



A Framework for Assessing Mortality and Morbidity After Large-Scale Disasters

Committee on Best Practices for Assessing Mortality and Significant Morbidity Following Large-Scale Disasters

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Abbreviated Statement of Task

An ad hoc committee will conduct a review and assessment of the current state of the field and best practices in assessing and quantifying mortality and significant morbidity following large-scale disasters, with a specific focus on disasters declared under the Stafford Act.

Specifically the committee will:

- Describe the importance of mortality and significant morbidity data after disaster impact, their use, and the organizations that capture these data or could benefit from use of the data.
- Describe the current architecture, methodologies, and information systems currently in use or available to SLTT public health agencies for the sharing and reporting of this data, highlighting the diversity of processes and identifying potential best practices.
- Identify current challenges to collecting, recording, and reporting mortality and significant morbidity data after disasters, including, as feasible, challenges related to lack of standardization for data collection and disaster attribution, coordination, and training.
- Identify best practices for collecting, recording, and reporting mortality and significant morbidity data after disasters, and recommend priority areas of emphasis and allocation of resources to enhance SLTT mortality and significant morbidity data collection and reporting after disasters, considering feasibility, sustainability and impact to SLTT and healthcare organizations.

Study Timeline

2019

May – First committee meeting

August – Second committee meeting and workshop

October – Third committee (site visits in Butte County, CA)

2020

January – Fourth Committee Meeting

March – Fifth Committee Meeting

June-August – Response to review

September – Prepublication report public release

November – Final report released and hard copy books

Ongoing – Report dissemination

How the Pandemic Influenced the Report

- Original charge did not focus on disasters related to infectious diseases.
- Many challenges identified by the committee became starkly evident in real time as we saw the narrative around COVID-19 related deaths roll out in the latter phases of Committee's deliberations.
- Following Stafford Act declaration for COVID-19 in March 2020, FEMA approved the committee's request to include considerations related to the pandemic (May, 2020).
- Not the focus of the report, but provided practical context for the Committee's recommendations – see Appendix C which describes early experiences assessing COVID-19 related mortality and morbidity.

There is no singular federal entity that oversees disaster related mortality & morbidity reporting practices

Response Period

Mortality and morbidity data can be used to identify vulnerable populations and immediate needs to adapt and target response efforts.

Example: Rapid deployment of resources and disaster mortuary operational response teams to affected areas.

Recovery Period

Mortality and morbidity data can be used to describe a disaster's initial impact and guide recovery efforts, particularly for vulnerable populations.

Example: Development of targeted programs and access to services for populations at risk of worsening or exacerbated outcomes due to existing chronic disease, such as patients on dialysis.

Interdisaster Period Mitigation and Preparation

Mortality and morbidity data can be used to evaluate the effectiveness of response and recovery activities, define the impact of the disaster more completely, and craft mitigation and prevention strategies that respond to identified risks and vulnerabilities.

Example: Enhanced planning for resource distribution to prepare for future services and provisions of services to reduce population and environmental vulnerabilities. Activation of partnerships between research institutions and SLTT stakeholders to assess disaster impact.

A systems approach is critical with strong leadership at every level to foster mutual commitment

The Life Cycle of a Disaster

Action Areas

1. **Adopting a Uniform Framework and Terminology for Attribution**
(Recommendations 2-1 and 2-2)
2. **Strengthening Systems and Practices for Individual Counts**
(Recommendations 3-1 and 3-2)
3. **Improving the Use of Analytical Methods for Population Estimates**
(Recommendations 4-1 and 4-2)
4. **Setting Standards for Morbidity Data Collection**
(Recommendation 3-3)
5. **Improving Access to and Use of Mortality and Morbidity Data**
(Recommendation 4-3)
6. **Enhancing Professional Training and Support**
(Recommendations 3-4 and 3-5)

Uniform Framework & Terminology for Attribution

- There is variation in *what* is being assessed and its *context*, as well as variation in how its relation to a disaster is described. This variation undermines trust in the quality and usability of these data for informing disaster management.
- Current terminology and definitions fail to capture important differences between estimation approaches and methods and the dynamic nature of these estimates.
- Lack of a consistent **national framework** and **definitions for attributing mortality and morbidity results** in inconsistent collection and reporting of data, hinders the ability to compare and learn from different disasters.

Primary Approaches for Estimation

- Two primary approaches for the estimation of disaster-related mortality and morbidity: **individual counts and population estimates**.
 - Individual counts are estimates derived from reported cases
 - Population estimates are estimates of the impact of a disaster at a population level derived using various statistical methods and tools, including sampling, surveys and excess mortality
- Both produce *estimates* of the impact of a disaster at a **specific point in time**, within a **defined context**, and based on **specific assumptions**.
- Both individual case counting and population estimation approaches **encompass multiple methods and techniques** – with unique strengths and weaknesses – so neither is always preferable to the other.

Terminology for Attribution

- **Direct death or morbidity**: A death or morbidity directly attributable to the forces of the disaster or a direct consequence of these forces (e.g. structural collapse, drowning, radiation exposure)
- **Indirect death or morbidity**: A death or morbidity not from a direct impact but due to unsafe or unhealthy conditions around the time of the disaster, including while preparing for, responding to, and during recovery from the disaster. (e.g. lack of access to dialysis, CO poisoning from improper use of generator)
- **Partially attributable death or morbidity**: A death or morbidity that cannot be tied definitively to the disaster but where the disaster more likely than not has played a contributing role in the death (e.g. stroke in person with underlying disease, suicide in person with underlying mental illness)

Uniform Framework & Terminology for Attribution - Recommendations

Recommendation 2-1: Adopt and Support the Use of a Uniform Framework for Assessing Disaster-Related Mortality and Morbidity

The **Department of Health and Human Services and the Department of Homeland Security**, including the Office of the Assistant Secretary for Preparedness and Response, the Centers for Disease Control and Prevention, the Centers for Medicare & Medicaid Services, and the Federal Emergency Management Agency, **should adopt and support the use of a uniform framework** for assessing disaster-related mortality and morbidity before, during, and after a disaster by state, local, tribal, and territorial (SLTT) entities; public health agencies; and death investigation and registration systems. **To implement this uniform framework nationally, the National Center for Health Statistics** in conjunction with state and local vital records offices, medical examiners and coroners, medical certifiers, and all relevant professional associations **should jointly adopt and apply this framework to practice**, including the routine use of uniform case definitions and data collection, recording, and reporting practices. Additionally, **all Stafford Act declarations should require affected states and regions to comply with the reporting requirements for individual count and population estimation approaches as described in the framework**. Timely guidance should be disseminated to SLTT entities regarding the proper certification of individual deaths with provision for direct, indirect, and partially attributable deaths following a large-scale disaster.

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Uniform Framework & Terminology for Attribution - Recommendations

Recommendation 2-1 Continued:

The following terminology and approaches for defining mortality and morbidity following large-scale disasters should be adopted immediately:

- **Total reported mortality and morbidity estimation using individual counts:** Individual counts are point-in-time estimates of disaster-related mortality and morbidity derived from reported cases.
 - Direct death or morbidity: A death or morbidity directly attributable to the forces of the disaster or a direct consequence of these forces.
 - Indirect death or morbidity: A death or morbidity not from a direct impact but due to unsafe or unhealthy conditions around the time of the disaster, including while preparing for, responding to, and during recovery from the disaster.
 - Partially attributable death or morbidity: A death or morbidity that cannot be tied definitively to the disaster but where the disaster more likely than not has played a contributing role in the death.
- **Total mortality and morbidity derived from population estimates:** Population estimates are point-in-time estimates of the impact of a disaster at a population level derived using various statistical methods and tools, including sampling.

Uniform Framework & Terminology for Attribution - Recommendations

Recommendation 2-2: Report Both Individual Counts and Population Estimates

Both individual counts and population estimates should be used as accepted standards for reporting by state, local, tribal, and territorial entities and supported by the federal agencies as indicators of mortality and morbidity to determine the impact of disasters over time. State and federal reporting of total mortality and morbidity estimates following disasters should use both individual counts of direct and indirect deaths and population estimates of mortality and morbidity as these data become available following a disaster. **Individual count data should be referred to as reported cases or reported deaths** and should not be referred to as reflecting *total mortality* or a *death toll*. **Total mortality estimates should be derived from population estimation methods**, which provide a more complete assessment of overall impacts of large-scale disasters.

Improving Systems for Individual Mortality Counts

- Collection of consistent and accurate mortality data is dependent on systems' functions and capacities.
- Heterogeneity in death investigation and registration prevents accurate recording and reporting of disaster-related mortality data and impedes the meaningful analysis and use of these data to save lives.
- Need uniform national practices around death certification and improvement of electronic systems to achieve greater coordination and usefulness of data

Systems and Practices for Individual Counts – Recommendations

Recommendation 3-1: Strengthen Existing Systems to Improve Individual-Level Mortality Data Quality

The **Centers for Disease Control and Prevention**, through the National Center for Health Statistics (NCHS), should lead an **enterprise-wide initiative to strengthen existing death registration systems** to improve the quality of disaster-related mortality data at state, local, tribal, and territorial (SLTT) levels. These efforts should prioritize the standardization of methods for data reporting and recording and to improve the capacity of death investigation and registration systems to capture more detail on contributing causes of death following disasters.

The following immediate actions should be undertaken:

- **NCHS should fund and support the transition of the remaining states and territories with paper-based death registration systems to electronic death registration systems (EDRSs)** and lead, in collaboration with state vital records offices, the integration of best practices for capturing and coding disaster-related death data into state-based EDRSs.

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Systems and Practices for Individual Counts - Recommendations

Recommendation 3-1 Continued:

- **NCHS** should directly fund improvements in and the **standardization of medical examiner and coroner (ME/C) death e-filing systems** and **require interoperability** with these systems and state EDRSs. Similarly, NCHS and state registrars should require that EDRSs adopt the following standard improvements:
 - Automatic filing of death information with state EDRSs via ME/C e-filing systems to reduce the administrative burden on medical examiners and coroners
 - Automated and uniform alert flags, prompts, drop-down options, and decision-making support for use by medical certifiers when entering data into a death record in both a routine and just-in-time capacity
 - Offline data entry and other continuity mechanisms
 - Geocoding of deaths based on both place of residence and location of death

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Systems and Practices for Individual Counts – Recommendations

Recommendation 3-1 Continued:

The following **long-term actions** should be prioritized:

- **NCHS should fund and adopt where appropriate artificial intelligence technologies** to improve the throughput of its automated medical coding systems so as to improve the throughput of ME/C deaths to a level equivalent to that of other natural causes of death.
- State vital records offices and medical examiner and coroner offices, with the support of CDC, should develop continuity plans to sustain the functions of these offices during emergencies.

Systems and Practices for Individual Counts – Recommendations

Recommendation 3-2: Standardize Data Collection and Reporting of Individual-Level Reported Disaster-Related Mortality

The **National Center for Health Statistics (NCHS)**, working with the states, should **update the Model State Vital Statistics Act** to drive uniformity of data collection and recording with respect to disaster-related mortality. To promote uniformity in definitions and practices for collecting and recording disaster-related mortality data and enhance the quality and comparability of these data, NCHS should revise the Model State Vital Statistics Act to provide clear guidance and data standards to state vital records offices and medical certifiers. **These changes should include the use of automated flags, prompts, and drop-down options to collect data on the relationship of a death to a recent disaster and provide decision-making support for medical certifiers.**

Analytical Methods for Population Estimates

- There can be more than one appropriate response to the question “How many deaths and severe morbidities were caused by this disaster?”
- Still, methodological best practices can be specified, and a national research program is needed to identify, further develop, and validate these best practices.
- Analytical and fieldwork requirements of optimal methodologies are often beyond the capabilities of SLTT health departments.
- Federal partners and support are needed to build and sustain capacity

Analytical Methods for Population Estimates - Recommendations

Recommendation 4-1: Fund and Conduct Research on Analytical Methods for Population Estimates

The **Centers for Disease Control and Prevention, the National Institutes of Health, and the National Science Foundation** should establish a **national research program to advance analytical methods for conducting population-level estimates of mortality and morbidity related to disasters**. This national research program should include the development and refinement of minimum standard methods and protocols for conducting population-level mortality and morbidity assessments as well as the creation and testing of tools for use by researchers, states, and localities to enhance their capabilities to carry out and use these analyses.

Analytical Methods for Population Estimates - Recommendations

Recommendation 4-2: Enhance Capacity to Collect and Analyze Population Estimates for Mortality and Morbidity

The **Department of Health and Human Services**, together with state, local, tribal, and territorial (SLTT) agencies, should **proactively develop partnerships to enhance the capacity to collect and analyze population-level disaster-related morbidity and mortality information**. This includes the identification of appropriate mortality and morbidity datasets and sampling frames that might be brought to bear and the pre-negotiation of data-sharing agreements to ensure access to these data when needed.

The following immediate actions should be undertaken:

- The **Secretary of Health and Human Services** should push forward the collection of survey data on disaster-exposed and comparison populations to provide *population-representative data* on how disasters and their contributing stressors affect morbidity and to build the evidence base on differences in mortality and morbidity impacts across types of disasters.

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Analytical Methods for Population Estimates - Recommendations

Recommendation 4-2 Continued:

- The federal statistical system, including the Centers for Disease Control and Prevention (CDC), the Substance Abuse and Mental Health Services Administration (SAMHSA), and others **should harness existing survey infrastructure and develop standard, institutional review board-approved sampling frames and methods** for dealing with methodological challenges, such as population migration, for use by researchers conducting population estimates following large-scale disasters.
- The stakeholders listed above should address issues with informed consent procedures under the Common Rule, respondent burden issues under the Paperwork Reduction Act, and privacy under the Health Insurance Portability and Accountability Act Privacy Rule in advance and ensure alternative arrangements to protect privacy and confidentiality.

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Analytical Methods for Population Estimates - Recommendations

Recommendation 4-2 Continued:

- **SLTT agencies and academic research centers** with the capability of conducting population estimates of disaster impact should **formalize working relationships, data-sharing agreements, and Institutional Review Board approvals in advance** of a disaster to reduce delays in access to health data needed to conduct population estimates following a disaster and develop baseline assessments during the inter-disaster period.
- **CDC and the Federal Emergency Management Agency** should **integrate frontline public health practitioners** (e.g., epidemiologists and others) in the disaster response teams to help gather data and begin detailed analyses of mortality and morbidity data early in the disaster.

Standards for Morbidity Data Collection

- When available and actionable, morbidity data can help reduce mortality (i.e., by preventing morbidities from becoming mortalities).
- Collection of morbidity data is challenging due to many possible outcomes and data scattered across multiple unique systems.
- Also, different types of disasters create different types of morbidities, over different timelines
- Uniform standards for morbidity data collection are needed, specified to common types of disasters.
- Understanding the morbidity data of greatest value for improving management of specific types of disasters requires more research.

Standards for Morbidity Data Collection - Recommendation

Recommendation 3-3: Develop a Set of Standards for Morbidity Data Collection

The **Centers of Disease Control and Prevention**, in collaboration with the Centers for Medicare & Medicaid Services, the Council of State and Territorial Epidemiologists, and the National Association of County & City Health Officials should **establish and promulgate national standards for the collection of disaster-related morbidities before, during, and after disasters**. These activities should include investment in **research to identify common morbidities that occur as a result of or are exacerbated by the conditions of specific types of disasters** (e.g., floods, hurricanes, blizzards, radiation events, pandemics, etc.) **and across multiple disaster types**. This should include the identification of minimum timelines for data collection, the development and validation of morbidity data systems for use by the disaster management enterprise, and pilot testing and implementation of approaches to collect these data in a standardized manner.

Mortality and Morbidity Data Access and Use

- Access to mortality and morbidity data from the state and federal level is essential, but access is not actionability.
- SLTT's require expertise and capacity to use these data in decision making, including tools to read, analyze, and display data in meaningful ways.
- Opportunities exist to streamline use of mortality and morbidity data as essential components of disaster management.

Mortality and Morbidity Data - Access and Use

Recommendation 4-3: Facilitate Access to and Use of Actionable Mortality and Morbidity Data by State, Local, Tribal, and Territorial (SLTT) Entities

- The **Department of Health and Human Services (HHS)** should work with the Centers for Disease Control and Prevention, the Federal Emergency Management Agency (FEMA), the Office of the Assistant Secretary for Preparedness and Response (ASPR), and other federal agencies *facilitate access to essential mortality and morbidity data to SLTT entities and academic research institutions throughout the disaster cycle*. These **data should be provided proactively and in a manner that is actionable** for situational awareness and disaster response at a state and local level.
- Additionally, state and federal agencies should **fund the development and testing of analytical tools** and work collaboratively with local entities to use mortality and morbidity data in meaningful ways.

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Mortality and Morbidity Data - Access and Use

Recommendation 4-3 Continued:

The following immediate actions should be undertaken to ensure SLTT access to and use of mortality and morbidity data:

- **National Center for Health Statistics** (NCHS) should code and automatically provide, with the assistance of FEMA and ASPR, location-specific, **baseline mortality data** and up-to-date data on disaster deaths following a declared disaster and upon request, as well as offer ready-to-use tools within a set timeframe following disasters to states and localities.
- **NCHS** should make available to researchers and SLTT investigators the mortality data from the **National Death Index**.
- **NCHS and state vital records** offices should **retrospectively geocode death registry entries in select areas that were previously affected by large-scale disasters** to provide sample data for modeling future impact and other research.
- **ASPR and CDC** should provide state and local officials with guidance on standard practices for assessing mortality and morbidity and facilitate the analysis of these data by state and local health and emergency management officials.

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Mortality and Morbidity Data - Access and Use

Recommendation 4-3 Continued:

- **CDC in collaboration with FEMA and ASPR** should fund and conduct **research to establish standard practices for analyzing disaster-related causes of death and its contributing causes**, including guidance on standard timelines for data analysis (e.g., 30 days) and geographic parameters for defining a disaster's geographic scope.
- **CDC and the Centers for Medicare & Medicaid Services (CMS)** should **use existing systems to pilot the collection of relevant morbidity data following disasters to serve as an inter-disaster baseline.**
- **CMS**, in collaboration with electronic health record companies and health systems, should **pilot and evaluate the inclusion of disaster-related ICD-10 codes in electronic health records.**
- **HHS should use both existing and novel data sources to improve mortality and morbidity data acquisition and reporting**, including the use of surveys, artificial intelligence, machine learning, and other big data methods

Professional Training & Support

- Many stakeholders are involved in the collection and recording of mortality data – each requires appropriate training and professional support.
- Not all medicolegal professionals (ME/C) today are equipped to implement the report's recommendations related to adoption of standardized definitions, practices and systems.
- The value of disaster-related mortality and morbidity data needs to be recognized by the medicolegal workforce.

Professional Training & Support - Recommendations

Recommendation 3-4: Strengthen the Capacity of the Medicolegal Death Investigation System to Assess Disaster-Related Mortality

The **Centers for Disease Control and Prevention** (CDC), in collaboration with state agencies and professional associations, should strengthen the value, capacity, and capability of the medicolegal death investigation system to **improve investigation, training, data development and collection, and case management.**

The following immediate actions should be undertaken:

- **CDC** should fund and re-launch the Medical Examiner and Coroner Information Sharing Program to provide guidance and support to medical examiners, coroners, and other medical certifiers.

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Professional Training & Support

Recommendation 3-4 Continued:

- **The National Association of Medical Examiners, the International Association of Coroners & Medical Examiners, the American Board of Medicolegal Death Investigators, and state-based medical examiner and coroner professional organizations should support the proposed framework** for collecting and recording uniform mortality and morbidity data, encourage the use of existing CDC tools and guidance by all professionals, and **provide continuing education courses for their members** that reflect this guidance.
- CDC, through the **National Center for Health Statistics**, along with appropriate licensing bodies should **provide standardized training and materials designed for medical certifiers** (physicians, nurse practitioners, physician assistants, and others as applicable by state) who encounter natural deaths and are responsible for entering death information into the death record.

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Professional Training & Support

Recommendation 3-4 Continued:

- Death investigation systems should develop relationships with state or university-based demographers and epidemiologists to formalize proactive data collection and sharing agreements for natural disasters that are typical for the state as well as mass mortality and morbidity due to disease.
- To promote more accurate death certification, **the above agencies should incentivize and support the conversion of coroner systems to regionalized medical examiner systems staffed by forensic pathologists and medicolegal death investigators** professionally trained to identify and classify disaster-related deaths per the framework described in Recommendation 2-1.

Professional Training & Support - Recommendations

Recommendation 3-5: Strengthen the Role of the Medicolegal Death Investigation and State Death Registration Systems in the Disaster Management Enterprise

State, local, tribal, and territorial public health and emergency management departments should integrate the professionals and agencies from the medicolegal death investigation and death registration systems in all aspects of preparedness and planning. This should involve the **consideration of moving mortality management out of Emergency Support Function #8 (ESF8) and creating a separate ESF dedicated to mortality management.** This new function could complement ESF8 and ensure focused attention on assessing mortality during and after disasters, while those charged with ESF8 responsibilities are focused on providing services to survivors. This new function could include the involvement of medical examiners, coroners, and other relevant professionals in planning drills for mortality management; effective, efficient, and unbiased data collection during disasters; trainings for family assistance centers; and standards for after-action reports and other mortality data reporting activities.

Meeting the Mission

- No single federal entity oversees all operations of disaster-related mortality and morbidity reporting practices.
- No lasting change will be possible without mutual commitment and coordination across systems and stakeholders.
- A coordinated enterprise approach will allow entities to overcome fragmentation—particularly in a time of crisis—and work toward a mutual goal.

Thank You!

Public Release – September 9

- 11 a.m. ET web release (resources become available online; email announcement)

Public Webinar – September 30

Dissemination materials (available online on September 9)

- Complete prepublication report
- Report highlights
- Slide set

Free PDF of the report (available at the time of public release)

