

**Minutes of the First Meeting of the
National Library of Medicine Board of Regents
Working Group on the Disaster Information Management Research Center
May 2, 2011**

The first meeting of the NLM Board of Regents Working Group on the Disaster Information Management Research Center was convened on May 2, 2011 at 9:00 a.m. in the Board of Regents Room, Building 38, National Library of Medicine (NLM), National Institutes of Health (NIH), in Bethesda, Maryland. The meeting was open to the public. The meeting adjourned at 3:00 p.m.

Attendees:

Working Group Members Present

The Honorable Robert E. Windom, M.D., Chair
Dr. Marvin Birnbaum
Dr. Ward Casscells
Dr. James James
Ms. Cathy Norton
Ms. Virginia Tanji
Dr. Bailus Walker

Working Group Members Absent

Mr. Jack Herrmann
Dr. Patrick Soon-Shiong

NLM Staff

Dr. Donald A.B. Lindberg, Director
Dr. Milt Corn, Deputy Director for Research and Education
Dr. Steven Phillips, Associate Director, Specialized Information Services (SIS)
Ms. Gale Dutcher, Deputy Associate Director, SIS
Ms. Stacey Arnesen, Head, Office of DIMRC, SIS
Mr. Jim Charuhas, DIMRC/SIS
Mr. Victor Cid, DIMRC/SIS
Ms. Cindy Love, DIMRC/SIS
Ms. Jennifer Pakiam, DIMRC/SIS
Mr. Ivor D'Souza, Director, Office of Computer and Communications Systems (OCCS)
Ms. Wei Ma, Branch Chief, OCCS
Dr. George Thoma, Branch Chief, Lister Hill National Center for Biomedical Communications (LHNCBC)
Dr. Samir Antani, LHNCBC
Mr. Jerry Sheehan

Consultants and Guests

Dr. Elliot Siegel, NLM Outreach Consultant to the Working Group
Dr. Ken Schor, National Center for Disaster Medicine and Public Health
Mr. John Scott (afternoon), Center for Public Service Communications, Consultant
Ms. Kandra Strauss Riggs, National Center for Disaster Medicine and Public Health

Welcome and Introductions

Dr. Windom called the meeting to order and welcomed the working group members, NLM staff and guests.

Dr. Lindberg also welcomed the members, staff and guests and thanked them for their participation. He complimented the DIMRC activities and described some of the efforts regarding the Bethesda Hospitals' Emergency Preparedness Partnership (BHEPP). He described how NLM was asked to participate due to our expertise in communications & research and to devise a research program for the Partnership.

Dr. Windom asked each person to introduce themselves.

Overview of NLM & Legislative Authority – Presentation by Dr. Steven Phillips

Dr. Phillips provided an overview of NLM including a description of legislative authorities affecting NLM. He also provided an overview of the federal legislation affecting preparedness, response, and recovery. Of significant note was the recent amendment to the Stafford Act in January 2011 to include libraries as critical infrastructure and eligible for temporary relocation if damaged in a disaster. Other critical infrastructure includes police and fire/rescue departments. *Dr. Phillips* also described the Pandemic and All Hazards Preparedness Act that created the Office of the Assistant Secretary for Preparedness and Response in HHS and the recent Presidential Policy Directive for the creation of a National Preparedness System.

Dr. Phillips continued with a description of DIMRC and how it was created by the NLM 2006-2016 Long Range Plan – Charting a Course for the 21st Century. NLM's history of providing information in responding to and recovering from disasters (Bhopal, hurricane Mitch, etc.) was also described. *Dr. Phillips* emphasized the need for evidence-based information in the disaster medicine and public health arena and described the need not only for peer-reviewed journal literature (commercial), but also the non-commercial literature (government documents, technical reports, after action reports, etc.). NLM has made inroads in these areas with the addition of disaster medicine journals to PubMed and with the revamping of the Resource Guide for Public Health Preparedness. In addition, NLM has worked with journal publishers to provide free access to online books and journals in times of disasters via the Emergency Access Initiative. A brief discussion of the role of books versus journals during disaster response followed. *Dr. Birnbaum* indicated that books were often more useful as they summarize and synthesize the information of many experts. Journal articles are often very specific and hard to assimilate quickly. *Dr. Phillips* also briefly described other NLM resources and initiatives. *Dr. Phillips* concluded with the role of librarians as disaster information specialists to support disaster personnel with information management, tools and training.

The role of telemedicine as a next step was discussed by *Dr. Lindberg*. *Dr. Schor* questioned if telemedicine is a type of one-way communication and recommended focusing on bidirectional communication with an enabler in preparedness and response available to identify needs and find ways to meet those needs. He also emphasized the importance of information and knowledge management during disaster response (such as the work Victor Cid was doing in Haiti with the Pan American Health Organization). *Dr. Schor* discussed the role of disaster information specialists to be proactive and to assist disaster/emergency personnel through education/training and knowledge management.

Discussion – Ms. Norton and Dr. Casscells, Discussants

Ms. Cathy Norton described the Woods Hole Oceanographic Institute's (WHOI) role in disasters. WHOI primarily deals with disasters in the clean-up (recovery mode) phase (e.g. oil cleanup & recovery of aircraft, location and recovery of lost atomic weapons off the coast of Spain, etc.). The Marine Biological Laboratory has medical and biological experts focusing on embryology, parasitology, and biomedical informatics. *Ms. Norton* emphasized that information regarding disaster management should not be kept a secret and that better outreach is needed so motivated people would become interested in the field. She showed a map of marine libraries around world - all are vulnerable to disasters, especially flooding as they are in coastal areas and therefore the librarians are already motivated to be Disaster Information Specialists. *Ms. Norton* also described the Global Biodiversity Heritage Libraries (BHL) with 5 clusters on biodiversity around the world that have a project to preserve the biodiversity literature by scanning it. UNESCO is interested in the project. *Ms. Norton* emphasized the need to broadcast out into other spaces where you have motivation for people to help protect their health and citizens.

Dr. Casscells commented that DIMRC was a terrific initiative and raised two points: 1) it is not as well-known as it should be and therefore utilization is not what it should be and 2) utilization is hard. For example, it is difficult to increase web site traffic. Partners are needed to serve as channels of distribution. Partners could include FEMA, Public Health Service (PHS), University of Pittsburgh Supercourse, the military's National Center for telehealth and communications (give out grants). *Dr. Casscells* also noted that Presidential Policy Directive #8 on National Preparedness calls for a unified common language. He suggests using semantic technology to help and that there is no better organization than NLM to do this.

Further Discussion by WG

The discussion continued about the need for a discipline of disaster medicine and public health preparedness. *Dr. Jim James* commented that we still live in our stove pipes (even professionally) and we need to do better. We need a DISCIPLINE of disaster medicine & public health preparedness. This would not be a specialty or something most health professionals would do full time. However, the knowledge, linked to competencies and academic standards are needed across different fields first. He compared this to the (Army MOS - military occupational specialty – this is in addition to regular jobs and is as needed. *Dr. James* indicated that this is not just for the U.S., but needs to be a global system. *Dr. Birnbaum* agreed that a discipline is needed, but emphasized that the information is based on science. The science is available for epidemiology but not necessarily for other subject areas. Little information is available on the impact of interventions. Most data is from case studies. *Dr. James* responded that new science/epidemiology is not needed but need to build on what's there and enhance with new and evolve. *Dr. Birnbaum* indicated that evaluation is important, but can be a complicating factor because people don't want to risk losing their funding if an evaluation is not favorable. He finds that this is a concern among the participants in the global health cluster organizations. *Dr. Casscells* supports *Dr. James'* comments, but not sure how much people want a certificate. Cost may be an issue for people and he suggested that if AMA and others can support the effort to lower the cost of certification, it might help encourage participation. *Ms. Norton* asked if it would help to have DMPH discipline sit with ER discipline to see how competencies overlap? *Ms. Arnesen* inquired about NLM's potential role in this endeavor. *Dr. James* asked about the role of social media. Not in a scientific way, but in terms of a mechanism for communication.

Dr. Birnbaum indicated the need for a framework for the information (particularly the gray literature) to provide structure. He estimates that approximately 70% of the disaster medicine and public health literature is in gray literature (non-journal literature). This estimate is based on his research for his book on the 2004 tsunami. *Dr. Siegel* inquired if there is a potential new role for a conventional journal to help organize this structure? For example, could the journal provide interactive links within an article to relevant resources outside that journal? *Dr. James* suggested a new concept for authoring – the Medical Wikipedia approach – this would allow for multiple contributors and provide a level of peer-review. Social media has shown it can provide some framework. Time and funds are needed.

Disaster Information Management Research Center (DIMRC): Resources and Outreach – Presentation by Stacey Arnesen and Cindy Love

Ms. Arnesen reviewed the objectives for DIMRC and described NLM's role in providing information in times of disaster including the Haiti earthquake and cholera outbreak, the Gulf oil spill, and the earthquake, tsunami, and radiation event in Japan. She emphasized the need for preparedness and the development and training of tools needed in times of disaster such as the Radiation Emergency Medical Management tool (REMM). *Ms. Arnesen* raised the issue of impact and showed the statistics for REMM before and after the nuclear reactor accident in Japan, the usage of the Gulf oil spill and Haiti pages, etc.

Dr. Windom mentioned a recent Wall Street Journal article about popularity of mobile devices. iPhone is #1, followed by androids, and Blackberries. *Dr. Antani* indicated that it may make sense to follow the trends/markets rather than lead in the field of mobile devices as it changes rapidly.

Ms. Arnesen discussed the nature of disaster preparedness, response, and recovery information as "Just-in-time, just-what-I-need information. The medical literature is NLMs backbone but traditionally it's been mostly peer-reviewed journals. NLM includes 7 disaster-focused journals in PubMed and many more emergency medicine journals. NLM needs input from the working group on the gray literature (and its many different formats). This can be very valuable information and although it may not be in a published journal, much of it has some level of peer-review. NLM has funded a small database, the Resource Guide for Public Health Preparedness that provides links to relevant gray literature. NLM has been funding it since 2002, but until recently it has operated independently of NLM. Major changes have occurred since DIMRC's involvement over the past few months and more will occur. We will consider changing the name to reflect disaster medicine and all phases of disasters, modify the scope and coverage, and utilize NLM's Medical Subject Headings to index the articles. At this time NLM is not hosting the full text (just linking to the documents at their source), but that will be considered in the future. Statistics indicate that it is not well known or well used at this time and that more publicity is needed. (<http://phpreparedness.nlm.nih.gov>). DIMRC plans to investigate mechanisms to integrate the disaster literature available from multiple sources such as DHS' Lessons Learned Information Sharing (LLIS.gov), the Responder Knowledge Base, the Homeland Security Digital Library, FEMA, etc.

Dr. Casscells described how a menu of approximately 130 scenarios/categories was developed for FEMA after Katrina. The state governors used these categories to help them decide what they needed. This type of system was helpful.

Ms. Arnesen then described NLM's HazMat/CBRN emergency response tools: WISER, REMM, and CHEMM. The Wireless Information System for Emergency Responders (WISER) contains information on handling chemical, biological, and radiological incidents including a decision support tool to aid in the identification of unknown chemicals. The Radiation Emergency Medical Management system provides health care providers with guidance on the diagnosis and treatment of radiation injuries. It was developed in conjunction with ASPR/HHS, CDC, NCI, and NLM. The newest tool will debut this summer and contains information for first responders, health care professionals, and planners on mass casualty chemical incidents.

Dr. Walker stated that it is important to draw the boundaries between medicine and public health because he thinks the general public doesn't understand the difference. He also asked if NLM had any interaction with the American Waterworks association, as they are also active in disasters.

Dr. Casscells suggested trying to craft the tools in user profiles and to include the Public Health Service. Note: WISER and CHEMM do include user profiles, but not PHS at this time.

Other NLM resources, such as DIRLINE, a database with over 8,500 health organizations. Including nearly 900 agencies involved in disasters; TOXNET; and MedlinePlus were described.

Ms. Arnesen raised the issue of next steps in terms of Information & communications - where do we go from here to leverage current tools, platforms, and social media. How do we evaluate the utility of the technology? She referred to Dr. Nicole Lurie, Assistant Secretary for Preparedness and Response concerning the signal to noise ratio in terms of the usefulness of data from social media.

Dr. Walker asked what the NLM scope is. How far do you go for DIMRC, & where do you stop? It can be difficult to separate medical and health issues related to disaster from other subject areas.

Dr. Corn inquired about FAQs for specific topics?

Ms. Dutcher commented that much of today's discussion has been about response. She reminded the group that we need to know what to do about involvement in preparedness and recovery information, who to partner with, etc.

Dr. James described that at time of H1N1, a study of authoritative web sites for H1N1 information was conducted and - over 100 good sites were identified. He expressed the focus on finding the trusted authoritative sites.

Dr. Casscells indicated that he thinks most people go to Google or Google Scholar for information. A survey needed to see how and where people search.

Ms. Love presented on the role of librarians and libraries in disaster preparedness, response, and recovery. She described who are serving as disaster information specialists - some full time staff, but mostly falls under "other duties as assigned" She went on to describe the wide variety of tasks DIS are doing and their role in between disasters. Ms. Love indicated that the librarian's role is much more on the preparedness side, compared to response. NLM is trying to identify roles for librarians, encourage to them to offer their services, and develop training programs and a continuing education specialization (to be offered by the Medical Library Association). NLM maintains a disaster information outreach listserv for librarians and

information specialists that aims to build a community of practice and build partnerships. She emphasized that the roles for DIS are quite varied and they can work on the ground in a disaster zone or at regular cubicle away from site. NLM recently held a disaster information outreach symposium to further educate librarians about roles they can play in disaster preparedness, response, and recovery. Nearly 200 people attended the event at NLM with over 150 participating via videocast.

Discussion

Ms. Tanji indicated that she thought there must be a way to gather all that info & make it usable by all. She described a library component of Voyager called Primo that may help. She asked why PubMed or MedlinePlus don't do this. What about a disaster Wikipedia? This would allow for the ability to capture the gray literature that is so important.

Dr. Birnbaum indicated that structure is an essential element for gray literature as it is so diverse, however he is not sure which structure is best to adopt. He also indicated that the terminology needs to be organized and simplified as there are over 60 glossaries of disaster terms. Common terminology across disciplines/clusters is NEEDED! ... Who best to do this? WADDEM AMA NLM? He also noted that the use of indicators is important and that we need to think about impact, not just numbers of hits, etc. In addition, we need to think about synthesis - how to synthesize so much into meaningful information and how to move forward. He indicated that chemical and radiation information is really needed. Other softer topics are also needed, such as triage. Dr. Birnbaum emphasized that NLM needs to look at impact – what difference does it make? Also need to focus on who should synthesize information and how to turn data into information into knowledge. Looking at the literature we have today, very little of it has to do with interventions. Need to look at what was done and then what happened. Evidence is based mostly on case reports. Not just look at what was done, but what difference did it make.

Mr. Scott stated that terminology important but historically there's been interplay between engineers (e.g., earthquake) & the health sector. He reminded us that there may be politics involved in terms of who has claim to the terminology. He suggested the need to get the various disciplines/groups together to discuss.

Ms. Norton stated that there are ways to make terminology common among groups. Look for critical points of failure & critical points of success.

DIMRC Continued: NLM Disaster Informatics Research Initiatives

Dr. Phillips described the NLM disaster informatics research initiatives to help hospitals prepare for disasters including tools to assist in managing the surge of patients. Dr. Phillips described the Bethesda Hospitals' Emergency Preparedness Partnership (BHEPP) and how it can serve as a model for other hospital partnerships across the country. The BHEPP video was shown.

Dr. Walker asked if NLM could engage ASTHO in discussion. He also thought the video should be shown more widely.

Dr. Windom described that hospitals need many supplies for disasters and places to store them (ventilators, slides, Geiger contours, etc.)

Ms. Arnesen mentioned that some hospitals- involve libraries in assisting with credentialing of non-staff physicians & nurses.

Dr. James stated that this is hard to think about all this in one state, let alone across state lines and internationally. The big issue is liability. How do you ID & credential people? DHS is using smart cards for verification of responders. Propose a public health security card - through a thumbprint verify someone's credentials on the spot. This is already being done in some areas, but need to get it into the provider and local community practice.

Presentation on NLM Grants including Disaster Informatics Grants - Dr. Valerie Florence

Dr. Florence described the type of informatics activities that NLM is currently funding. For most NIH institutes they fund research on diseases. Information is NLM's disease and NLM funds biomedical information/informatics activities. *Dr. Florence* described the Research project (R01) awards, the ARRA grants, the exploratory/developmental research grants (R21), NLM Resource grants, NLM Applied Informatics grants (G08), and Small Business Innovation Research (SBIR/STTR) grants. She showed the EP awards page and search widget as well as the RePORTER database of all NIH grants.

Presentation on WIISARD – an NLM grant - Dr. William Griswold, University of California, San Diego

UCSD developed triage tags and scanners to assist in triaging victims at a disaster scene. They participated in the Golden Guardian disaster drill in April 2010. A command center was set up according to the National Response Framework Incident Command System (ICS) and the system allowed for identifying the location and triage status of victims. The equipment used for the mass casualty drill is the same as would be used for every day, small incidents. Responders using paper and radio encountered errors and found it to be labor intensive and slow to disseminate the information. The WIISARD system provided tools designed for the user's daily needs so they do not need to change their routine. A supervisor level digital clipboard provides situational awareness for the incident commander and section heads. For reliable communication systems, peer to peer broadcasts were needed to allow users to communicate with each other. They also investigated if drills are worth the extra time and expense. They did demonstrate that the drills showed greater effectiveness by the responders than just classroom training.

For future consideration, WIISARD is investigating crowd-sourcing disasters such as tools by USHAHIDI (mapping, etc.). How the data can be validated (to avoid errors) needs to be investigated. They are also exploring disaster telemedicine since there is a shortage of specialized expertise at disaster scenes. They would like to develop an on-demand expertise network.

Dr. Griswold concluded that cost effectiveness is critical. IT can help, but off-the-shelf systems can fall short. The future lies in interfacing with local communities (crowd-sourcing) and remote expertise (telemedicine).

Areas summarized by Dr. Philips of relevance for the Working Group to provide recommendations to the NLM BOR:

Current activities/funding

Authorization process

Literature

- terminology/dictionary
 - peer-reviewed journal literature vs. authoritative non-journal literature
- organization of gray literature

Collection & delivery technologies

Disaster Information Specialists (DIS)

Conventional vs. social media

Just-in-time & just-what-i-need information

Areas of potential focus:

Disaster planning and preparedness, as well as response

Process & impact evaluation in disasters

BHEPP Model – Reproduction in other communities

Partnership development

- Hospital partnerships (BHEPP model)
- Library and librarian roles in working with disaster/emergency personnel

Disaster Informatics research and development resources

Discussion

Dr. Windom reported that he will meet with legislators and their staff to educate them on the contribution the NLM/DIMRC has made and the importance of disaster health and public health information, as well as communication and informatics research, in emergency preparedness and response.

Dr. Windom inquired about the possibility of making the Office of DIMRC into an NIH Center. A Center is a higher administrative level than an office and has right to transfer funds. He also noted that NLM is the best kept secret. *Dr. Lindberg* replied that NLM has no authorization currently and that authorization is needed for a Center. *Dr. Windom* also noted that NLM is already working on several areas described in the Presidential Policy Directive #8 on a National Preparedness System.

Dr. Birnbaum inquired as to why authorization and appropriation (request for funding) can't occur at the same time. *Dr. Lindberg* discussed the example of the National Center for Biotechnology Information (NCBI) at NLM. This legislation was introduced by Rep. Claude Pepper in the House and Senator Kennedy for the Senate. The legislation can be short, but needs to be part of other authorization or appropriations legislation. NCBI was part of the Health Omnibus Extension Act (HOPE) legislation of 1988 (?). *Dr. Lindberg* explained that very little or new legislation is being issued, but this could be part of any bill that is issued.

Dr. Birnbaum suggested discussing with Senator Harkins staff, as they might be able to add some DIMRC language to the Pandemic and All Hazards Preparedness (PAHPA) legislation. *Mr. Scott* suggested talking to Senator Mikulski and her staff. *Dr. James* further emphasized the importance of trying to add a paragraph about DIMRC to the PAHPA reauthorization legislation.

Dr. Windom thanked the Working Group for their attendance at the meeting and their thoughtful comments. He asked that they all consider mechanisms for encouraging authorization language for DIMRC. The meeting was adjourned at 3:00 p.m.