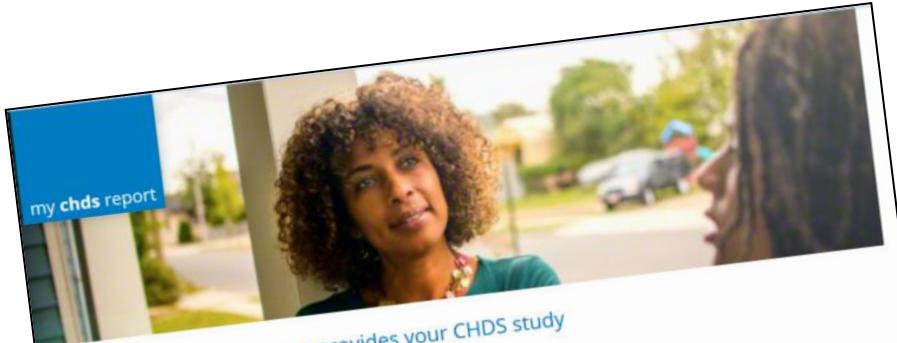


# Communicating Biomonitoring Results

Julia Brody, PhD, Silent Spring Institute, [brody@silentspring.org](mailto:brody@silentspring.org)

NASEM Guidance on PFAS Testing and Health Outcomes

Meeting 6, August 12, 2021



**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.

reduce levels of these chemical in your



**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

Logout

Click here to jump to your results

**Your Results: PFASs**  
Highly fluorinated compounds

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

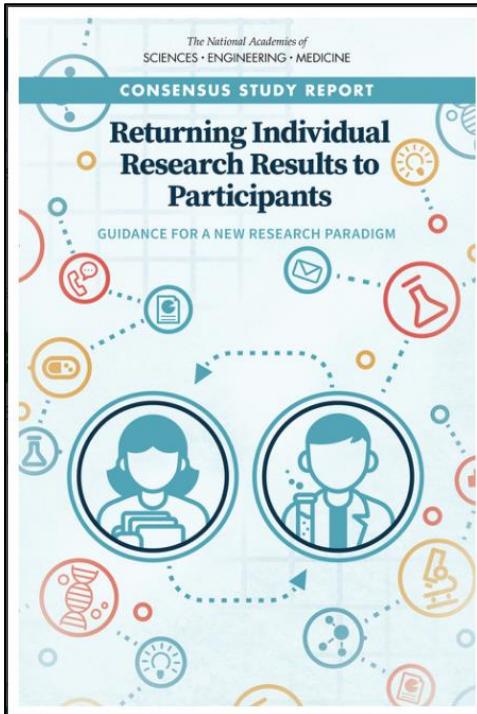
Where do these chemicals come from?

PFASs are used to make fabrics, packaging, and other products resistant to staining, greases, or water. They are used in stain-resistant textiles (like carpets, furniture, and clothing), water-proof 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 foams called aqueous film-forming foam (AFFF). See the following table for more information.

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 exposure?
- What chemicals did you test for?
- What does "not detected" mean?

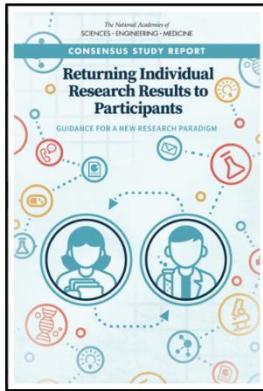
# NASEM 2018 consensus report



- Encourages researchers and IRBs to routinely report back

“...as a matter of reciprocity, respect, transparency, and trust, the return of results should be routinely considered ...”

# Key points are relevant to PFAS



NASEM 2018

- High-quality report-back requires dedicated guidance, expertise, and resources
- Potential harms of report-back have been overstated & benefits are under-appreciated
  - Benefits extend beyond the clinic and beyond actionable results
  - Vital to building trust

# Personal Exposure Report-Back Studies

- 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*

# Report-Back Outcomes

The “exposure experience” of learning about chemicals in the body informs and motivates health actions

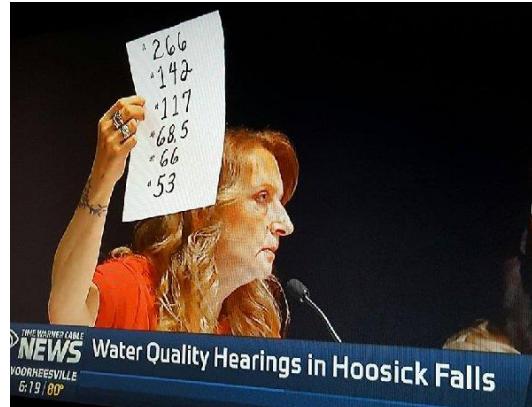
# How have people responded to learning their results?

- Gratitude – people want their reports
- Increased trust in the research team
- Learning about environmental health, without undue worry
- Brainstorming about personal exposure history and changes they could make
- Reflection on family illnesses, with understanding of uncertainty
- Sense of “toxic trespass”
- Frustration at knowledge gaps
- Community context matters



# People use their results in practical ways

- 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*

# Report-Back Design Basics

How to return personalized results in context

# Results are more than a number

- What did you find? How much? Is that high?
- Is it safe? – What we do/don't know about health
- Where did it come from?
- What can I do?

# DERBI: Digital Exposure Report-Back Interface

- A software framework for generating personalized exposure reports for print, computer/tablet, and smartphone
- Researcher dashboard (report-authoring interface)

## DERBI design basics

- Multi-level: Headlines and deep-dive
- Context for understanding – extensive content library
- Multi-language capability
- Tailored with participant/community input
- User-centered -- 1-on-1 usability testing

# DERBI Report Examples

Digital reports layer information using “details on demand,”  
a user-centered design.



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

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 biomonitoring study



Home

Your Results

- Antimicrobials
- 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: [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](#)



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

From: Women Firefighters  
Biomonitoring Collaborative



WFCBReport

Summary of Your Results

Chemicals 

PFAS

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

Sign Out

## Your Results: PFASs

### Highly fluorinated chemicals

- 1 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 help 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

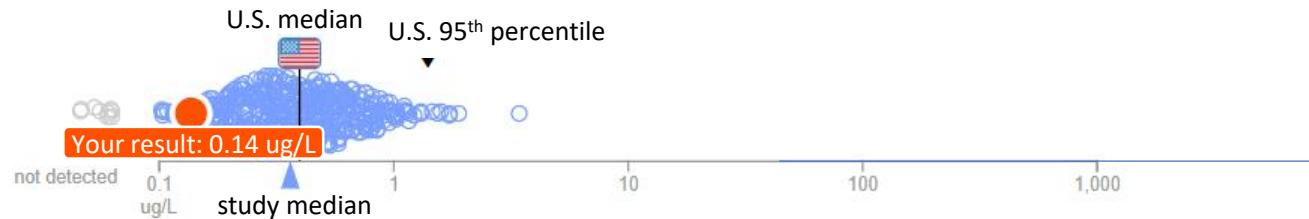
# Scroll down to individual results graphs

- Graphs use visual abilities to communicate “gist”

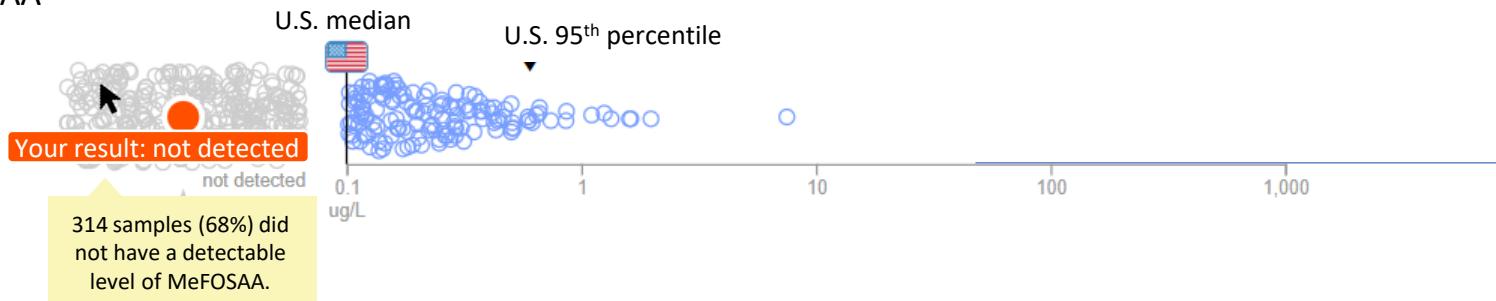


# Hover to access graph-reading tips, results detail

## PFNA



## MeFOSAA



# Graph features could turn on and off to answer different questions

- Comparisons to the community or US
- Results for demographic groups
- Change over time
- Summary variables for multiple PFAS



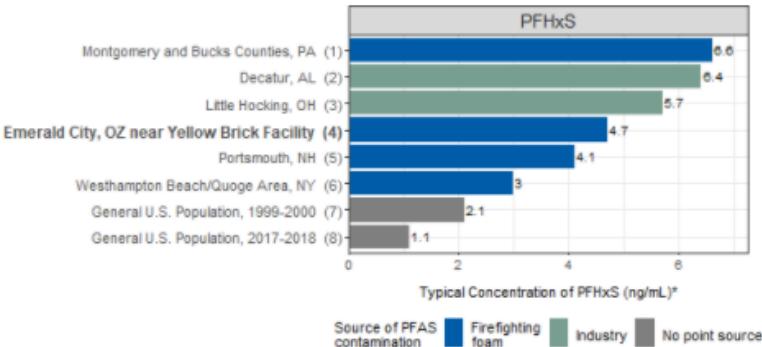
Community headlines on the summary page link to findings that provide context for personal results

Stakeholders asked for more detail.



### Higher levels of PFHxS are often found in communities contaminated by firefighting foam.

The typical level of PFHxS among Emerald City residents is similar to levels in other communities where drinking water contamination was caused by firefighting foams. To reduce future exposures, many communities are switching to firefighting foams that don't contain PFAS and doing fire training without the PFAS foams.



\*Typical concentrations represent medians or geometric means. These two measures are very similar for most exposure distributions.

The PFHxS level in Emerald City is also similar to two communities where PFAS contamination came from an industrial source. However, Emerald City residents have much lower levels of PFOS and PFOA compared to communities that were impacted by industry.

[Show graphs for PFOS and PFOA](#)

[Show references](#)

*Hypothetical example*

# People value information to reduce exposure and protect health

- Individual and community action
- Medical monitoring guidance could be included

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

## What You Can Do

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



Water



Food



Home



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

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 In You

Your sample had higher levels of some [PFAS](#) than 95% of Americans.

[Learn about actions that could help reduce your exposure](#)

## Health Concerns

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 can stay in people's bodies for years. So far, studies of people have found that higher levels of PFAS are linked to:

- Increased cholesterol levels
- Decreased vaccine response in children
- Changes in liver enzymes
- Increased risk of high blood pressure or pre-eclampsia in pregnant women
- Small decreases in infant birth weights
- Increased risk of kidney or testicular cancer

Based on what we know now, we can't link your results to specific health concerns for you or your family. We still want to show you your chemical results, because participants have a right to learn about their exposures. There are some things

## Community Results

ATSDR measured 7 PFAS in 459 people from Emerald City, OZ. Like nearly all Americans, everyone in the exposure assessment had PFAS detected in their blood. [read more](#)

Participants had higher levels of PFHxS compared to other Americans. More than half of Emerald City residents had higher levels of PFHxS than 95% of Americans. [read more](#)

Higher levels of PFHxS are typical in communities contaminated by firefighting foam. Many communities are switching to firefighting foams that don't contain PFAS and doing fire training without the PFAS foams to prevent future contamination. [read more](#)

*Hypothetical example*

# Resources to facilitate consultation with doctors



**Resources For Your Doctor**

You may wish to share these results with your doctor- it's your choice. Keep in mind that, based on what we know now, scientists usually can't link your results to specific health concerns for you or your family.

If you decide to talk to your doctor, we suggest following these steps:

- 1. Print your personal results report.**  
Use the "Print Report" button on the left-menu to generate a printer-friendly version of your results report. Print it out or save a digital copy. Your report contains your personal exposure information, and it will also help your doctor learn more about PFAS and exposures in your community. Your doctor can add your PFAS exposure results to your medical record.
- 2. Print the ATSDR Clinician Fact Sheet on PFAS.**  
Go to <https://www.atsdr.cdc.gov/pfas/resources/clinical-guidance.html> to download the ATSDR Clinician Fact Sheet on PFAS. Print it out or save a digital copy. This fact sheet will help your doctor learn about PFAS and health. Many doctors may not be familiar with PFAS or the potential health effects of PFAS exposure.
- 3. Think about how you have been exposed to PFAS.**  
Your doctor may ask how you were exposed to PFAS in the past, and about sources of PFAS that you are still exposed to. Before speaking with your doctor, read the Water, Food, and Home pages under "What You Can Do" on the left-menu. Think about ways you may have been exposed in the past, and how you might be exposed now.
- 4. Show your personal results report and the Clinician Fact Sheet to your doctor.**

**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**

**Sign Out**

*Hypothetical example – work-in-progress*



Reports could  
be added to  
EMR as a pdf  
or as data in a  
csv file

From: STEEP SRP

Home

Your Results

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

Overall Study Results

What You Can Do

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

Common Questions

About STEEP

Methods

Contact Us

Table of Your Results

Print Report

Sign Out

## Your Results: PFAS



Your sample had one of the highest levels in the study of PFAS.

[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, PFHhA, 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**

# Reports support environmental health literacy and 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.”

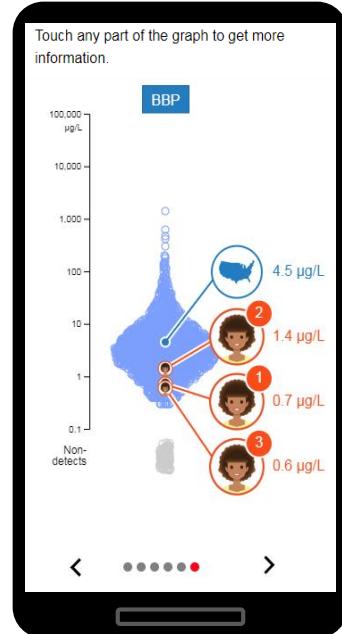
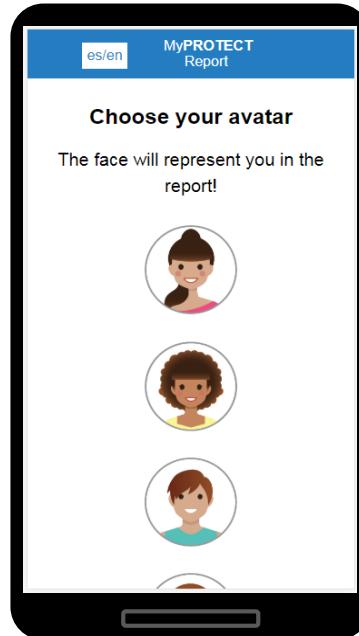
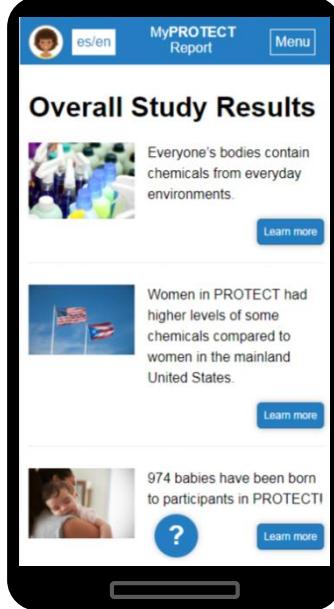
- Antimicrobials
- Bisphenols
- Chlorinated Phenols

Child development, the nervous system, and cancer.

The chemicals in Detox Me Action Kit have been detected at different levels in people throughout the U.S. Detecting these chemicals in your urine doesn’t mean you will get sick.

“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 DERBI expands access in low-income communities



My CIOB/ECHO Report Español



## Welcome to My CIOB/ECHO Report

- View your CIOB/ECHO study results
- Learn about the chemicals in the study
- Reduce chemicals in your home and community
- Learn about overall study results

**Get started**

[Cambiar al Español](#)

My CIOB/ECHO Report Español ≡

## Overall Study Results



Everyone's bodies contain chemicals from everyday environments.

[Learn more](#)



PBDEs are flame retardants. Levels of PBDEs have been going down over time, because they were banned. Changes in public policy can protect everyone from harmful chemicals.

[Learn more](#)



Women with higher levels of PBDEs tended to deliver their babies earlier.

[Learn more](#)

< ? >

My CIOB/ECHO Report Español ≡

## Summary of your personal results



Your sample had higher levels of a PFAS chemical than 75% of reproductive-aged women in the U.S.

[Learn more and find ways to improve](#)



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

[Learn more and find ways to improve](#)

< ? >



## 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](#)



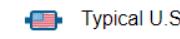
## Your Results

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.

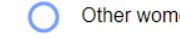
### Legend



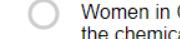
Your result



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



Not detected



1ng/g lipid

1,000

[Back to  
Summary](#)

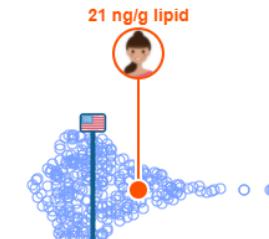


### › PBDE 153

21 ng/g lipid

Not detected

42%



Not detected 1ng/g lipid 10 100 1,000

Tap each part of the graph to learn more

### › PBDE 99

Not detected



1,000

### › PBDE 47

Not detected



1,000

### › PBDE 100

[Back to  
Summary](#)



# Some advantages of digital reports

- Details-on-demand – user decides what info to access
- Easily tailored to community context
- Easy to update with new data or information
- Multi-language
- In clinical context, data can be displayed, printed, or downloaded as a csv to add to EMR
- Efficient, inexpensive to produce and disseminate

# Example reports and bibliography

- Links to example reports

<https://silentspring.org/project/digital-exposure-report-back-interface-derbi>

- Selected bibliography

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

# Principles for biomonitoring communication

- Biomonitoring results can be meaningful even when chemicals are persistent in the body and levels of health concern are uncertain
- Report-back improves environmental health literacy and promotes actions to protect personal and community health
- Consider that chemical exposure monitoring in highly exposed people will someday become routine. Your recommendations for PFAS can be a step toward including environmental health as a part of patient care.

## Study partners

- Julia Brody, Ruthann Rudel, Katherine Boronow, Jennifer Ohayon, Erik Haugsjaa , Anisha Nakagawa, Silent Spring Institute
- Phil Brown, Northeastern SSEHRI
- Rachel Morello-Frosch, UC Berkeley
- Sharlye Patton, Commonweal
- Krzysztof Gajos, Ken Arnold, Harvard Human Computer Interaction Group
- Shaun Goho, Harvard Environmental Law & Policy Clinic
- Ginger Chew, Gary Adamkiewicz, CDC/HUD Green Housing Study
- Barbara Cohn, Piera Cirillo, Child Health and Development Studies
- Thanks to many collaborating studies: PROTECT, CIOB/iKIDS, ELLA, WWBC... and support from NIH, NSF, CDC, CBCRP