Brief History of Centers for Disease Control and Prevention Disaster-related Mortality Activities

Introduction
This document provides a brief history of the Centers for Disease Control and Prevention’s (CDC) efforts to improve disaster-related mortality reporting practices from 1986 to the present. To develop and implement evidence-based interventions to prevent disaster-related deaths, it is important to understand the circumstances around deaths that occur during disasters and to have standard definitions and reporting practices. Standardization is critical because the final “official” death count is based on the death certificates reported into state-based vital statistics departments, which is reported to CDC’s National Vital Statistics System (NVSS).

Medical Examiner and Coroner Information Sharing Program (MECISP)
In 1986, CDC’s National Center for Environmental Health (NCEH) established the Medical Examiner and Coroner Information Sharing Program (MECISP). This program arose from CDC recognizing that much of the information it needed for various programs and studies resided in the offices of the nation’s medical examiners and coroners (ME/C) and that information there was more detailed than that on the death certificate (1).

The primary goals of the MECISP were to:
- Improve the quality of death investigations in the U.S. and promote the use of standardized policies for when and how to conduct these investigations,
- Facilitate communication among death investigators, the public health community, federal agencies, and other interested groups,
- Improve the quality, completeness, management, and dissemination of information on investigated deaths, and
- Promote the sharing and use of ME/C death investigation data.

The MECISP work impacted disaster mortality data with several notable achievements:
- Published and disseminated an annual directory that described death investigation laws and listed the contact persons for all ME/C jurisdictions in the U.S. and Canada and was used by MECISP during data collection efforts in times of disasters.
- Participated in, or provided data for, research studies conducted by public health researchers from 1997 through 2005. A sample of CDC-based publications is shown in the Table in the Hanzlick article (1).
- Established and refined the public health practice of disaster-related mortality tracking/surveillance at NCEH from 1989 to 2000.
- Developed and published a classification matrix and case definition for consistently attributing deaths to a disaster. The CDC disaster mortality case definition was published in the scientific literature in 1999 and established CDC’s recommendation that both direct and indirect exposures from a disaster should be included when attributing deaths to a disaster (2). For the first time, uniform definitions were available for use by the forensic science and public health communities.

The MECISP moved from NCEH to CDC’s Epidemiology Program Office in 2000 where it resided until 2004, when the activity was dissolved as part of a CDC reorganization. Since 2004, CDC has not had a unified point of contact for liaising with the ME/C communities and other federal agencies that are involved with ME/C. Renewed efforts are underway by CDC’s National Center for Health Statistics (NCHS) to strengthen these relationships, especially in the area of accurately reporting acute drug toxicity deaths (3).

Use of 1999 CDC Uniform Disaster Mortality Case Definition and Evidence of Underreporting
Since 1999, CDC has used the uniform disaster mortality case definition developed under MECISP guidance in all
CDC conducted or supported mortality studies. CDC and other public health researchers applied these definitions to categorize deaths in retrospective studies of large-scale natural disasters including Hurricane Katrina in 2005 and the Florida 2004-2005 hurricanes (4-7). Following Hurricane Katrina, CDC’s NCHS released some examples of how to complete death certificates for both directly and indirectly related deaths attributed to hurricanes (8).

In 2007 NCEH developed and published a disaster-related mortality surveillance data collection form to enhance the timely reporting of disaster-related deaths and encourage the use of the 1999 CDC disaster mortality case definition (9). The form was intended to be used by ME/Cs during a response to collect preliminary information such as demographic characteristics, circumstances, causes, dates of deaths, and note the relation of the death to the disaster. These forms then can be shared with public health epidemiologists involved in the response. During this same time period, CDC posted the data collection form on the NCEH website and provided training on the form to ME/Cs, justices of the peace (JPs), epidemiologists, and public health practitioners in disaster-prone jurisdictions such as Texas, Tennessee, Kentucky, South Carolina, Florida, Alabama, and American Samoa.

The Texas public health department adopted the CDC disaster-related mortality surveillance form as part of its plan to conduct active mortality surveillance with ME/C and JPs on direct and indirect deaths in “near-real time” after natural disasters. Texas used the mortality surveillance form during the response to Hurricane Ike in 2008 (10). In 2010, Texas invited CDC to conduct an evaluation of their Hurricane Ike active surveillance efforts including comparing the number of disaster-related deaths captured using the state’s active surveillance process (N=74) with the number identifiable in Texas’ vital records system. The evaluation found that only four of the 74 deaths reported by ME/Cs and JPs using the active surveillance form had recorded a disaster term, such as “hurricane,” “Ike,” “storm surge,” or “flood waters due to Ike” on the final death certificates (11).

Similar evaluation studies found underreporting of disaster-related deaths on death certificates after the 2011 tornadoes in the southeastern states, 2012 Hurricane Sandy in New Jersey, and 2013 Oklahoma tornadoes (12-13). The death certificates did not include key disaster terms that identified the death as related to a specific event. NCHS uses the literal text or information written on the death certificate to assign disaster-related International Classification of Diseases, 10th Revision (ICD-10) codes. Mortality statistics at the state and national level only reflect what was reported on the death certificate and ICD-10 codes. If disaster-related terms are not reported on the death certificate, then NCHS will not assign an ICD-10 code that reflects that the death was caused by a disaster. Without this information, official counts of disaster deaths are being underreported in state and national databases.

**Disaster-related Death Certification Reference Guide**

CDC continued addressing disaster-related mortality by providing trainings and technical assistance and participating in round-table discussions at national, regional, and state conferences and meetings. Despite these efforts, awareness and adoption of the 1999 CDC disaster mortality case definition by the ME/C was limited. In 2012, NCEH and NCHS started a dialogue with key stakeholders in the ME/C and vital statistics communities about the underreporting of disaster deaths. In these conversations, it became apparent that many did not know about the existing 1999 CDC disaster mortality case definitions and did not consider the 1999 manuscript in their practice. In addition, some ME/C expressed that they did not agree that natural deaths from exposures to a disaster, such as certain indirect disaster deaths resulting from exacerbation of chronic conditions, should be attributed as disaster-related deaths. In addition, research indicated that for even directly related deaths, for example, “struck by a tree limb” during a hurricane, the disaster terms were not noted on the death certificate.

Increased awareness and understanding of the importance of including the role of the disaster on the death certificate and adherence to the application of the uniform case definitions could improve the type of information collected at the disaster death scene by death investigators that can be used to assist in the
accuracy of the certifier to attribute the death to the disaster (14-15). For this reason, NCEH and NCHS decided to create a “desktop” reference guide on how ME/Cs can accurately identify disaster-related deaths and correctly complete the death certificate, or certify the death. In October 2014, CDC provided support to the national professional organization for vital statistics (National Association for Public Health Statistics and Information Systems [NAPHSIS]) to lead this project. A cross-disciplinary work group was formed and charged to develop the reference guide. The 15-member work group was comprised of ME/Cs, vital registrars, vital statisticians, and epidemiologists from CDC, NAPHSIS, Council of State and Territorial Epidemiologists (CSTE), National Association of Medical Examiners (NAME), and the International Association of Coroner & Medical Examiners (IAC&ME). Through virtual meetings (starting in October 2014) and a two-day in-person workshop (April 2015) the reference guide was developed. The content for the guide was based on the 1999 manuscript and included the CDC disaster mortality case definitions. NCHS and NCEH collaborated in finalizing the reference guide with input from the work group, other centers within CDC, and subject matter experts. The “Reference Guide for Certification of Deaths in the Event of a Natural, Human-induced, or Chemical/Radiological Disaster” was published in October 2017 (16) and included with other NCHS training and instructional materials. In January 2018, FEMA revised eligibility requirements for their funeral assistance program to include both direct and indirect deaths and referenced the new CDC guidance. The Reference Guide is available at https://www.cdc.gov/nchs/nvss/reporting-guidance.htm.

Disaster-related Death Scene Investigation Toolkit
Death certifiers, including ME/Cs and JPs, use information collected during the death scene investigation,1 to assist in determining cause and manner of death and if the death was related to the disaster. Standardizing the data collected during the death scene investigation for disaster-related deaths can potentially provide the certifier with consistent and useful information to determine the disaster relatedness of the death. If key disaster-related information is not collected at the scene, the certifier may not be able to attribute the death to the disaster and would therefore not record the event type and name, for example, Joplin tornado, on the death certificate. Enhanced death scene investigation data in ME/C reports might assist state and local public health officials to better target response and recovery efforts by identifying people at high risk of mortality and refine strategies to prepare, respond, and recover from future disaster events. In addition, having national standards for death scene data collection of disaster-related deaths would further promote consistent practices by medical death certifiers to classify and report disaster circumstances correctly on death certificates, resulting in more accurate, searchable, and useful mortality data.

To this end, CDC funded a three-year contract with NORC at the University of Chicago to develop death scene tools for disaster-related deaths. In the first year (2015), NORC conducted an environmental scan of relevant peer-review and grey literature studies, forms, protocols, and worksheets from state and local ME/C and death scene investigator offices and ME/C-related professional and nonprofit organizations (14). Nearly 200 documents were included, and the results found variation in attribution of deaths to a disaster and limited use of death scene data collection tools after a disaster, indicating the potential for widespread inconsistency in data captured at the scene (17). In the second year of the project, NORC convened a 12-member work group with representation from ME/Cs, forensic pathologists, death scene investigators, forensic anthropologists, and epidemiologists. Over an eight-month period, this work group collaboratively developed a disaster-related Death Scene Investigation (DSI) Toolkit that included a series of disaster-specific data collection tools and resources for investigators. The draft data collection forms were piloted in four states to evaluate if these death

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1 Death scene investigation is a process where ME/Cs or death scene investigators gather critical data to understand how and why a person died. During a death scene investigation information is obtained from several sources including, but not limited to, the location and scene of the death; police and other emergency service workers; key informants, for example, individuals who witnessed the death, and family members; and medical records.
scene collection forms captured information that would be available to death scene investigators. The pilot consisted of a death scene investigator extracting data onto the form using previously investigated disaster-related deaths. The forms were revised based on this pilot, and, in 2017, CDC published the DSI Toolkit (14). In 2018, NORC developed a free online training of the DSI Toolkit with continuing education credits. The toolkit is available at [www.train.org/cdctrain/course/1083843/](http://www.train.org/cdctrain/course/1083843/).

This project was modeled after CDC’s Sudden Unexpected Infant Death (SUID) Initiative which successfully engaged and received input from ME/Cs, law enforcement personnel, and their professional organizations to develop a toolkit with standardized SUID death investigation practices, reporting guidelines, and training modules. CDC’s rationale for using similar processes is that the SUID Initiative’s tools and practices have been widely adopted as standard ME/C practice for investigating and reporting these deaths.

**Enhancing the Use of Electronic Death Registration Systems (EDRS) for Disaster-related Mortality Tracking**

CDC has actively engaged in and committed resources for advancing efforts to improve mortality data and the utility of electronic death registration systems (EDRS) for routine public health surveillance and emergency response. This work focuses on strategic planning, actions, and resource provision.

The strategic planning involved partner meetings, senior-level tactical sessions, and dissemination of a document which articulated the urgent need and “call for action” to improve timeliness of mortality data as a national priority (18). As a result, “Mortality Surveillance-related Initiatives with the National Vital Statistics System” was included in CDC’s Surveillance Strategy 2014 (19-20). Other actions involved joint Center for Preparedness and Response (CPR) and NCHS state site visits to bring together state-based Public Health Emergency Preparedness (PHEP) program directors, vital statistics staff, and state epidemiologists to discuss leveraging the EDRS for surveillance. From those state conversations and other evidence, it became apparent there was a need for more support and guidance to enhance existing systems and exploration of best methods to modernize the EDRS infrastructure to make these systems more useful for surveillance.

In 2015, NCHS hosted a strategic planning workshop, “Next Generation Electronic Death Registration System Supporting Improved Quality and Timeliness of Vital Records Data (21).” CPR and NCEH also participated in the workshop reflecting the interest and support of multiple centers across CDC. A formal NCHS Modernization Initiative began in 2017 and CPR and NCEH have attended several meetings and provided specific input into the capabilities needed in a state-based EDRS for it to be leveraged for response. More information may be found at [www.cdc.gov/nchs/nvss/modernization/index.htm](http://www.cdc.gov/nchs/nvss/modernization/index.htm).

**Addressing Capacity Building**

Having a modernized EDRS is not the only gap to close to improve disaster mortality data. It is important to engage and support the ME/C community as they certify deaths that occur during disasters and other important public health emergencies such as drug overdose deaths. CDC has made a concerted effort to make resources accessible for mortality projects to provide capacity building of ME/C and vital records offices. Since 2015, CDC has continued to work with states, including projects such as

- Funded three internal mortality projects, including interoperability of ME/C case management and EDR systems, a pilot of NVSS as a national disaster-related mortality surveillance systems, and a data quality project.
- Included EDRS language in CPR’s PHEP cooperative agreement guidance encouraging 62 award recipients to coordinate with epidemiological and vital records partners to implement EDRS.
- Updated CDC’s public health preparedness capabilities with aforementioned tools and guidance.
In 2018, Congress appropriated disaster supplemental funding to CDC for response, recovery, preparation, mitigation, and other expenses directly related to the consequences of 2017 Hurricanes Harvey, Irma, and Maria. NCEH and NCHS are supporting three jurisdictions (Puerto Rico, Texas, and U.S. Virgin Islands) in their efforts to strengthen disaster-related death certification and registration processes to improve death count accuracy. These jurisdictions are receiving training on certifying disaster-related deaths based on CDC’s 2017 disaster-related death certification reference guide. The project in Puerto Rico also includes designing and implementing the jurisdiction’s first EDRS. Lessons learned and best practices from these two-year projects could be informative to the other jurisdictions interested in improving their capacity to identify, collect, and report disaster-related deaths and modernizing their EDRS for emergency response.

REFERENCES


