

# **Citizen Science: After the Study**

## **Perspectives from Biomonitoring and Personal Exposure Research**

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**Workshop on ELSI and Citizen Science Related to the NIH Mission**

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# Citizen science: “A lab of our own”



Brody et al.  
2005 AJPH

Government Center, Boston 1993

[www.silentspring.org](http://www.silentspring.org)

# Household Exposure Study

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- 120 homes
- 89 EDCs
- Air
- Dust
- Urine

*Rudel et al. 2003, ES&T*

# Household Exposure Study

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# ELSI after the study

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**Reporting results to  
participants & communities**

**Online data sharing**

- **What (if anything) should researchers tell study participants about their results when health effects are uncertain?**



# What are participants' experiences?

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- Participants wanted their results
- Increased trust in researchers
- Pride in contributing to science and to their community
- Learning and conceptual shifts
- Reflections on family illnesses, “toxic trespass”
- Motivation to reduce exposure

COMMENTARY

Open Access

## Reporting individual results for biomonitoring and environmental exposures: lessons learned from environmental communication case studies

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### Abstract

Measurement methods for chemicals in biological and personal environmental samples have expanded rapidly and become a cornerstone of health studies and public health surveillance. These measurements raise questions about whether and how to report individual results to study participants, particularly when health effects and exposure reduction strategies are uncertain. In an era of greater public participation and open disclosure in science, researchers and institutional review boards (IRBs) need new guidance on changing norms and best practices. Drawing on the experiences of researchers, IRBs, and study participants, we discuss ethical frameworks, effective methods, and outcomes in studies that have reported personal results for a wide range of environmental chemicals. Belmont Report principles and community-based participatory research ethics imply responsibilities to report individual results, and several recent biomonitoring guidance documents call for individual reports. Meaningful report-back includes contextual information about health implications and exposure reduction strategies. Both narrative and graphs are helpful. Graphs comparing an individual's results with other participants in the study and benchmarks, such as the National Exposure Report, are helpful, but must be used carefully to avoid incorrect inferences that higher results are necessarily harmful or lower results are safe. Methods can be tailored for specific settings by involving participants and community members in planning. Participants and researchers who have participated in report-back identified benefits: increasing trust in science, retention in cohort studies, environmental health literacy, individual and community empowerment, and motivation to reduce exposures. Researchers as well as participants gained unexpected insights into the characteristics and sources of environmental contamination. Participants are almost universally eager to receive their results and do not regret getting them. Ethical considerations and empirical experience both support study participants' right to know their own results if they choose, so report-back should become the norm in studies that measure personal exposures. Recent studies provide models that are compiled in a handbook to help research partnerships that are planning report-back. Thoughtful report-back can strengthen research experiences for investigators and participants and expand the translation of environmental health research in communities.

**Keywords:** Bioethics, Biomonitoring, Community-based participatory research, Exposure assessment, Health literacy, Informed consent, Research ethics, Risk communication

## WHEN POLLUTION IS PERSONAL

HANDBOOK FOR REPORTING RESULTS TO PARTICIPANTS  
IN BIOMONITORING AND PERSONAL EXPOSURE STUDIES



[Bit.ly/SilentSpring\\_ReportBack](http://bit.ly/SilentSpring_ReportBack)

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# What are researchers' experiences?

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- Opportunity for discovery!
- Temptation to reassure
- Challenge to address policy-level change
- Resources, timing, and other challenges
  - Digital methods for larger studies, methods that tap into universal cognitive capacities and rely less on “literacy”

# ELSI after the study

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## Sharing data online

**Consent, privacy, and “immortalized”  
data in the digital era**



*Henrietta Lacks*

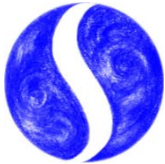
*Source: R Skloot 2010*

# Citizen Science: Issues on my mind

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- Justice issues
  - Resources for all communities to benefit
  - Support data infrastructure and validated measurement tools to make citizen data useful
- New IRB models – How can IRBs... ?
  - Cover NGOs, citizen researchers?
  - Give leeway for communication and negotiation?
  - Replace unrealistic fears with learning from data?
- Ethical expectation for researchers to participate in translating results to individuals and communities

# Partners



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- Harvard Environmental Law Clinic  
Wendy Jacobs, Shaun Goho
- Harvard Data Privacy Lab  
Latanya Sweeney

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