The National Institutes of Health (NIH) Disaster Research Response (DR2) Program hosted a federal interagency meeting on March 10, 2017 at the NIH Campus in Bethesda, MD. The meeting sought to explore federal efforts for enhancing its collective ability to conduct timely research in response to disasters. Representatives from across the federal government shared information about recent activities, learned about ongoing efforts and plans among federal partners, and identified opportunities for progress and collaboration on creating a national platform for disaster research.

Following the welcoming and initial presentation by the HHS Office of the Assistant Secretary for Preparedness and Response (ASPR) agencies highlighted their disaster research programs, activities, and resources related to issue identification and prioritization, research processes, and infrastructure to support implementation. ASPR has recently expanded its science preparedness personnel in order to enhance its role in coordinating public health preparedness and response. While most of the focus is on the more frequently occurring disasters, ASPR noted that they are also looking at economic impact research and low occurrence/high consequence events to study. ASPR continues to look for opportunities to conduct and fund disaster research, such as it did during Hurricane Sandy and during the Flint, MI water contamination crisis, where ASPR played a role in coordinating the federal efforts. ASPR is also interested in using science to inform improvements in the disaster response infrastructure. While Stafford Act events get the bulk of the attention, there continue to be public health emergencies that can and should be researched for valuable information.

Following the ASPR presentation, NIEHS presented a unified vision for disaster research and described a model for achieving that vision based on 4 pillars—Empowerment, Engagement, Training, and Funding and 3 cross-cutting principles—collaboration, coordination, and communication. The pillars support a science based platform of policies, frameworks, and guidance. This platform, in turn supports bench, field, and operational disaster research. Ultimately, the vision is for a goal of a “national framework for disaster response research” to be developed to serve as the construct or strategy by which disaster research is organized and coordinated, much like the National Response Framework. The ensuing discussion was generally supportive of this model and it served as the framework for the remainder of the meeting.

The new National Academies Standing Committee on Medical and Public Health Research During Large-Scale Emergency Events- Coordinates with units across the National Academies of Science, Engineering, and Medicine to provide a venue for discussion of issues related to short- and long-term strategic planning and how best to perform medical and public health disaster science research activities during a significant event or disaster. The Committee is currently funded by ASPR, NIH, CDC, USGS, and NSF. The standing committee, consisting of federal, academic, and private industry members, is involved in the planning and development of ‘fast-track’ post-disaster research activities to convene experts on specific disaster related topics rapidly following an event, such as it did during the Ebola virus disease outbreak. The committee can rapidly convene governmental, academic, and private industry stakeholders to discuss issues and identify research approaches and priorities on an as-needed basis. Questions were raised about the how the Standing Committee would measure its impacts related to its activities and efforts. For example, those involved in the Ebola response strongly indicated that DHS benefitted from having
academic experts assist with generation of a research priority list. PAHO used Committee findings to develop research surveys and NSF funded projects based on the Committee’s meeting outcomes. All agreed that the meetings of the Committee have advanced specific research in a timely manner during major outbreaks. The Committee is now looking at ways to have infrastructure in place to reduce delays in meetings for future disasters.

- **DOI Strategic Sciences Group (SSG)** was established in 2012 within the Office of the Secretary, DOI. The SSG provides DOI with a standing capacity to rapidly assemble teams of scientists to construct interdisciplinary scenarios of environmental crises affecting DOI resources. The SSI advises DOI decision-makers based on these scenarios, which helps them consider options and make objective-based responses. This approach is also being used proactively for potential hazards and threats as a means of planning future mitigation and response actions. Additionally, the SSG has formed relationships with a number of professional societies to help identify subject matter experts that can be called upon to assist with SSG efforts in response to a crisis. Through the development and application of science-based scenarios, the SSG assists strategic response, mid-term recovery, and long-term restoration.

- **National Center for Disaster Medicine and Public Health** is operating under new leadership and is currently in the midst of an internal review of its mission and operational strategy. They are developing two scoping exercises that look at disaster science in all phases of the disaster cycle and hope to utilize the findings in developing their research agenda.

**IRB AND ETHICS IN DISASTERS**

NIH Office of the Director presented information about the NIH Public Health Emergency Research Review Board (PHERRB). The PHERRB was established in 2012 to provide centralized and rapid institutional review board (IRB) review of public health emergency research protocols. The PHERRB can be used for:

- Public Health Emergency protocols conducted, supported, or regulated by HHS, and on a case by case basis - other agencies and sponsors;

- Protocols are generally multisite; single site studies may be reviewed on a case by case basis

- Protocols subject to 45 CFR 46 and/or 21 CFR 50 and 56

The group questioned the value of previously prepared vetted protocols given that situations evolve and the protocols may need substantial modifications to be useful for a new event. Overall, the pre-vetted protocols were recommended as they appear to help speed up and support needed IRB reviews more rapidly.

In 2015, NIEHS created the Rapid Acquisition of Pre-and Post-Incident Disaster Data (RAPIDD) protocol: a disaster research protocol that has been pre-approved by the NIEHS IRB to minimize the time to the beginning of a study and that can be downloaded and customized for disaster research in a number of scenarios. As part of this ongoing effort, NIEHS formed a working group and held a workshop on ‘Special Considerations for IRB Review of Disaster Research’ in July 2016. During this meeting the group identified particular elements of disaster research for an IRB to consider when reviewing a protocol. These include: Type of disaster, magnitude and aftermath, type of research (interventional vs natural history study), the appropriateness of the risk/benefit ratio, the sensitivity of the research to immediate needs of a subject and the subject’s status, relationship and stability. A publication is forthcoming. Additionally, the group is continuing to move forward and is looking to create a training and toolkit for (Non-NIH/HHS) IRB’s that may be involved in the review of disaster research protocols.

It was noted by NIOSH that they are currently working with the NIOSH IRB to create an expedited review process for disaster responses within their Agency.

**INFRASTRUCTURE TO SUPPORT IMPLEMENTATION**

OMB clearance was also discussed. For many of the participants, OMB clearance of data collection surveys was noted as a significant impediment to rapid post-disaster research. The Paperwork Reduction Act is a time-
consuming process that can take up to 6 months to complete. While OMB is willing to review questionnaires in advance, many felt that the process prevents many from undertaking research. As noted below, the 21st Century Cures Act exempts certain NIH research from OMB clearance as well as research falling under ASPR in response to identified situations. All felt that this was a step forward, but needs further definition and clarification for the federal agencies.

The NIH DR2 program introduced a concept called the DR2 Café- the intent of which is to create a ‘one stop shop’ or ‘Café’ to support disaster researchers from any field. The goal is to create a robust publicly accessible website/interface for researchers to quickly obtain research process information, tools (e.g., survey instruments, protocols, biospecimen collection data, environmental sampling methods, etc.), guidance, forms, and training in an ‘ala carte’ fashion to support rapid development and performance of their investigations. The tools and resources currently available on the DR2 website include disaster specific trainings, protocols, questionnaires and reference materials. It is hoped that the DR2 Café will further advance and strengthen the available information to a wider audience of researchers that can not only empower research during disasters but in general. Efforts are also intended to help address ongoing concerns that disaster researchers deploy to the field without pre-approved/validated surveys and do not get data that is scientifically sound and does not lead to useful conclusions. Using data collection tools that have been validated and providing improved and consistent training and information to researchers were considered to be ways to prevent bad science and greatly improve disaster research responses going forward.

Attendees shared additional tools and programs that support research implementation including:

- **National Library of Medicine (NLM) Disaster Information Management Research Center**- offers several resources for disaster researchers, such as Disaster Lit, a database of links to free disaster medicine and public health documents. Additionally, NLM will be housing repositories of literature and information from other federal agencies including NASA, NIST, EPA, and DHS. This will create a vastly improve capability to support a “DR2 Café” concept of one-stop shopping for researchers to find and use information they need during an emergency. Additionally, NLM is developing new approaches based on “Common Data Elements” that could transform our ability to rapidly generate surveys, questionnaires, and protocols for research.

- The **NIH DR2** has a repository and website consists of research questions and assessment tools that have been used in past events that can be used and searched by researchers. NIH has also posted rapid disaster research protocols from grantees to the site. The NIH DR2 has recently been asked to host the NOAA-sponsored Environmental Disaster Data Management (EDDM) repository which consists of methods related to the collection of biospecimens and methods for collection of environmental samples. Efforts are now underway to combine these repositories and make the information available to the research community.

- **National Oceanic and Atmospheric Administration (NOAA)**- has a rapid research funding mechanism that consists of cooperative agreements with institutes that have long standing relationships with NOAA. They support the ongoing efforts of the National Centers for Information on observational data on climate, fisheries and specimen preservation, etc.

- **NIOSH’s Disaster Science Response Researcher Program (DSRR)**- Focuses on worker safety and health. NIOSH has undertaken several significant disaster research projects related to disaster science: self-assessment of PPE in the event of public emergency; development of exposure assessment planning during the first 72 hours following a disaster; and modeling radiation exposure of first receivers in the event of a RDD event. NIOSH continues to enhance Emergency Responder Health Monitoring and Surveillance (EHRMS) by developing an information management system that facilitates field work by those using Epi-Info for data collection.
EMPOWERMENT

- Local stakeholders in affected communities are an important component of disaster research. In each of the DR2 exercises, community/responders expressed a willingness to help to collect data. How research incorporates local data in a science response and response process, is important. During the planning stage, state and local stakeholders MUST be included to improve understanding of community concerns, support for data collection efforts, participation in research, “groundtruthing” of research, and assistance with risk communication efforts, acceptanceability, and credibility of findings and resultant decisions.
- Efforts to include community engaged research/citizen science during the Gulf Oil Spill, Superstorm Sandy, etc. have been invaluable and appear to improve recovery and resilience. Federal agencies have had differing experiences over the past several years with respect to these efforts. The group noted that the federal agencies need to continue to develop tools, strategies, and approaches for supporting community engaged research/citizen science in response to disasters as part of all planning efforts. The National Science Foundation will be hosting a workshop on citizen science and will share details when plans are further along. Existing resources developed for community engaged research/citizen science need to be more widely shared with researchers, including Public Health Service (PHS) officers, who are usually deployed to disaster sites.
- It was also noted that mental health issues can occur with deployed personnel and others involved in the research responses and that resources need to be available as an integrated part of these activities. It was also noted that physical and mental health resources and referral systems need to be available for participants of any studies that have been impacted by the disaster.
  - ASPR posed the question of providing mental health resources and training to all responders, including citizen responders who might be exposed to events that have downstream mental health consequences. An example is the Medical Reserve Corps which utilizes over 200,000 volunteer responders, yet provides little mental health training.
  - SAMHSA also noted their role in response and asked to be considered when mental health research is being considered. They do not perform research, but provide mental health services but have contacts at the state and local levels and can provide expertise.

FEDERAL COORDINATION

- Several existing regional agencies can serve as platform to engage state and local stakeholders, such as ASPR Regional Emergency Coordinators, Regional HHS Offices
  - Federal Regional Councils exist to coordinate across agency lines and they know who the Federally funded grantees are within their boundary.
- The 21st Century Cures Act, which changed PRA requirements for some NIH and HHS studies, may introduce new efficiencies for disaster research studies.
  - HHS ASPR and NIH are working to understand the new changes and develop new guidance and procedures for the impacted research communities. CDC researchers were especially interested in understanding how these changes could benefit their capacity to more rapidly implement investigations, etc.
- Impacted communities must be considered during any research response—ensuring that they are not asked the same questions by different agencies. This means better coordination and integration for research and response organizations as well as emphasizes the importance of the OMB clearance that will reduce survey fatigue of affected populations.
  - Importantly, researchers, as well as responders need to be invited into the community to assist. This improves the chances that research activities are coordinated and integrated with other
activities and local problems are addressed by the research. Including locals in the planning phases of any research improves the chances of getting an invitation.

- Participants recommended that a platform for ongoing engagement and exchange, similar to the ASPR SPIRIT, be created across agencies and departments to help coordinate the existing efforts, including sharing information regarding funded disaster research programs and related activities.
- The National Institute of Standards and Technology (NIST) teams have existing relationships with federal and academic partners and they deploy together: HOT teams are mixes of NIST staff and academic/engineering experts. They have an MOU with the FEMA Mitigation Assessment Team and NIST deploys with them.
  - HOT teams are looking to standardize the information collected when they deploy. They don’t collect human data but can work with those who do.
- DHS, NIST, NIH and CDC have arrangements with academic centers and would like to engage them more in disaster research, training, and funding.
- USGS conducts disaster research related to environmental health exposures as well as infectious disease, in cases that may be related to environmental causes of disease. They have a series of lessons learned from scenarios that can help inform future research and response.

**TRAINING**

- There is a need for training for disaster scientists to ensure safety before deployment
  - NOAA, NIST, and CDC all have developed training programs for their researchers in order to have a pool of trained researchers who can be readily deployed within hours of an event.
  - NIEHS Worker Training Program (WTP) has been providing just-in-time training for disaster workers for many years and has created a new Field Deployment Guide for Disaster Researchers that can be shared among federal partners.
- The National Weather Service has fire investigation teams that deploy to investigate fires. They require constant training and preparedness and are integrated with ICS during an event. Their model could be used for researchers in other fields for training and deployment.
- Participants recommend research agencies consider partnering and collaborating with other agency programs that do not have research mandates to better understand the impacts of disasters.
- A working group was recommended to be formed to look at harmonizing existing training for deployed researchers.

**FUNDING**

- Attendees noted that Agencies should be better prepared to take advantage of congressional supplemental appropriations in response to specific emergencies while waiting for more strategic frameworks and policies to be developed.
- CDC is exploring the use of a Broad Agency Agreement that will serve as a ‘cross center’ mechanism that any part of the CDC can use during an emergency. The BAA was used and while a step forward in rapid funding, planning took 506 months and the goal is to reduce the timeline to only 2 months.
- There is a need for more strategic funding of research, especially to ensure the continuity of funded university programs.
  - NOAA (through Coastal Resiliency Programs) has cooperative institute relationships with universities around the country. In a response, these institutes can be more quickly supported with funds.
  - DHS University Programs have 11 Centers of Excellence funded through cooperative agreements. They are highly collaborative and involved in communities. These Centers and their affiliates can also be responsive.
Participants recommended that a platform/working group for ongoing engagement and exchange be created across agencies and departments to help share information regarding funding mechanisms, new opportunities of funding for disaster research, activities of existing research centers, and ongoing efforts to promote disaster research.