



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

# **Citizen Science and Community-engaged Research:**

**The importance of building the capacity of all project partners**

**Liam O'Fallon**  
**Program Analyst, Population Health Branch**

**May 19, 2015**



# The National Institute of Environmental Health Sciences

## Mission

The mission of the National Institute of Environmental Health Sciences is to discover how the environment affects people in order to promote healthier lives.

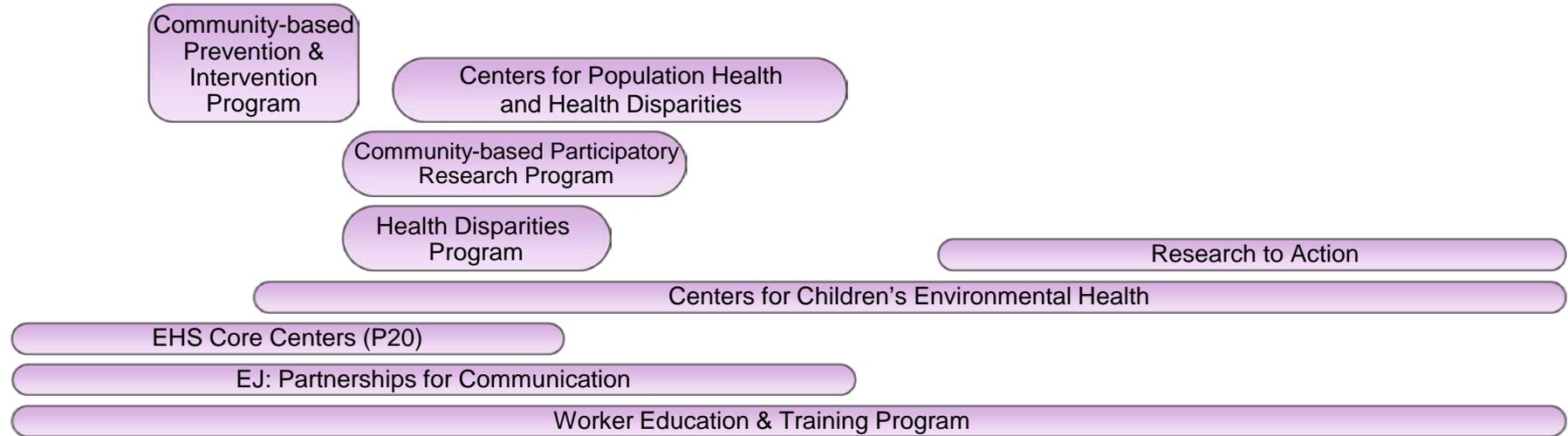
## Vision

The vision of the National Institute of Environmental Health Sciences is to provide global leadership for innovative research that improves public health by preventing disease and disability.

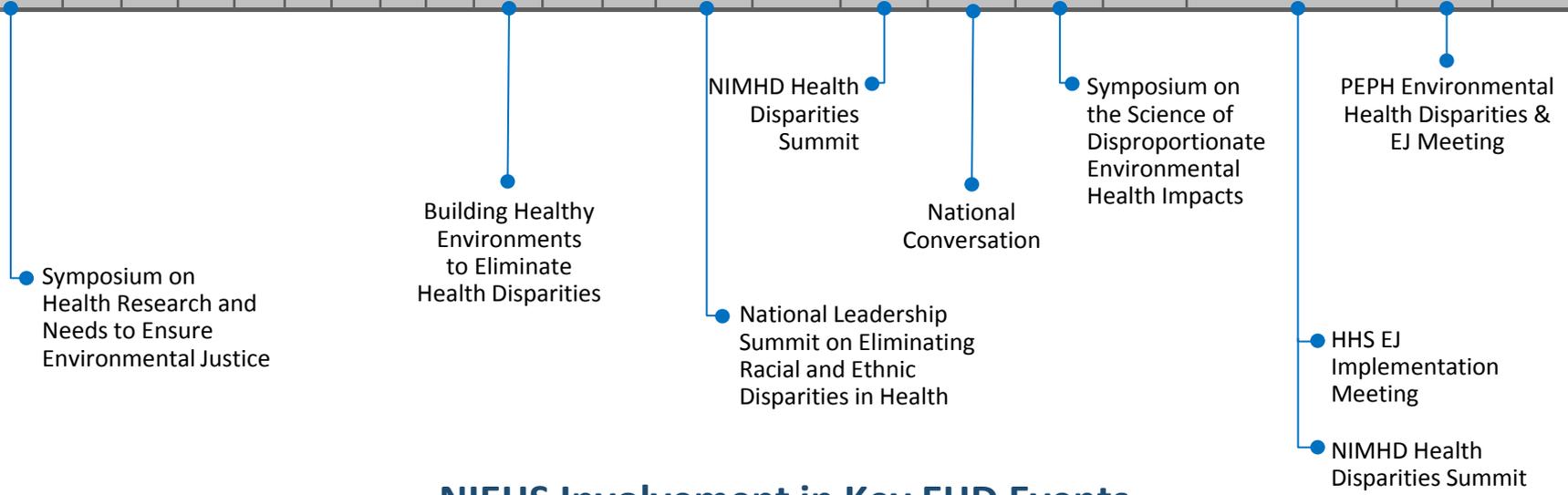




## NIEHS Programs Fostering Community-Engaged Research (CEnR)



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### NIEHS Involvement in Key EHD Events

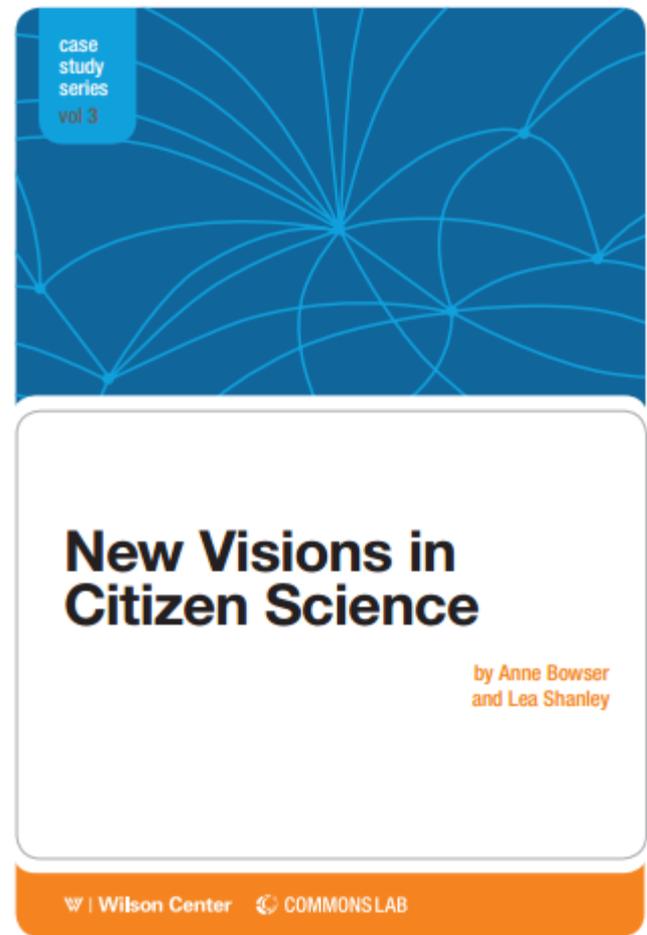
# Value of Community-Engaged Research

- Advance the research agenda
- Strengthen commitment to partnerships
- Bolster youth engagement
- Develop next generation of EHS researchers
- Increase diversity of EHS researchers
- Advance use of evaluation tools
- Build the capacity all partners
- Raise the environmental health literacy of community partners in the research, and
- Raise the environmental health literacy of researchers in culturally sensitive methods for translation of findings.



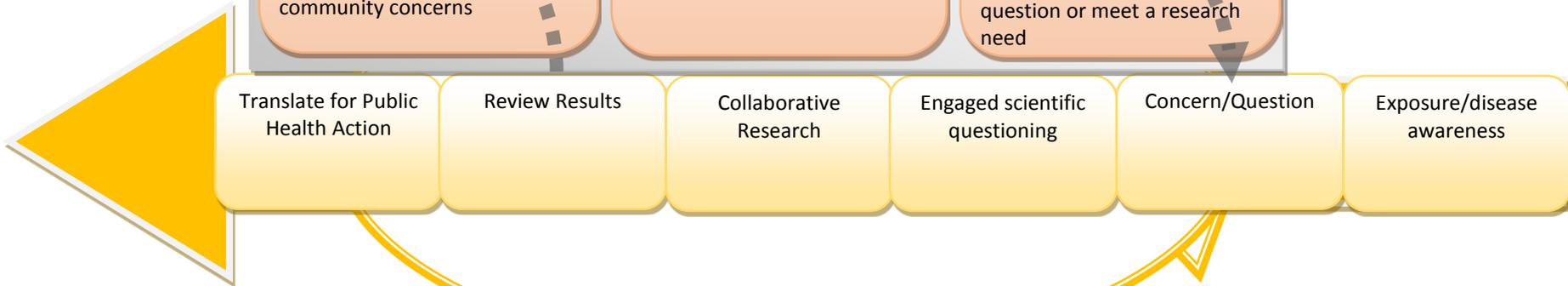
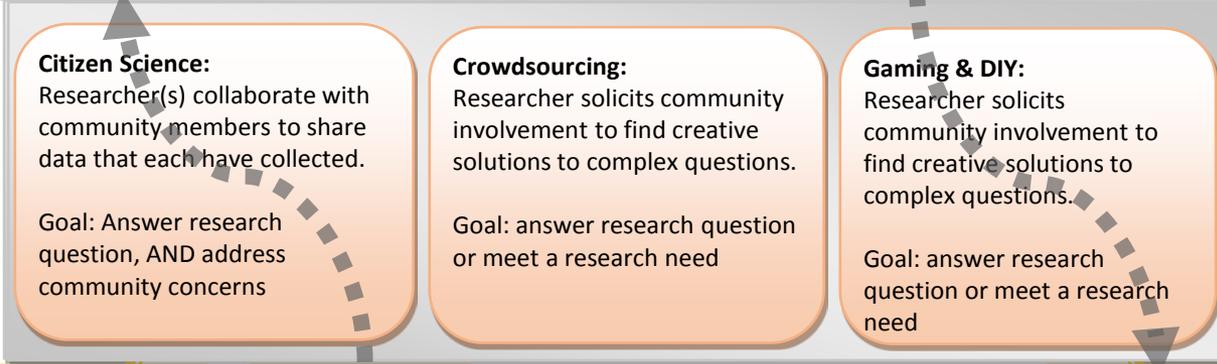
## Recent Emphasis on Citizen Science

The Preview Report for the Second Open Government National Action Plan, released October 31, 2013, specifically states that the United States will commit to **"harness the ingenuity of the public by enabling, accelerating, and scaling the use of open innovation methods such as incentive prizes, crowdsourcing, and citizen science within the Federal Government."**



# Community Engagement & Citizen Science: Parallel Frameworks

**Research Enterprise  
Includes CEnR**



**Citizen Science Enterprise**

## Commonly Identified Challenges

### Community

- Motivation
- Skills
- Tools used
- Scientific literacy
- Education

### Researcher

- Ethics
- Subject protection
- Cultural competency
- Communication skills
- Conflicts of interest

**Trust**

# Application of Citizen Science in EHS

- Exposure Science
- Environmental Health Disparities
- Big Data
- Sensor Development
- Emerging Issues
- Disaster Response

National Institute of Environmental Health Sciences
Environmental Factor, January 2014

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**Validating civic perspective, grassroots resources for environmental science**

*By Joe Baltrity*

Research by members of the public can meet the rigors of science and help advance environmental health efforts, according to [Sara Wylie, Ph.D.](http://www.northeastern.edu/socant/faculty-and-staff/sara-wylie-2), (<http://www.northeastern.edu/socant/faculty-and-staff/sara-wylie-2>) assistant professor of anthropology at Northeastern University. Wylie visited NIEHS Dec. 9 and presented a seminar titled "Toward a Civic Science: Putting Tools for Rigorous Research into Public Hands."

"[I'm] really trying to show how changing the tools that we use for science, how building online databases for gathering community experiences, and then how expert analysis of data could produce a responsive network for community-based environmental monitoring," Wylie said.

Wylie outlined what she called a civic approach to environmental health research, with people on the front lines becoming directly involved in doing rigorous science. Using such devices as balloons, modified consumer cameras, and free-source software, the end results of a grassroots approach can include better images of oil spills, more epidemiological data on endocrine-disrupting chemicals, and more thorough monitoring of well water.

Listen as Wylie describes her concept of civic science and the ways today's tools can be modified to encourage popular, grassroots research (01:45)

[Listen Now \(1MB\)](#)

[Transcript \(72KB\)](#)

**Tools in the hands of those closest to the sources**

What started as development of an inexpensive way to make satellite-like maps, using helium balloons and digital cameras, evolved into a resource platform called [Public Lab](#).

Wylie pointed out how her research projects connect to NIEHS strategic goals 5-8. (Photo courtesy of Steve McCaw)

A balloon map of the Gulf oil spill in Wilkinson Bay, La., shows broken booms better than satellite images can. This kind of mapping can also be integrated with satellite images and Google maps. (Photo courtesy of Public Lab)



# My Air My Health



National Institute of Environmental Health Sciences  
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# Project Highlights

# Exposure Science

- **Air Pollution**

- Barrio Logan & National City
- Los Angeles

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**Building a co-created citizen science program with gardeners neighboring a superfund site: The Gardenroots case study**

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- **Soil Contamination**

- Arizona
- New York
- South Carolina



Photo by Ted Soqui from article in L.J. Weekly, "Black Lung Lofts"



Photo courtesy of Urban Environment Program, Cornell University Cooperative Extension-New York City

# Environmental Health Disparities

- **Tribal Communities**

- Yupik, AK
- Navajo Nation, NM

- **Farmworker Communities**

- Migrant Communities, Florida
- Immigrant Communities, Washington



Formerly Used Defense Site on St. Lawrence Island, Alaska; and Elder, Annie Alowa



## Emerging Issues

- **Goods Movement**
  - Air pollution
  
- **Hydraulic Fracturing**
  - Air pollution

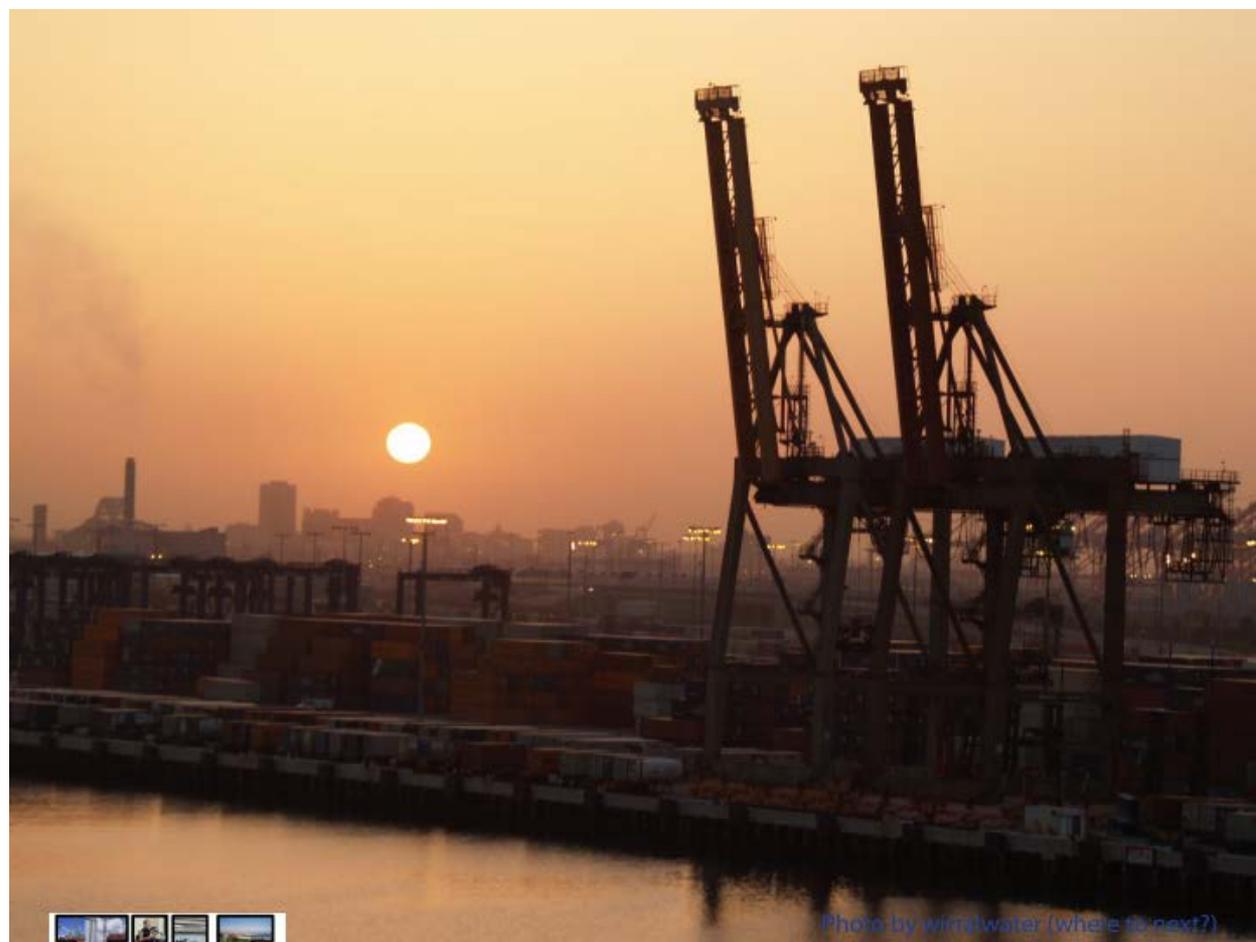


Photo by wiralwater (where to next?)



Trade, Health and Environment Impact Project  
[www.theimpactproject.org](http://www.theimpactproject.org)

## Disaster Response

- **Deepwater Horizon**
  - Seafood contamination
  
- **Superstorm Sandy**
  - Mold remediation



*“Timely research is critical to prevent injury & illness and support recovery”*  
Lurie, Manolio, Patterson, Collins, Frieden. NEJM Mar 2013

## Reflections

- CEnR & Citizen Science are complementary
- CEnR & Citizen Science are approaches that may not be right for every project
- All partners have an important skill
- Capacity Building is critical
- New partnerships are important with emerging technologies/issues
- Identify best practices:
  - Community-Engaged Research
  - Ethical, Legal, and Social Implications
  - Tool development

“Citizen science is a flexible concept which can be adapted and applied within diverse situations and disciplines. citizen science lends itself to cross-disciplinary work, bringing new perspectives and skills to a research project.”

ECSA Working Group, from 10  
Principles of Citizen Science

# Role for Public Health Laboratories

- Training
- Tool lending
- Tool comparison & validation
- Sample collection
- Sample analyses
- Confirmatory analyses

**APHL** ASSOCIATION OF PUBLIC HEALTH LABORATORIES

JANUARY 1 - DECEMBER 31

# 2015 Webinars

Training By the Experts!

Earn your choice of laboratory (P.A.C.E.<sup>®</sup>), Florida laboratory or CPH re-certification credits at your convenience! See inside for details.

[www.aphl.org/webinars](http://www.aphl.org/webinars)

The graphic features a grid of 15 icons representing various public health and laboratory topics: a virus, a tree, laboratory glassware, a biohazard symbol, a baby, a cell, a DNA helix, a petri dish, an apple, a microscope, a dome, and a head with gears.



# Location of State Public Health Labs



# Opportunities for Coordination/Collaboration?



# Location of Core Centers (+ other Landmark Programs)

Multiple centers at same locations are stacked

# UNC Chapel Hill – Healthy Homes

- Contract to coordinate Clinical Pb Training for nurses & other healthcare professionals
- Live & web-based
- PHL uses UNC maintained listserv to share updates
  - Data collection
  - Reporting methods

# 5 steps TO A healthy home

Home hazards may lead to serious health problems for children.

### 1 Get the Lead Out.

Lead may be found in pre-1978 housing paint, water pipes, vinyl mini-blinds, soil and toys. Childhood **lead poisoning** can cause problems with learning, growth and behavior that last a lifetime.

### 2 Eliminate Moisture and Mold.

Leaky roofs, water pipes, windows air conditioners and basements can spur **mold** growth. Mold is an allergen and **asthma** trigger.

### 3 Manage Pests Safely.

Used unsafely, some **pesticides** may cause **poisoning**, birth defects, nerve damage and even cancer.

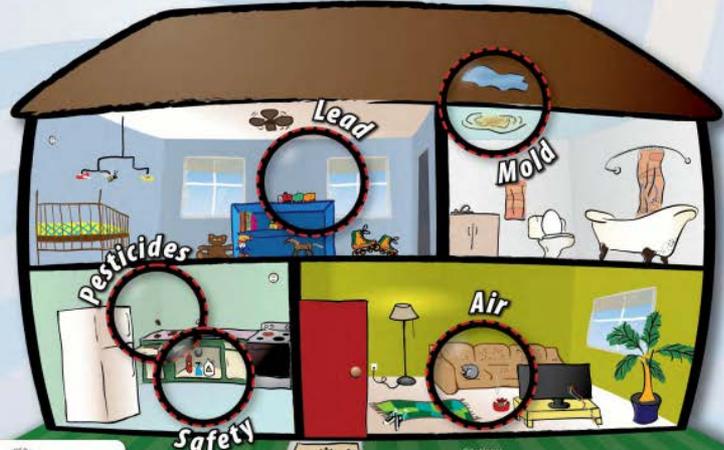
### 4 Clean Up Indoor Air.

**Pollutants** from tobacco smoke, fragrant candles, new furniture, carpets and some cleaning products can make air **unsafe** to breath.

### 5 Use a Home Safety Plan.

Young children and older adults are most likely to **get hurt** at home by falls, drowning, fires, poisoning, suffocation, choking and guns.

Learn more at: [www.nchealthyhomes.com](http://www.nchealthyhomes.com)



## National Jewish – Children’s EH



- Provided filters from state monitors
- Filters analyzed for 10 metals
- Results helped to inform new community-engaged project development



# DR2 Outreach, Implementation, and Integration with partners

## Environmental Health Science (EHS) Network

### What: working with our partners to...

- Help develop and prioritize DR2 concepts, tools, website, training materials
- Build off acute response “Public Health Practice” (surveillance, x-sectional surveys)
- Get timely environmental exposure and toxicology data to support health research

### Who:

- **New EHS Network Workgroup**
  - NIEHS Training Program, Academic Centers, & Grantees input
- **Federal Partners (HHS Agencies and Others)**
- **Other Stakeholders**
  - Public Health, Responders, & Community (incl. “citizen science”)



# Research Responder Training & Education

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

## Training Exercises

- 2014 Los Angeles & 2015 Houston
- Participants: federal, state, local, academia and community, industry
- Evaluate State and partner research capabilities & DR2 Project concepts and training tools
- Discussion: integration, issues of concern



# Repository of Data Collection Tools

## Surveys, Questionnaires, Protocols, Guidance, Forms

- **Tools** to help establish **early baselines and cohorts** for research
  - **Search:** NIEHS studies (e.g., DWH), literature searches, CDC, USCG, other
    - 450 research tools evaluated (rosters, epi-data, clinical forms, etc.)
    - 165 tools selected for initial inclusion in database
- **Broad categories** (eight to start)
- **Implementation guidance and forms** (e.g., consent forms, clinical testing)
- **Training and Exercise Materials**
- **Useful to researchers regardless of federal response**
  - e.g., local events, tornados, wildfires, factory explosions



# NIH DR2 Web Site

<http://dr2.nlm.nih.gov>

U.S. Department of Health and Human Services
www.hhs.gov

## NIH Disaster Research Response

National Institute of Environmental Health Sciences  
U.S. National Library of Medicine

Home
Tools & Resources
Training & Exercises
Protocols
Networks
Collaborations
News & Events
Search
About

### Tools & Resources

A searchable database of federally reviewed research tools including surveys, questionnaires, clinical forms, etc., meant to help establish baselines and cohorts for research following disasters. [Click for more](#)

**Find Tools & Resources**

### Training & Exercises

Training and Exercise materials designed and utilized to prepare scientists to conduct research in the post-disaster field environment. Materials are now available for nationwide researcher and disaster planner use.

**Learn More**

### Protocols

An NIH initiative to develop pre-approved research study protocols and research design templates. These tools will be available for use in the planning and rapid implementation of time-sensitive data collection and research after a disaster. Research study protocols will undergo IRB and OMB review and approval for immediate use after an event.

**Learn More**

### Networks

The Environmental Health Science Disaster Research Network is a new group consisting of NIEHS- sponsored research centers, grantees, and academic partners interested in facilitating improved national research capabilities and responding to environmental emergencies and disasters.

**Learn More**

### Collaboration & Projects

Information on initiatives to advance disaster research capabilities across the federal government including:

- ▶ HHS Science Preparedness Research Intra-agency Team (SPIRIT)
- ▶ The NIOSH Disaster Science Research Initiative to Enhance Responder Safety & Health
- ▶ Intra-NIH Disaster Interest Group (I-DIG)

**Learn More**

### News & Events

Click for a full list of upcoming Disaster Research Response (DR2) events as well as summaries and archived materials from past events.

Next Event: Interagency Federal Partners meeting: January 16, 2015, 1:00 p.m., Natcher Center, Room D, NIH, Bethesda, MD

**Learn More**

- [Tools & Resources](#)
- [Training & Exercises](#)
- [Protocols](#)
- [Networks](#)
- [Collaborations & Projects](#)
- [News & Events](#)



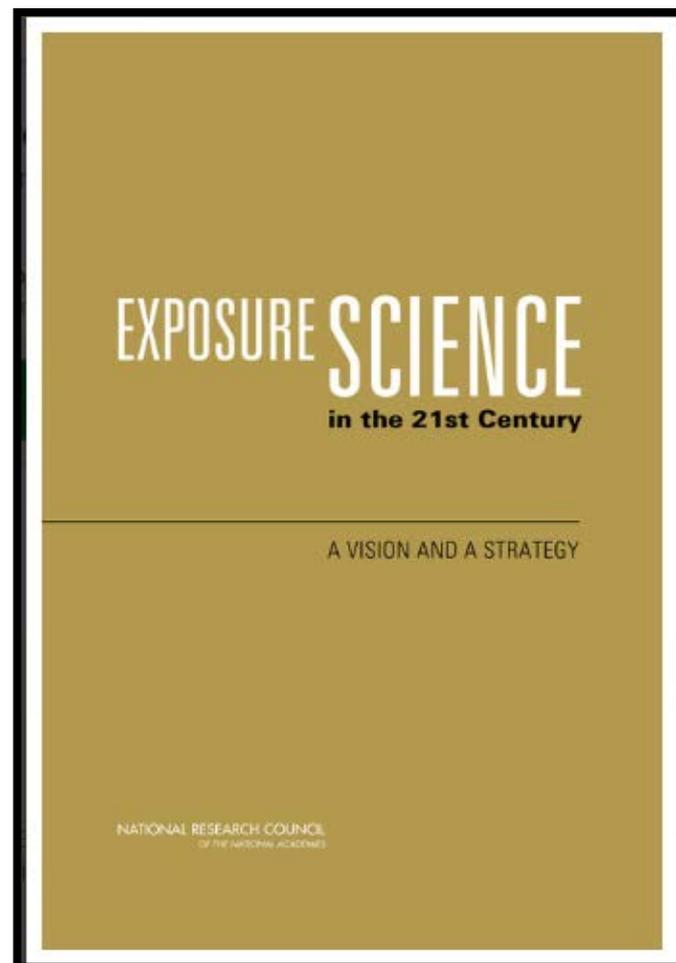
## Federal Working Groups

- Exposure Science 21: Community Engagement & Citizen Science
- Federal Community of Practice in Crowdsourcing & Citizen Science

Tier	Application Area	Pollutants	Precision & Bias Error <sup>2</sup>	Data Completeness <sup>2</sup>
I	Education and Information	All	<50%	≥ 50%
II	Hotspot Identification and Characterization	All	<30%	≥ 75%
III	Supplemental Monitoring	Criteria pollutants, Air Toxics (incl. VOCs)	<20%	≥ 80%
IV	Personal Exposure	All	<30%	≥ 80%
V	Regulatory Monitoring	O <sub>3</sub> CO, SO <sub>2</sub> NO <sub>2</sub> PM <sub>2.5</sub> , PM <sub>10</sub>	<7% <10% <15% <10%	≥ 75%

## Concluding Points

- NIEHS uses a variety of grant mechanisms to foster partnerships
- Capacity building is needed for researchers and community members
  - Rapid technology development
  - Increasing environmental health literacy
  - Report back of results
- Opportunities for coordination
  - NIEHS grantees
  - Federal Working Groups





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***Thank you!***

**<http://www.niehs.nih.gov>**

**[ofallon@niehs.nih.gov](mailto:ofallon@niehs.nih.gov)**

