


What Can GXE Studies Learn from Personalized Report-Back for Chemical Exposures?

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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.

...duce levels of these chemical in your



My WFBC Report

Home

Your Results: PFAS

Highly fluorinated compounds

Your Results

- o Flame retardants
- o PFAS

Overall Study Results

Methods

Reducing exposures for firefighters at work

Table of Your Results

Print Report

en Our

Information Your sample had a higher level of PFDoA than most others in the study. Your levels of other PFAS were lower or similar to others in the study.

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

Where do these chemicals come from?

PFASs are used to make fabrics, packaging, and other products resistant to stains, grease, or water. They are used in stain-resistant textiles (like carpets, furniture, and clothing), waterproof outdoor gear, and grease-repellent food packaging (such as fast-food wrappers and microwave popcorn bags). PFASs are also used to produce polytetrafluoroethylene (PTFE or "Teflon"), which is used on nonstick pots and pans, and in some dental flosses and personal care products. PFASs are found in some firefighter turnout gear and certain firefighting foam called aqueous film-forming foam (AFFF).

Common Questions

- How can I reduce my levels of these chemicals?
- Is there a safe level of exposure for these chemicals?
- Was my cancer caused by my chemical exposures?
- What chemicals did you test for?
- What does "not detected" mean?

Early ethics questions: Returning environmental exposure results when health effects are uncertain

- Would people be harmed?
- Would report-back create legal obligations to tell others?

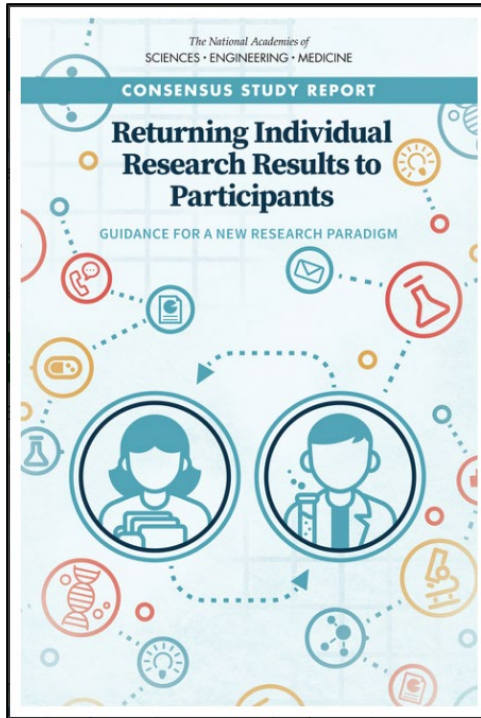
*Goho, S. 2016. **The Legal Implications of Report-Back in Household Exposure Studies.** Environ Health Perspectives, doi:10.1289/EHP187.*

- Would reports create privacy risks of re-identification?

*Boronow, K.E., et al. 2020. **Privacy Risks of Sharing Data from Environmental Health Studies.** Environ Health Perspectives. doi.org/10.1289/EHP4817*

- How to maximize benefits?

NASEM 2018 consensus report



- Encourages researchers to routinely report back
 - “...as a matter of reciprocity, respect, transparency, and trust, ...”
- Potential harms of report-back have been overstated & benefits under-appreciated
 - Benefits extend beyond the clinic and beyond actionable results
 - Vital to building trust

Report-back supports values of equity and community engagement

- Co-learning, co-ownership of data
- Knowledge is power --
Right-to-know, right to act
 - Teach and empower individual and community action



Examples of Individual Data in G X E studies

- Genes
 - High risk genes
 - Lower penetrance genes -- that affect cell repair, hormone metabolism...
- Chemicals in blood, urine, personal air, homes...
 - Actionability affected by whether the chemicals are persistent or rapidly metabolized and whether they are phased-out or current use
- Early effect markers – metabolomics, epigenomics

Example G x E report-back scenario



*Example drawn from work
by Mary Beth Terry,
Columbia University and
Columbia Presbyterian
Hospital, and her colleagues*

- Clinic for families with breast cancer history
 - Tests for high-risk genes (BRCA1/2...) and results with counseling in healthcare context
- Some enrolled in G x E research
 - Tests for other genes (cell repair genes...) and exposure to PAHs

Methods: Report-Back Developed from Participatory Research

- Multi-disciplinary expertise and community partnerships
- Interviews with participants, researchers, and IRBs before and after report-back
- 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/ATSDR

Report-Back Outcomes

What happens when people get their environmental chemical results?

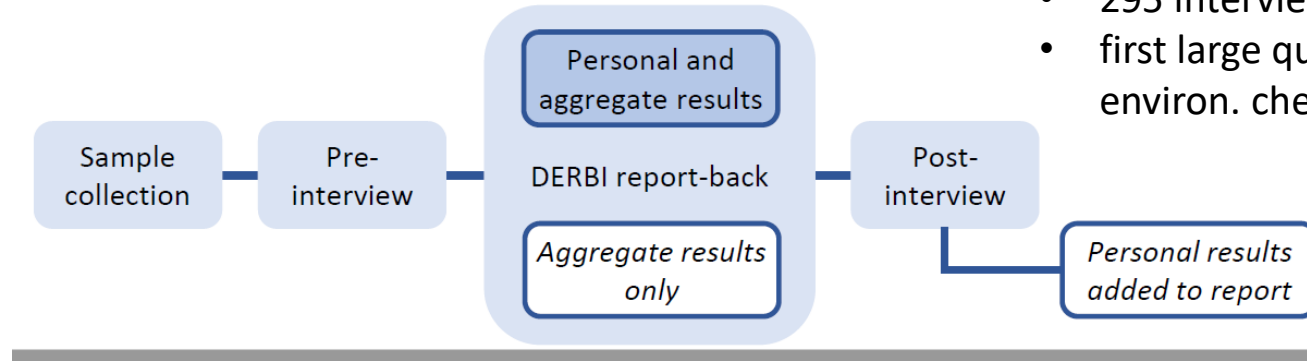
How have people responded to personal reports?

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



*Altman, 2008, JHSB; Adams, 2011, JHSB;
Hernick, 2011, EHP; Ramirez-Andreotta 2016
Env. Health; Perovich, 2018, Env. Health*

Experiment: Personal reports draw more engagement



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

- Participants spent twice as long on personal reports, creating more opportunity to increase environmental health literacy

Brody et al., EHP, 2021. In collaboration with the Child Health and Development Studies

search

Search

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.

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

Chemicals We Found

- 1 Your blood had one of the highest levels of [a PFC](#).
- 1 Your sample had more [PCBs](#) than most others in the study. You may have been exposed through the fish you ate.
- 1 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.

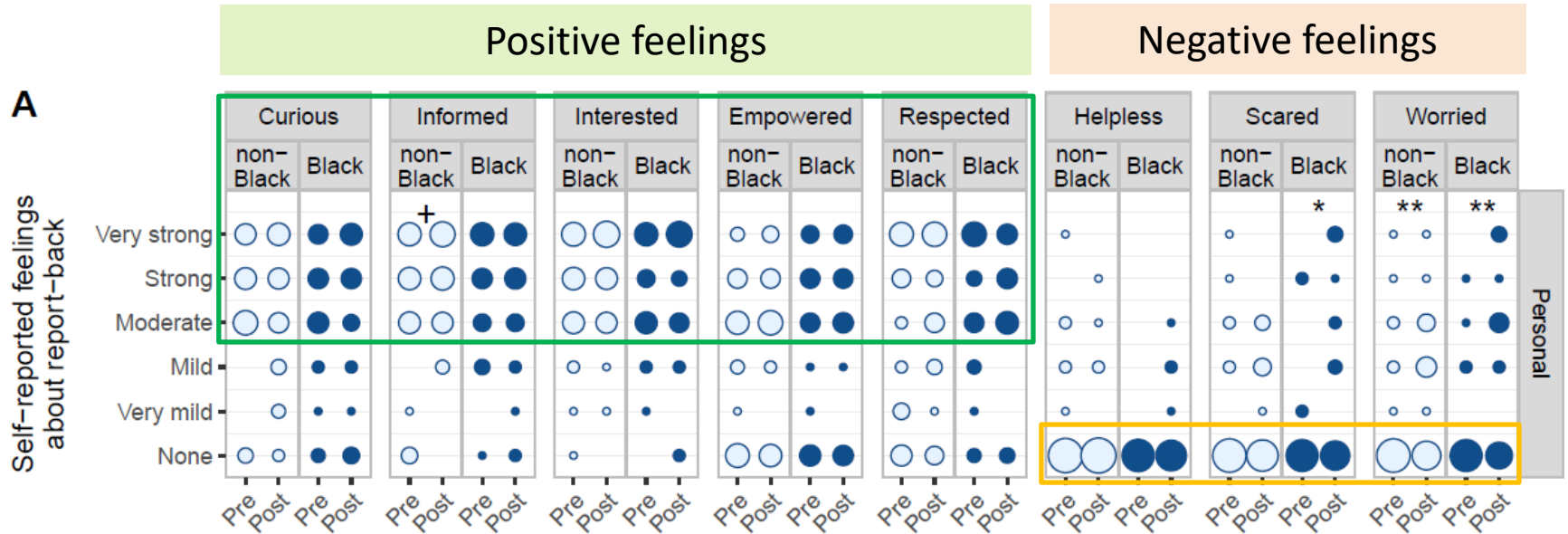
- We found at least 5 flame retardants, 9 PFCs, 5 banned pesticides, and 11 PCBs, which are industrial pollutants.

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

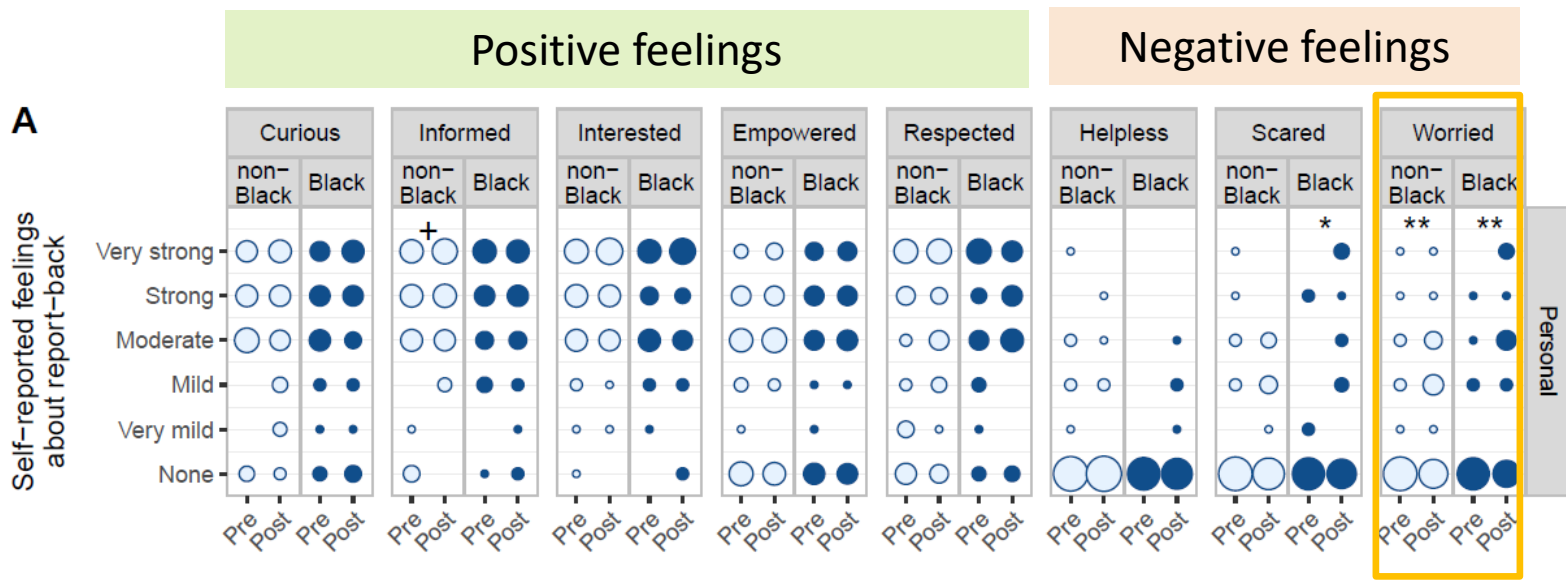
Brody et al., EHP, 2021. In collaboration with the Child Health and Development Studies



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



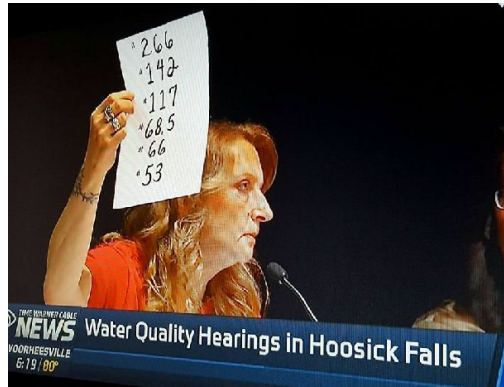
Brody et al., EHP, 2021. In collaboration with the Child Health and Development Studies



- Moderate increases in worry -- may motivate action
- Among Black participants, increased worry - associated with high exposure
- Would we see similar effect for group with genetic vulnerability?

How do people use their results?

- Personal choices
- Medical settings
- Policy change



G x E results will also have policy implications, but the dynamic could be different as people consider whether to share genetic risk

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 outcomes from report-back

- Study participants helped win a court case to limit a Chevron refinery
- Public housing residents said results led to better care from doctors who were ignoring their child's asthma
- Office workers – comparison group in study of firefighters – advocated for new purchasing rules for flame-retardant-free office furnishings
- Communities are using PFAS results on social media to change policies



Report-back Design

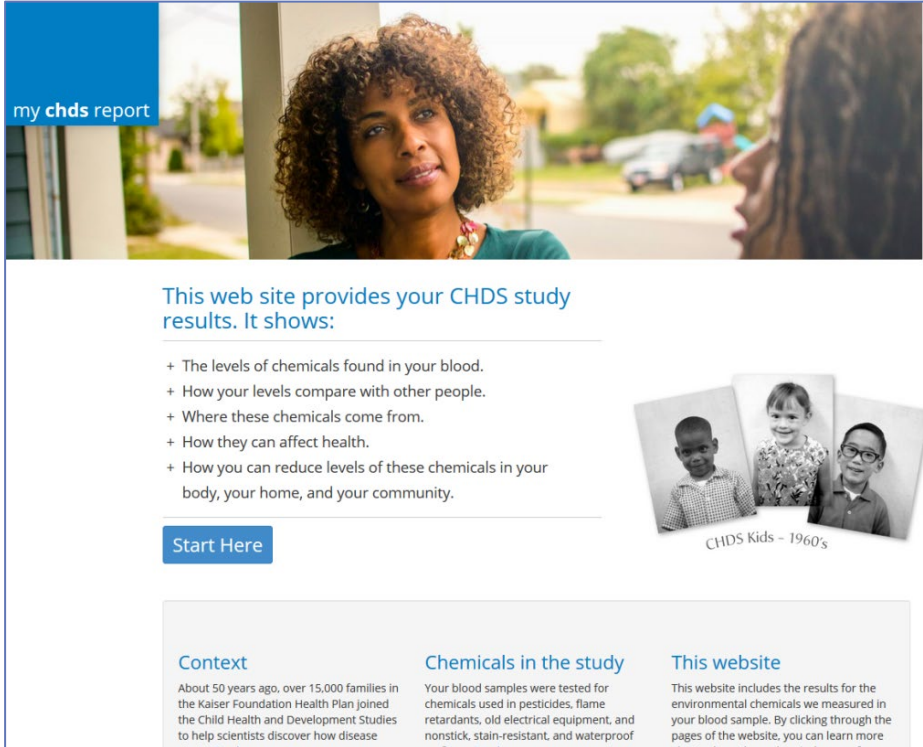
Participants want to know...

“What, so what, now what?”

– Dr. Maida Galvez

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, adaptable to community context



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](#)

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



CHDS Kids - 1960's

my chds report

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CHDS Kids - 1960's

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
- Suited to G X E because info can be integrated
- Links to detail

From: Detox Me Action Kit Study



Home

Your Results

- Antimicrobiols
- Bisphenols
- Chlorinated Phenols
- Flame Retardants
- Parabens
- Sunscreen Chemical

What You Can Do

- Home
- Food
- Community
- Personal Care

Overall Study Results

List of Chemicals

About Detox Me Action Kit

Print Report

Username and Password

Sign out

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: [Antimicrobiols](#) / [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, antimicrobiols 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](#)

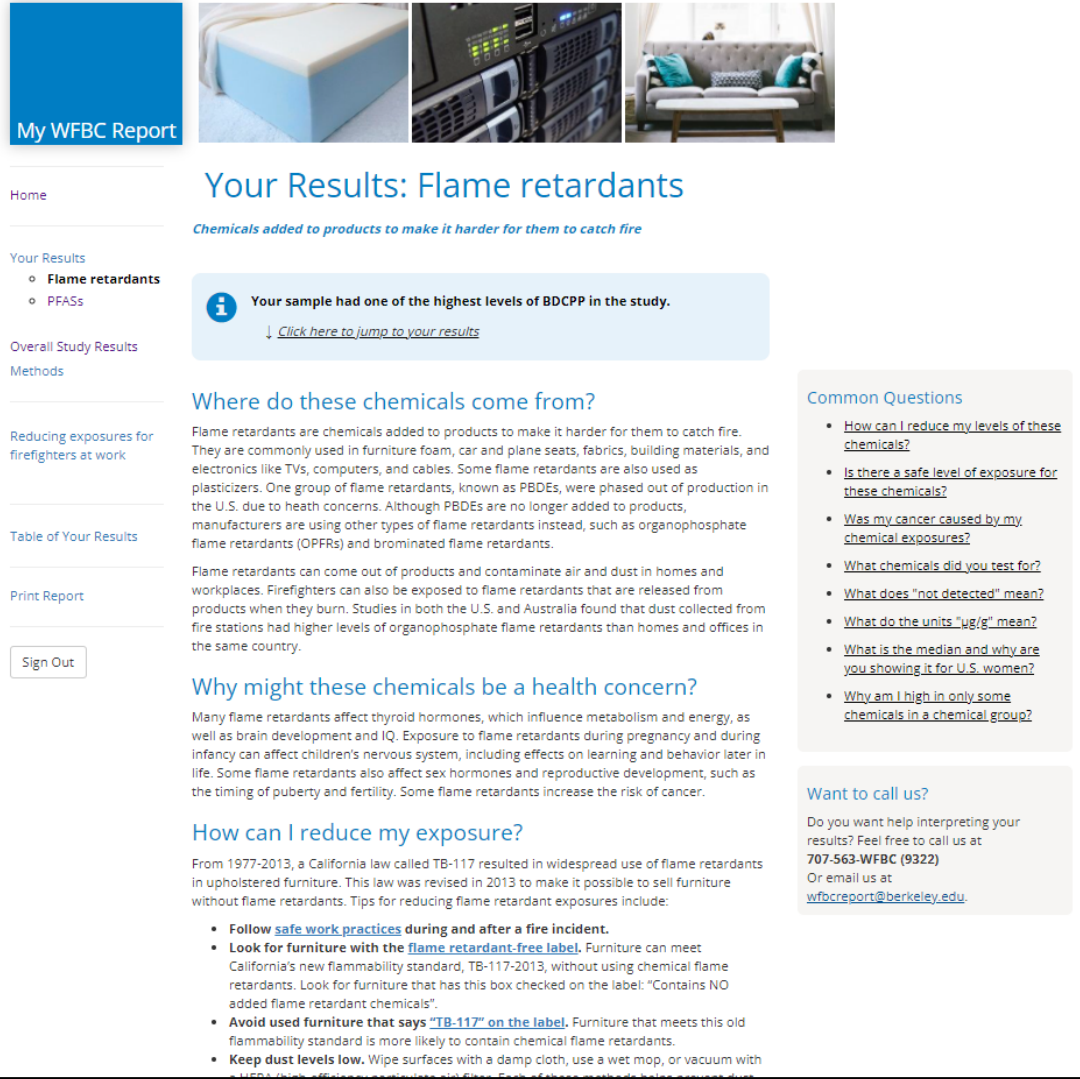


Action Kit participants have lower levels of Bisphenol A (found in some plastics and food packaging), but higher levels of the related chemical Bisphenol F. This suggests that industry is replacing one harmful chemical with another, a practice known as "regrettable substitution." [read more](#)

“Details-on-demand” for a group of chemicals

- Genes results could have parallel details pages
- Chemicals pages could link to genes that are relevant

*From: Women Firefighters
Biomonitoring Collaborative*



My WFBC Report

Home

Your Results

- **Flame retardants**
- PFASs

Overall Study Results

Methods

Reducing exposures for firefighters at work

Table of Your Results

Print Report

Sign Out

Your Results: Flame retardants

Chemicals added to products to make it harder for them to catch fire

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

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

Where do these chemicals come from?

Flame retardants are chemicals added to products to make it harder for them to catch fire. They are commonly used in furniture foam, car and plane seats, fabrics, building materials, and electronics like TVs, computers, and cables. Some flame retardants are also used as plasticizers. One group of flame retardants, known as PBDEs, were phased out of production in the U.S. due to health concerns. Although PBDEs are no longer added to products, manufacturers are using other types of flame retardants instead, such as organophosphate flame retardants (OPFRs) and brominated flame retardants.

Flame retardants can come out of products and contaminate air and dust in homes and workplaces. Firefighters can also be exposed to flame retardants that are released from products when they burn. Studies in both the U.S. and Australia found that dust collected from fire stations had higher levels of organophosphate flame retardants than homes and offices in the same country.

Why might these chemicals be a health concern?

Many flame retardants affect thyroid hormones, which influence metabolism and energy, as well as brain development and IQ. Exposure to flame retardants during pregnancy and during infancy can affect children's nervous system, including effects on learning and behavior later in life. Some flame retardants also affect sex hormones and reproductive development, such as the timing of puberty and fertility. Some flame retardants increase the risk of cancer.

How can I reduce my exposure?

From 1977-2013, a California law called TB-117 resulted in widespread use of flame retardants in upholstered furniture. This law was revised in 2013 to make it possible to sell furniture without flame retardants. Tips for reducing flame retardant exposures include:

- Follow [safe work practices](#) during and after a fire incident.
- Look for furniture with the [flame retardant-free label](#). Furniture can meet California's new flammability standard, TB-117-2013, without using chemical flame retardants. Look for furniture that has this box checked on the label: "Contains NO added flame retardant chemicals".
- Avoid used furniture that says "[TB-117" on the label](#)". Furniture that meets this old flammability standard is more likely to contain chemical flame retardants.
- Keep dust levels low. Wipe surfaces with a damp cloth, use a wet mop, or vacuum with a HEPA filter.

Common Questions

- [How can I reduce my levels of these chemicals?](#)
- [Is there a safe level of exposure for these chemicals?](#)
- [Was my cancer caused by my chemical exposures?](#)
- [What chemicals did you test for?](#)
- [What does "not detected" mean?](#)
- [What do the units "ug/g" mean?](#)
- [What is the median and why are you showing it for U.S. women?](#)
- [Why am I high in only some chemicals in a chemical group?](#)

Want to call us?

Do you want help interpreting your results? Feel free to call us at **707-563-WFBC (9322)**
Or email us at wfbcreport@berkeley.edu.

Scroll down to individual results graphs

- Graphs use visual abilities to communicate “gist”
- Hover to see graph-reading tips and results details
- New visualization needed for G x E

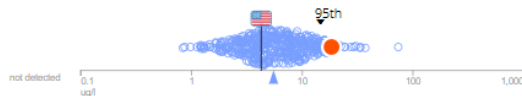
Your Results

Graph legend

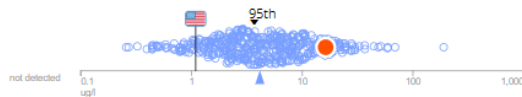
- your chemical level
 - other participants' chemical levels
 - participants for whom the chemical was not detected
- 🇺🇸 [median](#) chemical level for [other Americans](#)
- 95th [95th percentile](#) chemical level for [other Americans](#)
- ▲ [median](#) chemical level for this study
- µg/L: micrograms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

Tip: Mouse over your graphs to learn more.

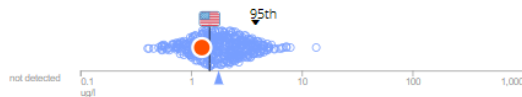
PFOS (perfluorooctane sulfonic acid)



PFHxS (perfluorohexane sulfonic acid)



PFOA (perfluorooctanoic acid)



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.”

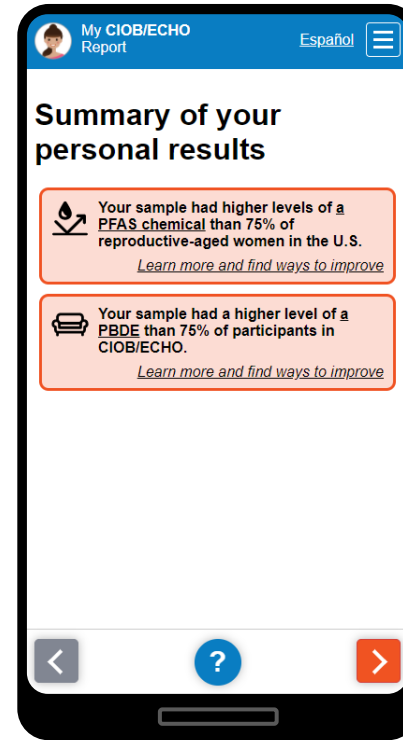
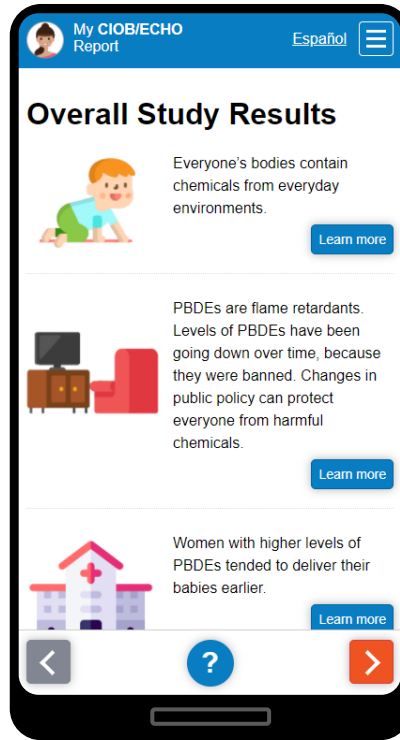
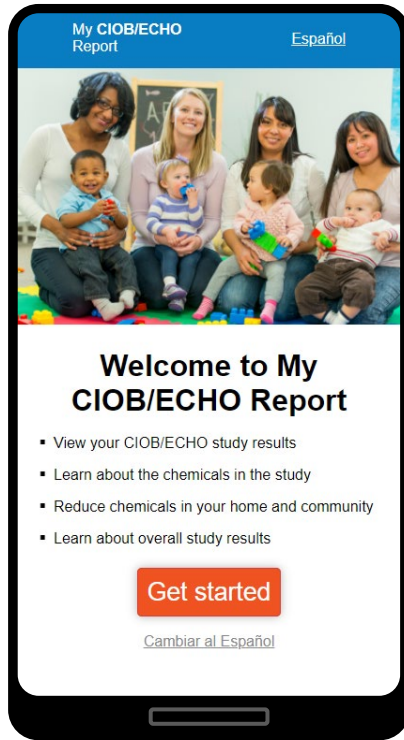
“So far, studies of people have found that higher levels of PFAS are linked to:

- 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




People value information to reduce exposure and protect health

- Individual and community action
- G x E can sometimes change actionability compared with G-only
- Actions often are outside of clinical care


What You Can Do

Learn ways to lower PFAS exposure for yourself, your family, and your community.


- 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




[Water](#)



[Food](#)



[Home](#)



[Community](#)



Study participant views on collective action

- Focus groups of peripartum moms:
 - Motivated to act despite time burdens
 - Asked for action tips to be time-conscious
 - Built new ideas on their other experiences of civic participation
 - Expressed willingness to share knowledge with their network
 - Were wary of advocating exposure reduction in settings such as with childcare providers

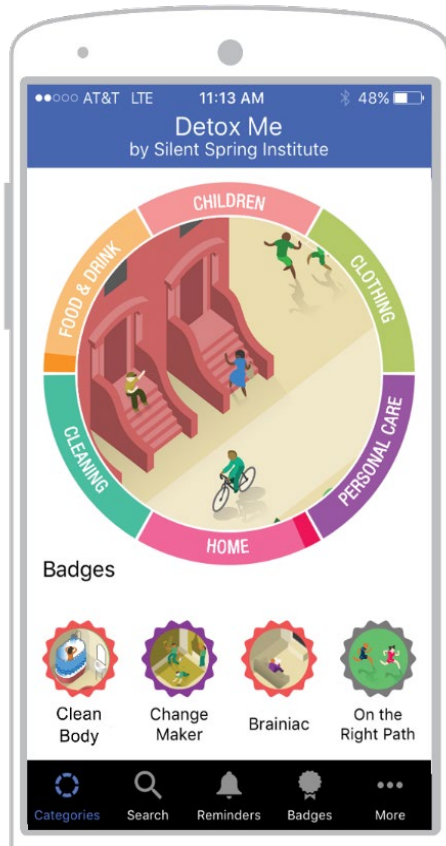
In collaboration with ECHO / CIOB, IKIDS. C. Oksas et al., in preparation.

Community resources and context-setting

- Meetings
- News media
- Influencers



Community resource



Detox Me *smartphone app 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.
- Follow a curated newsfeed

www.detoxmeapp.org

In English and Spanish!

Questions and Recommendations

Questions about G x E report-back

- How to make report-back most empowering?
 - What is the ethical responsibility of the researcher to facilitate results translation to public health?
 - Opportunities for study participants to share experiences and form collectives
- Does receiving E results change the response to G results?
- How to integrate G x E results into clinical care?
- G x E studies will reveal vulnerable populations. What does this imply?
- Both G and E results have multi-generational implications. What are the obligations to share results or not?
- Protocols, resources for outliers outside of clinical care?
- How to adapt for nontargeted analysis, metabolomics, epigenetics?

Recommendations to NIH: Support personal report-back

- Provide guidance, training, and resources for report-back
 - Support shared infrastructure for generating reports
 - Develop guidance for QA/QC outside of CLIA
- Develop legal protections for personal enviro results
- Require proposals to include a report-back plan or explain exceptions
- Support research to keep improving report-back methods and adapting for new science

Example reports and bibliography

- Links to example reports

<https://silentspring.org/derbi>

- Selected bibliography

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

Acknowledgments

- Katherine E. Boronow, Ruthann Rudel, Jennifer Liss Ohayon, Erik Haugsjaa, Anisha Nakagawa, Silent Spring Institute
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