Moments Of Uncertainty: Ethical Considerations and Flame Retardant Chemicals

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Fire Retardant Dilemma
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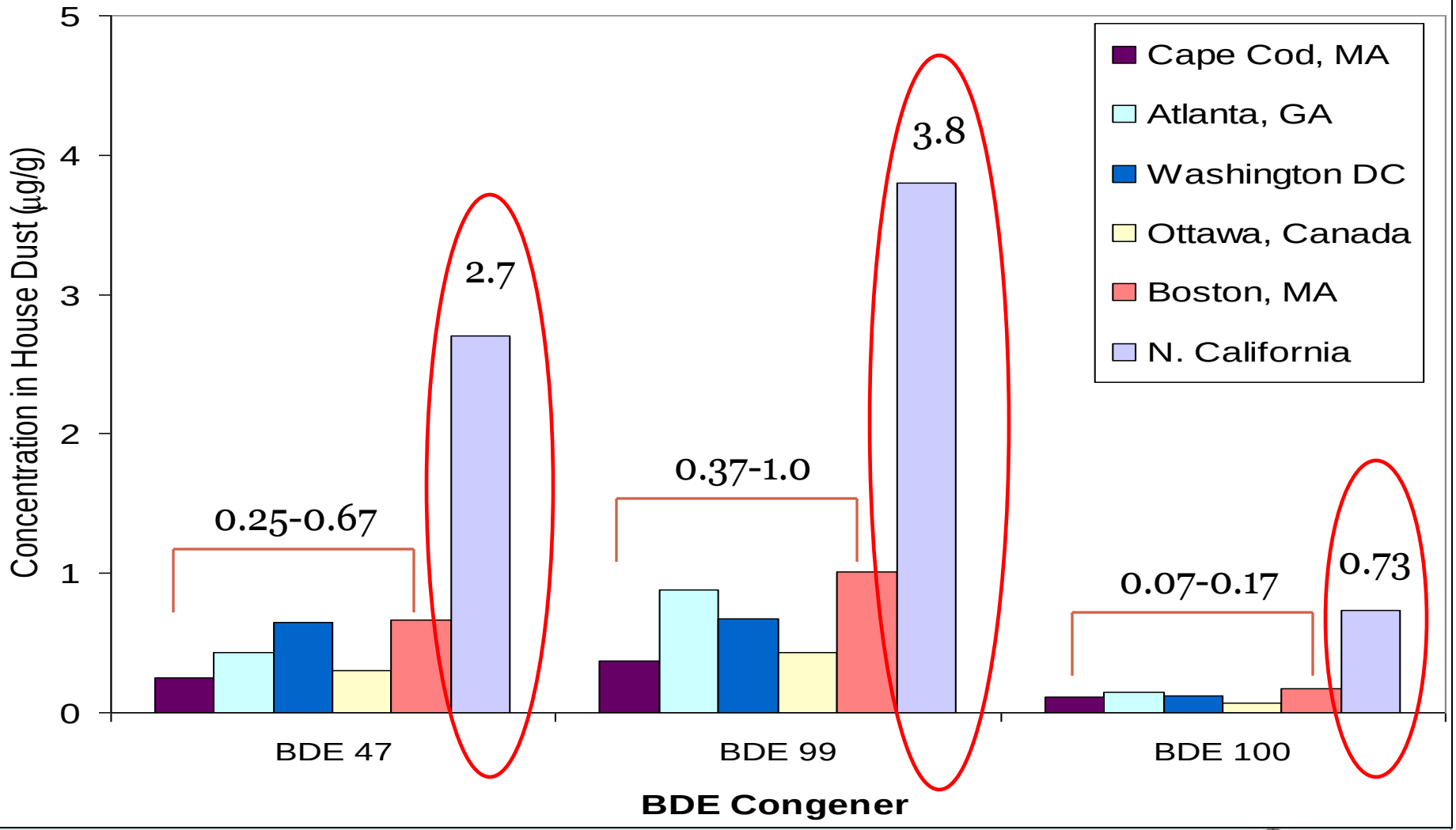
- **Research Question:** How do scientists make ethical decisions regarding research practices in the face of scientific uncertainty, and what are the consequences of scientific uncertainty for the practice and use of research on policy-relevant topics?

- **Case study:** biomonitoring and exposure research on flame retardant chemicals

Our Project's Origins: Household Exposure Study (Cape Cod and Northern California) – Silent Spring Institute/Brown/UC-Berkeley



Zota et al. "Elevated house dust and serum concentrations of PBDEs in California: Unintended consequences of furniture flammability standards *Environmental Science and Technology* 2008 42:8158–8164

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Risk and Uncertainty

- Risk Society (Beck 1992, Giddens 1990)
- Social psychology (Slovic 1987, Sandman 1989)
- Culture and identity (Douglas 1990)
- Organizations (Clarke 1988)
- Governmentality (Foucault 1991, Althaus 2005)
- Medical sociology (Fox 1980 & 2000, Atkinson 1984, Light 1979)
- Environmental Sociology (Auyero & Swistun 2008)

Ethics and Uncertainty

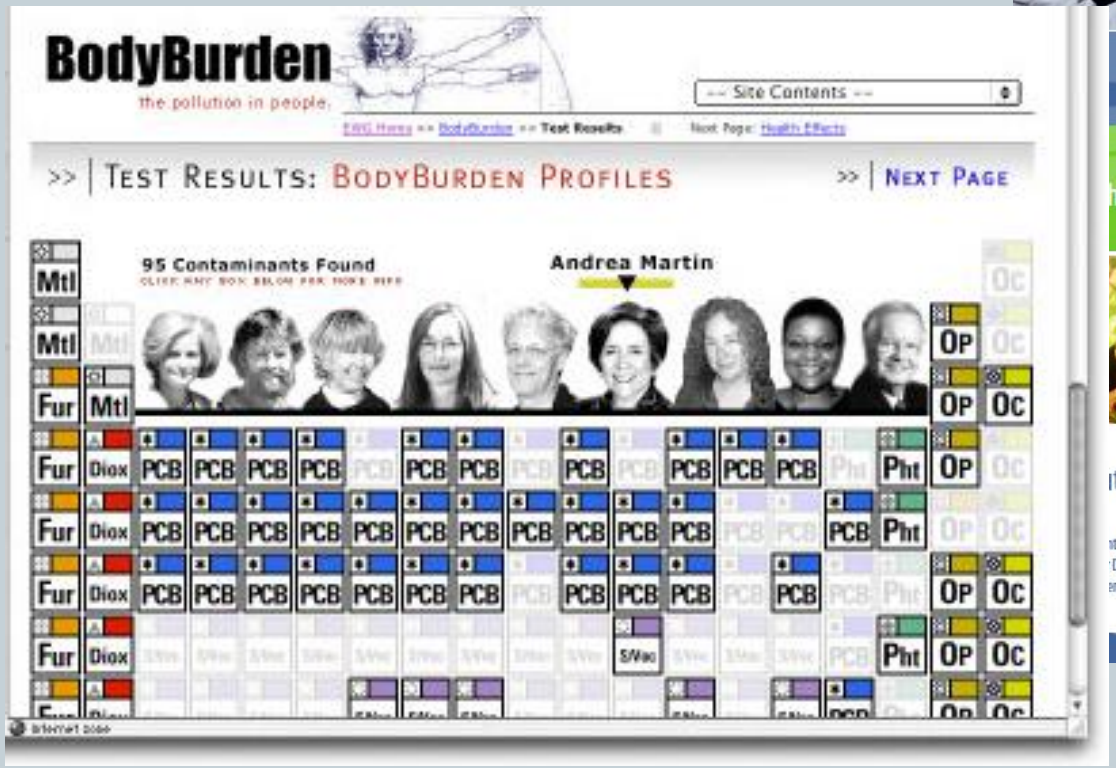
- Ethical guidelines
  - Formal – e.g., IRBs, professional codes of conduct
  - Informal – e.g., personal decision-making, research team discussions

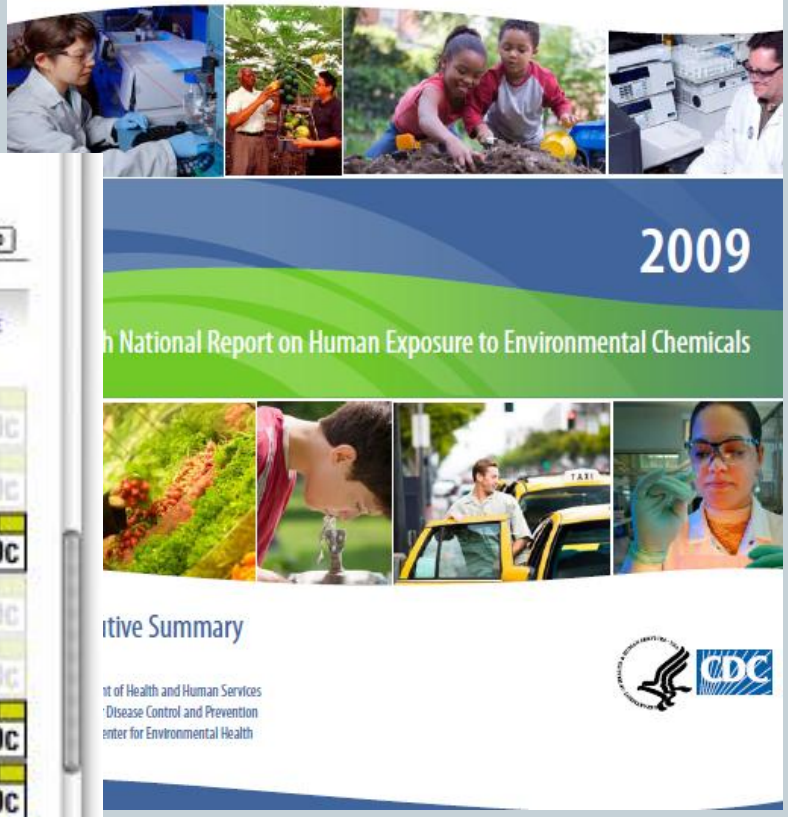
- **Reflexive research ethics**: deliberate, continuous self-awareness and responsiveness at all research stages

Reflexive Research Ethics

- Identify and establish interactive discussions with the full range of publics relevant to their research
- Identify norms and principles that govern research
- Assess ethical tensions that arise from the prioritization of particular interests, publics or principles
- Respond to emergent ethical tensions
  - Cordner, Ciplet, Brown & Morello-Frosch. Forthcoming 2012. "Reflexive Research Ethics for Environmental Health and Justice." *Social Movement Studies*.

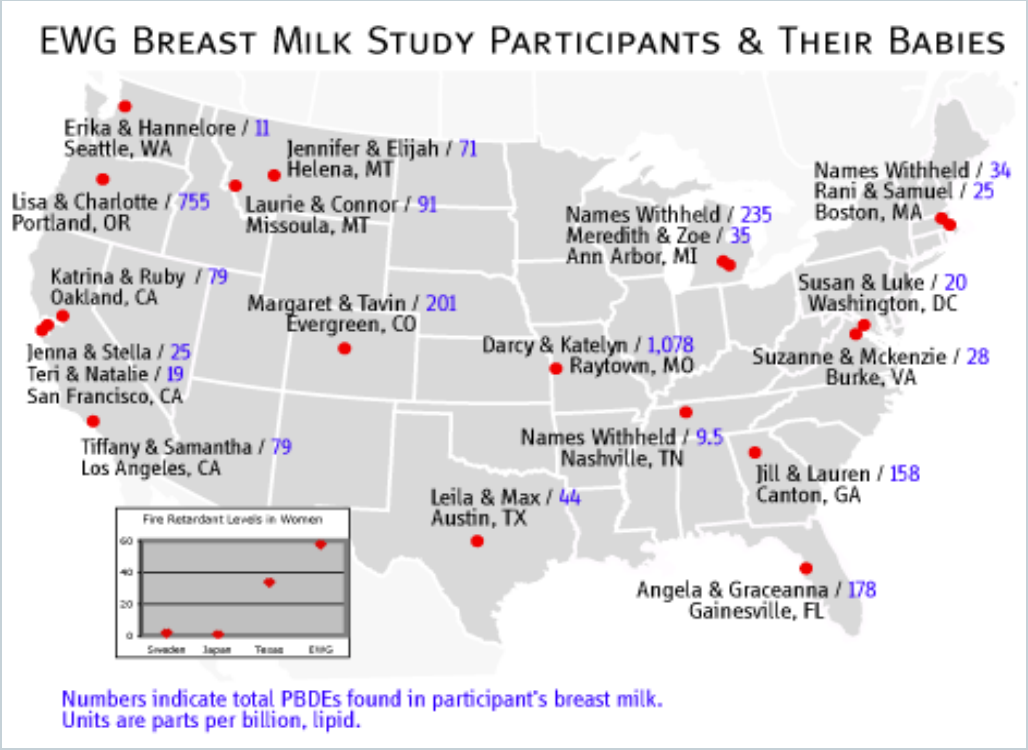
Biomonitoring





"Advocacy Biomonitoring"

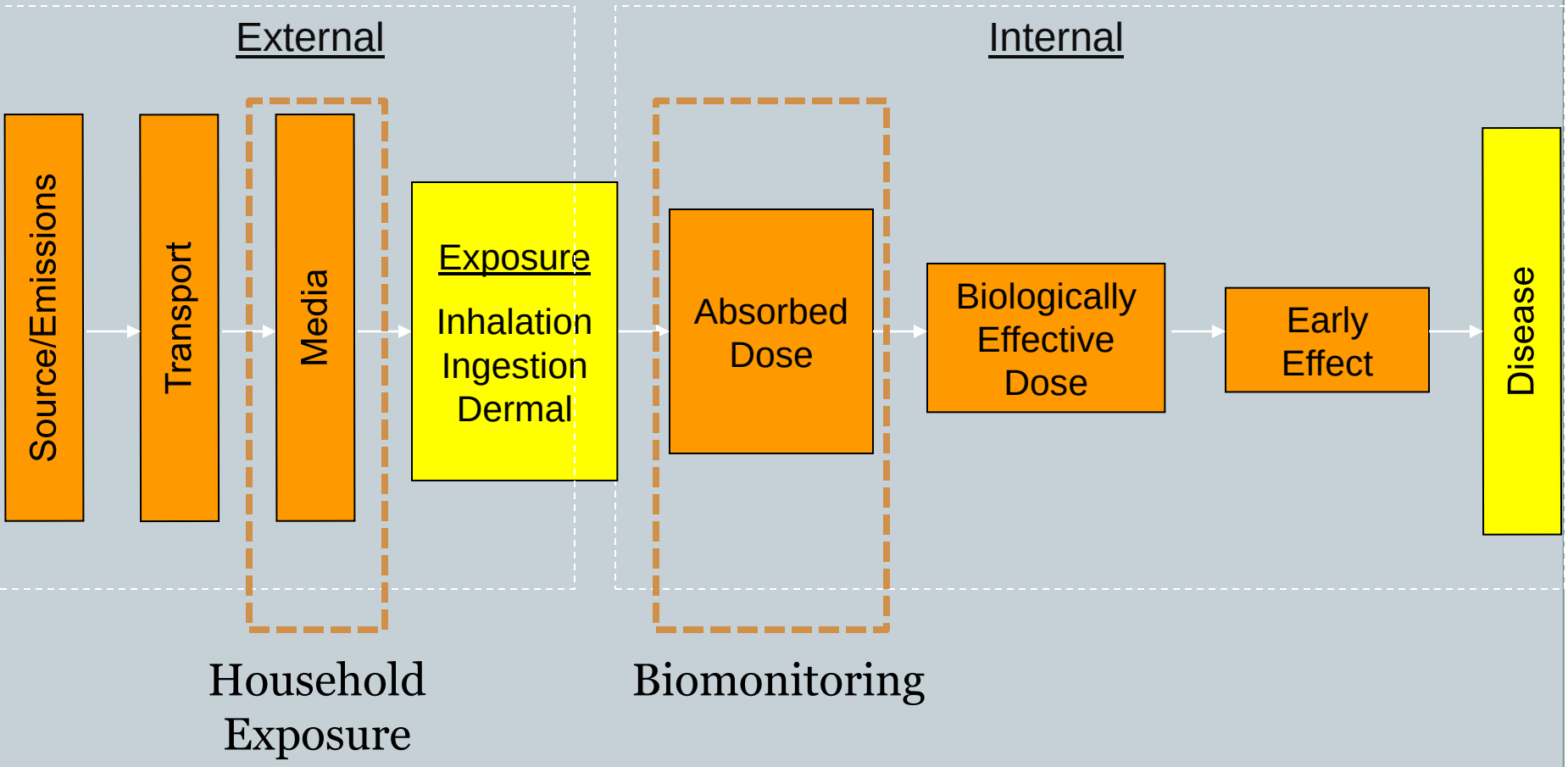
- EWG Sept. 2003
- 20 mother/ daughter pairs
- Tested for PBDEs



Biomonitoring and Ethics

- Communication of results
  - The ability to detect has outpaced the ability to interpret.
  - A “Research Right-to-Know” – “subjects should be told (or offered the chance to be told) whatever researchers know (or do not know)” National Research Council 2006
  - Breastfeeding?

Exposure Pathway



Slide courtesy of Mike McClean
Boston University School of Public Health

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Methods

- Ongoing NSF-funded Project – "Flame Retardant Chemicals: Their Social Discovery as a Case Study for Emerging Contaminants" – NSF SES–0924241
- In-depth interviews with over 50 respondents – scientists, regulators, industry representatives, fire safety experts, and organizers from environmental and health social movements
- Interviews were recorded, transcribed, and analyzed in NVivo

Moments of uncertainty in emerging and policy-relevant science	Example of corresponding ethical questions

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Production of knowledge	What methods are ethically appropriate?

1: Production of science

- Research on breast milk contamination
  - Breast milk "is very important scientifically because babies are developing, and so breast milk exposures have the potential to have effects beyond the effects on adults. So it is genuinely troubling that there are contaminants in breast milk" *Environmental Health Scientist*
- Some IRBs deny protocols that test breast milk for biomonitoring, others approve similar protocols

Moments of uncertainty in emerging and policy-relevant science	Example of corresponding ethical questions
Production of knowledge	What methods are ethically appropriate?
Interpretation of research results	How should findings be interpreted when there is a small body of comparable research?

2: Interpretation of results

- Interpreting individual-level biomonitoring data
  - "What if you're [looking at results from] that person who represents the 99th percentile exposure of body burden?… What do you tell them?" *Public Health Scientist*
- One-time testing vs. chronic exposure
  - "When you biomonitor you're taking a snapshot of what was found at that moment of collection. So some of these chemicals that we're learning about… you may have excreted it in your urine and so you get a non-detect." *Environmental Activist*

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Communication of results to multiple publics	Who owns research data? Should participants have access to all the data that researchers collect?

3: Communicating Results

- Communicating to Participants
  - "I like the idea of reporting to people because I feel like it respects… them as adults, you know, as people who can think for themselves… I've asked them to take their blood, I've asked to analyzed things in their blood. It doesn't seem right that I don't tell them the results." *Public Health Scientist*
- Communicating to the Public
  - "You get a level of a particular chemical, and that doesn't tell you anything about the biological impacts of that. But that's getting too complicated for the general public." *Environmental Health Activist*

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Production of knowledge	What methods are ethically appropriate?
Interpretation of research results	How should findings be interpreted when there is a small body of comparable research?
Communication of results to multiple publics	Who owns research data? Should participants have access to all the data that researchers collect?
Use or application of scientific results	How involved should a researcher be in policy decisions?

4: Using science for regulation

- Identify regulatory failures
  - "They [chemicals in the body] are the canary in the coal mine." *Industry Consultant*
- Assist in risk assessment
  - "So if for example the substance has an adverse effect on human health if you're exposed to 10 milligrams per day of it,… if in reality you're only exposed to 0.01 grams per day, it doesn't pose any risk." *Industry Representative*
- Concerns over application of science
  - "It's a political battle that they [activists] are fighting, and in a political battle, they are not really clinging tightly to the science." *Public Health Scientist*

Risk and Scientific Interpretation

- Institutional definitions of risk are tied to institutional goals and perspectives on chemistry
  - Industry – chemicals are useful products to be marketed
  - EPA – chemicals are potentially dangerous substances to be regulated

Implications

- Uncertainty in biomonitoring research is unlikely to be resolved anytime soon
- IRBs should not use scientific uncertainty as justification for withholding information from participants
- Salience of *informal* ethical practices in emerging fields of science

Implications (2)

- Need for real-time social science investigation of uncertainty
- Greater social science attention to supply chains

Implications (3)

- Flame retardant work plays a pioneering role in reflexive research ethics and the "research right-to-know" issues of reportback

- Concerted effort can take a relatively unknown class of chemicals and make them widely discussed

Implications (4)

- Unique perspective from sociology
  - Frame the problem so that we understand the many component that go into scientific discovery
  - Apply "policy ethnography" method
  - Emphasize impact of social movements and unlikely alliances (e.g. firefighters)
  - Introduce an approach to uncertainty which is larger than the usual ways scientists deal with uncertainty
  - Understand the cultural significance of breastmilk biomonitoring
  - Related to the above, emphasize the "embodied" experience of body burden and potential disease

Thank You!

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See our recent article

"Lessons Learned from Flame Retardant Use and Regulation Could Enhance Future Control of Potentially Hazardous Chemicals" (Phil Brown and Alissa Cordner). *Health Affairs* 2011 30 (5):1-9.

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