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

Our Environment, Our Health: *Engaging Researchers and Empowering Communities*

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The National Institute of Environmental Health Sciences

- One of the 27 National Institutes of Health, but located in RTP, NC
- Wide variety of programs supporting our mission of environmental health:
  - Intramural laboratories
  - Extramural funding programs
  - Disease prevention
  - Clinical research program
  - National Toxicology Program
  - Public health focus

NIEHS Strategic Plan

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.

Strategic Themes for Environmental Health Sciences

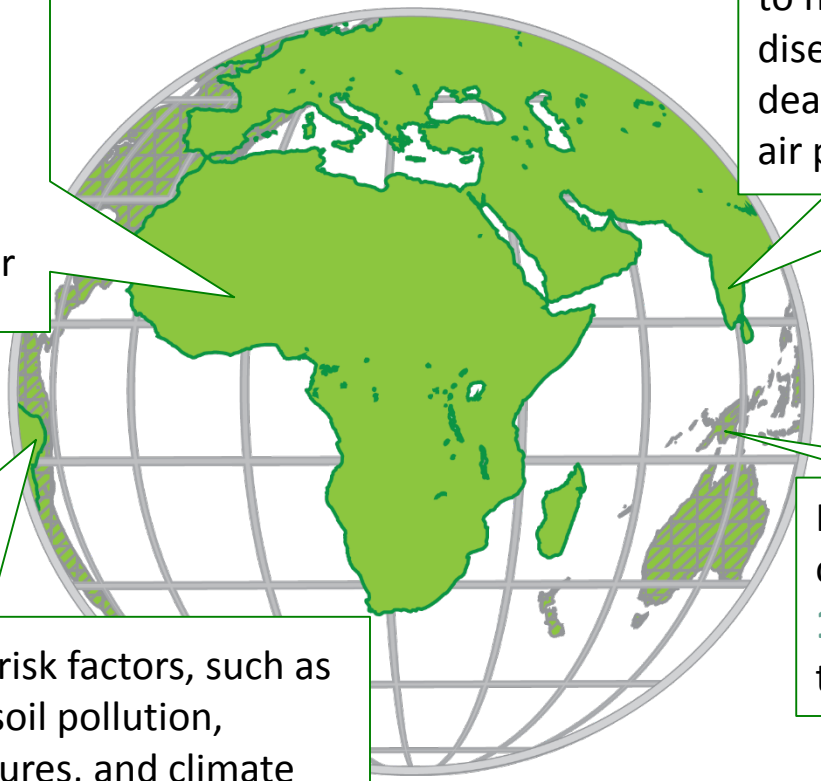
Vision

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.

Environmental Burden of Disease

23% of all global deaths are linked to the environment — that's roughly **12.6 million** deaths a year

8.2 million deaths caused by the environment are due to noncommunicable diseases. Most of these deaths are attributable to air pollution.

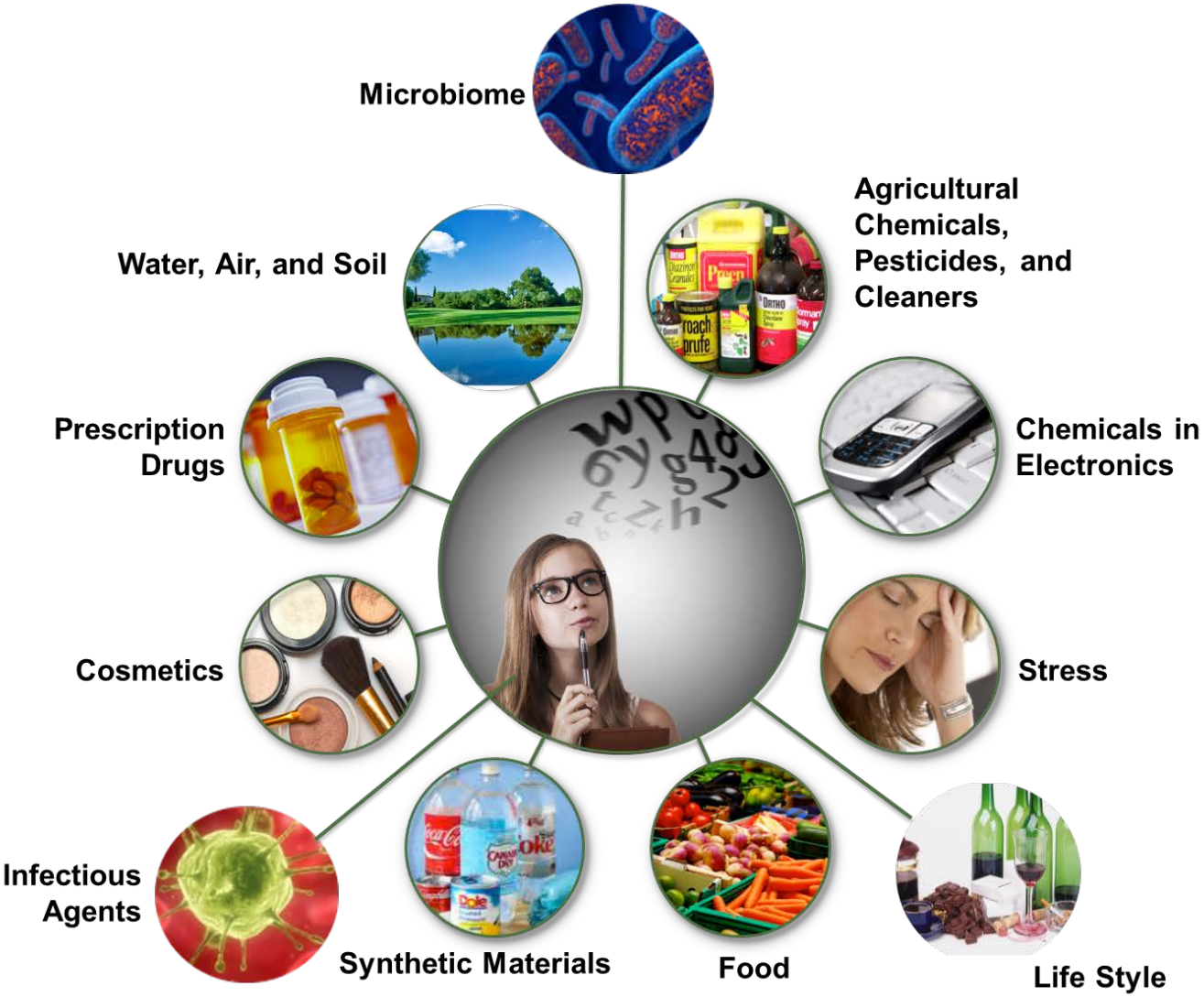


Environmental risk factors, such as air, water, and soil pollution, chemical exposures, and climate change contribute to more than **100 disease and injury types**

Healthier environments could prevent the deaths of **1.7 million children** under the age of 5 each year

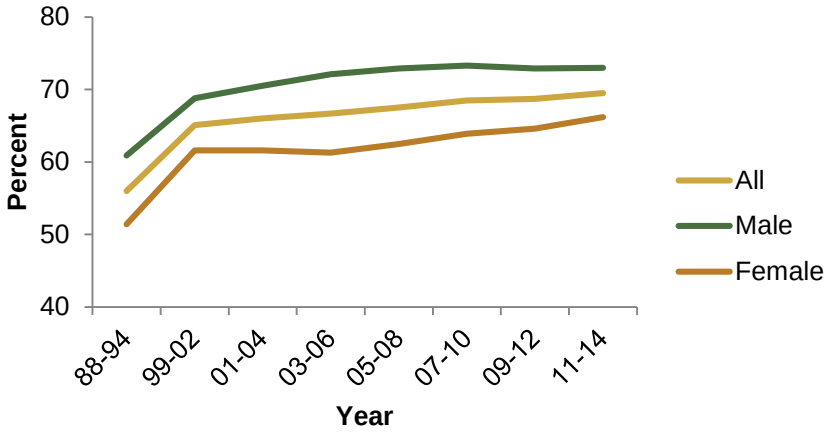
Source: WHO, 2016

What is our environment?

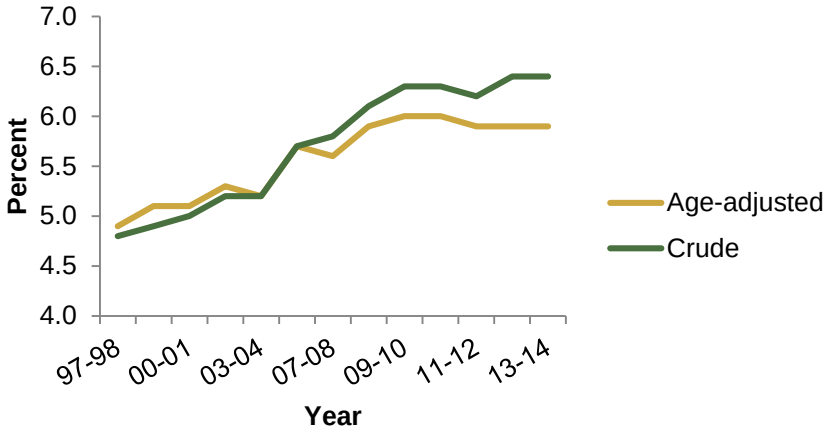


Should we be concerned?

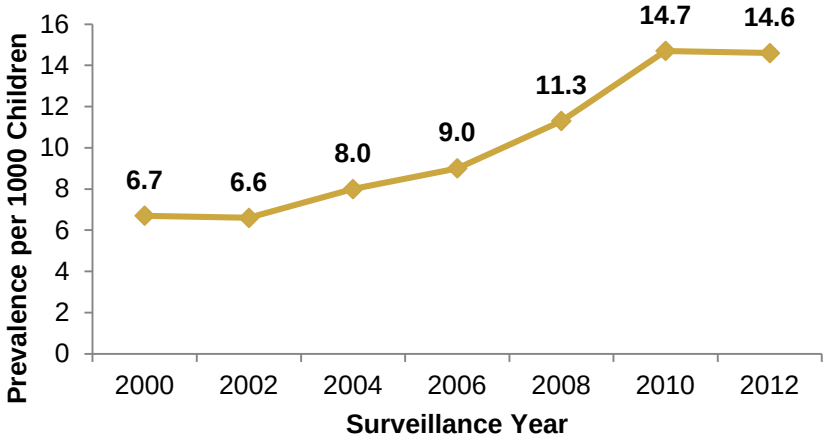
Increase in Overweight and Obesity



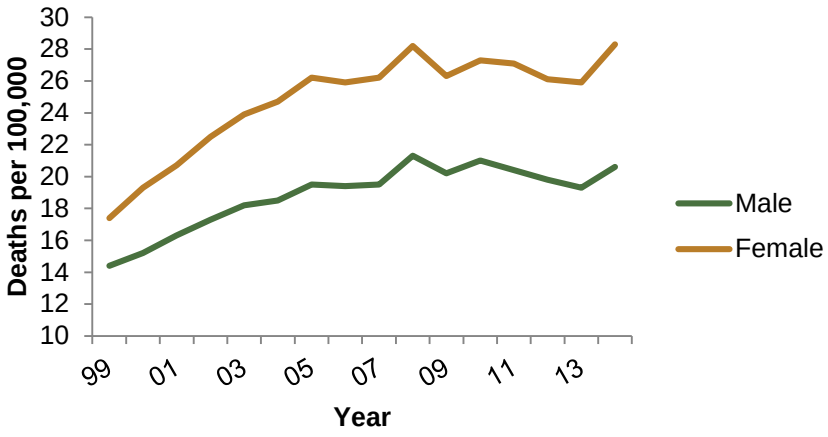
Increase in Cancer Prevalence in Adults



Increase in Autism Prevalence



Increase in Alzheimer's Deaths



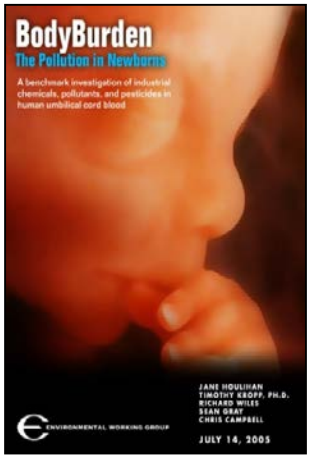
Source: CDC/National Center for Health Statistics (2016)

NIEHS research is focused on understanding the interaction of our genetic susceptibilities and our environmental exposures.

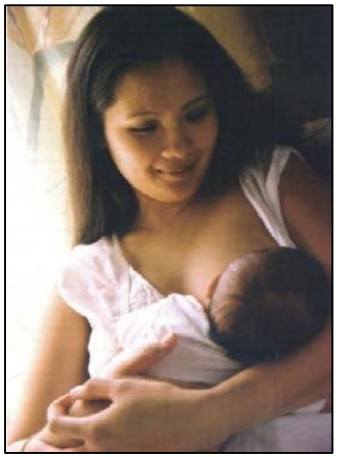
We All Carry a Chemical Body Burden

Of people tested by CDC:

- BPA in 93%
- PAH 100%
- Phthalates 50-97%
- PFCs in 91-99%
- PBDEs in 100%
- Triclosan in 80%
- PCBs in 100%



- 47 chemicals in every pregnant woman tested
- In breast milk (PCBs, dioxins, pesticides, mercury, flame retardants)
- 287 chemicals in cord blood



MIXTURES!

The Genes, Environment, and Health Initiative

Exposure Biology Program

Identify genetic variants in animal models, develop technology and biomarkers

- Diet
- Physical Activity
- Environmental Exposures
- Psychosocial Stress and Addictive Substances

Genetics/Epigenetics

GxE

Environment

Time

Human Genetics Program

Identify genetic variants

- GWA Studies
- Data Analysis
- Replication
- Sequencing
- Database
- Function
- Translation

The Exposome

Define the exposome

- An untargeted (hypothesis free) assessment of the totality of environmental exposures
- External, internal, or both?

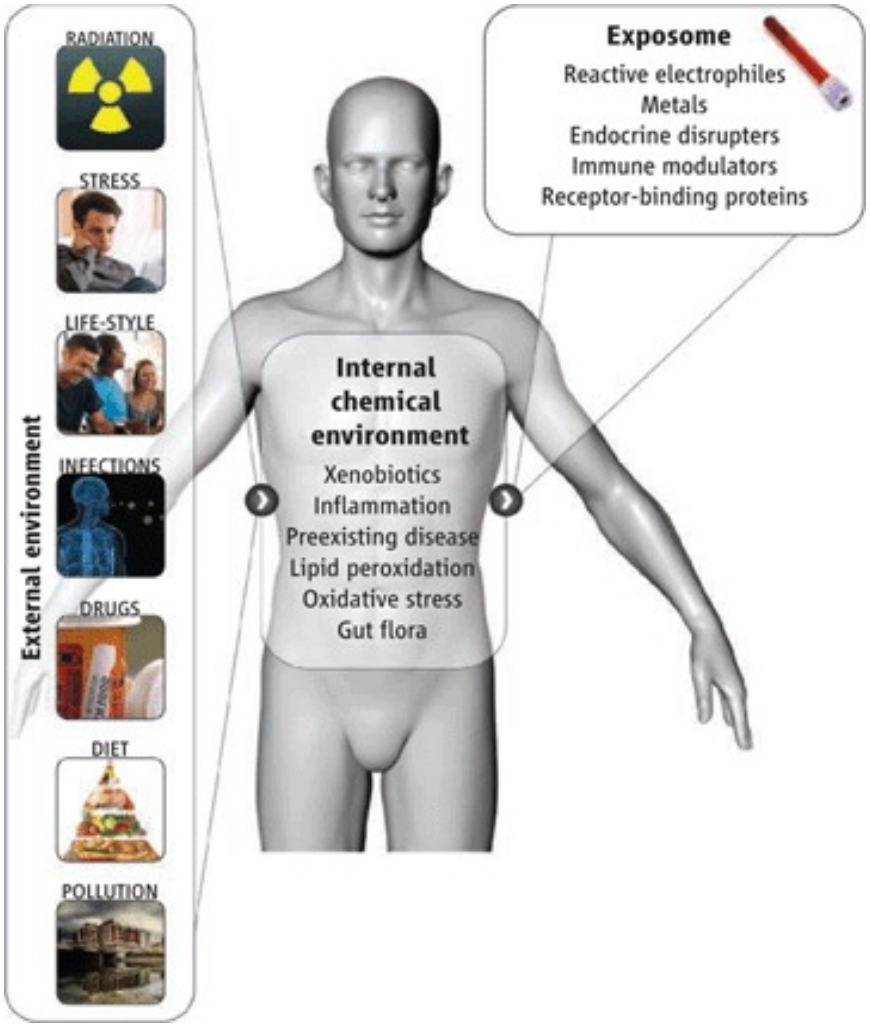
How to measure it

- New tools necessary to monitor exposure
- Can use biomonitoring or untargeted metabolomics to begin to do ‘top-down’ approach

Mixtures

- Chemical
- Non-chemical (infectious agents, diet, pyscho-social)

Microbiome

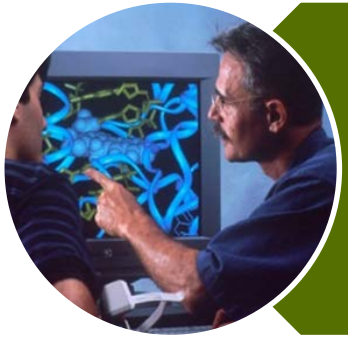


Rappaport and Smith (2010), Science, 330:460-461

Children's Health Exposure Analysis Resource (CHEAR)

Goal 1

Advance understanding of the impact of environmental exposures on children's health and development



Goal 2

Provide infrastructure for adding or expanding exposure analysis to studies involving research in children's health

Coordinating Center:

Administrative management and interface with the research community

National Exposure Assessment Laboratory Network:

Laboratory analysis of environmental exposures in existing biological samples

Data Repository, Analysis, and Science Center:

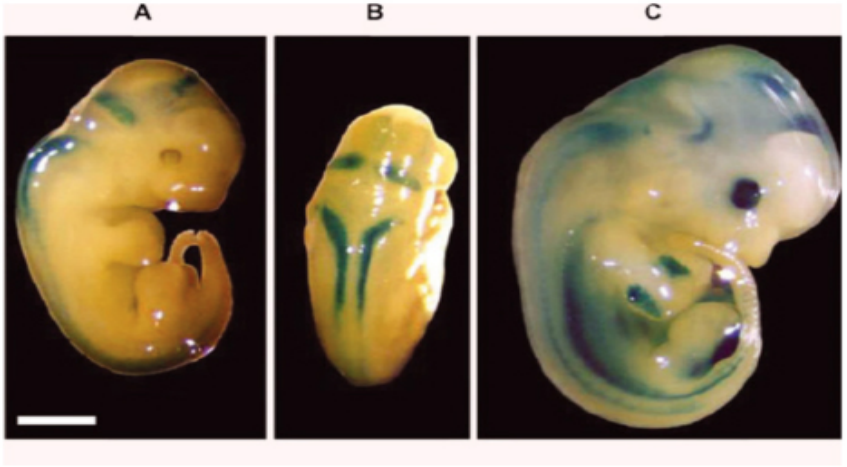
Data Repository and support for statistical analysis and interpretation

Early Life Exposures Have Lasting Effects

Developmental Origins of Health and Disease (DOHaD)

- Early life is a sensitive time for exposure:
  - Organs are forming
  - Gene expression programs are being established
  - **Epigenetic** reprogramming is occurring
  - Changes occurring during development permanently alter the potential of an organ

Endocrine disruptor action is life-stage specific



Q11

Developmental Effects
(Organizational)

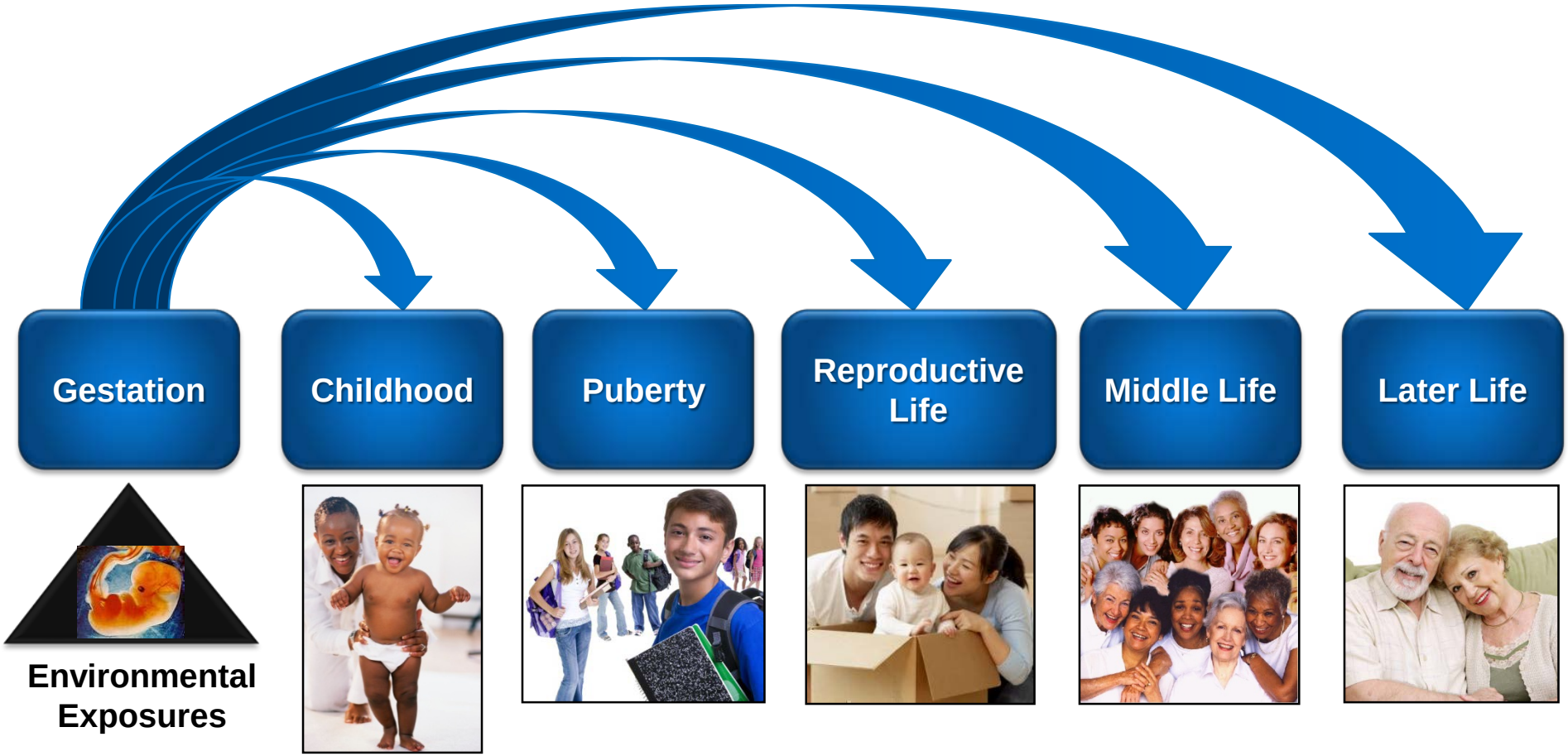
- Most sensitive exposure window
- Persistent effects
- Latent periods

Adult Effects
(Activational)

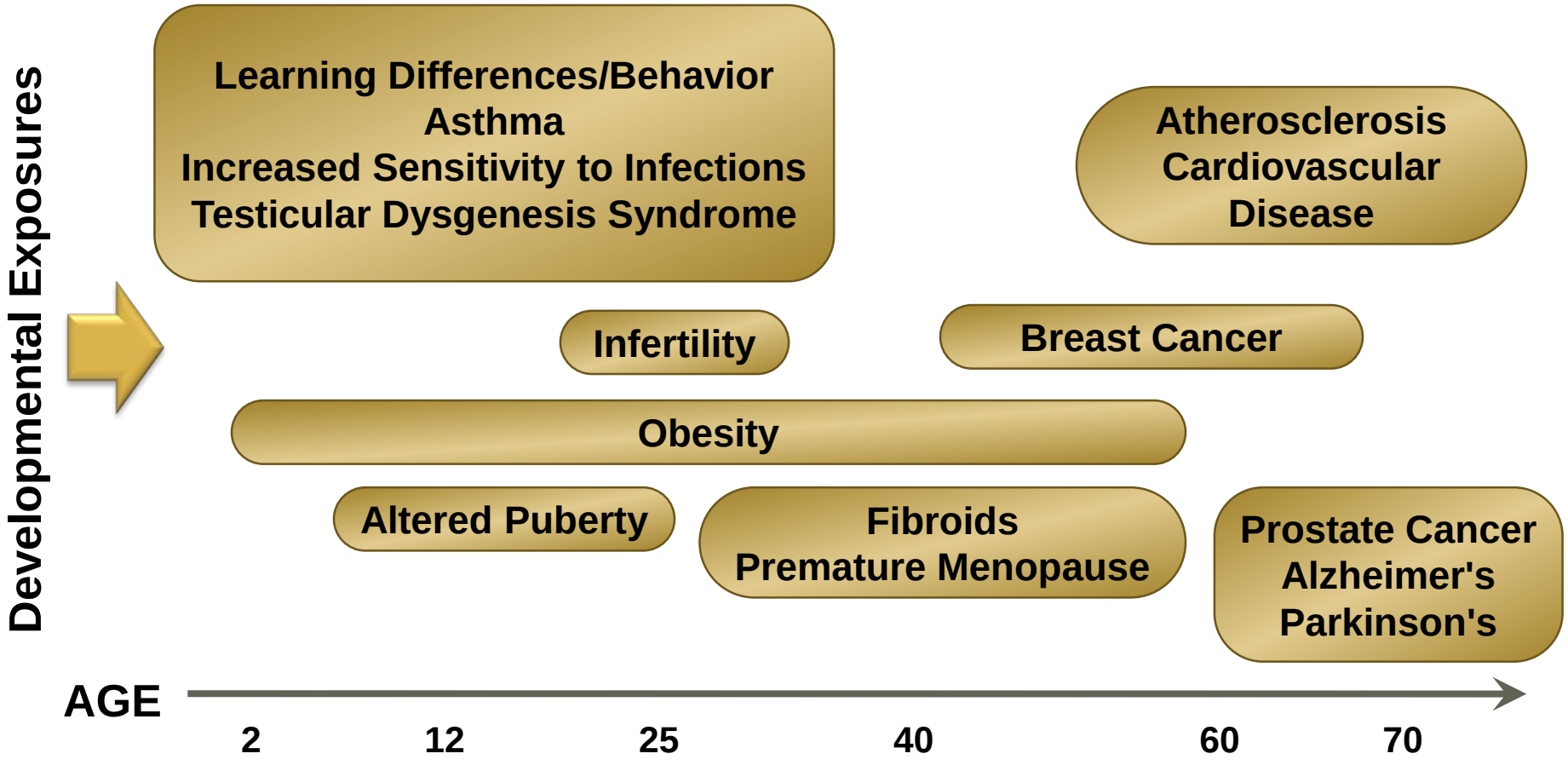
- Usually higher doses
- Effects as long as EDC present
- Can augment developmental effects

A bad start…lasts a lifetime!

Windows of Susceptibility/Lifelong effects of early-life exposures

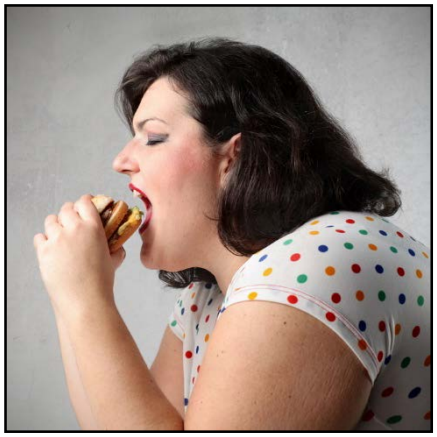


Examples of DOHaD



What about Preconception?

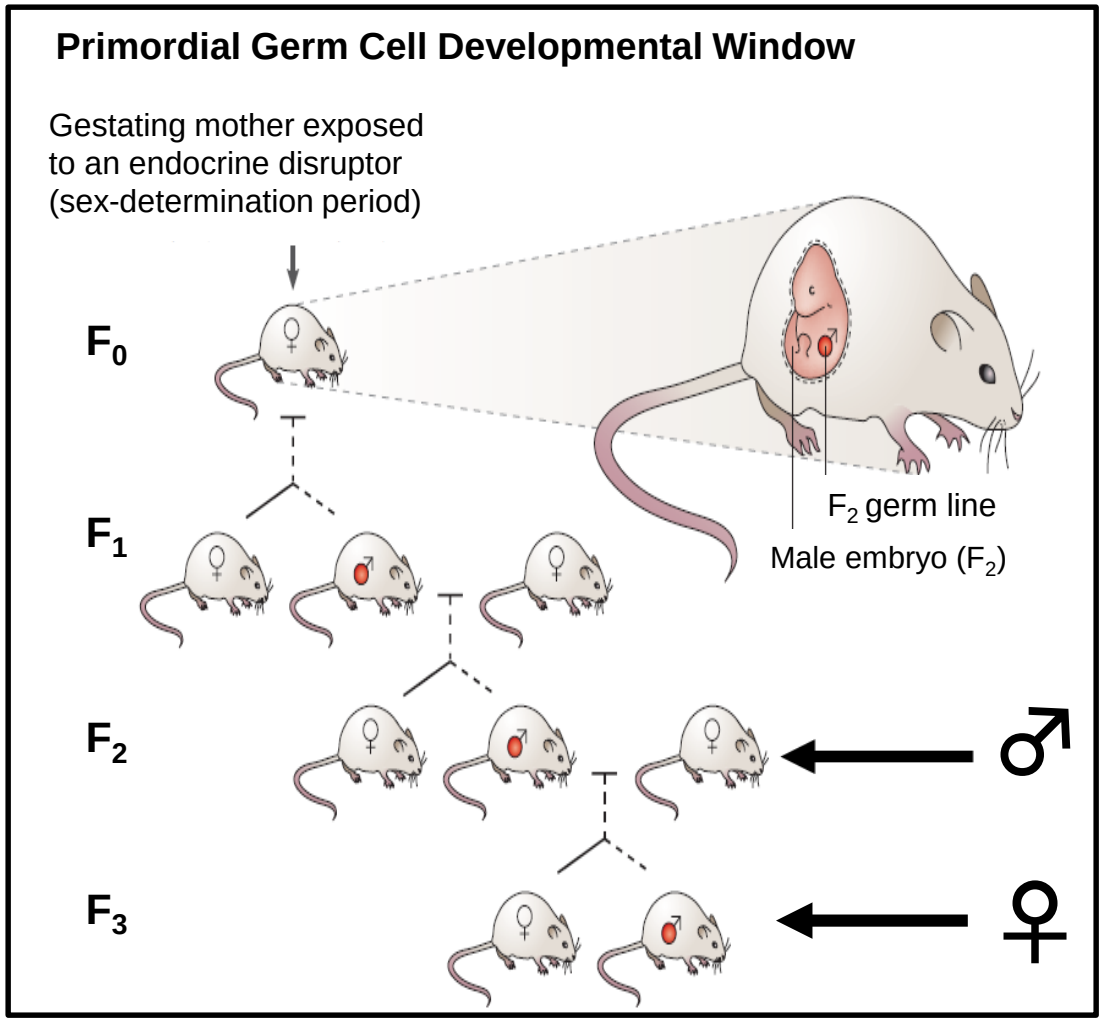
- **Obesity**
  - Maternal obesity alters oocyte maturation, embryo redox state, and offspring growth and metabolism (Simmons, 2014)
- **Social behaviors**
  - Mom's anxiety effects offspring behavioral disorders (Saavedra-Rodríguez, 2013)
- **Smoking**
  - Preconceptional smoking associated with increased risk of congenital heart defects (Karatza, 2009)
- **Chemicals (POP's)**
  - Preconceptional paternal and maternal exposure to POP's associated with low birth weight (Buck Louis, 2014)



And… Fathers Matter!

- **Nutrition/ Obesity**
  - Offspring of adult males fed a Low Protein Diet show impaired liver function (Rando, 2010)
  - Offspring to dads fed a High Fat Diet have diabetes and poor semen quality (Ng, 2014)
  - Paternal obesity results in obese offspring (Freeman, 2011), increased rates of autism (Suren, 2013)

Transgenerational Inheritance:



Chemicals Causing Transgenerational Changes

Chemical	Transgenerational Effects	Mechanism
BPA	Behavioral changes through F4 Obesity	Alteration of neuropeptide genes. DNA methylation
Methoxychlor	Steroid biosynthesis, ovarian effects	Unclear
DES	Uterine and mammary gland changes	Expression of Hox genes, ER signaling
Vinclozolin	Sperm counts	DNA methylation on imprinted genes
Dioxins	AhR expression in prostate, liver, and sperm	DNA methylation on imprinted genes
TBT	Obesity, hepatic steatosis	Mesenchymal stem cell changes, epimutations

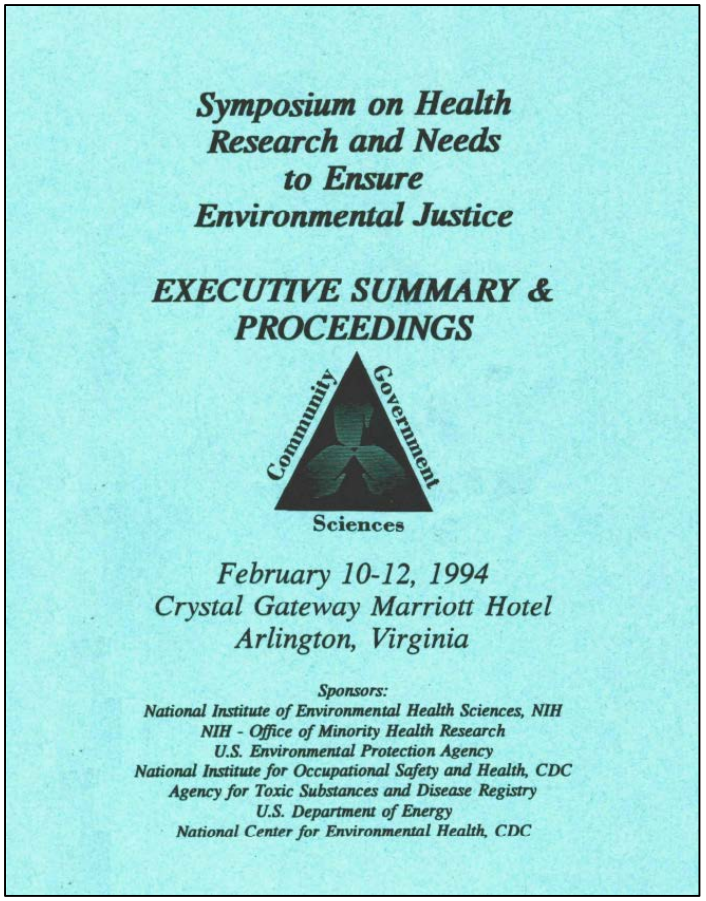
Xin F, et al. 2015

"You cannot study environmental health without engaging community residents."

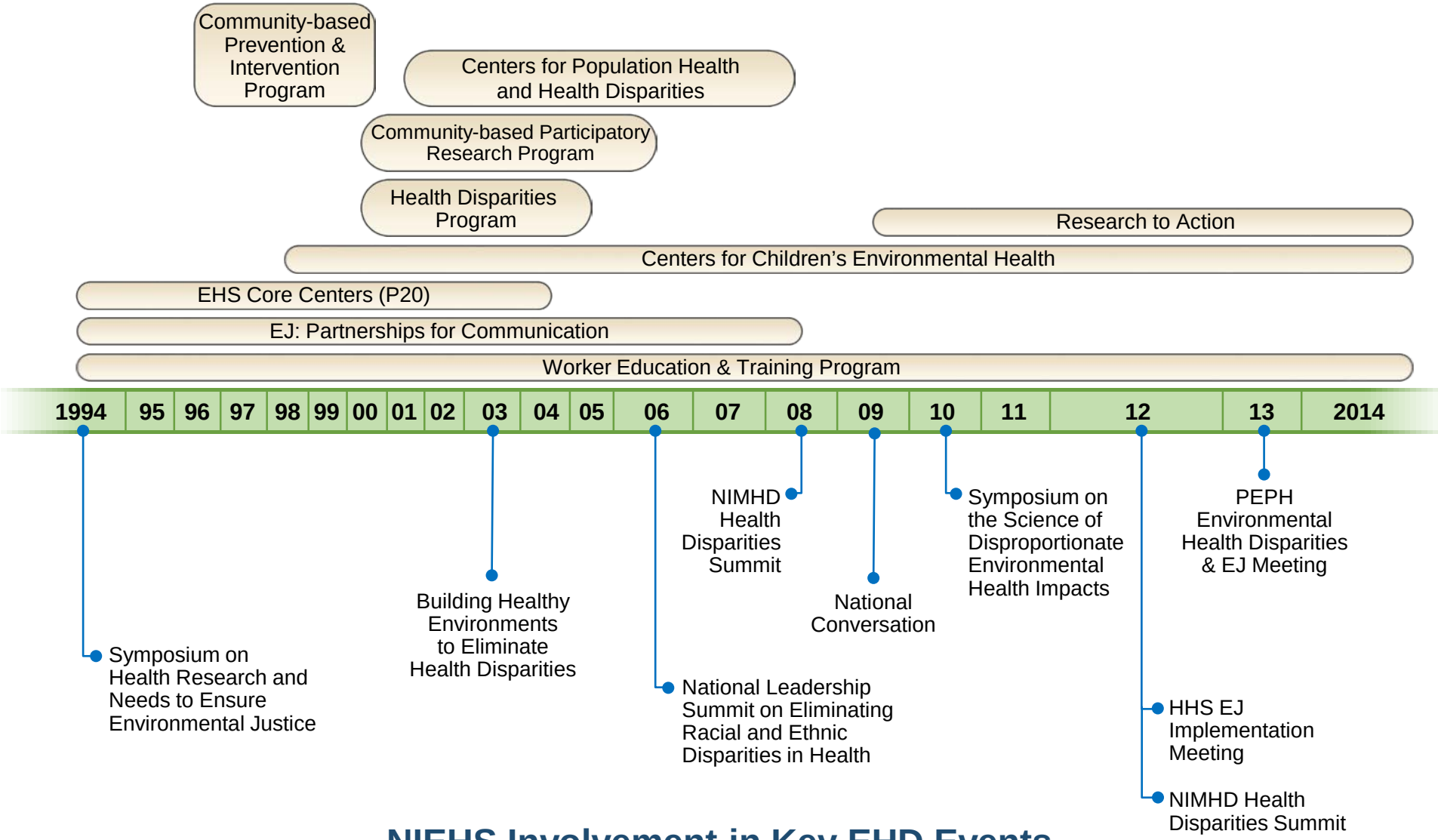
– Linda Birnbaum

Citizen Science & Community-Engaged Research

1. Recognize that people are not a tool for science; science is a tool for people.
2. Recognize that scientific knowledge has limits and other ”ways of knowing” are equally valid.
3. Ensure that research is done in the community, for the community, by the community.
4. Ensure that environmental research serves the needs of the community and the needs of industry or government.



NIEHS Programs Fostering Community-Engaged Research (CEnR)



NIEHS Involvement in Key EHD Events

Citizen Science & Community-Engaged Research

Partnerships for Environmental Public Health

- Coordinates grant programs related to environmental public health

Research to Action

- Bring together community members and researchers to investigate the potential health risks of environmental and occupational exposures of concern to the community

NIEHS Strategic Plan Goal 11

- Promote bidirectional communication and collaboration between researchers and stakeholders

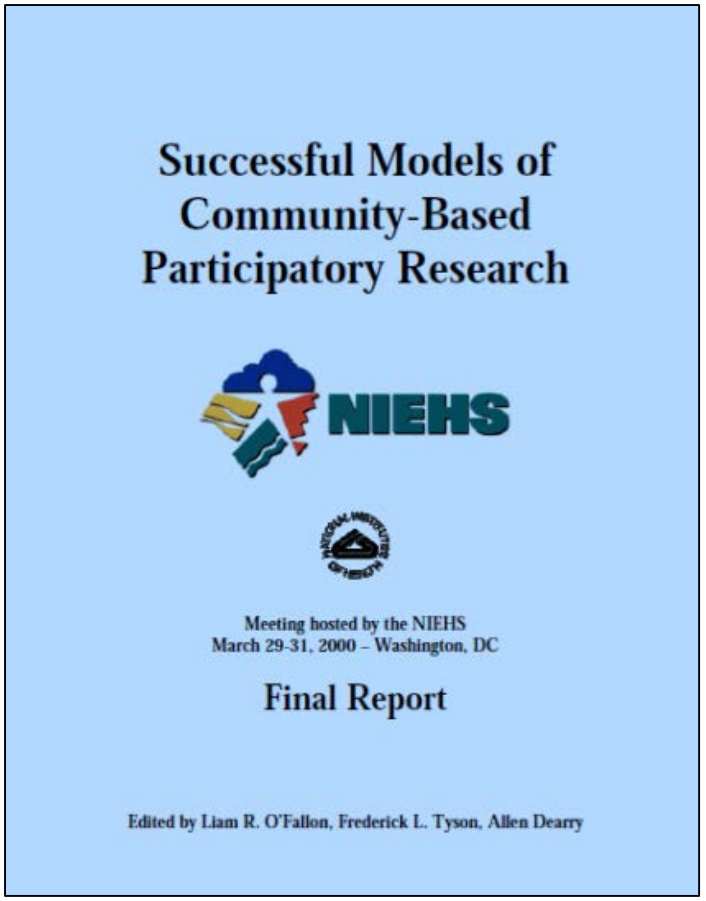
Citizen Science & Community-Engaged Research

Outreach and Engagement

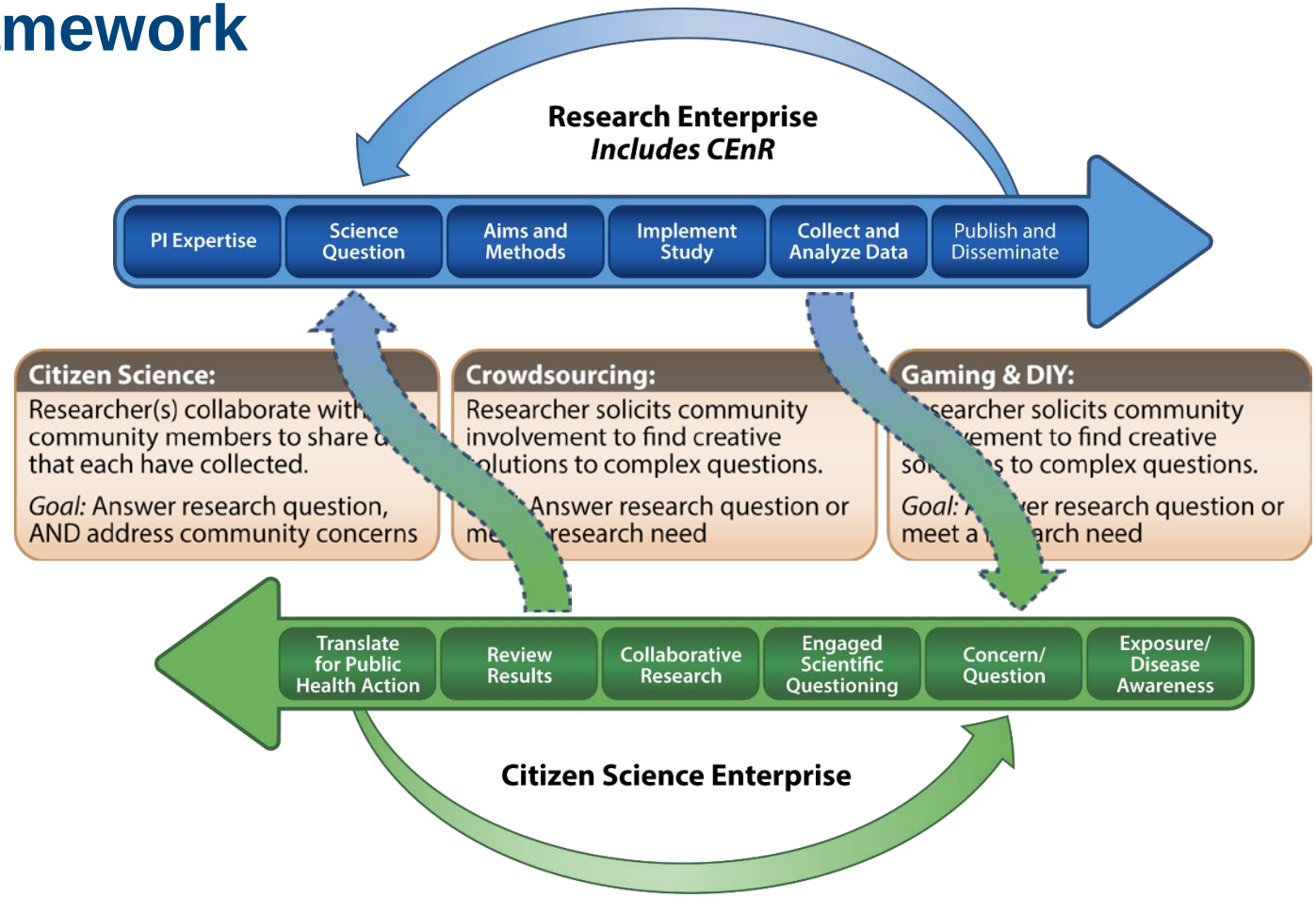
- Individuals and communities are entitled to results of research, translated into information they can understand and use to advocate for environmental and health improvements.

Community-Based Participatory Research

- An approach that equitably involves community members, organizational representatives and researchers in all aspects of the research process



Community Engagement & Citizen Science: Graphic Framework



Finn & O'Fallon
APHL, Lab Matters

Fall 2015

Applicable Community-Engaged Research Lessons for Citizen Science

- 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.

Engaging the Community

- Research to Action: Assessing and Addressing Community Exposures to Environmental Contaminants
- Children's Centers & Children's Health Exposure Analysis Resource (CHEAR)
- Environmental Health Sciences Core Centers
- Climate Change and Human Health
- Global Alliance for Clean Cookstoves
- The Sister Studies, Obesity and Puberty Study
- Biomarkers of Oxidative Stress Study (BOSS)
- Community Fora:
  - Brooklyn NY: Toxic Risk, Climate Change, & Health
  - Tucson AZ: Environmental Health Challenges Faced by Native Americans
  - St. Lawrence Island, Anchorage, and Nome, AK: Protecting Environmental Public Health in Alaska
  - Los Angeles, CA: Public Health & City Planning

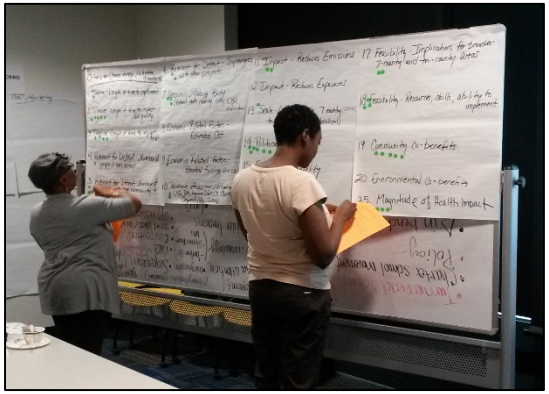
THE SISTER STUDY
BREAST CANCER RESEARCH

Citizen Science & Community-Engaged Research

Looking Ahead

Exposure Science

Big Data



Dissemination & Implementation Research

Economic Evaluation

Key Points

- Like CEnR, Citizen Science is a spectrum
- Like CEnR, Citizen Science & Crowdsourcing are tools that may not be right for every project
- We must be careful not to conflate Community Engaged Research and Citizen Science
  - Different time scales and values for getting involved
- “Citizen Science” is defined variously depending on the context
- Capacity Building is critical
- Cultural sensitivity is even more important than ever!

Opportunities and Next Steps (Solutions-oriented)

- Research to Action
- Fellowships
  - Learn how to conduct research using CEnR methods, co-create outreach and education programs with community partners in research
- Conference Grants
- Engage with professional societies & networks
  - Learn about & promote implementation of successful models
- Advance EHL of healthcare professionals and other partners
- Children's EH Center and PEHSU coordination

Resources

- PEPH Webinars
- Podcasts
- Newsletter
- Resources page
- PEPH Evaluation Metrics Manual
- NIEHS Program Staff!

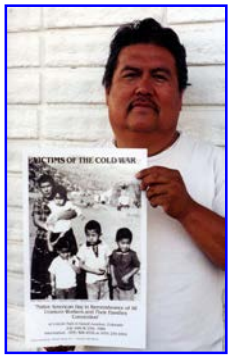
PEPH Webpage: www.niehs.nih.gov/peph

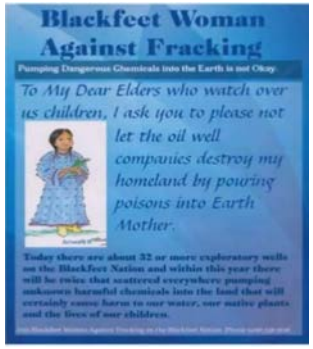
Aspects of Cultural Sensitivity

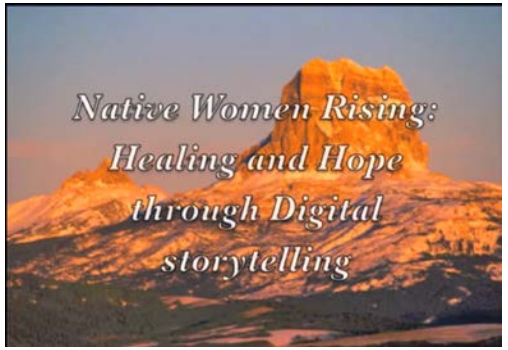
There are a number of socio-cultural issues that underlie the appropriate engagement of citizen scientists from particular communities.

- **Who are citizen scientists**
- **Diversity within communities**
- **Sanctity of place**
- **Gender**
- **Age**
- **Ethnicity and Race**
- **Local language use**
- **Literacy/health literacy/environmental health literacy**
- **Economic status**
- **Bi-directional communications**

Gender and Age







In certain communities, men, women, children or the elderly may be restricted from participating in certain activities or in certain places. In contrast, specific genders may be more active in certain activities.

Likewise, interactions with certain age groups may require additional cultural sensitivity.

Ethnicity, Race and Socioeconomics

Interactions with racial and ethnic groups may be best accomplished by “gatekeepers” - those with connections to the community.

In some instances, researcher interactions with citizen scientists is improved when conducted by individuals from the same ethnic or racial group.

There may be issues between racial and ethnic groups that preclude or constrain coordination around a citizen science activity.

Consideration should also be given to economics that influence ability to participate in research.

Local Language, Literacy/Health Literacy

It is important to ascertain what languages are used by local citizen scientists and their communities, and to provide them with information, tools and instruction in their native language(s).

This may mean involving ‘gatekeepers’ or members of the local community to facilitate the translational of information into the local language.

Materials for use in studies may need to be provided in several formats.

The Importance of Listening



It is important to understand who are the citizen scientists and the communities they represent.

The foundations of cultural sensitivity are

- to not make assumptions
- **to listen carefully**
- to be respectful of the different ways of contributing to a project and
- to be open to local needs and cultural considerations.

EMERGING ISSUE: Research during Disasters

"The knowledge that is generated through well-designed, effectively executed research in anticipation of, in the midst of, and after an emergency is critical to our future capacity to better achieve the overarching goals of preparedness and response: preventing injury, illness, disability, and death and supporting recovery."

Lurie, Manolio, Patterson, Collins, & Frieden. New England Journal of Medicine. 368; Mar 2013

Despite Its Importance: Disaster Research is Typically Delayed or Missed

- No formal ways to activate and coordinate research responses
- Lack of needed funding for intramural and extramural research
- Slow reviews of protocols and multisite study issues (IRB & OMB)
- Lack of ready-to-go research components and personnel
- Stakeholders not included in the development and implementation of studies

Missed Opportunities for Key Research Questions!

Disaster or Public Health Emergency	Issues and Delays
H1N1 Flu Virus Response	***IRB issues*** with treatment research
Deepwater Horizon Oil Spill	***9 months*** to start GuLF Study
Hurricane Sandy	***11 months*** to fund extramural research efforts

Resulting in missed opportunities to understand:

- Longer-term physical & mental health impacts of exposures
- Efficacy of mitigation efforts to address health impacts
- Risk factors to improve recovery and future preparedness

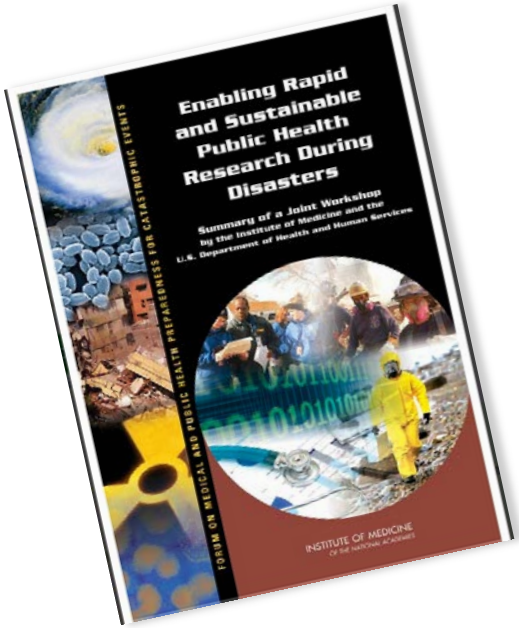
NIH Disaster Research Response (DR2) Program

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

Improving Disaster Responses, Reducing Health Impacts, and Preventing future harm through:

1. Timely and integrated collection of health & environmental data
2. Creating national network of transdisciplinary researchers
3. Broad inclusion of public health, academia, and community stakeholders
4. Training researchers on data collection questionnaires, protocols, guidance, and safety issues

Building National Research Response Capacity



<u>Vision:</u> working together to…

Create a national "Network" for timely environmental health research

<u>What:</u>

- **Improving on the DR2 Program platforms**
- **Identifying ways that you & your programs can contribute**
  - –expertise, science, training, community skills, innovative tools…..
- **Fostering new connections across our centers and grantees**
- **New collaborations with public health & emergency management to understand & include the EHS enterprise**

NIEHS & Our Research Community Are There!

"One" NIEHS Helping to Build Disaster Research Capacity

- **Office of Director:**
  - **National leadership & coordination of the DR2 Program**
- **Division of Intramural Research:**
  - **Developing tools, protocols, IRB efforts, & conducting epidemiology research** (e.g., GuLF STUDY)
- **National Toxicology Program:**
  - **Rapid toxicology tools & approaches, literature-based assessments, federal agency coordination and support**
- **Division of Extramural Research:**
  - **Supporting & coordinating research by centers and grantees, worker training in response to wide range of emergencies**
- **All: Empowering others to conduct disaster research**
  - Supporting responses (e.g., DWH, Superstorm Sandy, Flint, Ebola, Zika)
  - Workshops, Meetings, & Training Exercises (Los Angeles, Houston, Boston)

NIH Disaster Research Response (DR2) Program

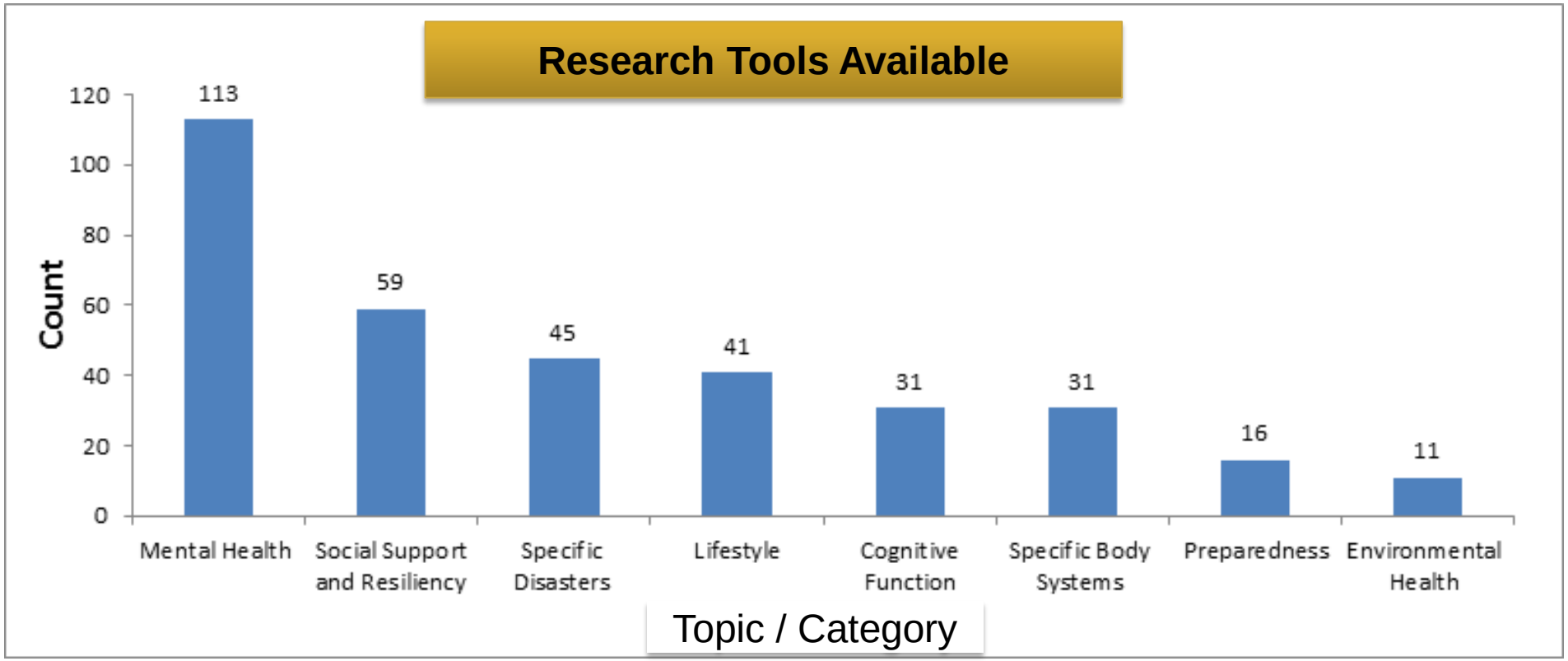
Improving disaster responses, reducing health impacts, and preventing future harm through timely research

- Improved ability for NIH, academic researchers, and others to quickly collect data through available tools & protocols
- Helping researchers be better prepared to participate and trained for performing studies after disasters
- Integrate our environmental health researchers and their community partners into existing emergency management and public health planning efforts AND disaster responses.

Building Capacity for Researchers to Respond

Repository of Surveys, Questionnaires, Protocols, Guidance, Consent Forms, etc.

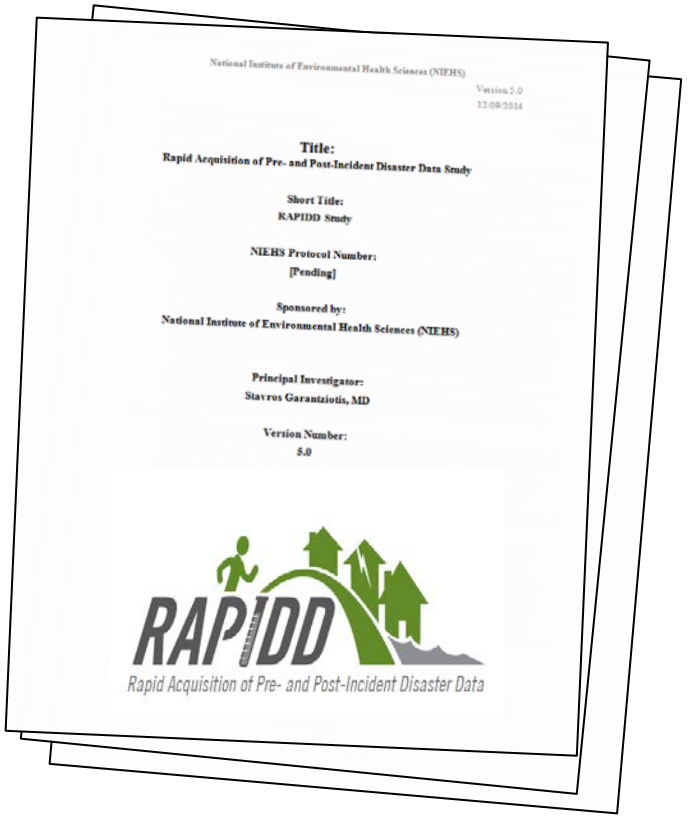
- **300+ new tools to help start early baselines and identified research**



Building Capacity for Researchers to Respond

The Rapid Acquisition of Pre-and Post Incident Disaster Data (RAPIDD)

- Generic Disaster Research Protocol
  - Survey tools, medical testing, consent forms, etc.
- Can be modified to fit the situation as needed
- Focus of 1st RAPIDD on workers, efforts underway for a community protocol
- NIEHS IRB pre-reviewed (May 2015)
  - Similar protocols developed by Universities
    - University of Iowa
    - University of Texas, Medical Branch



Helping Researchers Prepare to Participate & Integrate DR2 Sponsored Tabletop Exercises

- **Exercises held**:
  - Los Angeles (2014) – tsunami in the Port of LA
  - Houston (2015) – storm surge in Houston Ship Channel
  - Boston (2016) – mass flooding East Boston & Chelsea

- **Focus Areas included**:
  - Helping stakeholders understand the need for research and the research process
  - Identify true capacity to perform research for situations & ways to improve state / local capabilities
  - Need to integrate into existing emergency response infrastructure
  - Enhance relationships between stakeholders

Exercises /Workshop

- **Participants: federal, state, local, academia and community, industry and other key partners**
- **Evaluate State and partner research capabilities and DR2 concepts & training tools**

NIH Disaster Research Response Website

Tools & Resources

Protocols

Networks

Collaborations & Projects

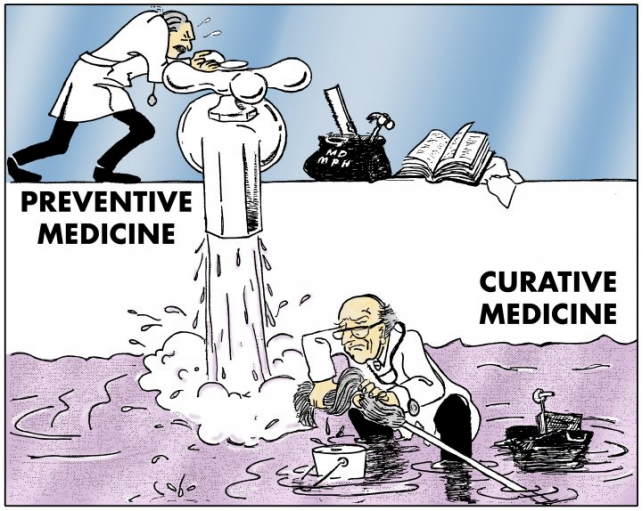
News & Events

Funding Opportunities

Training & Exercises

http://dr2.nlm.nih.gov

Preparation and Partnership are the keys to Prevention!



Environmental factors are more readily identified and modified than genetic factors, and therefore, present a tremendous opportunity to prevent non-communicable disease.

We can change our environments, but we can't build healthy environments without Communities!

Thank you!

National Institute of Environmental Health Sciences

National Toxicology Program
U.S. Department of Health and Human Services

http://www.niehs.nih.gov