



National Institute of Environmental Health Sciences  
*Your Environment. Your Health.*



# NIH Disaster Research Response: Translating Lessons Into Action

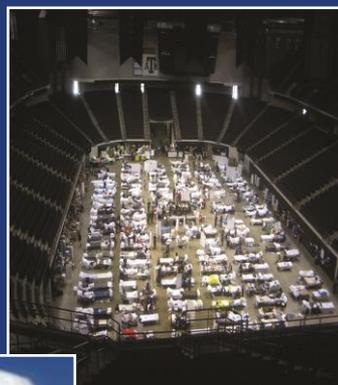
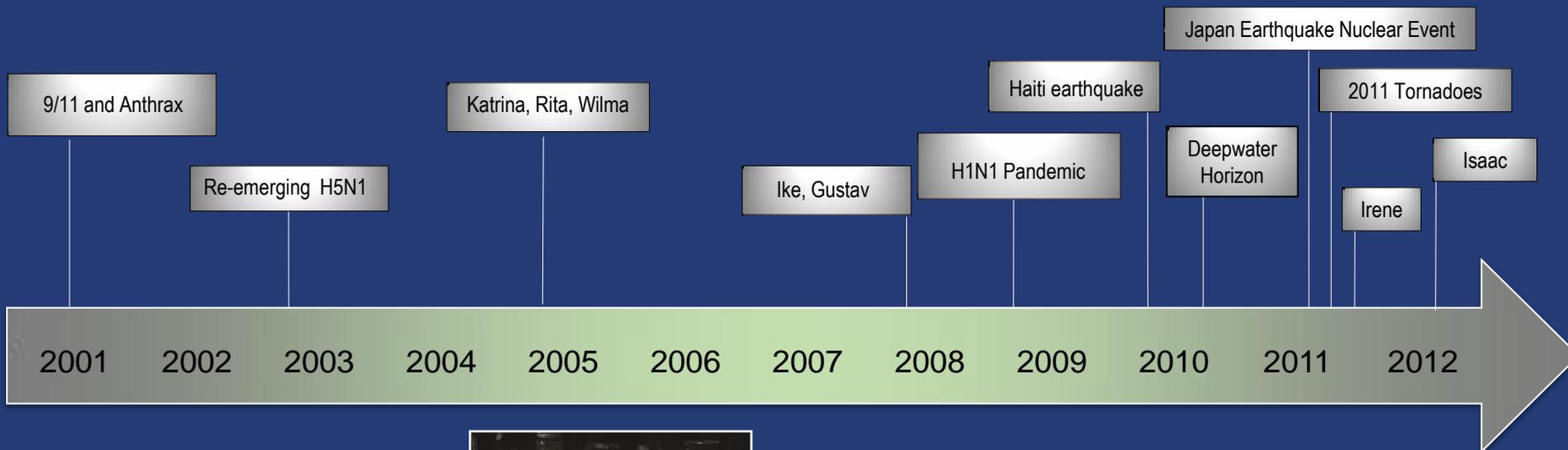
## PEPH Public Health Disaster Research Response

### September 19, 2014



# Events come in all shapes and sizes

## Environmental Health a part of most!



# World Trade Center 9/11/01



Widespread Contamination

Complex Mixed Exposures

**Study: 27,500 Responders\***

- Asthma 28 %
- Sinusitis 42 %
- Lung Tests 42 %
- PTSD 9 %
- Panic 8 %
- Depression 28 %

\*Wisnivesky et al, 2011. Lancet. 378:9794:888-897



# Limited Health Studies on Oil Spills

- 38 supertanker oil spills in past 50 years
- Only 8 studied for health effects, all but one cross-sectional or very short term

	<u>Barrels of Oil</u> (1 B = ~ 40 gallons)
1989 Exxon Valdez, USA	270,000
1993 MV Braer, UK	620,000
1996 Sea Empress, UK	525,000
1997 Nakhodka, Japan	>44,000
1999 Erika, France	146,000
2002 Prestige, Spain	460,000
2003 Tasman Spirit, Pakistan	270,000
2007 Hebei Spirit, South Korea	73,000
<b>2010 Deepwater Horizon, USA</b>	<b>4,900,000</b>
- Dispersant Use > 1.8 M gallons	



- Exposure Assessment:
  - only 1 study had estimates of exposure (used surrogate measures e.g. distance from spill)



# NIH Funded Gulf Oil Spill Research



## Intramural Research



## Toxicology Research



## Extramural Research



## Worker Training *Oil Spill Cleanup Initiative*

## GuLF STUDY (Gulf Long-term Follow-up Study)

- **Prospective study of 32,762 adults involved in oil spill clean-up or support**



- Enrolled March 2011 to March 2013
  - Baseline telephone interview on clean-up jobs, symptoms, health
  - **In-home clinical assessment and biospecimen collection – 11,210 from Gulf states**
- Followed 10 or more years
  - Telephone interview every 2-3 years
  - Subgroup with repeated mental health and resiliency assessments
  - Linkage to vital records and cancer registries
- Comprehensive clinical exam (~4,000 from AL, LA) started 8/14

## Deepwater Horizon Consortium

- **5-year \$25.2 M program**
- **Four university/ community partnerships**
  - Tulane
  - LSU
  - Univ. of Florida
  - Univ. of Texas Medical Branch
- **Steering group leadership**
  - Includes GuLF STUDY
  - Input from NTP
- **Distinct populations & foci**
  - Women and children
  - Pregnant women
  - Cultural/ethnic minorities
  - Seafood safety
- **Shared approaches**
  - Seafood
  - Resiliency
  - Population studies
  - Community outreach and dissemination

## Elk River WV Chemical Spill, Jan. 2014

### *Is it really safe? How can we prepare for the next one?*

- ~10,000 gallons of 4 methylcyclohexane methanol (MCHM) + polyglycol ethers (PPH) leaked into Elk River
- No water for over 300,000 residents, affecting some for more than a week
- About 500 patients seen in response
- Missed opportunity to assess exposures and health impacts
- **Currently:** CDC looking at surveillance opportunities and NIEHS/NTP developing toxicology studies

**Issue: No toxicology/health data >50,000 chemicals!**

**How can we get rapid toxicology information?**



# Disaster Environmental Health Research Issues

- Building on acute response platforms (surveillance, cross sectional studies)
- Ad-hoc, convenience based collection of health and env. data
- Missing Data: baseline and longitudinal data
- Exposure data not collected/measured to understand effects
- High risk groups: pregnancy, elderly, pre-existing illness
- Lack of toxicity / health data for exposures, especially mixtures
- Minimal community engagement



## Disaster Research Response (DR2) Project Genesis

- **National Biodefense Safety Board Recommendations (Apr, 2011)**
- **Sep. 2012 NIH/ASPR Federal Partners Meeting: Identified Areas of Concern**  
Funding, IRB/OMB, Data collection tools, trained research workforce, infrastructure support, and community engagement
- **Ongoing Lessons: research too slow and critical data is perishable!**
  - **H1N1 Response-** treatment research, IRB issues
  - **DWH Oil Spill-** 9 months to start GuLF Study
  - **Hurricane Sandy-** 11 months to fund extramural efforts

***“Timely research is critical to prevent injury & illness and support recovery”***

Lurie, Manolio, Patterson, Collins, Frieden. NEJM Mar 2013:



# Key components to ensure robust science response



## Components

## Making it operational

**Rostered experts in research design, technology, and topical areas of concern**

**Identify and roster experts, including modelers; plan for 'ready reserve'**

**"Science response" is part of core response plans**

**Amend planning documents; consider organizational structure and pre-scripted mission assignments for science**

**Identification of knowledge gaps and research questions**

**Prioritize, assess feasibility, and recommend which to pursue**

**Generic and scenario-specific templates and protocols**

**Pre-approval of core survey documents; pre-scripted clinical protocols and minimum data set**

**Rapid IRB review & oversight mechanisms**

**Establish PHERRB, modify the Common Rule, grantees commit to faster review**

**Rapid funding**

**Implement administrative changes/mechanisms to enable**

**Registries and networks for studies**

**"Registry in a box"; add capabilities for baseline surveys & specimen collection**

**Involvement of affected communities**

**Establish mechanisms to directly engage community to discuss concerns; share findings**

# NIH Disaster Research Response (DR2) Project

## Project Started Aug. 2013 and is ongoing

*Pilot project to help galvanize and accelerate needed infrastructure as part of a larger HHS Effort*

### Objectives

1. Central repository data collection tools & research protocols
2. NLM public website: “Disaster Research Responder”
3. **Rapid Data Collection Capability**: baseline epi., clinical, & biospecimens
4. Environmental Health Research Response Network (**EHS Network**)
5. Training intra/extramural disaster researchers
6. Share & Integrate: HHS/federal response & recovery frameworks
7. **Toxicology Support information and testing**
8. **Environmental Data to go with human health information**

# Repository of Data Collection Tools

## Surveys, Questionnaires, Protocols, Guidance, Forms

- **Tools** to help establish **early baselines & cohorts** for research
  - **Search:** NIEHS studies (e.g., DWH), literature searches, CDC, USCG, Others
    - 450 research tools evaluated (rosters, epi-data, clinical forms, etc.)
    - ~200 tools selected for initial inclusion in database
  - **Menu:** selectable categories and items (mold, respiratory, mental health)
- **Metadata**
  - Ease of use, length/time, differing languages, history of use and references
- **Implementation guidance & forms** (e.g., consent forms, clinical testing)
- **Pre-approval by NIEHS IRB & OMB** to the extent possible
- **Useful to researchers regardless of federal response**
  - e.g., local events, tornados, wildfires, factory explosions



# Disaster Research Response Website

## National Library of Medicine (NLM)

- Website to host the data collection tools repository (>160 currently available)
- Addition to **Disaster Information Management Research Center**
- Publically available information to support research response
  - Facilitates research in the absence of Federal Disaster Declarations

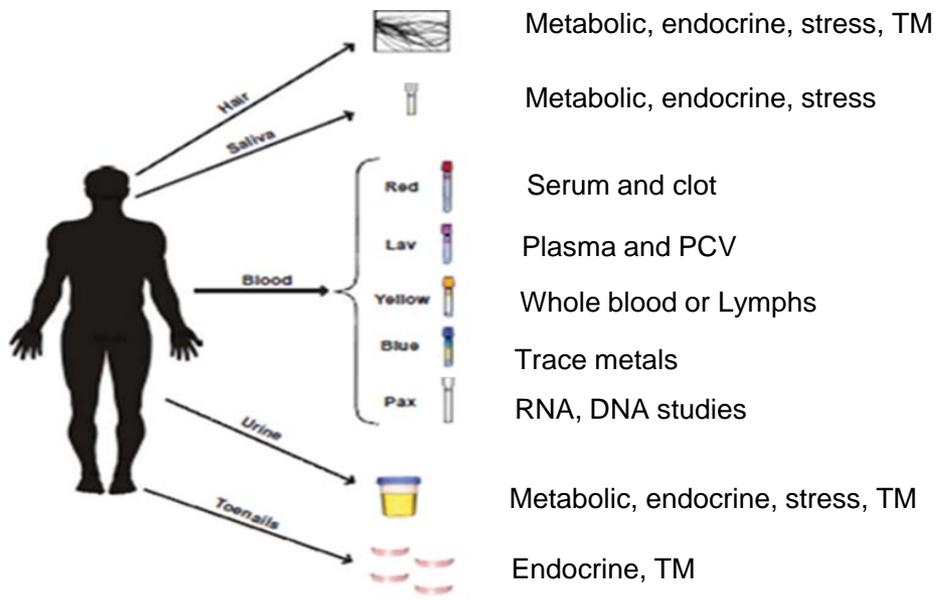
The screenshot shows the top navigation bar of the website with the U.S. Department of Health & Human Services logo and the URL www.hhs.gov. Below this is the header for the Disaster Information Management Research Center (DIMRC) and the National Library of Medicine (NLM). The main content area features a breadcrumb trail: SIS Home > DIMRC Home > NIH Disaster Research Response Project. To the right of the breadcrumb trail are text size options (S, M, L, XL) and a Share button. Below the breadcrumb trail is a list of links for the NIH Disaster Research Response Project, including About the Project, Background, Project Goals, Project Components, NIH Coordination and Collaboration, Stakeholder Opportunities, Timeline and Upcoming Events, Sustainment of Project, Previous NIH Disaster Experience, and Contact Us.

# NIEHS Rapid Response Data Collection Team

- **Deployment of Intramural Clinical Program Assets** (support contract)
  - Baseline/early data collection, medical tests, & biospecimens
  - Cohort development, contact information, etc.
  - Data & specimens for use by NIH, CDC, academia, and others for longer-term research
- **“Plug and Play”** protocol with pre-existing **IRB & OMB reviews**

**New NIEHS IRB: “Best Practices for Disaster Research”**

## Possible Biospecimens



# Env. Health Science (EHS) “Research Response Network”

## National EHS "Network" for future threats and disasters

- **Who:**
  - **Government** agencies (federal, state, local)
  - **Academia** (NIEHS funded centers & grantees)
  - **Community** and Worker partnerships

### Health and Hydrofracking –

#### Exposure to Airborne Unconventional Natural Gas Drilling Chemicals in Appalachian Ohio

- Erin Haynes (Cincinnati); Kim Anderson and Laurel Kincl (Oregon State)



- Determine volatile organic compounds before & during UNGD
- Personal passive sampling devices.
- State-of-the-art mobile exposure device
- Target: rural Appalachian Ohio

**NEW ASPR, NIEHS, etc. Project:** *IOM to pull together experts for disasters*

- **What:** “Working with our partners to...”
  - Help develop and prioritize the DR2 tools, website, training materials
    - Continuous feedback loop to create useful products for the research community
  - Forum to evaluate & improve “research response” concepts & objectives
  - Improve synergy & participation among EHS community, incl. “citizen science”
  - Develop a U.S. network of trained EHS researchers to assist in disaster responses

# Research Responder Training & Education

- **Training & Education** “those involved in research/data collection”
  1. National response plans & HHS mechanisms
  2. Training to use DR2 and other data collections tools, protocols, etc.
  3. Site/Situation Health and Safety Issues (just in-time training)
- **Training Exercises** on identified scenarios & issues

## 4/7 Port of Los Angeles Training Exercise

- **USGS Tsunami Scenario**
- **140 people involved: fed, state, academia and community**
- **Evaluate DR2 Project concepts and support**
- **Discussion: integration, issues of concern**



# NIEHS Disaster Research Response Looking Forward

1. **Data Tool Improvement**: build on DR2 Repository and NLM Website, Training
2. **RAPIDD Protocol**: for health data collection (IRB & OMB approvals / issues)
3. **“EHS Network”**: weave together interested partners to collectively create this
4. **Exercises** to assess our strategies, tools/protocols, and training (e.g., IRB/PHERRB)
5. **Environmental data** collection to go with health data!
  - Explore role of new technologies, social media, and “citizen science” in research
6. **Toxicology information and data**

**DISASTER  
RESEARCH**



**Communal  
Development**

**NIH**

**ASPR**

**CDC**

**IOM**

## **Disaster Research Response Workshop: June, 2014\***

### ***“Enabling Public Health Research During Disasters”***

- **Build a broader network**
- **Frame a national research agenda and action items**
- **Integrate research into existing response structures**
- **Identify critical research needs and priorities**
- **Identify obstacles and barriers to research**
- **Discuss structures and strategies needed for deployment**
- **Share ideas, innovations, technology to support research**
- **Explore data collection tools and sharing mechanisms**

#### **Upcoming Events**

APHA New Orleans Nov. 2014

GoMRI Houston Feb. 2015

*\*IOM Report available by November 2014*



National Institute of Environmental Health Sciences  
*Your Environment. Your Health.*

# THANK YOU! QUESTIONS?

For more information contact: **CAPT Aubrey Miller, MD, MPH**  
[miller.aubrey@nih.gov](mailto:miller.aubrey@nih.gov)

Or email the DR2 Staff at:  
[dr2@niehs.nih.gov](mailto:dr2@niehs.nih.gov)

Project Webpage  
<http://disasterinfo.nlm.nih.gov/dimrc/dr2/disasterresearch.html>

