Pollution Gets Personal
Reporting Exposures to Study Participants

Julia G. Brody, PhD
March 2012
Agenda

Reporting exposures to participants

- Why?
- How?
- What happens?
  - Experiences of study participants
- Recommendations and questions
Personal Exposure Report-back Ethics (PERE) Study

Julia Brody, Ruthann Rudel, Phil Brown, Jessica Tovar, Rachel Morello-Frosch, Shaun Goho
Silent Spring Institute, Brown University, CBE, UC Berkeley, Harvard Law School

- 5 peer-reviewed articles
- 2 NIEHS and 2 NSF grants
- Consultations with numerous other studies
- Workshop for 40 researchers, study participants, advocates, ethicists
Reporting personal exposures

- Why?
For emerging contaminants

- Early exposure measurements precede knowledge of...
  - Human health effects
  - Sources
    “None of these chemicals come with a return address.”
  - Toxicity, mechanism of action
Are U.S. Homes a HAVEN for TOXINS?

The most comprehensive analysis to date shows that people are exposed to a wide variety of potentially toxic compounds in their homes.

Rudel et al., ES&T 2003; Brody et al., AJPH 2009; Rudel et al. ES&T 2010

www.sileentspring.org
CBPR values: Partnership

- Mutual respect, open communication
- Collaboration to address community issues
- Build community capacity
- Knowledge is power
- Co-learning
- Co-ownership of data
Emerging contaminants: Clinical model doesn’t fit

- Expert-driven (doctors decide) but medical providers aren’t the experts
- Response isn’t medical
- Drawbacks when science is uncertain
  - Problems when knowledge evolves
  - Limits participants’ learning and action
- Medical practice has evolved
Human research ethics criteria

- **Autonomy, respect for persons**
  - Right to know or not know

- **Justice**
  - Information disparity / power disparity

- **Minimize harm**
  - Emotional distress
  - Ineffective action
  - Stigma
  - Expense, legal effect

- **Maximize benefit**
  - Informed action
  - Environmental health literacy
  - Validate health concerns
- Report-back methods
Household Exposure Study

• 170 homes
Data

- > 100 analytes
- Indoor, outdoor air
- Dust
- Urine, some blood
- Observation
- Self-report
Report-back methods

- **Individual data**
  - Informed consent
    - Set expectations: What can the study say?
    - Right to know or not know
  - Written report: text and graphs, context
  - Access to researcher by phone or in-person
  - Exposure reduction resources

- **Aggregated data**
  - Fact sheet, community meetings, news media, web
Individual report-back

- Multi-level
- What we know/don’t know
- Community and individual exposure reduction
Is It Safe?

Descriptive

★ What did you find?
★ How much?

Analytical

- Is that high?
- Is it safe?
- Where did it come from?

Recommendation

- What should I do?

Brody et al, 2007, AJPH

www.silentspring.org
Report-back packet

- Cover letter
- Text summary of individual results
- How to read … individual results graphs
- Individual results graphs
- How to read … community-level graphs
- Community-level results graphs
- Background: chemicals, sources
- Exposure reduction alternatives
“We detected many chemicals in every home in the study”

“One of the chemicals we found in your urine is a weed killer.... If you are using a weed killer in your yard, you could reduce your exposure by controlling weeds without these chemicals.”

“We are studying this chemical because....”
How to read your results

Each ○ represents one other home in the study

- is the sample from your home

X is the EPA Guideline

DEHP common uses: Plastics, inks, insect repellant, cosmetics, rubbing alcohol, liquid soap, detergents, lacquers, munitions, industrial lubricant.

Chemical abbreviation (di(2-ethylhexyl) phthalate)

Brody et al. *AJPH*, 2007
Part 2: Pesticides in Urine

Summary of Your Results

Pesticides are chemicals used to kill bugs, weeds, and other pests. We tested for 9 pesticides. We tested 85 mothers. We did not test babies for pesticides.

Your Pesticide Results: We found 6 pesticides in your urine sample. We found pesticides in most mothers we tested. You can use the Results Chart on the next page to compare your pesticide levels to the average (most common) levels for pregnant women in the U.S. The attached List of Chemicals Tested gives more information about each chemical tested.

<table>
<thead>
<tr>
<th>Pesticides are commonly found in</th>
<th>Possible risks to people</th>
<th>Possible ways to reduce exposure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bug and weed killers used in homes, yards, farming, and landscaping.</td>
<td>Some pesticides can affect hormone systems, reproduction, and brain development.</td>
<td>Control indoor and outdoor pests with less toxic methods, such as bait traps.</td>
</tr>
<tr>
<td>Insect repellants.</td>
<td>Some pesticides can affect the kidneys and liver.</td>
<td>Wash fruits and vegetables. California tests samples of fresh produce for pesticides and takes action if the amounts are too high. For even less exposure, you can buy “certified organic” or “pesticide free” produce.</td>
</tr>
<tr>
<td>Products to kill head lice.</td>
<td>Some pesticides can cause cancer.</td>
<td></td>
</tr>
<tr>
<td>Products to kill fleas on pets.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Termite and mosquito control.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For More Information

Biomonitoring California [www.biomonitoring.ca.gov](http://www.biomonitoring.ca.gov)

CDC National Biomonitoring Program [www.cdc.gov/biomonitoring](http://www.cdc.gov/biomonitoring)

If you have any questions, please call the Project Coordinator, Jackie Schwartz, at 510-986-8925.
Cincinnati BCERC

Used our model to report on PFOA

Source: Susan Pinney, Katie Brown, Ann Hernick
Community report-back

- Neighborhood meetings
Research

Phthalates, Alkylphenols, Pesticides, Polybrominated Diphenyl Ethers, and Other Endocrine-Disrupting Compounds in Indoor Air and Dust

RUTHANN A. RUDEL,* DAVID E. CAMANN, JOHN D. SPENCER, LID R. KORN, and JULIA G. BRODY
Silent Spring Institute, 29 Crafts Street.

Introduction
Current widespread interest in a range of health effects potentially associated with endocrine-disrupting compounds (EDCs) has made exposure assessment for these compounds a priority. Studies of potential health effects associated with EDCs have been hampered by lack of information about the major sources of exposure to EDCs. Furthermore, because many EDCs act additively through a common mechanism of action or have antagonistic or other interactive effects by occupying at different points in cell signaling pathways, \( \ldots \)

Environmental Health

PCB-containing wood floor finish is a likely source of elevated PCBs in residents' blood, household air and dust: a case study of exposure

Ruthann A Rudel, Liesel M Seryak, and Julia G Brody

Elevated House Dust and Serum Concentrations of PBDEs in California: Unintended Consequences of Furniture Flammability Standards?

AMIR ZOTA, RUTHANN A. RUDEL, RACHEL MORELLO-FROSCH, and JULIA G. BRODY

Silent Spring Institute, Havens, MA, Department of Environmental Health, Harvard School of Public Health, Boston, MA, and Department of Environmental Management and School of Public Health, UCLA, Los Angeles, CA.

Research notes...

Studies show higher house dust and body burdens of PBDE flame retardants in North America than in Europe because of the restriction in California. PBDEs are not extensively measured in California, as they are in Europe, and the contamination is lower in California than in other states, but the possibility has not been evaluated.

Three major PBDE commercial mixtures have been commonly used in consumer products: deca-PBDE, octa-PBDE, and penta-PBDE. Although PBDEs are moderately bioaccumulative and have low toxicity, they are toxic in the environment, and the increased levels in the environment, while useful for those products, may need to be controlled because of their neurotoxic potential, which may be associated with increased rates of autism in children. PBDEs have been used almost exclusively in the US (60%) and they are not used in Europe in order to comply with...

Pollution Comes Home and Gets Personal: Women's Experience of Household Chemical Exposure

REBECCA GASIOR ALTMAN
Brown University
RACHEL MORELLO-FROSCH
University of California at Berkeley
JULIA GREEN BRODY
RUTHANN RUDEL
Silent Spring Institute
PHIL BROWN
MARA AVERICK
Brown University


We report on interviews conducted with participants in a panel study about envi-...
Community report-back

- News media

---

**Is Your Furniture Making You Sick?**

Toxins can hide in bookcases, shower curtains, and old clothes. Scary, but protecting yourself is simple.

---

**CALIFORNIA**

- Californians have toxic flame retardant levels twice the national average
- Peer-reviewed study
- State and Federal Governments consider expand use of flame retardants

---

**CAPITOL WI**

Leno asks Governor to ban controversial fire retardants by executive order

---

**LAT Home | My LATimes | Print Edition | All Sections**

**Los Angeles Times | Science**

"Researchers find that residents not only have more of the chemicals than people elsewhere, but that levels in California homes can...

---

**SECONDARY CONTENT**

- MarketWatch
- Wall Street Journal
- WSJ.com
- Barrons
- The Financial Times
- Financial Times

---

**LATEST NEWS**

[VRSN] VeriSign Q3 net loss $1.02 a share vs 6c profit

---

**PRESS RELEASE**

Californians have toxic flame retardant levels twice the national average

---
Community report-back

- Online

Silent Spring Institute researches the links between the environment and women's health, especially breast cancer. Find us on Facebook.

FEATURING RESEARCH
Researchers call for reporting in breastlink studies
Flame retardants in some California homes exceed EPA guideline
Pollution from household and

www.silentspring.org

www.cbecal.org
What can I do?

**Polluters** (refinery, ships)
- Collective Action
  - Organize
  - Participate
  - Vote!

**Products hard to avoid** (flame retardant)
- Chemicals policies
  - Consumer campaigns
  - Vote!

**Products individual choices** (indoor pesticides)
- Individual Action
  - Product choices
  - IPM
Researcher responsibility to interpret

—“You have to ‘titrate’ the message.”

-- Susan Pinney
Feedback from study participants

• Prototype reviews
  – COB - usability testing (Rachel Morello-Frosch)
  – CYGNET focus groups (Larry Kushi)

• Report-back experiences
  – Growing Up Female survey (Susan Pinney)
  – HES interviews (Julia Brody, Phil Brown, Rachel Morello-Frosch)
Prototype reviews

• Reacted favorably
• Want to know
  – “More”
  – Results in comparison to other participants, national levels
  – Levels of health concern/benchmarks
  – Specifics about exposure reduction
• More people prefer graphs, some prefer text
• Want access to someone
Prototype reviews

• Understand basics, including health uncertainty
• View results as family resource for future reference
Experiences of our participants

Pollution Comes Home and Gets Personal: Women’s Experience of Household Chemical Exposure*

REBECCA GASIOR ALTMAN
Brown University

RACHEL MORELLO-FROSCH
University of California at Berkeley

JULIA GREEN BRODY
RUTHANN RUDEL
Silent Spring Institute

PHIL BROWN
MARA AVERICK
Brown University

Altman et al., 2008, Journal of Health and Social Behavior

Adams et al., 2010, Journal of Health and Social Behavior

We report on interviews conducted with participants in a novel study about environmental chemicals in body fluids and household air and dust. Interviews reveal how personal and collective environmental history influence the interpretation of exposure data, and how participants fashion an emergent understanding of environmental health problems from the articulation of science and experience. To the illness experience literature, we contribute a framework for analyzing a new category of embodied narratives—“exposure experience”—that examines the mediating role of science. We update social scientific knowledge about social responses to toxic chemicals during a period in which science alters public understanding of chemical pollution. This article is among the first published accounts of participants’ responses to learning personal exposure data, research identified as critical to environmental science and public health. Our findings raise the importance of reporting even uncertain science and underscore the value of a community-based reporting strategy.
Interviews with participants

- 50 participants
- 60-90 minutes, in-person
- Transcribed, coded in NVivo

- How do people assign meaning to their results? Do they get the messages?
- What is their experience?
- Is there a public health benefit/harm?
What did people learn?

- Many chemicals are detected in homes
- Banned substances are found today
- Many sources
- Comparisons to study distributions and EPA guidelines
- Common household chemicals are unregulated, understudied
Key experiences

- Participants wanted their results
- Increased trust in researchers
- Pride in contributing to science and health
- Dramatic conceptual shifts: Pollution becomes personal
- Reflections on family illnesses
- Sense of “toxic trespass”
Key experiences

- Frustration at information gaps
- Evolving interpretations, brainstorming
- Motivation to reduce exposure
Differences across communities

- Expectations grounded in community history
- Shared surprises about indoor sources
- Struggle to gain control
  - Action or psychological distancing
- Individual vs. community action
At first I was thinking, “God, I wish I didn’t know all this.” But the more I think about it, the more I understand it, the more I feel like it helps me to, … do whatever I can…if you know the information then you can’t not participate in trying to make change.
Richmond community action contributed to court ruling on cumulative impact assessment!
Researcher experiences

- Focus on understanding “high” results
- The temptation to reassure
  - “…there’s no evidence that…”
  - Outdated EPA guidelines
- Public health and good vs. bad worry
- Rethinking “health literacy” in light of
  - universal capacities
  - democracy
Backdrop for report-back

Psychology and sociology literatures on

- Cognition and cognitive heuristics
- Stress and coping
- Social networks, social knowledge
- Risk communication
- Public understanding of science
- … more
Backdrop for report-back

Public responses to contamination

- Love Canal
- Three Mile Island
- Bhopal
- Chernobyl
- Woburn
- Katrina

Brown and Mikkelson 1997
Backdrop for report-back

- Embodied health movements
  - Breast cancer
  - Asthma
  - Autism, learning disabilities

Brown 2007
Recommendations

- Build on community partnerships
- Begin with “right to know …not know” in informed consent
- Set expectations for what studies can/can’t say about exposure and health
- Provide context to make individual results meaningful
- Address opportunities for action
Recommendations

- Consider cultural context (of course)
- Respect multiple learning styles (verbal, graphic)
- Respond to unexpected or extreme results
Challenges

- Timing
- Consensus on benchmarks
- Managing overload for the participant
- Automating processes for the researcher
A HEALTHIER FUTURE

View a brief introduction to Silent Spring Institute’s research on the links between the environment and breast cancer, environmental health issues and the emerging field of green chemistry.

CLICK TO VIEW VIDEO

Silent Spring Institute researches the links between the environment and women’s health, especially breast cancer.

Featured Research
Tests find new contaminants in Cape Cod’s drinking water supply
President’s Cancer Panel highlights everyday exposures to environmental pollutants and cancer
Oil refinery toxics found in air of nearby homes
Researcher reporting in breastmilk studies
Pollution from household and personal care products has been a blind spot for society, according to study by the Silent Spring Institute

Media Coverage
Household Exposure Study highlighted by the NIEHS’ Gwen Collman, The Environmental Factor
Director of Research, Ruthann Rudel, participates in review of soy infant formula, The Environmental Factor
Silent Spring water tests reveal contamination, Cape Cod Times

New at Silent Spring Institute
Massachusetts Environmental Trust funds Silent Spring Institute research by the sale of specialty license plates
Dinner honoree, Judi Hirshfield-Bartek, interviewed by The Boston Globe

Did You Know?
Of the 3,000 high-production pesticides in use, 200 are banned in other countries but remain legal in the United States.