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.

http://www.niehs.nih.gov
National Institutes of Health
U.S. Department of Health and Human Services

NIEHS Programs Fostering Community-Engaged Research (CEnR)

- Community-based Prevention & Intervention Program
- Centers for Population Health and Health Disparities
- Community-based Participatory Research Program
- Health Disparities Program
- Research to Action
- Centers for Children’s Environmental Health

EHS Core Centers (P20)
- EJ: Partnerships for Communication
- Worker Education & Training Program

1994 95 96 97 98 99 00 01 02 03 04 05 06 07 08 09 10 11 12 13 2014

- Symposium on Health Research and Needs to Ensure Environmental Justice
- Building Healthy Environments to Eliminate Health Disparities
- NIMHD Health Disparities Summit
- NIMHD Health Disparities Program
- National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health
- National Conversation
- Symposium on the Science of Disproportionate Environmental Health Impacts
- PEPH Environmental Health Disparities & EJ Meeting
- HHS EJ Implementation Meeting
- NIMHD Health Disparities Summit

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 of 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*

- PI Expertise
- Science question
- Aims and Methods
- Implement study
- Collect and analyze data
- Publish & Disseminate

**Citizen Science:**
Researcher(s) collaborate with community members to share data that each have collected.
Goal: Answer research question, AND address community concerns

**Crowdsourcing:**
Researcher solicits community involvement to find creative solutions to complex questions.
Goal: answer research question or meet a research need

**Gaming & DIY:**
Researcher solicits community involvement to find creative solutions to complex questions.
Goal: answer research question or meet a research need

- Translate for Public Health Action
- Review Results
- Collaborative Research
- Engaged scientific questioning
- Concern/Question
- Exposure/disease awareness
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
Project Highlights
Exposure Science

- Air Pollution
  - Barrio Logan & National City
  - Los Angeles

- Soil Contamination
  - Arizona
  - New York
  - South Carolina

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

Photo by Ted Soqui from article in L.A. 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
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
Location of State Public Health Labs
Multiple centers at same locations are stacked

Location of Core Centers (+ other Landmark Programs)

Opportunities for Coordination/Collaboration?
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
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

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

<table>
<thead>
<tr>
<th>Tier</th>
<th>Application Area</th>
<th>Pollutants</th>
<th>Precision &amp; Bias Error(^2)</th>
<th>Data Completeness(^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Education and Information</td>
<td>All</td>
<td>&lt;50%</td>
<td>≥ 50%</td>
</tr>
<tr>
<td>II</td>
<td>Hotspot Identification and Characterization</td>
<td>All</td>
<td>&lt;30%</td>
<td>≥ 75%</td>
</tr>
<tr>
<td>III</td>
<td>Supplemental Monitoring</td>
<td>Criteria pollutants, Air Toxics (incl. VOCs)</td>
<td>&lt;20%</td>
<td>≥ 80%</td>
</tr>
<tr>
<td>IV</td>
<td>Personal Exposure</td>
<td>All</td>
<td>&lt;30%</td>
<td>≥ 80%</td>
</tr>
<tr>
<td>V</td>
<td>Regulatory Monitoring</td>
<td>O(_3), CO, SO(<em>2), NO(<em>2), PM(</em>{2.5}), PM(</em>{10})</td>
<td>&lt;7% (\leq 10%), &lt;15% (\leq 10%)</td>
<td>≥ 75%</td>
</tr>
</tbody>
</table>
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
Thank you!

http://www.niehs.nih.gov

ofallon@niehs.nih.gov