Improving Statistical Systems in Times of National Emergencies
-An Unexpected Journey -

What we will cover

- National Academies study on improving morbidity and mortality reporting during emergencies
- Modification of study and findings re covid outbreak
- Issues uncovered
- Recommendations of the report
- Related follow-up actions
- Related legislative activities

NAS Committee on Assessing Mortality and Significant Morbidity Following Large-Scale Disasters

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How the Pandemic Influenced the Report

- Original charge (May 2019 first meeting) 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 – Appendix C which describes early experiences assessing COVID-19 related mortality and morbidity.
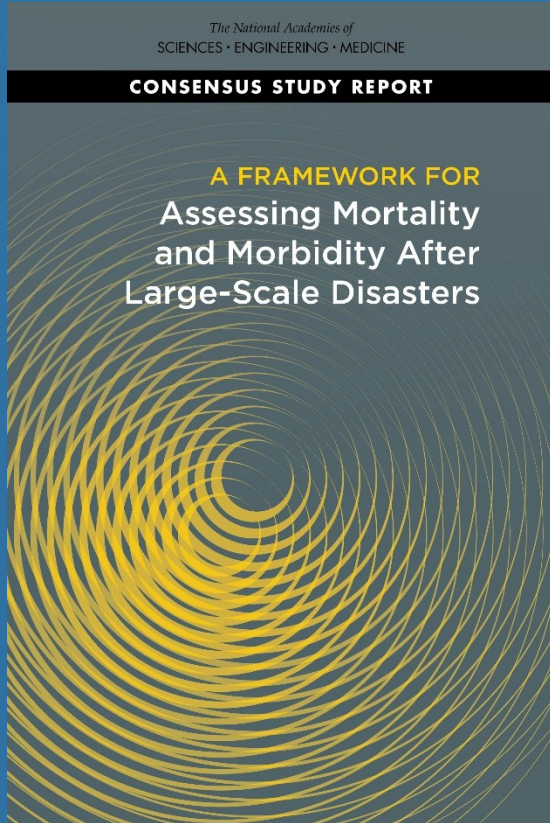
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Action Areas for Issues Uncovered

- **Adopting a Uniform Framework and Terminology for Attribution***
  (Recommendations 2-1 and 2-2)

- **Strengthening Systems and Practices for Individual Counts ***
  (Recommendations 3-1 and 3-2)

- **Improving the Use of Analytical Methods for Population Estimates ***
  (Recommendations 4-1 and 4-2)

- **Setting Standards for Morbidity Data Collection**
  (Recommendation 3-3)

- **Improving Access to and Use of Mortality and Morbidity Data ***
  (Recommendation 4-3)

- **Enhancing Professional Training and Support**
  (Recommendations 3-4 and 3-5)

Uniform Framework & Terminology for Attribution –

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

The Department of Health and Human Services and the Department of Homeland Security,, should adopt and support the use of a uniform framework for assessing disaster-related mortality and morbidity before, during, and after a disaster (or pandemic) by state, local, tribal, and territorial (SLTT) entities; public health agencies; and death investigation and registration systems.

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Uniform Framework & Terminology for Attribution

Recommendation 2-1 Continued:

The following terminology and approaches for defining mortality and morbidity following large-scale disasters (or a pandemic) should be adopted immediately:

- **Total <u>reported</u> mortality and morbidity estimation using individual counts:** Individual counts are point-in-time estimates of disaster-related mortality and morbidity derived from reported cases.
  - *<u>Direct</u> death or morbidity*: A death or morbidity directly attributable to the forces of the disaster or a direct consequence of these forces.
  - *<u>Indirect</u> 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.
  - *<u>Partially attributable</u> 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.

Significant Problems with Mortality and Morbidity Reporting Systems

- Paper based mortality systems in four states and Territories need automation

- ME/Coroner case management systems need to interoperable with electronic death registration systems (EDRS)

- EDRS need to be modernized for quick updates for data needed during emergencies

- Electronic health records need to be available, updatable and interoperable with EDRS and ME/coroner systems

Systems and Practices Needed for Improvement

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. 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)

- NCHS, in collaboration with state vital records offices, the integration of best practices for capturing and coding disaster-related (and pandemic) death data into state-based EDRSs.

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Systems and Practices Needed for Improvement

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 Needed for Improvement

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

Recommendation 3-2: Standardize Data Collection and Reporting of Individual-Level Reported Disaster-Related (and pandemic) 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.

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Analytical Methods for Population Estimates

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.** The following immediate action should be undertaken:

- The federal statistical system, including the Centers for Disease Control and Prevention (CDC), the Substance Abuse and Mental Health Services Administration, 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

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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 especially for electronic health records.

- Understanding the morbidity data of greatest value for improving management of specific types of disasters requires more research.

Problems with 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 actionable.

- 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 but are not happening.

Mortality and Morbidity Data – Actions to Improve 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 Federal Emergency Management Agency (FEMA)), and other federal agencies to facilitate access to essential mortality and morbidity data to SLTT entities and academic research institutions throughout the disaster (pandemic) cycle. These data should be provided proactively and in a manner that is actionable for situational awareness and disaster/pandemic 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 – Improving 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 – Improving 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

Overriding Requirement to meet the Mission in Times of Crisis

- No single federal entity oversees all operations of disaster or pandemic-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.

Follow-up activities

- Briefings of Congressional, FEMA and NCHS Staff
- CDC starting a study on how to improve training for state and local staff
- Data Foundation and NORC Impulse Survey on mental, physical and economic health impact of the pandemic and related public health actions
- Census with other statistical agencies developed and fielded the Pulse Survey

Legislative Activities

- Health Statistics Act of 2020 – Data standards for morbidity and morality reporting data linkage -bipartisan Bill in the House - no action taken

- Health Statistics Act of 2021 – Same as above but including more recommendations from the NAS report ie upgrading mortality reporting systems at the local, state and Federal levels, improved use of electronic health records for morbidity monitoring, improved data reporting back to local and state officials that is timely, understandable and actionable.

- Friends of NCHS recommendation to Congress to increase NCHS Budget by $25 million to modernize its statistical systems