

Reporting Back Personal Exposure Data to Participants

SRP Risk e-Learning October 22, 2021
Risk Communication Strategies to Reduce Exposures
and Improve Health

Julia Brody, Katherine Boronow, Silent Spring Institute
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SILENT SPRING INSTITUTE
Researching the Environment and Women's Health



Northeastern University
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 WEACTION
- 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



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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



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 Brown², Samarys Seguinot-Medina³, Lorraine Eckstein³, David O. Carpenter⁴, Pamela Miller³ 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

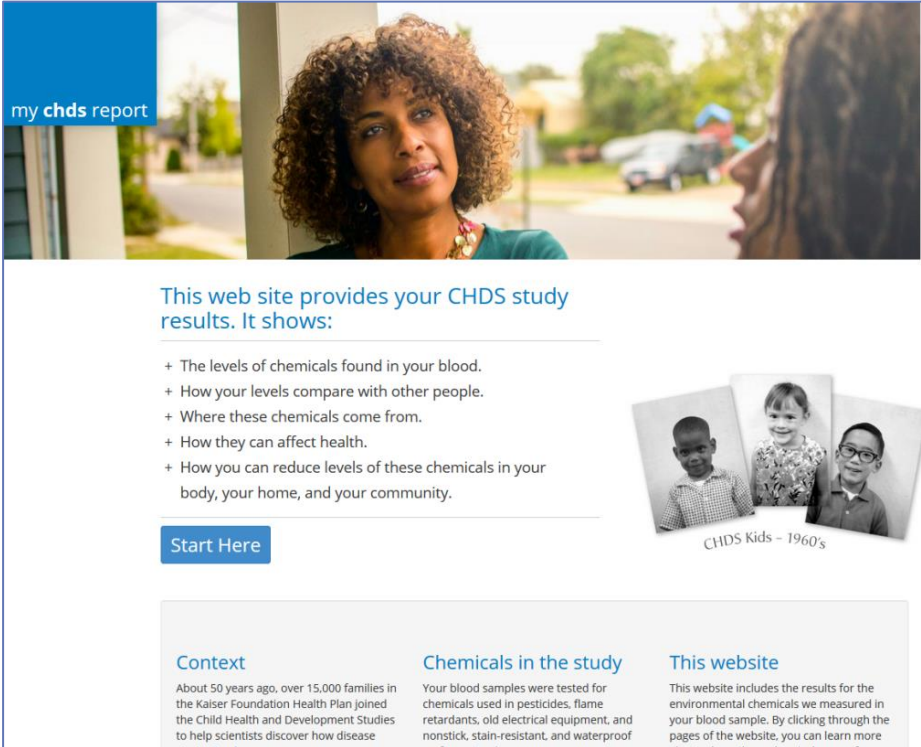
- What did you find?
- How much?
- Is that high?
- Is it safe?
- Where did it come from?
- What should I do?

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



my chds report

This web site provides your CHDS study results. It shows:

- + The levels of chemicals found in your blood.
- + How your levels compare with other people.
- + Where these chemicals come from.
- + How they can affect health.
- + How you can reduce levels of these chemicals in your body, your home, and your community.

Start Here

CHDS Kids - 1960's

Context
About 50 years ago, over 15,000 families in the Kaiser Foundation Health Plan joined the Child Health and Development Studies to help scientists discover how disease

Chemicals in the study
Your blood samples were tested for chemicals used in pesticides, flame retardants, old electrical equipment, and nonstick, stain-resistant, and waterproof

This website
This website includes the results for the environmental chemicals we measured in your blood sample. By clicking through the pages of the website, you can learn more

my chds report

This web site provides your CHDS study results. It shows:

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Start Here

Context

About 50 years ago, over 15,000 families in the Kaiser Foundation Health Plan joined the Child Health and Development Studies to help scientists discover how disease

Chemicals in the study

Your blood samples were tested for chemicals used in pesticides, flame retardants, old electrical equipment, and nonstick, stain-resistant, and waterproof

This website

This website includes the results for the environmental chemicals we measured in your blood sample. By clicking through the pages of the website, you can learn more



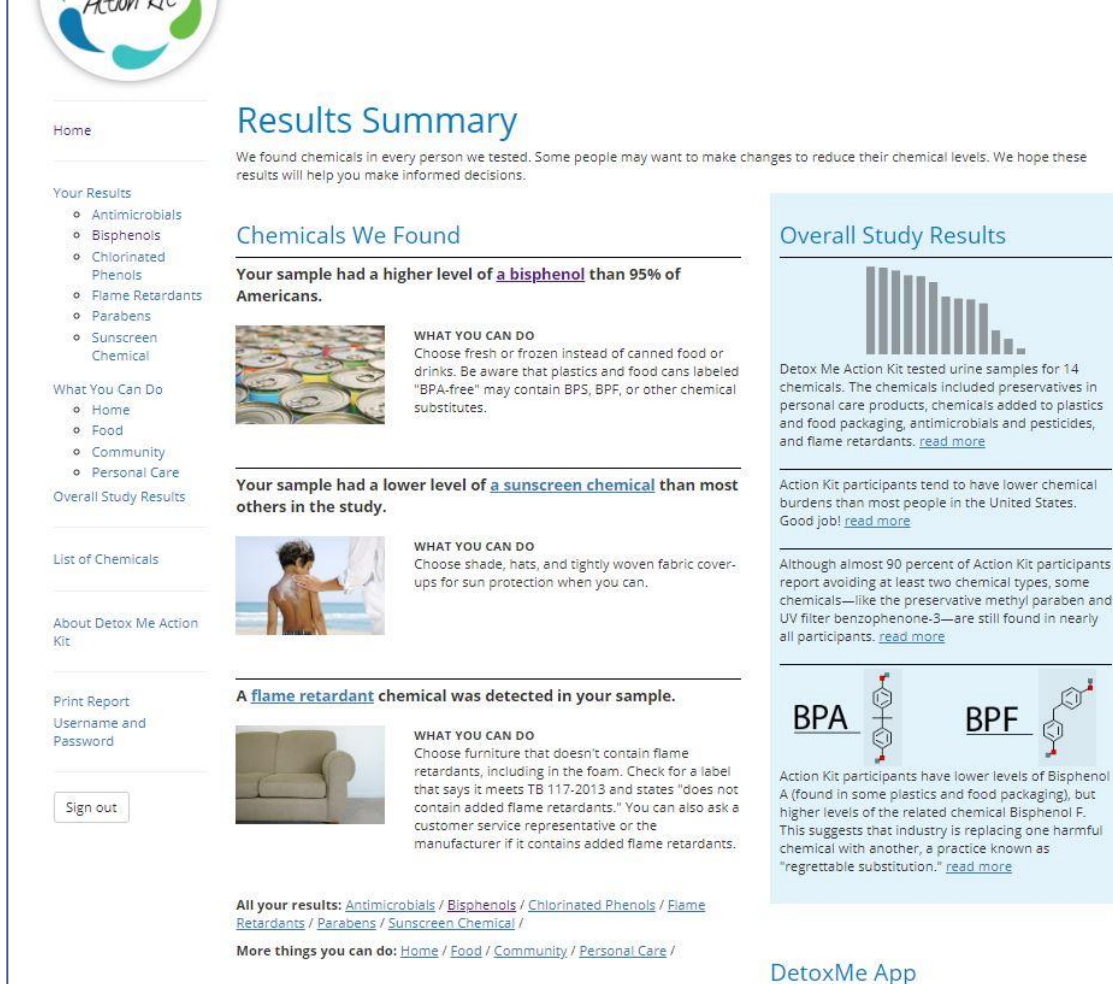
1. Welcome page
2. Individual login
(no overt personal identifiers)
3. Summary page with main messages – “headlines” – about individual- and community-wide results

From: Child Health and Development Studies

Personalized summary page

- “Headlines” about individual and community results
- Links to detail

From: Detox Me Action Kit Study




The screenshot shows a mobile application interface for the DetoxMe Action Kit. At the top, there is a circular logo with the text 'Action Kit'. Below the logo is a navigation menu with the following items: Home, Your Results (with sub-items: Antimicrobials, Bisphenols, Chlorinated Phenols, Flame Retardants, Parabens, Sunscreen Chemical), What You Can Do (with sub-items: Home, Food, Community, Personal Care), Overall Study Results, List of Chemicals, About Detox Me Action Kit, Print Report, Username and Password, and a Sign out button.

Results Summary

We found chemicals in every person we tested. Some people may want to make changes to reduce their chemical levels. We hope these results will help you make informed decisions.


Chemicals We Found

Your sample had a higher level of a [bisphenol](#) than 95% of Americans.




WHAT YOU CAN DO
Choose fresh or frozen instead of canned food or drinks. Be aware that plastics and food cans labeled "BPA-free" may contain BPS, BPF, or other chemical substitutes.

Your sample had a lower level of a [sunscreen chemical](#) than most others in the study.



WHAT YOU CAN DO
Choose shade, hats, and tightly woven fabric cover-ups for sun protection when you can.

A [flame retardant](#) chemical was detected in your sample.




WHAT YOU CAN DO
Choose furniture that doesn't contain flame retardants, including in the foam. Check for a label that says it meets TB 117-2013 and states "does not contain added flame retardants." You can also ask a customer service representative or the manufacturer if it contains added flame retardants.

All your results: [Antimicrobials](#) / [Bisphenols](#) / [Chlorinated Phenols](#) / [Flame Retardants](#) / [Parabens](#) / [Sunscreen Chemical](#) /

More things you can do: [Home](#) / [Food](#) / [Community](#) / [Personal Care](#) /

Overall Study Results




Detox Me Action Kit tested urine samples for 14 chemicals. The chemicals included preservatives in personal care products, chemicals added to plastics and food packaging, antimicrobials and pesticides, and flame retardants. [read more](#)


Action Kit participants tend to have lower chemical burdens than most people in the United States. Good job! [read more](#)

Although almost 90 percent of Action Kit participants report avoiding at least two chemical types, some chemicals—like the preservative methyl paraben and UV filter benzophenone-3—are still found in nearly all participants. [read more](#)

BPA



BPF



Action Kit participants have lower levels of Bisphenol A (found in some plastics and food packaging), but higher levels of the related chemical Bisphenol F. This suggests that industry is replacing one harmful chemical with another, a practice known as "regrettable substitution." [read more](#)

DetoxMe App

Individual results page

Personal headline

Sources

Health effects

Exposure reduction

WFCBReport

Summary of Your Results

Chemicals

Health Concerns

- Cancer
- Fertility and Child Development
- Brain / Thyroid

What You Can Do

- Home
- Food
- Clothing
- Pests
- Community

Overall Study Results

List of Chemicals

Methods

About

Your Results: PFAS

Highly fluorinated chemicals

i Your samples had more PFASs than most others in the study. PFASs can come from non-stick sprays on pots and pans or in stain-resistant clothing. [Scroll down to see all of your results.](#)

[Click here to jump to your results.](#)

Where do these chemicals come from?

PFASs are found in stain- and water-resistant textiles and sprays, non-stick cookware, grease-repellent food packaging (such as microwave popcorn bags and cardboard take-out containers), and some types of dental floss. They are also used in some firefighting foams.

Highly fluorinated chemicals can stay in your body for a long time. If your exposure to these chemicals stopped completely, it would take between 1 and 8 years for your body to remove half the amount of each of the PFASs currently in your body. It would take five times as long (5 to 40 years) to get rid of over 96 percent of the PFASs currently in your body.

Why might these chemicals be a health concern?

PFASs tend to persist in the body and environment. Exposure to PFASs has been associated with changes in hormone levels, puberty timing, and brain development in some studies. Animal studies show effects on pup growth and development, thyroid and reproductive hormone levels, mammary gland development and puberty timing, and mammary and liver tumors.

How can I reduce my exposure?

- **Avoid spray treatments** that make rugs, furniture or other textiles stain- or water- resistant.
- **Choose fresh foods** when you can to avoid food stored in grease-repellent food packaging such as pizza boxes and microwave popcorn bags.
- **Avoid clothing marked with labels** such as "stain resistant" or "wrinkle-proof."
- **Avoid lotions, moisturizer, and other personal care products** with the ingredient PTFE.
- **Avoid non-stick pots and pans.** Use pots and pans that are steel clad, enameled, cast iron, or anodized aluminum.
- **Keep dust levels low.** Wipe surfaces with a damp cloth, use wet mopping, or use a vacuum with a HEPA (high-efficiency particulate air) filter. Each of these methods helps prevent dust from being recirculated into the air.
- **Wash hands frequently.**

Although we suggest actions you can take to reduce exposure, individual action may not be sufficient to control your exposure to some chemicals. In some cases, policy change is required to limit personal exposure, such as legislative initiatives that prohibit the use of harmful chemicals. You can also seek out companies that use safer substitutes when available.

Common Questions

- + [What chemicals did you test for?](#)
- + [How can I reduce my levels of these chemicals?](#)
- + [Is there a safe level of exposure for these chemicals?](#)
- + [What is the 95th percentile and why are you showing it for US Women and CA Firefighters?](#)
- + [What does "not detected" mean?](#)
- + [Why am I high in only some chemicals in a chemical group?](#)
- + [What do the units "ng/ml" mean?](#)

Want to call us?

Do you want help interpreting your results? Feel free to call us at

555-123-4567

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

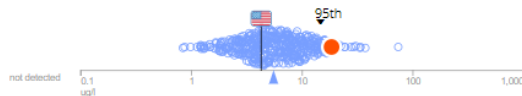
Your Results

Graph legend

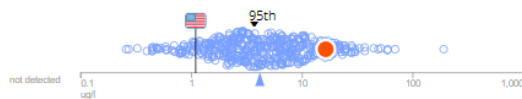
- your chemical level
 - other participants' chemical levels
 - participants for whom the chemical was not detected
- 🇺🇸 [median](#) chemical level for [other Americans](#)
- 95th [95th percentile](#) chemical level for [other Americans](#)
- ▲ [median](#) chemical level for this study
- µg/L: micrograms of the chemical per liter of blood
- Your results are shown on a [logarithmic scale](#).

Tip: Mouse over your graphs to learn more.

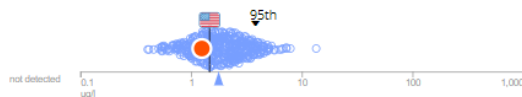
PFOS (perfluorooctane sulfonic acid)




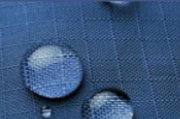



PFHxS (perfluorohexane sulfonic acid)



PFOA (perfluorooctanoic acid)



Home

Your Results

- o **PFAS**
- o Indicators of septic influence
- o Metals from plumbing
- o Other metals

Overall Study Results

What You Can Do

- o In Your Home
- o In Your Community
- o Treat Your Water

Common Questions

About STEEP

Methods

Contact Us

Table of Your Results

Print Report

Sign Out

Your Results: PFAS

i Your sample had one of the highest levels in the study of PFBS.

Jump to your results

Where do these chemicals come from?

PFAS (per- and polyfluoroalkyl substances) are water-, heat-, and oil-resistant chemicals found in a wide range of consumer products such as stain-resistant carpets and upholstery, waterproof clothing, floor waxes, nonstick cookware, grease-proof food packaging, and even some dental floss. They are also added to certain firefighting foams that are commonly used at military bases, airports, and fire training areas. Potential sources of PFAS contamination in Cape Cod groundwater include runoff from landfills and wastewater from homes and businesses, as well as firefighting foams.

How are PFAS regulated in drinking water?

Currently, there are no federal standards regulating PFAS in drinking water. The U.S. Environmental Protection Agency (EPA) has issued non-enforceable guidelines for two PFAS chemicals, PFOS and PFOA. In 2018, the Massachusetts Department of Environmental Protection (MassDEP) issued a health guideline of 70 parts per trillion (ppt or ng/L) for the total amount of five PFAS chemicals (PFOA, PFOS, PFNA, PFHpA, and PFHxS) in public water supplies. MassDEP is in the process of revising this guideline.

Why might these chemicals be a health concern?

Nearly all Americans have PFAS in their blood. Because of their strong chemical bonds, PFAS tend to persist in the body and the environment. Some PFAS chemicals are difficult for humans to excrete and can stay in our bodies for years. Exposures to PFAS chemicals have been associated with higher cholesterol, liver and kidney problems, decreased vaccine response in children, testicular and kidney cancer, changes in breast development, thyroid disruption, and effects on growth and development.

Of the more than 4,700 PFAS on the global market, most of these chemicals have not yet been studied for health effects. Nevertheless, scientists' understanding of PFAS is expanding rapidly as these chemicals are the target of significant new research and regulation.

Common Questions

- [How can I reduce my exposure to each of these chemicals?](#)
- [How do I get my water tested again?](#)
- [I already have water treatment, why am I still high in some chemicals?](#)
- [Is there a safe level of exposure for PFAS chemicals?](#)
- [Was my cancer or other illness caused by my chemical exposures?](#)
- [What does "not detected" mean?](#)
- [What do the units "ng/L" mean for PFAS levels?](#)
- [Which chemicals did you test for?](#)
- [Why did you select these chemicals to study?](#)
- [Why do I have more than one result per chemical?](#)
- [Why am I high in only some PFAS chemicals?](#)

Want to call us?

Do you want help interpreting your results? Feel free to call us at **617-318-5261**

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.”

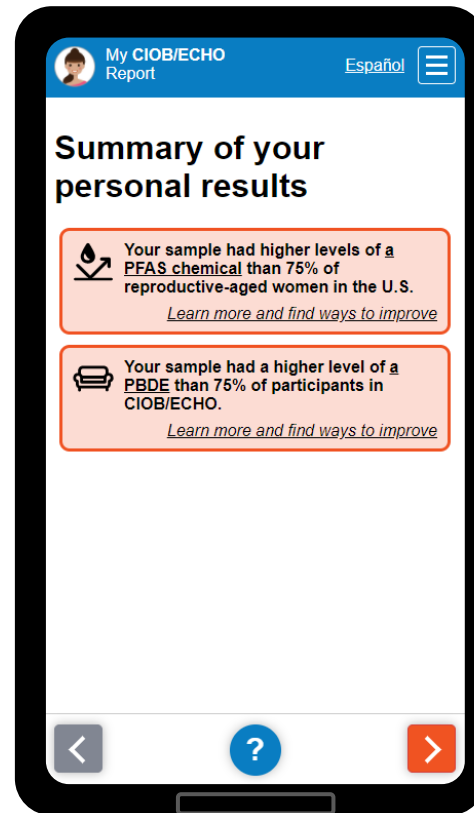
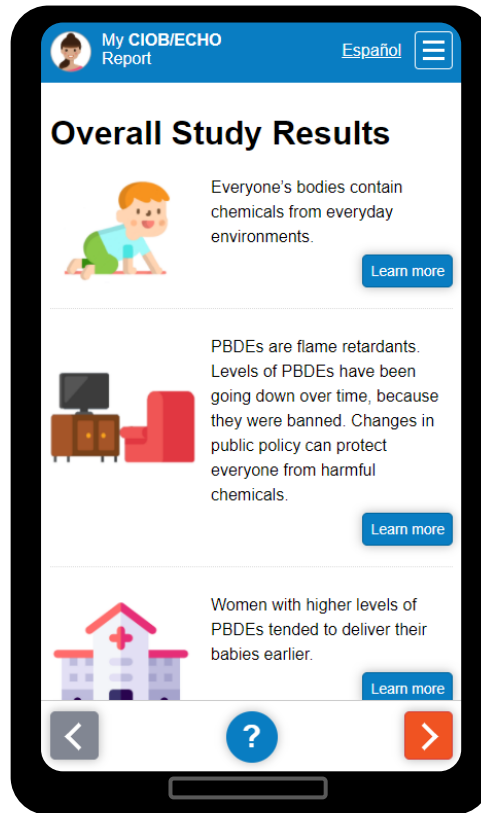
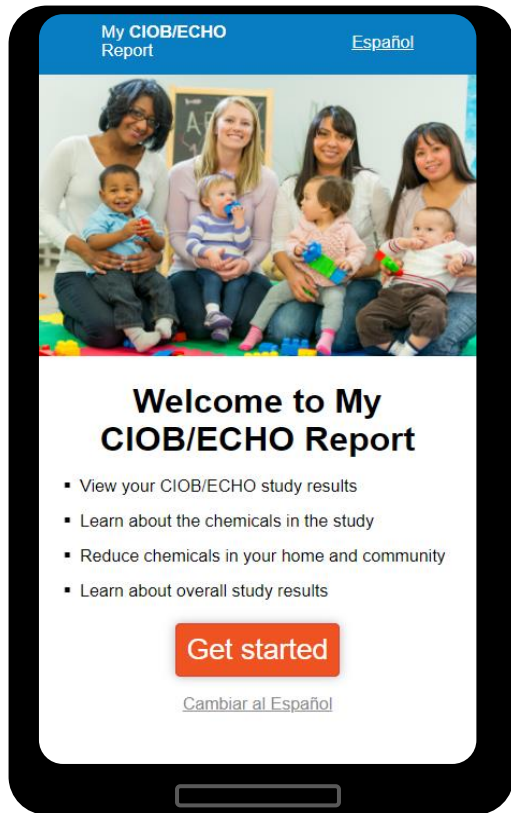
“So far, studies of people have found that higher levels of PFAS are linked to:

- 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





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 health 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.

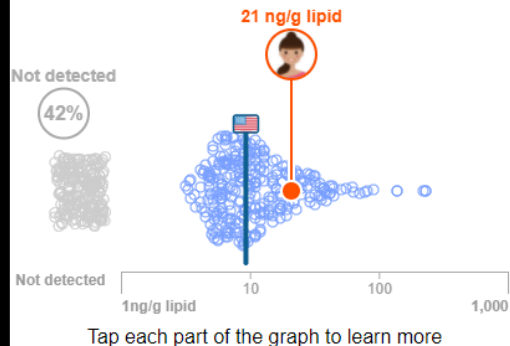
> PBDE 153



Back to Summary



> PBDE 153



> PBDE 99



> PBDE 47



> PBDE 100

Back to Summary



People value information to reduce exposure and protect health

- Individual and community action

The screenshot shows a website interface with a navigation menu on the left and a main content area. The main content area is titled "What You Can Do" and includes a sub-header "Learn ways to lower PFAS exposure for yourself, your family, and your community." Below this are four content tiles, each with an image and a caption:

- Water:** An image of water being poured into a glass.
- Food:** An image of a woman and a child preparing food in a kitchen.
- Home:** An image of a modern living room with a sofa and coffee table.
- Community:** An image of a young girl standing next to a "VOTE" sign with an American flag.

The navigation menu on the left includes the following items:

- Home
- Your Results
 - PFAS
- Community Results
- What You Can Do**
 - Water
 - Home
 - Food
 - Community
- About the Exposure Assessments
- Resources For Your Doctor
- Table of Your Results
- Print Report



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!



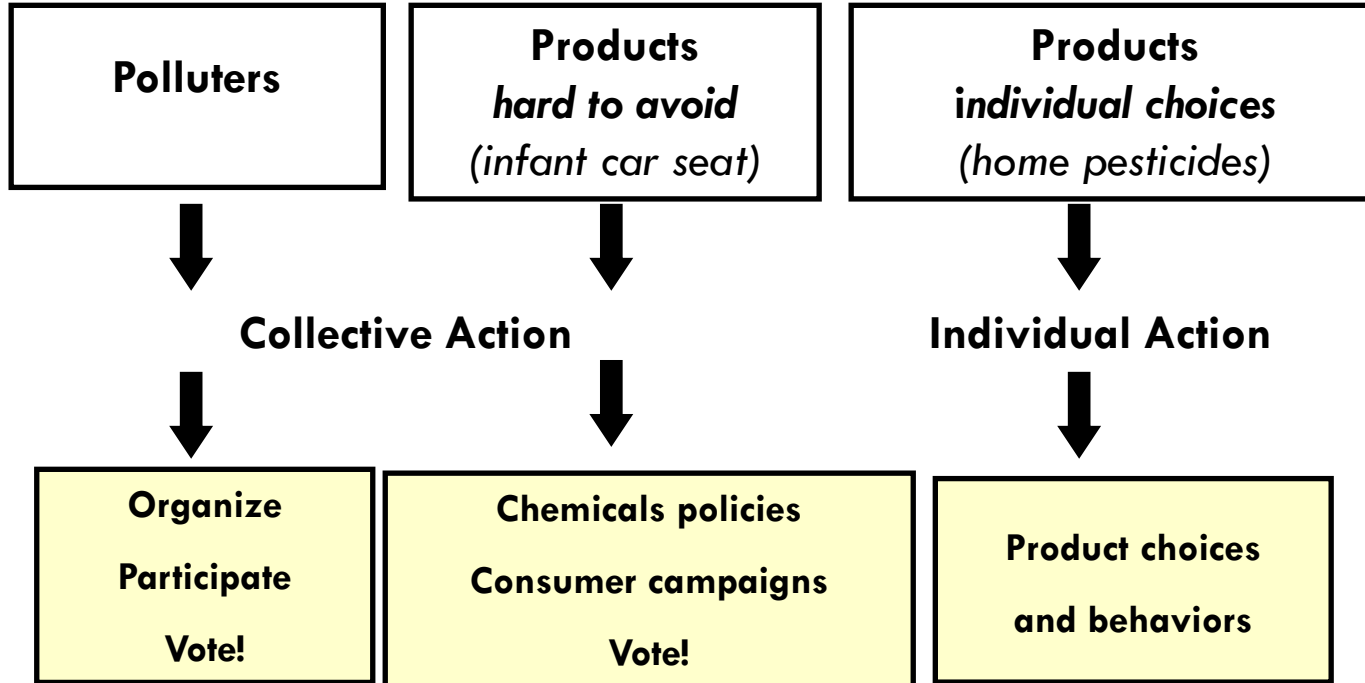
Detox Me

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?

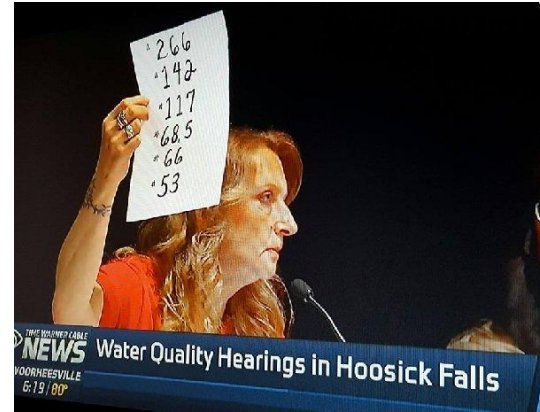
How have people responded to personal reports?

- 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



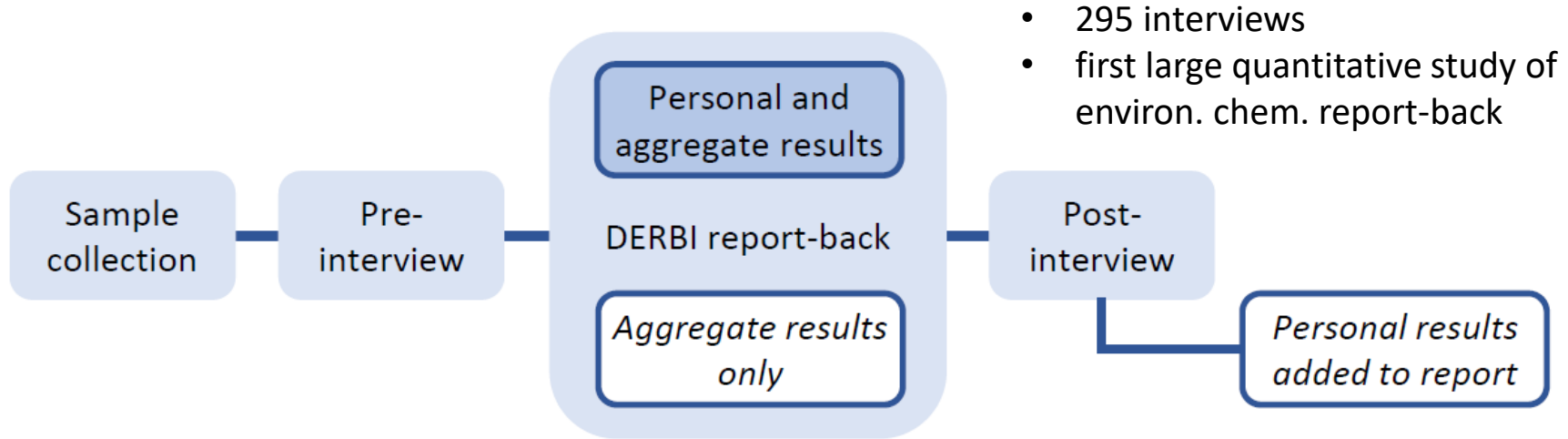
Emmett, 2009, JOEM; Brody, 2009, AJP; Adams, 2011, JHSB; Hernick, 2011, EHP; Brown, 2011, EHP; Ramirez-Andreotta 2016 Env. Health; Perovich, 2018, Env. Health; NASEM, 2018

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?



- **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

search

Search

Results Summary

Chemicals

- Flame Retardants
- PFCs
- Pesticides
- PCBs
- Lipids

Health Concerns

- Fertility and Child Development
- Brain/Thyroid
- Cancer

What You Can Do

- Home
- Food
- Clothing
- Pests
- Community

Study Results

List of Chemicals

Summary of Your Results

We found many chemicals in every person we tested. Some people may want to make changes to reduce their chemical levels. We hope these results will help you make informed decisions.

Chemicals We Found

- Your blood had one of the highest levels of [a PFC](#).
- Your sample had more [PCBs](#) than most others in the study. You may have been exposed through the fish you ate.
- Your samples had lower levels than most people for [flame retardants](#).

All your results:

[Pesticides](#) [Flame Retardants](#) [PCBs](#) [PFCs](#)

Overall Study Results

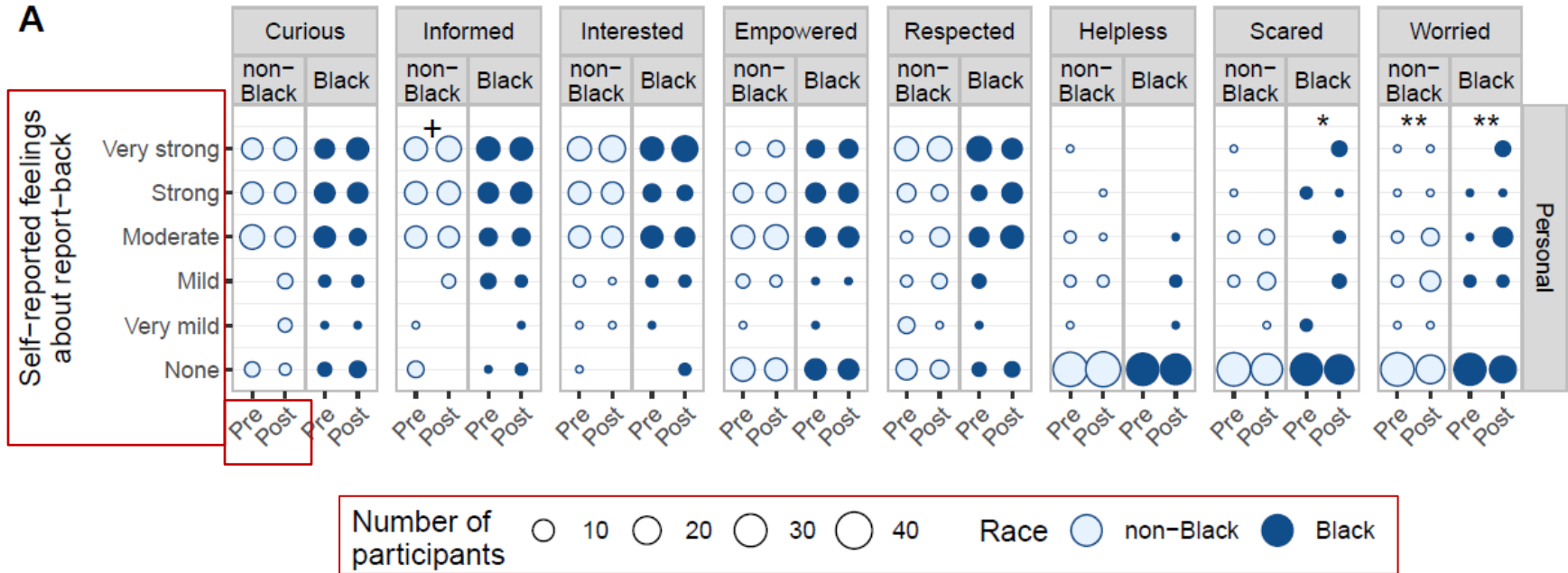
CHDS tested blood samples for 42 chemicals. The chemicals included old pesticides, industrial pollutants, flame retardants, and perfluorinated chemicals (PFCs) used to make things non-stick, stain proof, or water-resistant.

- We found at least 5 flame retardants, 9 PFCs, 5 banned pesticides, and 11 PCBs, which are industrial pollutants.

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

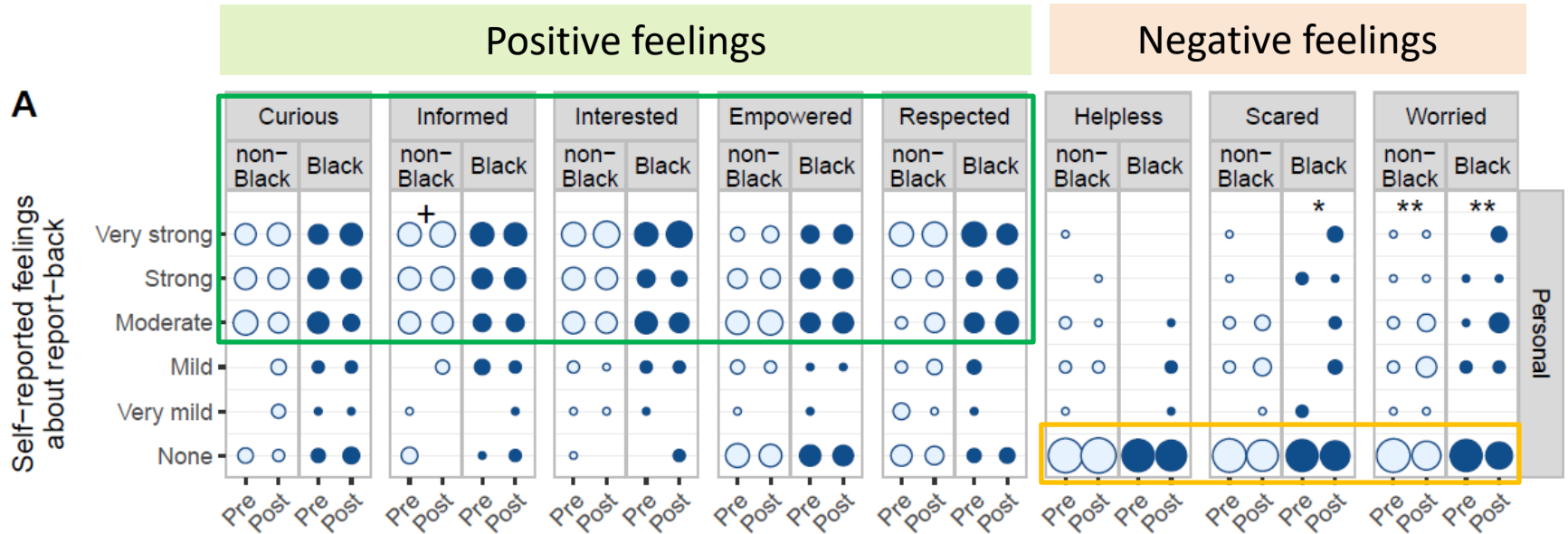
Brody et al., EHP, in press. In collaboration with the Child Health and Development Studies

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



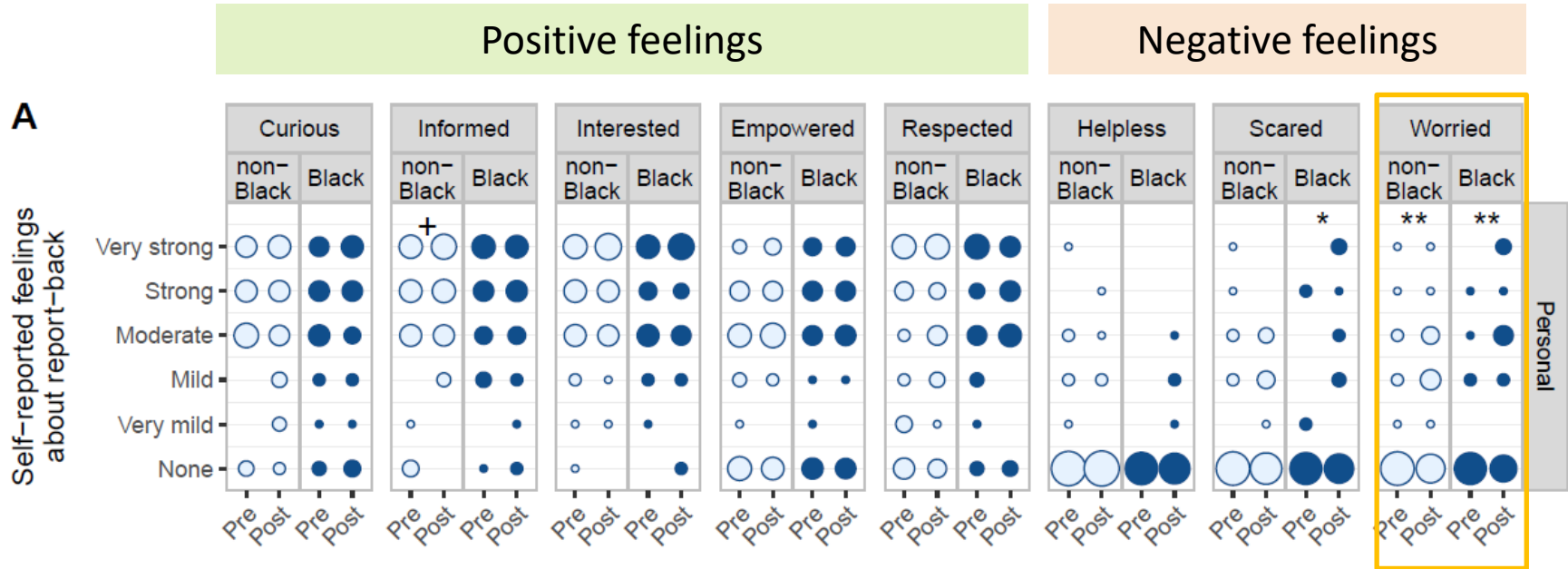
Brody et al., EHP, in press. In collaboration with the Child Health and Development Studies

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



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



Environmental Health Study Dedicated to Improving Women's Reproductive and Long-term Health
ERGO is a research study designed to examine the role of environmental chemical exposures on maternal and child health. Environmental exposures may affect our health, particularly during the time surrounding pregnancy. Through ERGO, we hope to learn more about the impact of environmental exposures on pregnancy and postpartum health. As a participant in the ERGO study, you will be helping researchers better understand how environmental exposures could impact pregnancy and long-term health in order to improve the health of women and their children.



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>