council of State and Territorial Epidemiologists, and the State and Territorial Injury Prevention Directors' Association produced a second edition of the *State Injury Indicators Report* using 1999 data voluntarily collected and submitted by 26 state health departments.¹⁵ The data is from states participating in the Public Health Injury Surveillance and Prevention (PHISP) Program. Indicators are calculated by using state-level data from death certificates, hospital discharge records, and data from several other surveillance systems (BRFSS, YRBS and U.S. Department of Transportation's Fatality Analysis Reporting System).
- Examine state Medicaid databases. Massachusetts, for example, conducts in-depth interviews with Medicaid recipients and feeds that information into its database. The experts said that such databases are an untapped source of information on suicide attempts.

¹⁵ National Center for Injury Prevention and Control. (2004). *State Injury Indicators Report, Second edition – 1999 Data*. Atlanta, GA. Online at <http://www.stipda.org/associations/5805/files/StateIndicatorsed2.pdf> [2006, June 21].

- Incorporate questions about suicidal behavior into the BRFSS on a consistent, uniform basis. Currently, suicide questions are contained in an optional module, and every state does not use the same questions for suicide. The experts recommended that all states use the optional module and eventually make suicide questions part of the core BRFSS.
- Coordinate efforts with other groups working on the issue of external-cause-of-injury reporting. At least two formal workgroups, one facilitated by the Council of State and Territorial Epidemiologists and one by the Public Health Data Standards Consortium, are examining this issue and drafting recommendations to improve external-cause-of-injury coding.
- Consider partnering with the American College of Surgeons (ACS). ACS manages the National Trauma Data Bank (NTDB) and is very interested in data collection. Explore whether questions about suicide attempts should be introduced into that registry (recognizing that drug overdoses would not be picked up by NTDB). ACS is currently working with NCIPC staff and statisticians at Research Triangle Institute (RTI) to establish a national sample of Level I and II trauma centers that participate in the NTDB. This system potentially could be used to obtain national estimates of suicide attempts by mechanism of injury for patients treated in U.S. trauma center hospitals in the future.
- Talk to National Highway Traffic Safety Administration Office of Emergency Medical Services (EMS) about its standardization efforts. EMS is working on the National Emergency Medical Services Information System (NEMSIS), a national database with standardized data elements from the country's local and state Emergency Medical Services agencies. Efforts should be made to see if standard data elements relevant to suicide and suicide attempts could be added to NEMSIS.
- Consider forming an Injury Surveillance Workgroup (ISW) focused on suicide once some of the definitional issues are resolved. STIPDA has sponsored ISW's on several surveillance topics (e.g., traumatic brain injury, use of hospital discharge data and falls) and the workgroup generated common methods and definitions for states to use. The expert group recommended that several steps need to occur before calling for an ISW, but that it might be a helpful step for the future.

(6) Hold a joint epidemiology/suicidology meeting

Noting the discussion led by the American Association of Suicidology about suicide nomenclature, the expert group urged the fields of suicidology and epidemiology to coordinate their efforts to standardize terms. Currently, each field is on its own track with suicide experts seeking to distinguish the clinical nuances of suicidal behavior, while the surveillance experts look for broad categories for collecting and comparing data. As one participant said, "For clinical purposes, the discussion about the shades of gray within the range of suicidal behavior is helpful; but for surveillance purposes, we need terms in black and white for comparison."

A meeting of the minds on terminology between the two fields is essential to compare suicide attempt data and, more importantly, evaluate and demonstrate the results of prevention and

treatment programs. The experts maintained that surveillance efforts will continue to be disjointed until definitions are standardized.

(7) Provide decision makers with the best data on suicide attempt that's currently available

The experts believed that the immediate, next step for the field was to find a way to synchronize the many current surveillance activities. An initial step toward this goal is publishing current best estimates of suicide attempts, as well as the advantages and limitations of current surveillance systems. Ultimately, this information will help guide and coordinate future steps toward improving surveillance.

The experts first called for a short paper (one or two pages) detailing the various estimates of suicide attempts and including an expert consensus opinion on which estimate is most accurate. Some participants also expressed interest in generating similar estimates for each state. While surveillance issues are being worked out, these numbers could serve as accepted estimates that are consistently used by the field and policy makers.

The other step is to create an inventory of all national and international surveys that inquire about self-inflicted injury. From this inventory, the surveillance and suicidology fields could examine specific suicide-related questions and available data on validation studies relevant to the wording of questions to help identify which wording is best for standard questions in future surveys. The potential survey questions then could be run through a questionnaire lab (such as the one directed by the CDC's National Center for Health Statistics - Questionnaire Design Research Lab) to test their validity and reliability. After testing the questions, the field could recommend a set of reliable and accepted survey questions for wide-spread use.

An inventory of questions also could lead to:

- Coordination between the current national surveys around their self-injury questions
- Ideas about what can be done with existing surveillance tools
- Movement toward using concrete, uniform terms across systems that are user-friendly for people from a variety of disciplines and educational backgrounds
- More consistent data elements for data companies that sell data collection packages to healthcare facilities
- Development of a Web site that features widely-used question modules and training protocols for others to use, thus maximizing the chance that collected data is more comparable.

Conclusion

Public health surveillance is a powerful tool that can be used to better understand the scope and impact of suicide attempts. Yet, surveillance systems that produce current suicide attempt data were not developed specifically for capturing that information. As a result, they provide an incomplete, and likely understated, account of a major public health problem: attempted suicide.

As the expert roundtable convened by SPAN USA discussed ways to enhance public health surveillance, they first agreed upon the following principles:

- Public health surveillance is necessary as a foundation for addressing suicide.
- Healthcare providers need to identify and report suicide attempts.
- Public health professionals need to track and analyze the data.
- A national data clearing house needs to aggregate the data and identify available data sources for suicide and suicide attempts.
- National and state-based data on the incidence and characteristics of suicide and suicide attempt events should inform policy and program decisions.

The group used these principles to generate seven broad recommendations for CDC's consideration plus multiple implementation strategies. Their first recommended step: coordinate information produced by current surveillance systems that ask about self-inflicted injury and put forth an expert consensus opinion on which estimate is most accurate.

Finally, the experts articulated their ideal vision for suicide attempt surveillance; not surprisingly, the picture they drew reflected their guiding principles. They envisioned a surveillance system with:

- An agreed-upon core data set to facilitate the collection of uniform, high quality, non-fatal suicide attempt data obtained using national and state-based surveillance systems and surveys
- Capacity within every state to generate, analyze and use its own data for suicide and suicide attempt surveillance. Each state needs the infrastructure and staffing expertise to pull data together and share it with other partners
- A national, Web-based query system (similar to WISQARS for fatal injury data) available to the public, planners, researchers and others to easily obtain national and state counts
- Connection between surveillance and interventions so that data collection does not occur in a vacuum. Ultimately, the goal is to enhance prevention strategies using valid and reliable data.

- Systematic examination of suicidal behavior in the United States on a regular basis (e.g., every decade). Since some who engage in suicidal behavior do not seek medical attention, routine national surveys are needed, especially among the adult population.

List of Roundtable Participants

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