Reporting Back Personal Exposure Data to Participants

SRP Risk e-Learning October 22, 2021

Risk Communication Strategies to Reduce Exposures and Improve Health

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SILENT SPRING INSTITUTE
Researching the Environment and Women's Health

SSEHRI
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Social Science Environmental Health Research Institute

Why is Report-Back an Equity Issue?

- **Research ethics: Respect the autonomy of study participants and increase benefits of research for them**
- **Opportunity for culturally competent communication**
- **Knowledge is power: Right-to-know, right-to-act**

EJ and other community groups like report-back

- It fits with their approach to community ownership of data
- It supports their belief that research should lead to action
- It develops community capacity
- It facilitates production of community-driven tools
- Communities for a Better Environment is partner in Household Exposure Study – leads to engagement with Concerned Citizens of Tillery and WEACT
- REACH study (PFAS Immunotoxicity) – Testing for Pease and Mass. Breast Cancer Coalition are partners, and many grassroots PFAS groups around US assisting in production of medical guidance documents

Social Science Elements

- "Exposure experience" derives from medical sociology concept of "illness experience"
- "Research altruism"

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

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Journal of Health and Social Behavior 2008, Vol 49 (December): 417–435

Contents lists available at ScienceDirect
Social Science & Medicine
journal homepage: www.elsevier.com/locate/socscimed

Research altruism as motivation for participation in community-centered environmental health research

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DEALING WITH IRBs

- Initial resistance from Brown IRB on report-back, continued contact with participants, public meetings, destroying data
- BU IRB and passive report-back for breastmilk study (virtually no one requested data, compared to our nearly 100% in active report-back)
- ACAT travails with IHS IRB
- Reluctance should change with NASEM 2018 report.

Saxton *et al. Environmental Health* (2015) 14:90
DOI 10.1186/s12940-015-0076-x

Environmental Health

COMMENTARY Open Access

CrossMark

Environmental health and justice and the right to research: institutional review board denials of community-based chemical biomonitoring of breast milk

Dvera I. Saxton[1*], Phil Brown[2], Samarys Seguinot-Medina[3], Lorraine Eckstein[3], David O. Carpenter[4], Pamela Miller[3] and Vi Waghiyi[5,3]

Report-back Design and Messages

What goes into making reports?

Report-Back Developed from Participatory Research

- Multi-disciplinary expertise
- Interviews with participants, researchers, and IRBs
- Focus groups, advisory councils, stakeholder workshops
- Observations at community meetings
- One-on-one user testing of reports
- Digital analytics

Funded by NIH, NSF, CA Breast Cancer Research Program, CDC

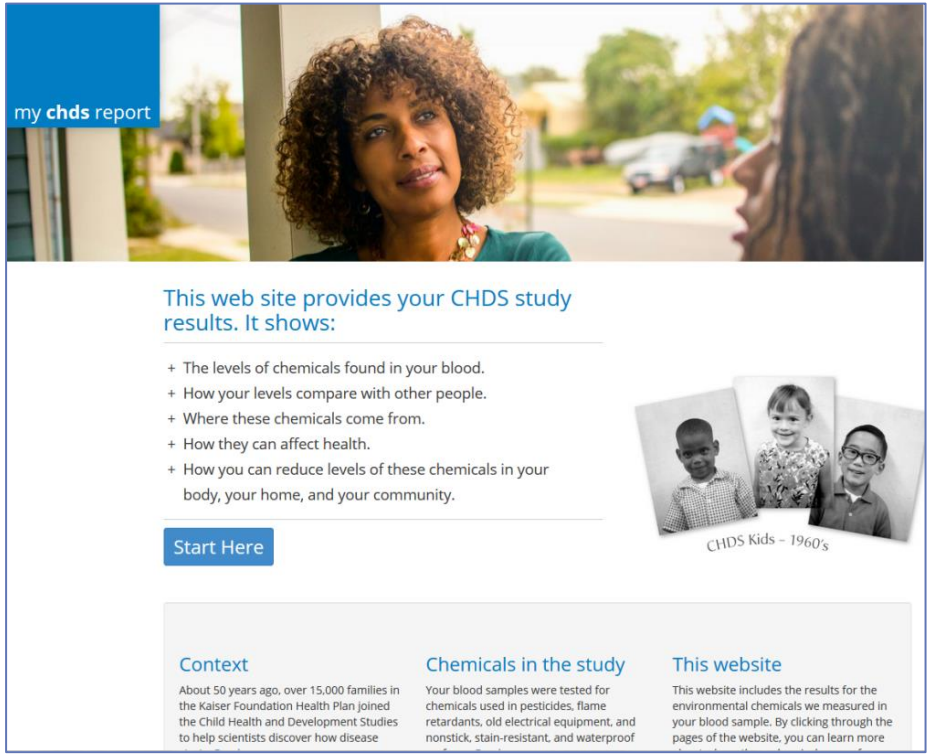
Results are more than a number

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

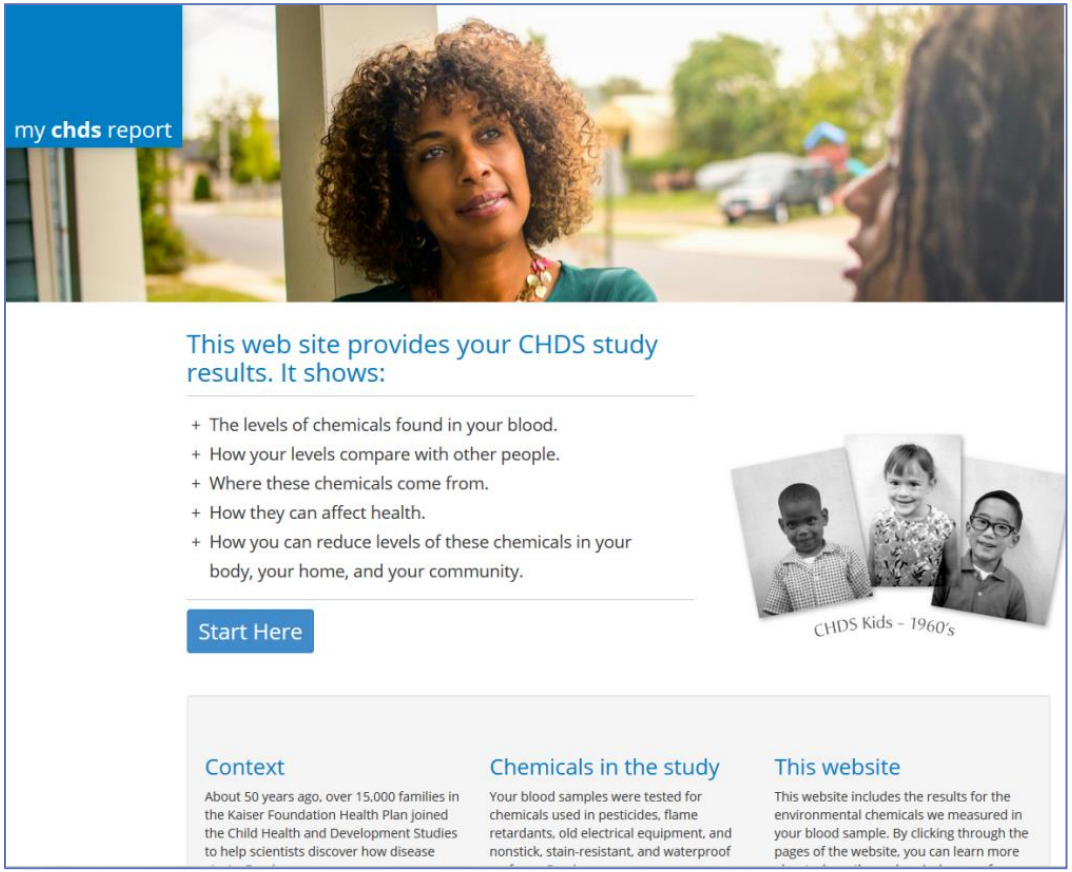
Brody et al. 2007 AJPH

DERBI: Digital Exposure Report-Back Interface

- A software framework for generating personalized exposure reports -- for computer, smartphone, print
- Scalable to studies of all sizes
- Researcher dashboard for authoring reports



Boronow et al. 2017 EHP



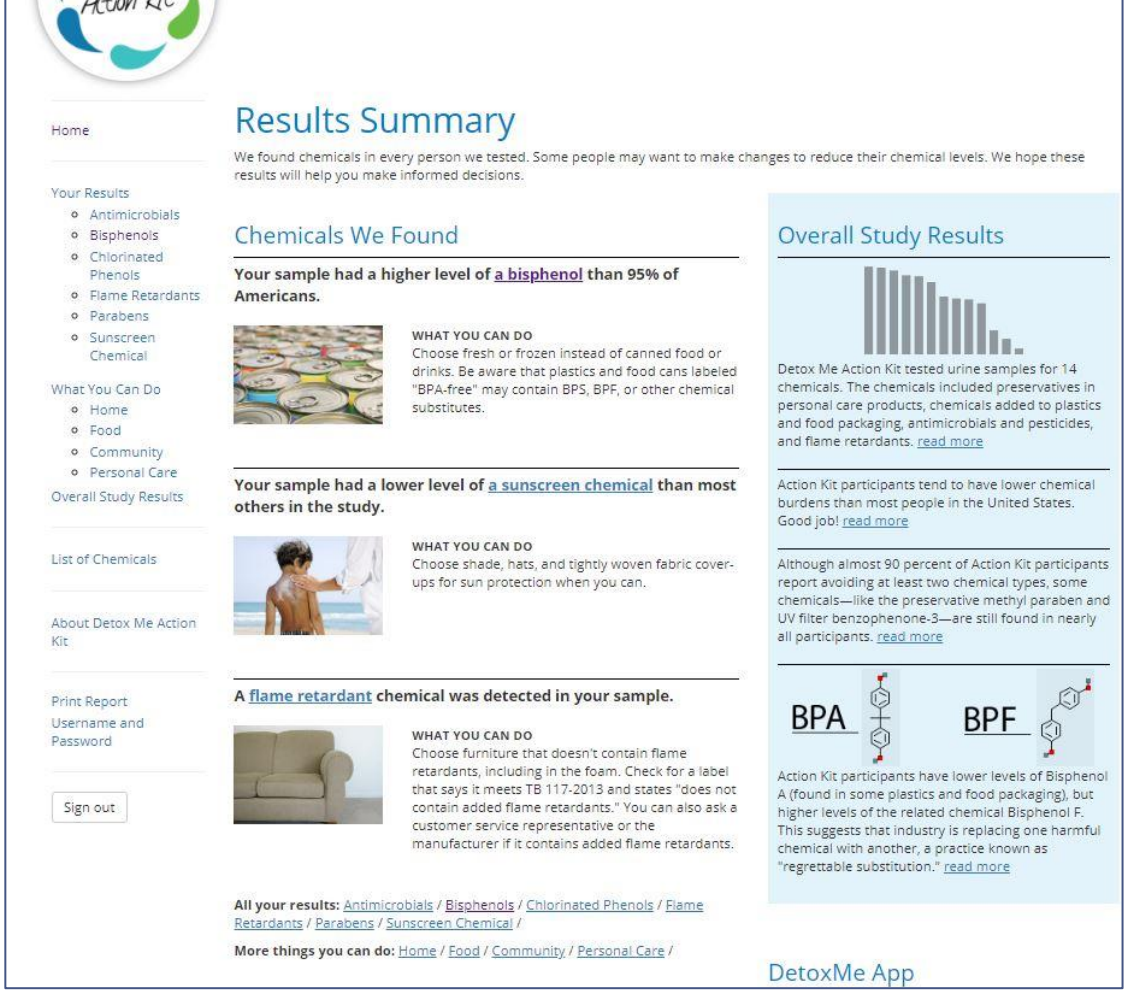
From: Child Health and Development Studies

1. Welcome page
2. Individual login
   (no overt personal identifiers)
3. Summary page with main messages – "headlines" – about individual- and community-wide results

Personalized summary page

- "Headlines" about individual and community results
- Links to detail

From: Detox Me Action Kit Study



Individual results page

Personal headline

Sources

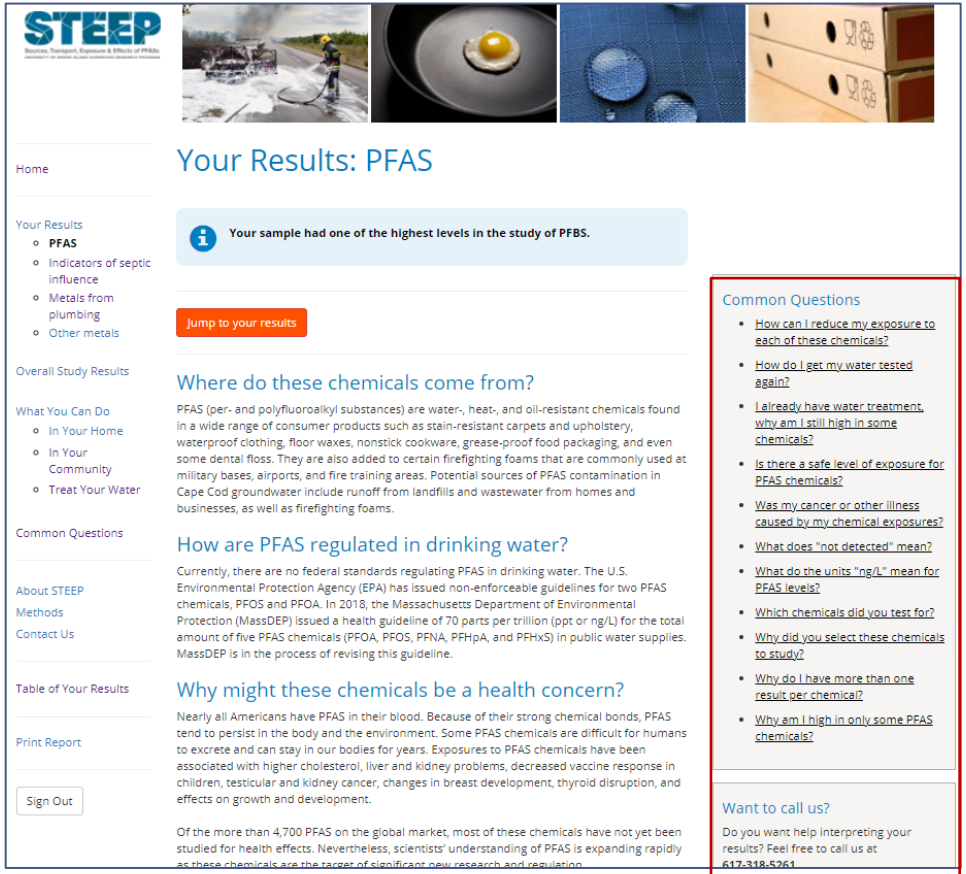
Health effects

Exposure reduction

From: Women Firefighters Biomonitoring Collaborative

Scroll down to individual results graphs

- Graphs use visual abilities to communicate “gist”
- Hover to see graph-reading tips and results details



From: STEEP SRP

Reports support environmental health literacy

Transparency about uncertainty

Chemicals in the study "have been detected at different levels in people throughout the U.S. Detecting these chemicals …doesn't mean you will get sick."

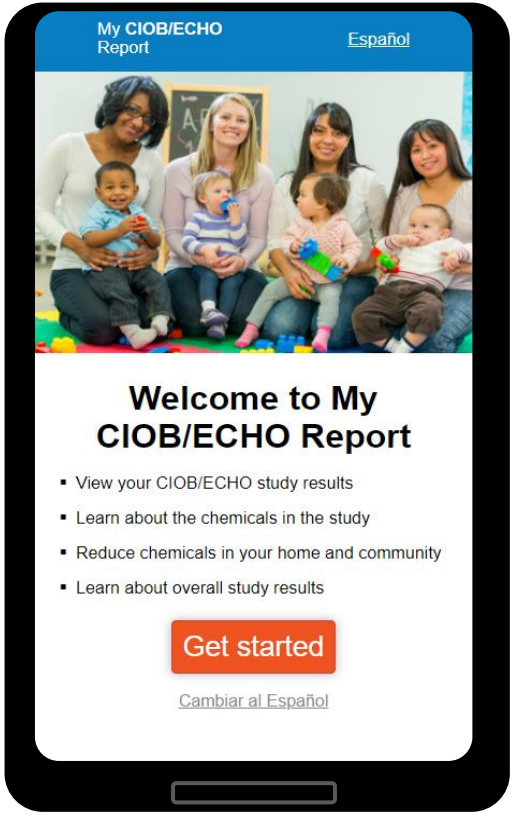
"So far, studies of people have found that higher levels of PFAS are linked to:

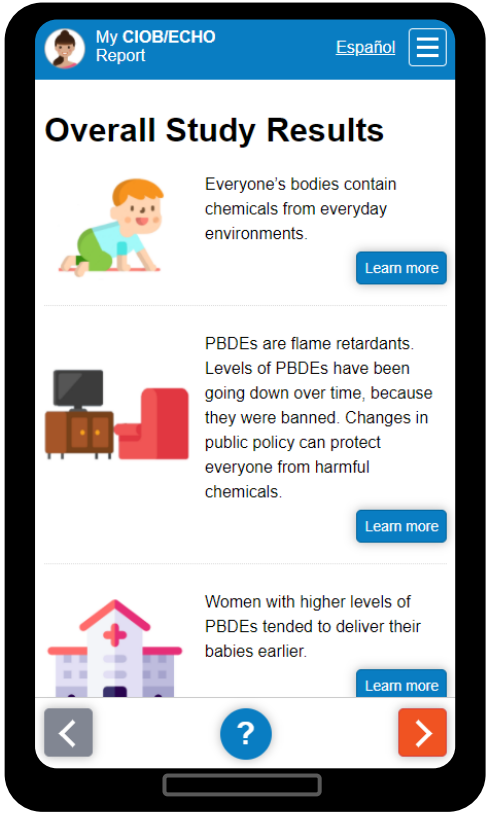
- Increased cholesterol levels
- Decreased vaccine response in children …

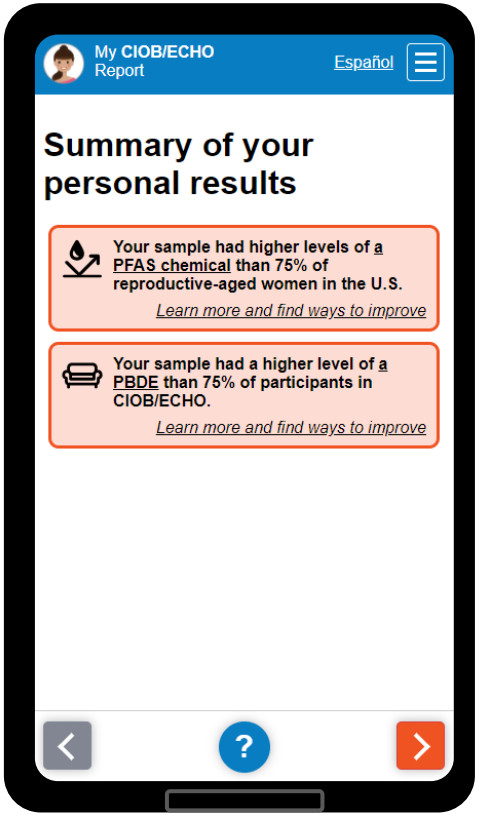
Based on what we know now, we can't link your results to specific health concerns for you or your family. …"

"Since we don't do experiments on people, we often learn how chemicals may affect health by testing in animals or cells, similar to the way we test new drugs for safety."

Smartphone reports improve access







My CIOB/ECHO Report

Español

PBDEs

Your sample had a higher level of PBDE 153 than 75% of participants in CIOB/ECHO.

↓ Jump to tips to lower your exposure

What are PBDEs?

PBDE (polybrominated diphenyl ether) flame retardants were widely used in furniture foam from 1960 until 2004, and in electronics like TVs, computers, and cables until 2013. Chemical flame retardants are one way of making it harder for products to catch fire. PBDEs were phased out of use in the U.S. due to heath concerns, but people can still be exposed to PBDEs from products made before the phase-out. Also, because many PBDEs take years to be eliminated from the body, PBDE levels may reflect exposures from a long time ago.

Although PBDEs are no longer added to products, manufacturers sometimes use other types of flame retardants, some of which also have serious health

Back to Summary

?

Your Results

We tested your sample for 18 PBDEs. Your results for 12 PBDEs are in the graphs below. Another 6 PBDEs were not detected in anyone in the study. These are not shown in the graphs.

Legend

- Your result
- Typical U.S. woman 20-39 years old
- Other women in CIOB/ECHO
- Women in CIOB/ECHO who did not have the chemical detected in their sample

ng/g lipid nanograms of the chemical per gram of lipid (fat) in your blood

Click on any graph to see an expanded version with more details.

PBDE 153

Back to Summary

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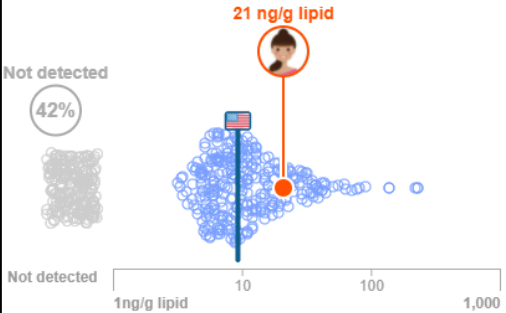
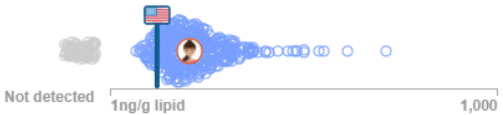
PBDE 153



Tap each part of the graph to learn more

PBDE 99



PBDE 47

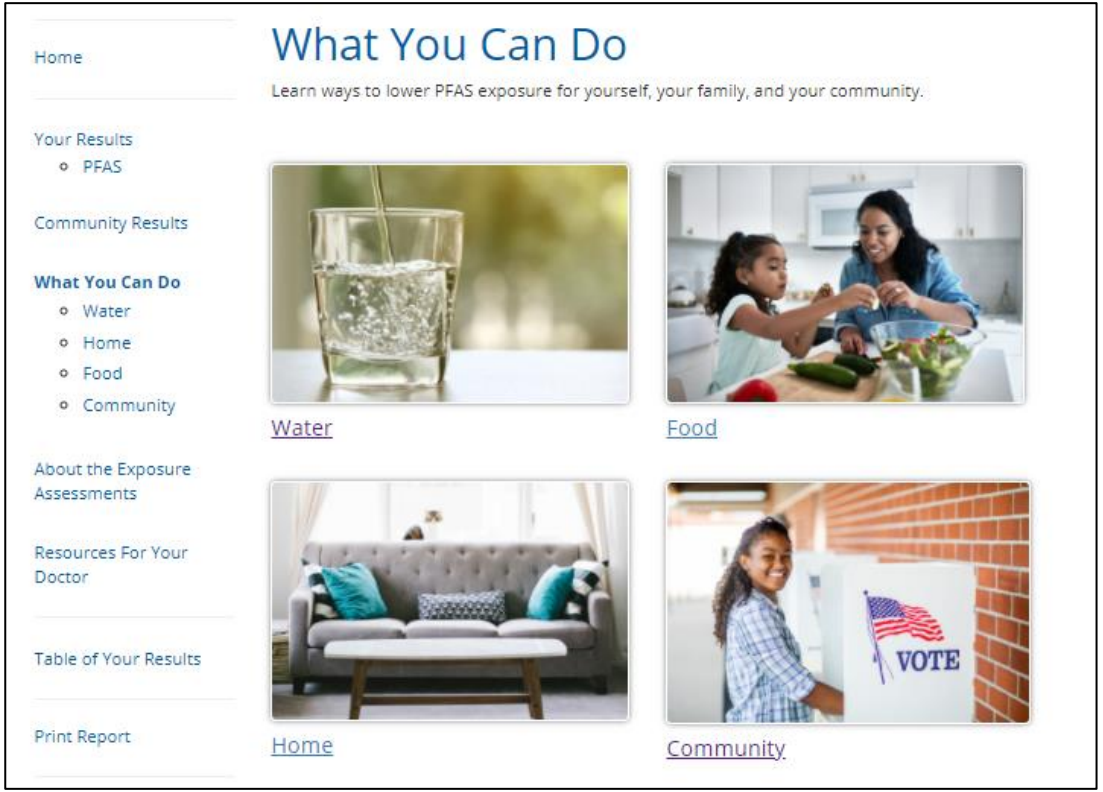
PBDE 100

Back to Summary

?

People value information to reduce exposure and protect health

- Individual and community action



Detox Me walks you through simple, ***research-based tips on how to reduce harmful chemicals***.

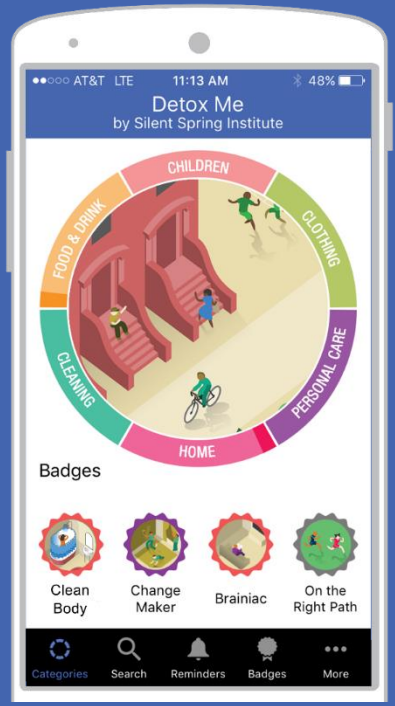
- ***Track*** your progress and get reminders.
- ***Scan*** product barcodes to find relevant tips.
- ***Share*** tips with friends, family.

www.detoxmeapp.org

Also in Spanish!

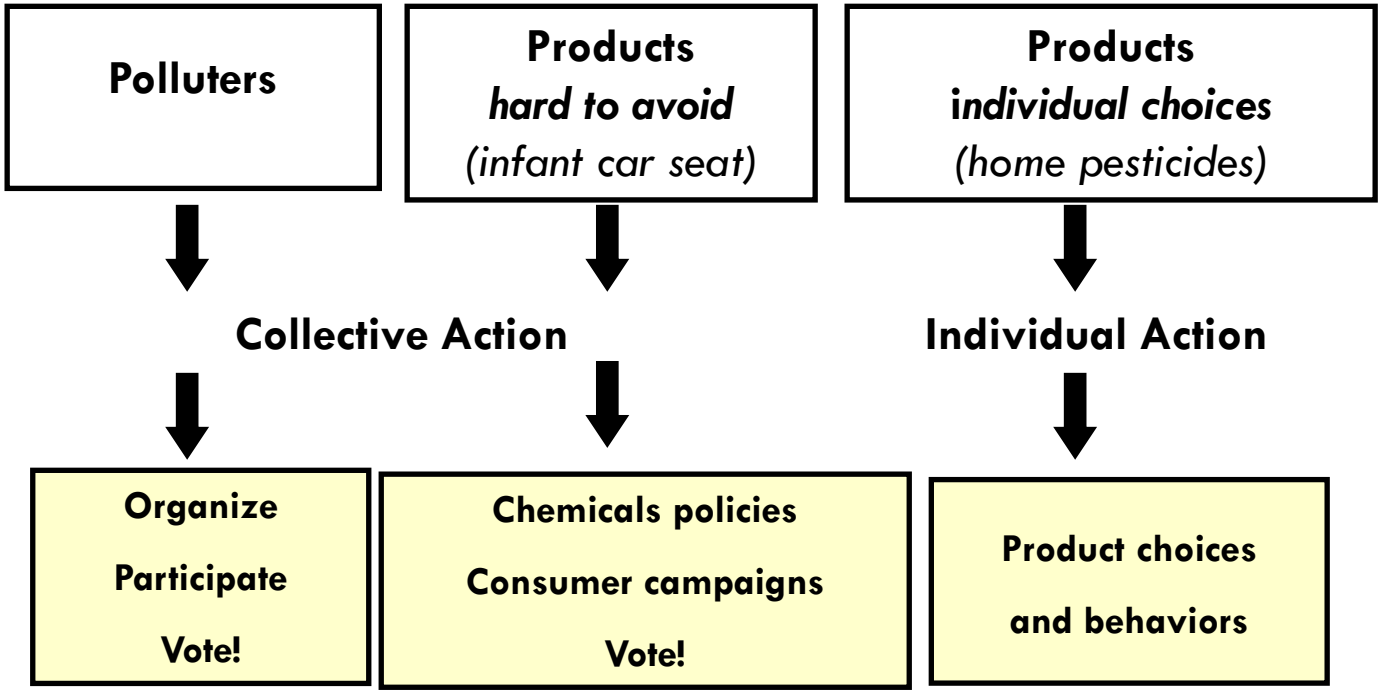
Detox Me

BY SILENT SPRING INSTITUTE



Action tips matched to exposures

Exposure sources



Study participant views on collective action

- Participants in 3 focus groups of peripartum moms:
  - Motivated to act to protect family health despite time burdens
  - Built new ideas on their other experiences of civic participation
  - Asked for time-conscious tactics and straightforward information
  - Expressed willingness to share knowledge with their network
  - Were wary of advocating exposure reduction in settings such as with childcare providers

In collaboration with ECHO / CIOB, IKIDS peripartum cohorts. C. Oksas et al., in preparation.

Report-Back Outcomes

What happens when people get reports?

How have people responded to personal reports?

- Gratitude – people want their reports
- Increased trust in the research team
- Learning – environmental health literacy
- Brainstorming about exposures and exposure reduction
- Reflection on family illnesses, with understanding of uncertainty
- Pride in contribution to science and community health

How do people use results?

- Personal choices
- Medical settings
- Policy change

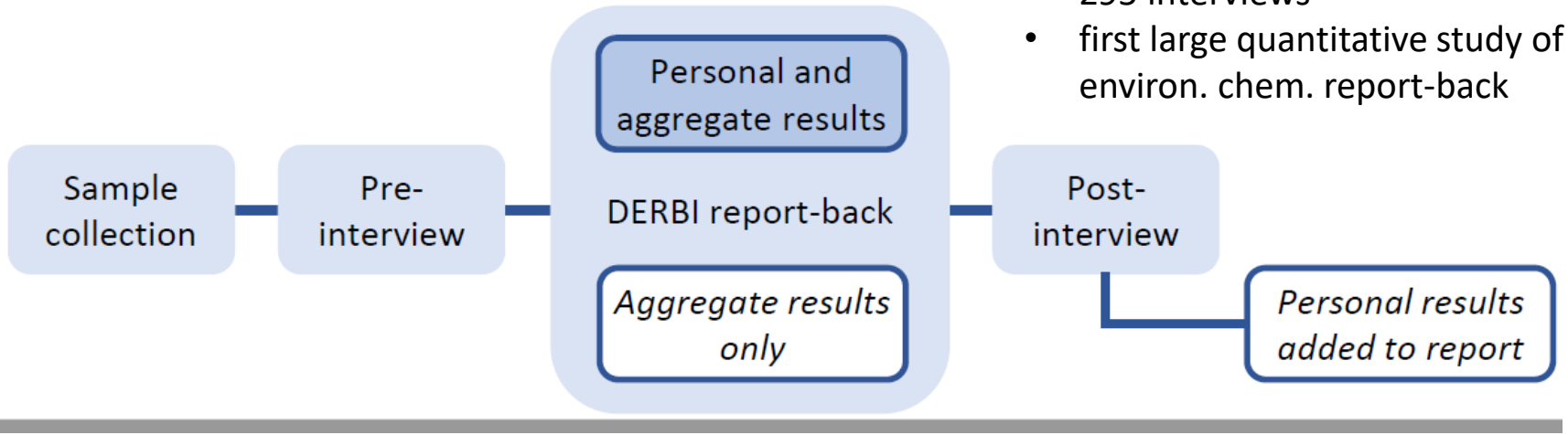
Emmett, 2009, JOEM; Brody, 2009, AJPH; Adams, 2011, JHSB; Hernick, 2011, EHP; Brown, 2011, EHP; Ramirez-Andreotta 2016 *Env. Health; Perovich, 2018, Env. Health; NASEM, 2018*

Public Health Initiatives from Report-Back

- Study participants helped win a court case to limit a Chevron refinery
- Public housing residents used reports to get better attention from doctors for their child's asthma
- WWBC office worker "controls" advocated for new purchasing rules to reduce flame retardants in office furnishings
- Communities use PFAS results on social media to engage elected officials to change policies

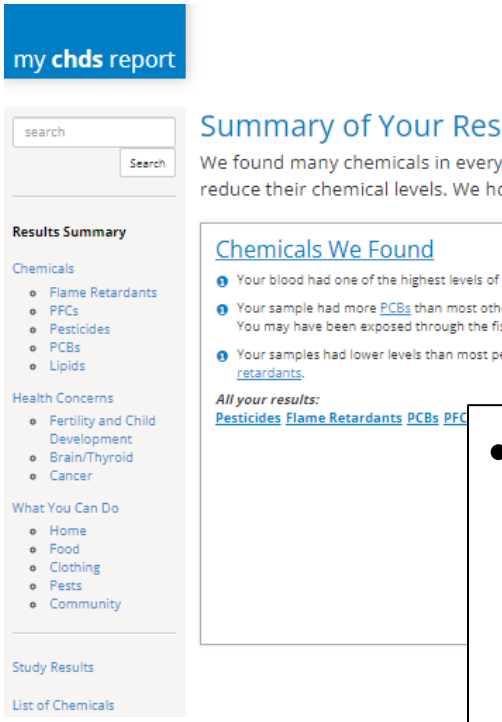
Experiment: Do personal reports matter?

- 295 interviews
- first large quantitative study of environ. chem. report-back



- **Participants spent twice as long on personal reports, creating more opportunity to increase EHL**

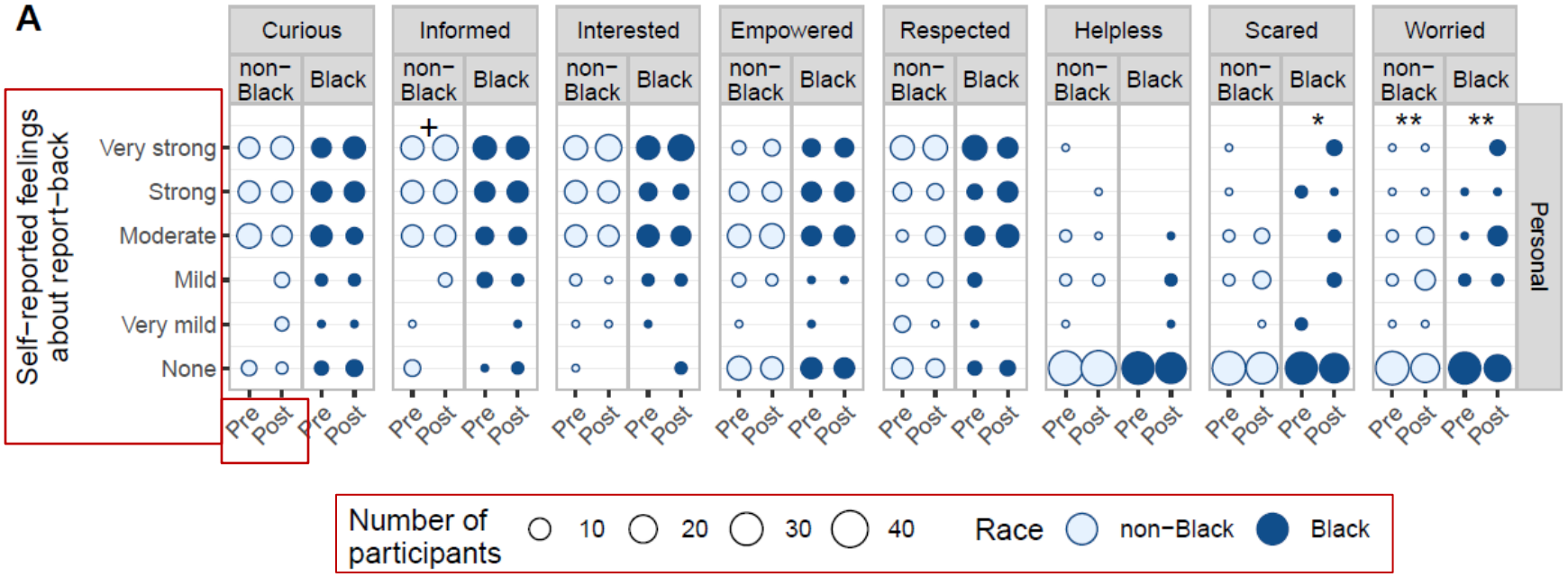
Brody et al., EHP, in press. In collaboration with the Child Health and Development Studies



- Analytics for personal reports showed
  - Nearly everyone (98%) spent long enough to read all of their personal headlines.
  - 84% clicked to more detail.

Brody et al., EHP, in press. In collaboration with the Child Health and Development Studies

Participants generally reported positive feelings both before and after receiving personal reports



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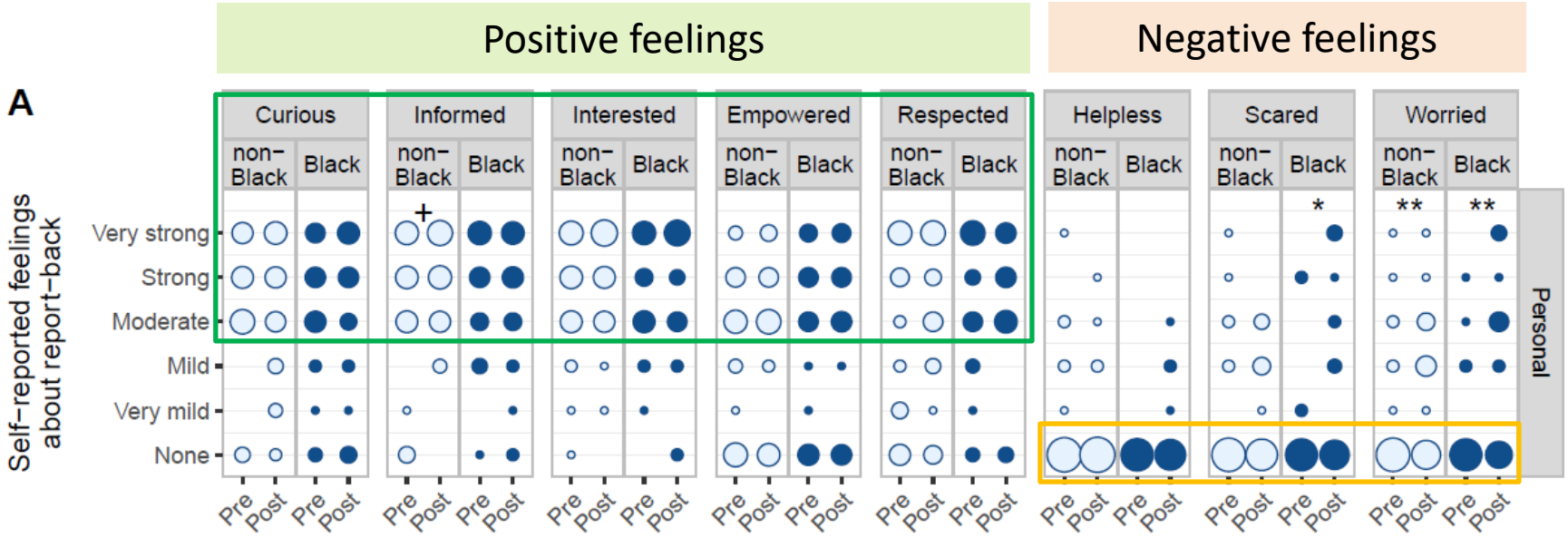
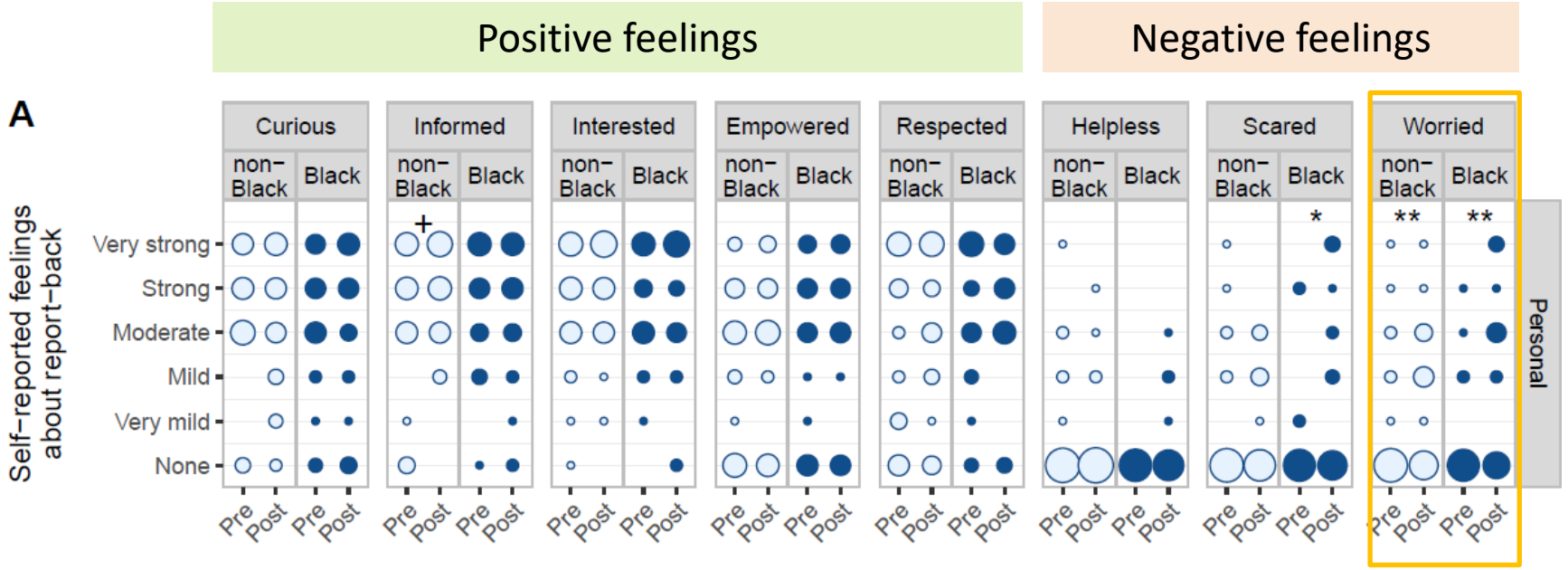


Brody et al., EHP, in press. In collaboration with the Child Health and Development Studies

Moderate increases in worry may motivate action



- Among Black participants, increased worry - associated with high exposure

Brody et al., EHP, in press. In collaboration with the Child Health and Development Studies

New Study: Research on Teaching Report-Back to Researchers and Clinicians

- Collaboration with
  - ERGO
  - PROTECT

Acknowledgements

- **Silent Spring Institute** – Ruthann Rudel, Erik Haugsjaa
- **Northeastern SSEHRI**
- **UC Berkeley** - Rachel Morello-Frosch
- **Harvard Human Computer Interaction Group** - Krzysztof Gajos, Ken Arnold
- **Participating studies**, including: CDC/HUD Green Housing Study, Child Health and Development Studies, BCERP ELLA Study, Women Workers Biomonitoring Collaborative, PROTECT SRP, STEEP SRP, CIOB, IKIDS, PRESTO
- **Supported** *by* ***NIEHS, NSF, CA Breast Cancer Research Program***

Publications:
https://silentspring.org/project/reporting-individual-exposure-results?pubs=all