Background and Framing of Results Communication and Report-back Issues

Rachel Morello-Frosch, Ph.D., M.P.H
University of California, Berkeley
School of Public Health & Department of Environmental Science Policy and Management

Outline

- Scientific Challenges in Results Communication
- Frameworks for communication

  1) clinical ethics
  2) community-based participatory research

- Our experience from household exposure studies
  - Cape Cod, MA
  - Northern CA
  - Interviews of scientists, study participants, IRB members
- Implications for future research

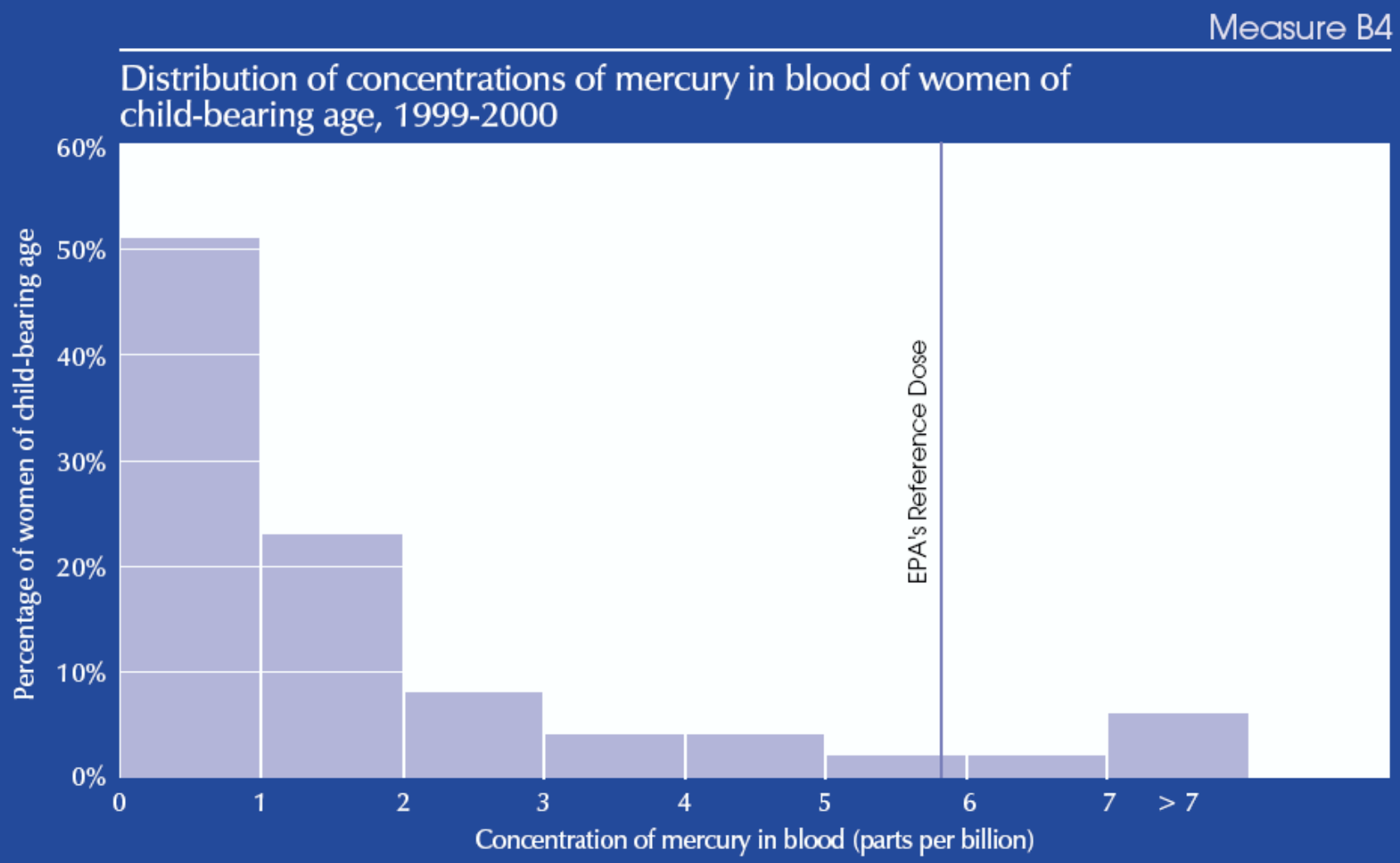
Scientific Challenges in Personal Exposure Assessment

- **Exposure:** Move away from chemical-by-chemical analysis toward a cumulative exposure approach
  - Assess population exposures for multiple "emerging pollutants"
- **Data Gaps:** regulatory challenge for many pollutants.
  - "No data, no problem?"
  - Enhance opportunities for exposure reduction when health implications remain unclear
    - Important for highly impacted and vulnerable communities

Biomonitoring & Household Exposure Studies

- History: critical to health surveillance
  - Lead testing
    - Workers
    - Children for lead paint exposure
  - Surveillance
    - Environmental tobacco exposure
    - Mercury
    - Lead

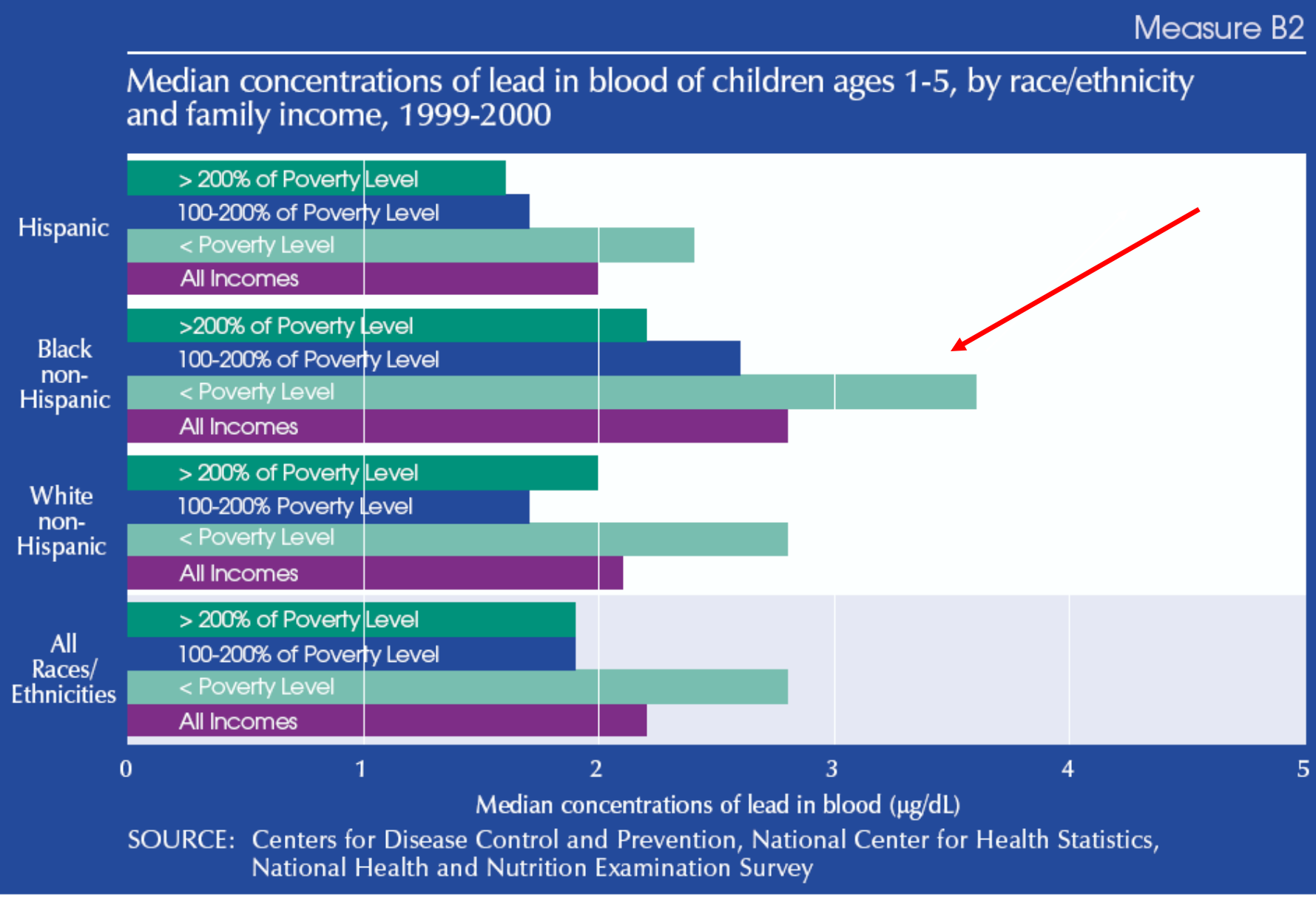
Surveillance – Mercury
Compare to Regulatory Benchmarks



SOURCE: Centers for Disease Control and Prevention, National Center for Health Statistics, National Health and Nutrition Examination Survey

Note: EPA's reference dose (RfD) for methylmercury is 0.1 micrograms per kilogram body weight per day. This is approximately equal to a concentration of 5.8 parts per billion mercury in blood.

Surveillance – Lead
Who Bears the Burden?



Biomonitoring

- New technologies for exposure assessment
  - Increased capacity, specificity, sensitivity
  - Techniques are more affordable and widely available
- Technology outpaces knowledge about chemical impacts on health
  - Particularly for “emerging pollutants”
    - Phthalates, brominated fire retardants, others

EHP, November 2006

Photo: United Farm Workers

Biomonitoring & Uncertainty

- Indicates chemical exposures, but often says little about sources
  - *"None of these chemicals come with a return address."*

    -biomonitoring study participant
- Capacity to detect precedes capacity to interpret
  - No regulatory benchmarks
  - Few comparison studies

Implications for Environmental Justice

- Communities conduct biomonitoring to:
  - track exposures and extent of contamination
  - leverage government action, funding, industry action, legal remedies

- EJ concerns about biomonitoring:
  - Biomonitoring may “over-scientize” environmental health disparities
  - Stigma and discrimination
  - Future use of biological samples

photos: top-Louisiana bucket brigade; bottom-Orion Magazine (July/Aug 2003)

Biomonitoring & Results Communication

- Uncertainty leads to different approaches to reporting results for study participants and the broader public

- Frameworks to consider:
  1) clinical ethics
  2) community-based participatory research (CBPR)

Morello-Frosch, Brody, et al. *Environmental Health*, 2009

Clinical ethics

- Health professionals decide whether results are clinically relevant
- Clinical action levels are determined prior to the start of the study.
- If results are below this level, no report-back to participants.
  - E.g. CDC NHANES

Drawbacks of clinical ethics

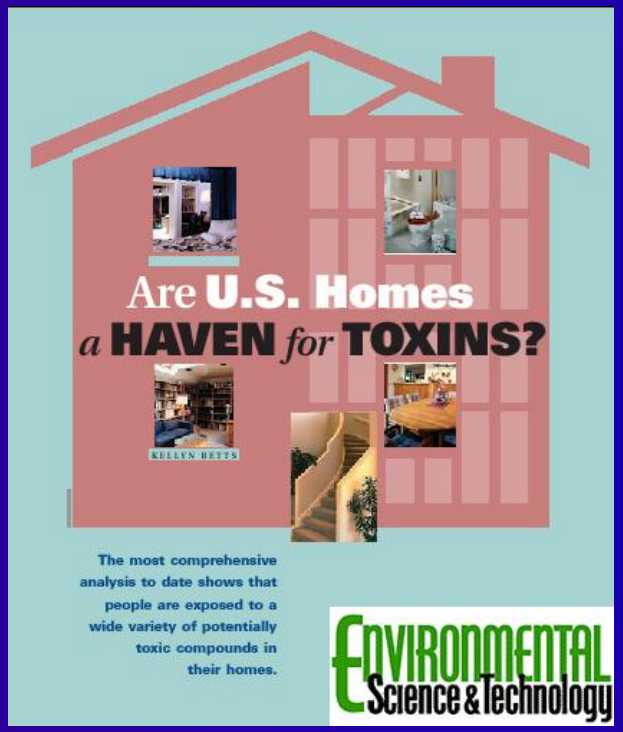
- Contradicts current medical ethics of:
  - Providing patients with more information;
  - Enabling patients to be proactive in directing their health care
- Underestimates participants' ability to process complex and uncertain information
- Precludes individual action
  - Potential health effects below action levels
    - lead
    - mercury
    - endocrine disrupting chemicals

Community-based participatory research

- Exposure assessment as joint venture -- researchers, community members, and study participants
- Shared decision-making
  - Both aggregate and individual report-back protocols
- Balance time spent reporting to communities and to scientific peers
- Researchers clarify what information exposure methods can and cannot provide

Cape Cod Household Exposure Study

Silent Spring Institute



Rudel et al. 2003 ES&T

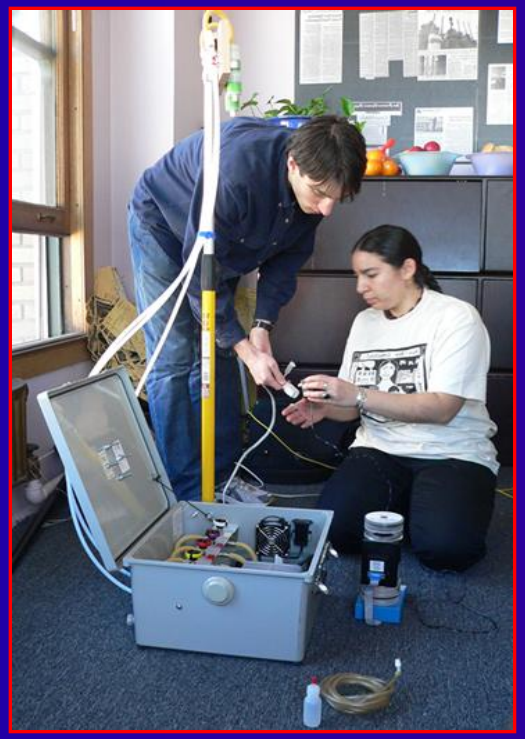
- 170 homes
- Air, dust, urine
- 89 endocrine disruptors

Results

- 67 EDCs
- 27 pesticides
- DDT 2/3 of homes
- Phthalates - 100% homes
- Phenols, parabens abundant
- Flame retardants 10 x Europe
- 28 chemicals have no health-based guidelines

www.silentspring.org

Household Exposure Study: Northern California



50 Homes

- Richmond, CA (N=40)
- Bolinas, CA (N=10)

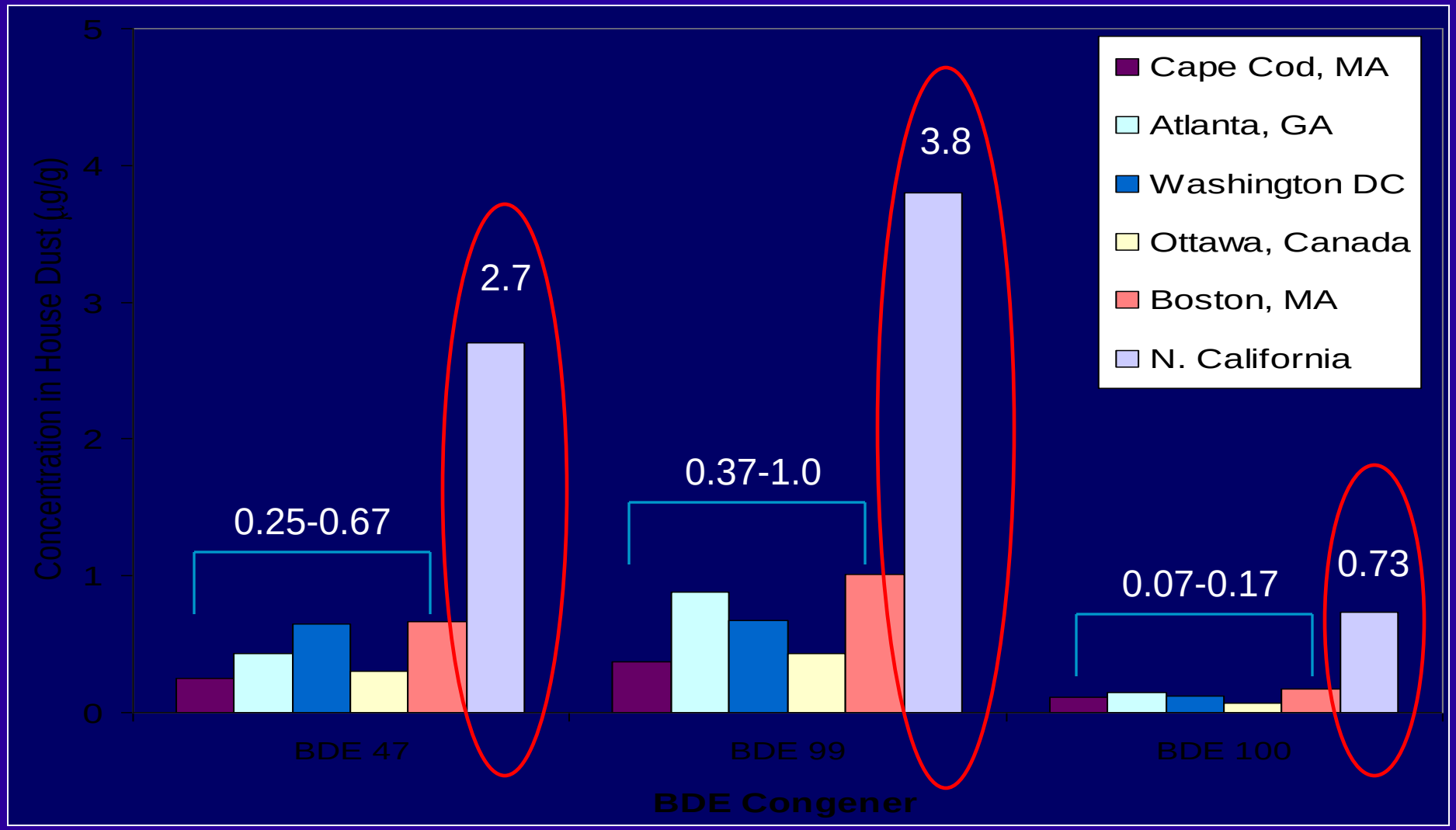
Methods

- Indoor/outdoor air & dust collected from each home
- 155 analytes -- industry, transportation sources and consumer products

Goals

- Compare pollutant levels in communities with and without major industry
- Assess cumulative impact and highlight local sources of concern
  - E.g. refinery activities, transportation

Median PBDE household dust concentrations across 6 regions in North America



Flame Retardants in Blood

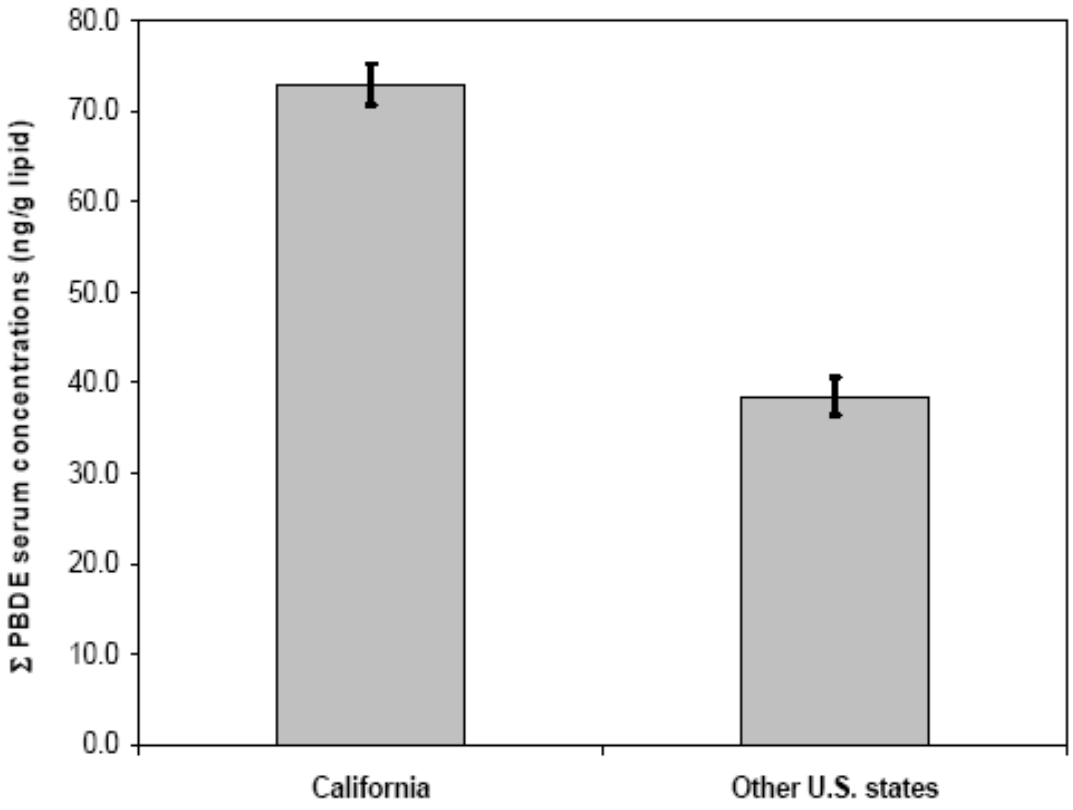
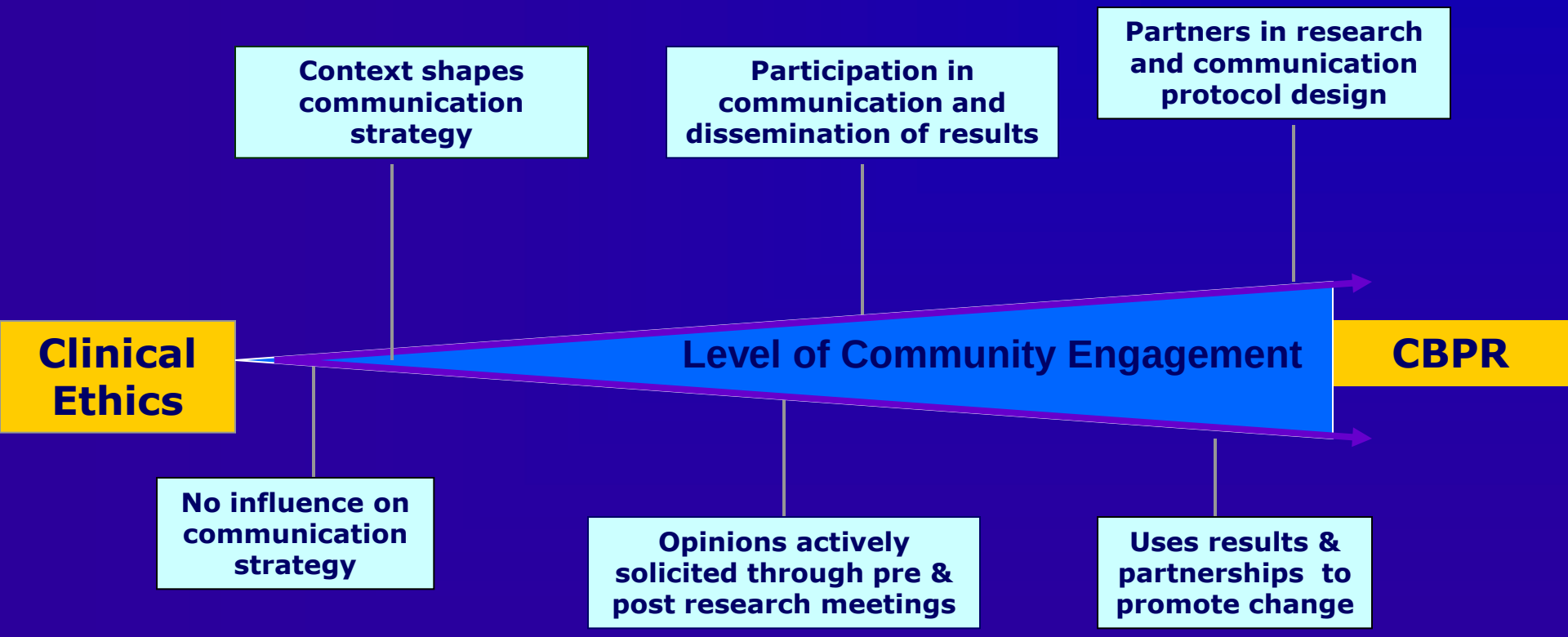


Figure S1. Least square geometric means (LSGM) and 95% confidence intervals of ∑PBDE serum in California versus other U.S. states after adjusting for age, gender, household income, country of origin, survey design and sample weights.

Zota, Rudel, Morello-Frosch, Brody, ES&T, 2008

Continuum of Community Engagement



From Study Participant…

…to Research Partner

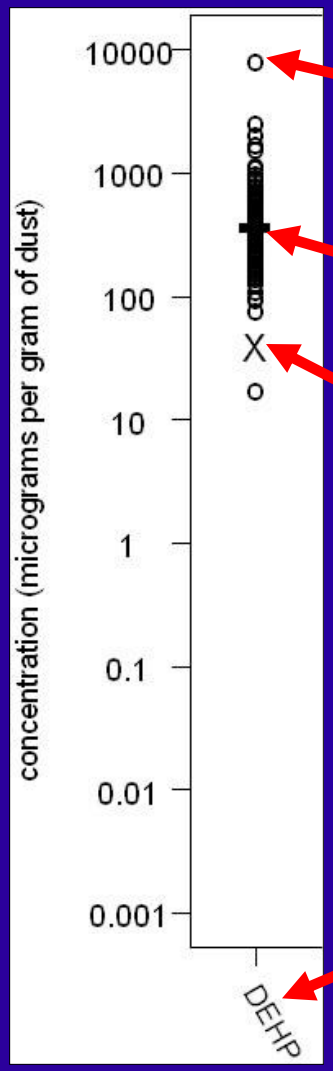
What to Report to Individual Participants?

- What did you find?
- How much?
- Is that high?
- Is it safe?
- Where did it come from?
- What should I do?

Report-back examples- Text

- 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.

Report of individual results



Each o 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)

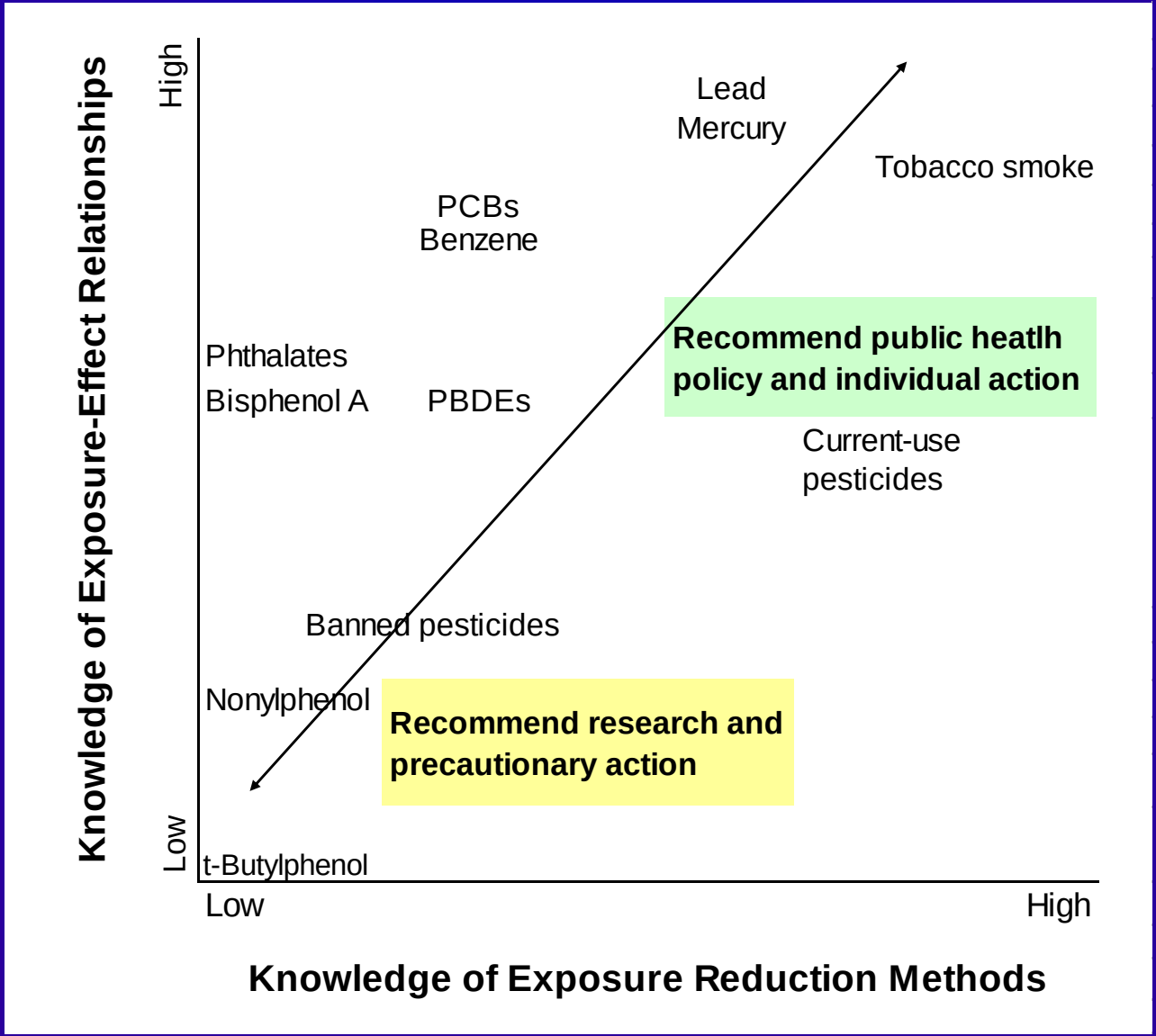
Brody, Morello-Frosch, et al. *AJPH*, 2007

Reactions of study participants regarding biomonitoring report-back

- Despite uncertainty, nearly all participants (97%) requested individual results
- Report-back experiences include:
  - Curiosity
  - “Research altruism” – advance scientific enterprise
  - Deeper understanding of exposure routes/sources of chemicals
  - Use results to take action
    - Individual
    - Collective

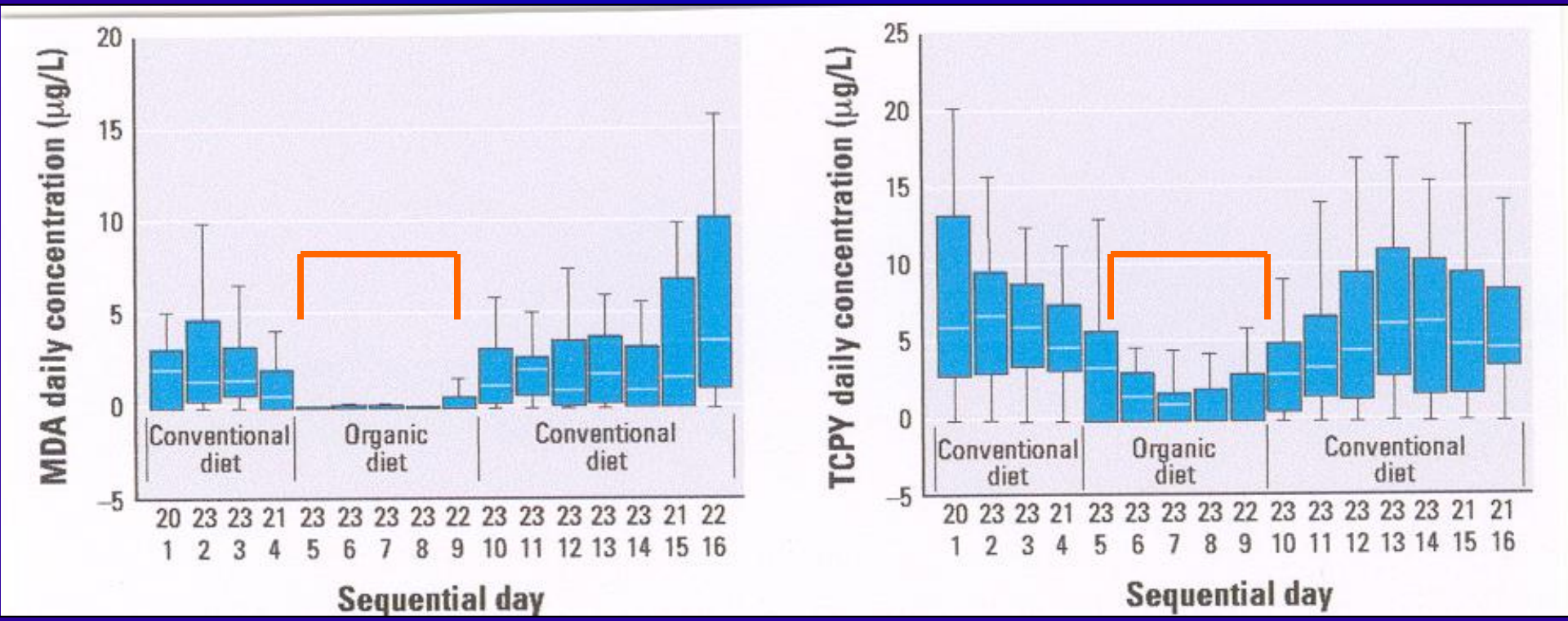
Altman, Morello-Frosch, et al. JHSB 2008.

Matching Messages to Strength of Evidence



Brody, Morello-Frosch, et al. *AJPH*, 2007

Organic Food Lowers Pesticides in Kids



Metabolites of malathion and chlorpyrifos in urine

Lu *et al*. (2006) EHP 114:260-263

Linking Results with Individual and Collective Action

Exposure Assessment

Pollutant Sources

Local Source Pollutants

E.g. Stationary & mobile sources

Consumer Products
little/no capacity to avoid

E.g. brominated flame retardants

Consumer Products
•*capacity to avoid*
•*sources known*
E.g. pesticides

Collective Action

Local Arena
*Permitting
*Land use decisions

Policy Arena
*SB 706 – banning halogenated flame retardants
*Lifting CA flammability retardant standard

Individual Action
*Use of IPM

Implications and recommendations

- Set expectations for what studies can/can't say
- Indicate how participants can use results to take action, where possible
- Provide information to make results meaningful
  - Aggregate and individual-level results are important
  - Apply regulatory benchmarks where possible
  - Distributional information for comparison
    - Study population distribution
    - CDC NHANES biomonitoring results
  - Categorize results into meaningful use & source categories

Implications and recommendations

- Address cultural context of communication strategies and be willing to modify approaches midstream
  - Literacy
  - Balancing right-to-know with capacity to act
- Clarify how much intervention is possible to reduce exposures
  - (e.g. due to cost, uncertainties, etc.)

Research Collaborative

Regulatory Science Research Group
http://espm.berkeley.edu

Contested Illnesses Research Group
www.brown.edu/contestedillnesses/
Silent Spring Institute
www.silentspring.org

Communities for a Better Environment
www.cbecal.org

Silent Spring Institute (MA)

Brown University (RI)

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UC Berkeley (CA)

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Contact information: rmf@nature.berkeley.edu