



NBSB Report on the Strategic Improvements to the National Disaster Medical System (NDMS)

December 13, 2018



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National Biodefense Science Board (NBSB) Report on the Strategic Improvements to the National Disaster Medical System (NDMS)

Preamble:

During a conference call on October 28, 2018, Dr. Ron Miller, Division Director of the National Disaster Medical System (NDMS) of the Office of the Assistant Secretary for Preparedness and Response presented members of the NBSB Disaster Medicine Working Group with a series of seven questions / topics to consider in guiding strategic improvements to the NDMS. In a series of four weekly conference calls, members addressed each question based on their general professional expertise, direct experiences with disasters, conversations with invited subject matter experts and literature guidance as needed. The NBSB recommendations to each of the topics are noted below in this document.

1. Identify common data elements within an electronic medical record that can be collected and used to guide decision making in a disaster.

NBSB Recommends Common Data Elements under the Following Categories (Appendix 2)

- Data for Identification, Long-Term Tracing and Possible Family Reunification
- Data for Specific Management of Current Illness, Infectious Risk
- Data Needed for Follow-Up
- Database / Formulary Considerations

2. How can NDMS data be useful to the broader disaster research community?

Recommendations:

- An NDMS database of disaster can be useful:
 - To predict medical and social outcomes of disasters
 - To predict elements of an effective response strategy and response needs.
 - To identify communication needs
 - Identification of simple communication strategies that can help groups identify available resources during and following a disaster.
 - Linking of social networks to NDMS data during disasters to help solve issues (e.g. missing family member, identification of medical needs)
 - For effective management of 'Ripple effect' for patient transport to local and regional medical centers
 - e.g., knowing where key resources (people, staff, facilities, equipment, medications) are located and how to access them in a catastrophe, as

well as the ability to provide a surge in these resources quickly when needed

- To measure time to care (throughput), transfer times
- To identify different types of resources that may be needed during different types of disasters
- The database should have last minute editable fields to NDMS that can be used for new research topic ideas during disasters.

3. Related to the September 12, 2018: National Advisory Committee on Children and Disasters (NACCD)/NBSB Joint Future Strategies for Children Report, Strategy 8, how does the Board define the “unique needs (and data sources) for children”? NDMS could look at incorporating some level in its planning and operational aspects across its infrastructure.

The Working Group identifies and Recommends three Categories of Unique Needs and Data Sources (Appendix 3 for details)

1. Physiologic and Anatomical Needs
2. Patient Tracking Needs and
3. Mental/ Emotional Needs.

4. Does the NBSB have recommendations for the “creation of a pre-positioned data set” that could be incorporated with NDMS data?

- Yes, we recommend including the data already mentioned in response to Item 1 above.

5. What capability does NDMS have to export Electronic Medical Records (EMR)/Healthcare Informatics Research (HIR) data into healthcare facilities systems?

Recommendations (Appendix 4):

- There should be common use and adoption of known standards.
- NDMS should use robust application programming interface (middleware) to enable connection to different systems including eHealth and regional health information exchange (HIE) systems.
- NDMS should use technology that will allow the mass queries that would likely be needed during disasters
- There should be enough computing power to allow massive querying of multiple EHRs at once.
- Legal and technical considerations for data sharing should be addressed upfront, including joint guiding principles and implementation of data use agreements.
- If linkage of NDMS to other databases is not feasible, NDMS should ensure that data is exported into a portable format such as a flash drive and print copy that can be provided to families.

6. Any additional data elements NDMS aims to collect is dependent upon the research questions we want answered. For example, does NDMS want information on diagnoses, lab results, etc. or the ability to identify gaps in services/care provided?

Recommendations (Appendix 5)

NDMS Should:

- Collect data that can help inform decision making during disaster response
- Enable access to insurance de-identified information databases to track different types of treatment associated with the catastrophe
- Track demographics (race, ethnicity, religion, zip codes) that may help understanding of how different groups are managed, their long-term outcomes and allocation of resources
- Collect data elements about time allocation that can help management of future disasters
- Identify elements that were associated with successful implementation of disaster plans versus lessons that could be learned from plans that were not as successful
- Clearly identify persons with special healthcare needs (especially mobility, cognitive and communication issues) as a special group

7. What are possible topics for ongoing research to help with the NDMS?

Recommendations for Possible Research Topics (Appendix 6)

- Identification (ID) tagging of children to get downloadable information to link to their guardians in the future
- Use of drones for moving goods including food and water when transportation mechanisms are disrupted.
- A low technology supply chain system should be developed to enable linking of resources to movement of such resources to where they are most needed.
- Provide resources to create and study opportunities for the best practice in managing “Dark Sky Events” (these are events in which there is total power disruption that could take weeks to months to restore).
- Re-evaluate the need for specific countermeasures during disasters – do we currently have the right mix, and right number of components?
- Members of the NBSB would be willing to help identify other potential research questions

Appendix 1: NBSB Disaster Medicine Working Group (DMWG) Members and Subject Matter Experts

Working Group Members:

H. Dele Davies, M.D., M.Sc., M.H.C.M., DMWG Chair
Carl Baum, M.D., FAAP, FACMT
John Benitez, M.D., M.P.H
Mark Cicero, M.D.
Marc Shepanek, Ph.D.
Joelle N. Simpson, M.D., M.P.H
David Schonfeld, M.D., FAAP

Subject Matter Experts

Dr. W. Scott Campbell

Bio: W. Scott Campbell, Ph.D., MBA is an associate professor in the Department of Pathology and Microbiology. He is the Senior Director of Research Technologies for UNMC and is the Director of Pathology Laboratory and Nebraska Public Health Laboratory Informatics. He specializes in controlled medical terminologies and integration of clinical information systems, works regularly with clinical, basic science, and public health investigators, and understands the importance of both sharing data for research collaborations as well as protecting data. Dr. Campbell is highly involved with SNOMED International where he chairs/co-chairs multiple pathology committees. He is also a newly appointed representative and member of the College of American Pathologists Informatics Committee.

Ms. Donna Weis

Bio: Donna Weis is the Director for Clinical Information Systems at Nebraska Medicine/UNMC. Donna has over 30 years of healthcare experience with the last 18 years in healthcare technology management. She has responsibility for the direction, strategy, staff, and budget that support the clinical and business information systems of Nebraska Medicine. She achieved her CPHIMS (Certified Professional Health Information and Management Systems) in 2008 and has been a HIMSS member for over 10 years.

Appendix 2: Recommendations on Common Data Elements That Should Be Collected to Guide Decision Making in a Disaster

Based on consideration of issues that may impact outcomes for children being managed during disasters and those that may require follow-up (e.g. past and current medical conditions, prior and current treatment regimens, specific management needs, and possible communicable illnesses that could lead to an outbreak situation), the common data items identified below were recommended by the NBSB. For effective management, it would be important for the NDMS to be linked to the patient's pre-existing and any follow-up electronic health records (EHR) to enable ease of collection of these data.

- **For Identification, Long-Term Tracing and Possible Family Reunification**
 - Date of Birth / Age
 - Contact information for parents/guardians/ and /or other family members or responsible party
 - Names of siblings
 - Address information for patient (if at an alternate location –current address where sheltered/treated)
 - If unknown, what school they attend and name of street?
 - Social Security Number

- **For Specific Management of Current Illness, Infectious Risk**
 - Chief Complaint/diagnosis
 - Allergies
 - Current medications, doses and frequency
 - Medical conditions
 - Any immunocompromise
 - Significant past medical history (PMH), ideally in a checklist format to enable ease of utilization during a disaster
 - Date of last physician visit and recommended follow-up?
 - Immunization history and records, especially tetanus
 - Exposure history for communicable diseases, e.g. Tuberculosis (TB)

- **For Follow-Up**
 - Disposition/Arrival date-time and release time (total time in care)
 - Disposition vitals
 - Contaminated/decontamination time
 - Transfer status? To what location? Via ground/air/etc?

- **Database / Formulary Considerations**
 - A-priori decision as to whether to use International Classification of Diseases (ICD-9 codes, ICD-10 codes or both); clarify which Diagnostic Statistical Manual (DSM) is being used.
 - The software should contain a formulary that includes the following:
 - Standard medication doses by weight/age/size, special conditions (especially for children/infants)
 - Doses for renal failure/age pre-calculated or with pop-up warnings

Appendix 3: Recommendations on Unique Needs and Data Source for Children

- **Physiological and anatomical needs**

- Children are more prone to dehydration, faster respiratory rate, larger surface area: mass, larger head size
 - These needs translate to ensuring the most appropriately trained staff available are caring for the children and that the proper equipment and medication doses can be readily located when needed for children from birth through adolescence.
- Ensure there is size/weight/age/special condition based dosing (e.g., special needs child with lower or higher than expected body mass index).
- Ensure availability of appropriate equipment needs for transport, restraint, and administration of fluids/meds

- **Patient tracking needs (GPS, database)**

There should be a communication process that ensures families can be reunited through the use of technology.

- There be removable chip-based tagging that can be worn which contains relevant data about who the child is and their health data or other relevant data.
- Such “bar-coded” data should be worn by children to enable data upload at any point for tracking the child and connecting to appropriate family or other care when separation occurs.
- When there is time prior to a pending disaster such as an approaching hurricane, there should be similar Global Positioning System (GPS) based tagging to link individual children to responsible adults during planned or anticipated separations, e.g., similar to “dog tags” that are used in the military that contain basic information on name, Department of Defense (DOD) ID number, blood type and religion. This is true as well for special needs persons of any age. Another example could be passive Radio-Frequency Identification (RFID) chip based shoe tags for runners.
- Such “bar-coded” tags (similar to hospital bar coded tags) should be worn by the children to enable identification and data upload at any point.
- These resources should also be made available all the time commercially to families who live in earthquake, hurricane or similar zones and who seek to have them.
- Because separation from family pets can also be traumatic, “chipping” the pets may also be of value for successful reunion. The family / child’s bar-code or chip should also be linked to the pet’s chip.

- **Mental health needs**

In the area of mental health needs there are two general categories of persons for consideration.

- I. *People who already have a diagnosed mental health issue.* For these persons, there should be:
 - a) Knowledge of current mental health medications

- b) Mental / behavioral health records; these are often kept separate from other health records.
 - c) Establishment of communications with:
 - Health Care Provider (prescriber or therapist)
 - Family member / responsible person to better understand condition and treatment
 - Social services for families who may need them to manage financial and emotional needs. This may also enable tracking some patients to ensure there is no post-traumatic stress disorder (PTSD), agoraphobia, or depression due to the trauma of the catastrophe
 - d) Provision of information about ongoing and future financial support for family or responsible person.
- II. *Persons with no prior mental health issue who may develop stress induced behavioral health issue due to pressure of disaster.* For these persons, need:
- a) Establishment of communications with:
 - Family or responsible persons
 - Social services availability for families who may need them to manage financial and emotional needs. This may also enable longitudinal tracking for some patients to ensure there is no post-traumatic stress disorder (PTSD), agoraphobia, or depression due to the trauma of the catastrophe
 - b) Provision of information about ongoing and future financial support for family or responsible person
 - c) Professional clinical assessment support through:
 - i. Physician / Psychologist / Social Worker / Licensed Professional Counselor
 - ii. Self-report to clinician in their network / work / other
 - iii. Psychoeducation provided to all parents/caregivers with access to clinical assessments and support made available as needed/requested.

Appendix 4: Recommendations on NDMS Capability to Export Electronic Medical Records (EMR)/Healthcare Informatics Research (HIR) Data into Healthcare Facilities Systems

The healthcare of individuals impacted by a disaster would be greatly enhanced by sharing of health information gathered and treatment provided by NDMS with those healthcare providers responsible for follow-up and ongoing management. This would be best accomplished through the use of linkages to existing databases and EHR using common standards. Not doing so would seriously compromise recovery and potentially result in iatrogenic harm.

- There should be common use and adoption of known standards. The NDMS should enable distribution and sharing of data on any patient in the database in a standard

format using encoded standardized data elements including; SNOMED CT (the Systematized Nomenclature of Medicine Clinical Terms), RXNORM (a catalogue of standard names given to clinical drugs and drug delivery devices), LOINC (the Logical Observation Identifiers Names and Codes – a database and universal standard for identifying medical laboratory observations) and the CVX (Codes for Vaccine Administered) code set. In addition, NDMS should use communication protocols as defined by the Health Level 7 (HL7) International standards using Continuity of Care (CCD) documents that major vendors (e.g. AllScript, Cerna, EPIC and others) currently support and that are part of the Office of the National Coordinator (ONC) meaningful use requirements for vendors.

- NDMS should use robust application programming interface (middleware) to enable connection to different systems including eHealth and regional HIE systems such as CRISP (Chesapeake Regional Information System for our Patients) and NEHII (Nebraska Health Information Initiative). There are several vendor companies that can provide such application program interfaces (APIs). All are used in exchange mechanisms that can enable one Electronic Medical Record (EMR) to view another through these protocols and queries.
- NDMS should use technology that will allow the mass queries that would likely be needed during disasters.
- There should be enough computing power to allow massive querying of multiple EHRs at once.
- Legal and technical considerations for data sharing should be addressed upfront, including joint guiding principles and implementation of data use agreements.
- If linkage of NDMS to other databases is not feasible, NDMS should ensure that data is exported into a portable format such as a flash drive and print copy that can be provided to families.

Appendix 5: Recommendations on Additional Data Elements that NDMS Should Collect

NDMS Should:

- Collect data that can help inform decision making during disaster response e.g., can any of the data entered into the electronic medical record be analyzed to inform assets needed on the ground, etc.?
- Enable access to insurance de-identified information databases to track different types of treatment associated with the catastrophe that allows long term tracking; information that comes from individual data that can be used to track outcomes of individuals based on social networks and resources available.
- Track demographics (race, ethnicity, religion, zip codes) that may help understanding of how different groups are managed and their long-term outcomes; help identify patterns that can be easily remedied or allow different allocation of resources.
- Collect data elements including time to provide service, time to discharge, time to get resources into disaster areas that can help management of future disasters.

- Identify elements that were associated with successful implementation of disaster plans versus lessons that could be learned from plans that were not as successful.
- Clearly identify persons with special healthcare needs (especially mobility, cognitive and communication issues) as a special group. This will enable special attention to be paid to their needs acutely. It will also enable anticipation of resources that need to be deployed to care for their ongoing needs.

Appendix 6: Recommendations for Possible Research Topics

- ID tagging of children (similar to what is done in hospitals) to get downloadable information to link to their guardians in the future.
- Development / use of bar codes that facilitate information download on the child when power becomes available.
- Other methods of retrieving such data with an informal power source.
- How to link needs with available resources, especially at remote sites and deliver those needs in a timely fashion.
- Study the economic, social and behavioral impact on individuals who spend prolonged periods of time (>6months) in shelters during and following a disaster.