Communicating Biomonitoring Results

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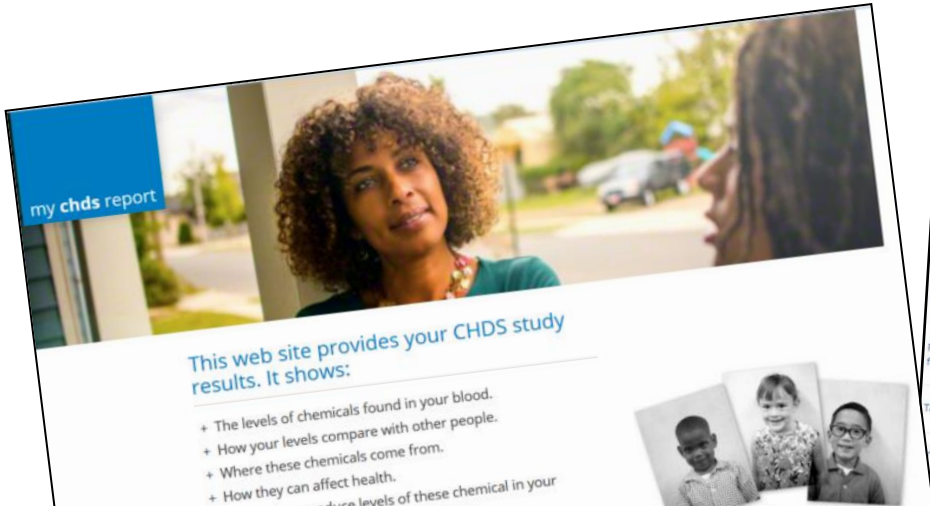
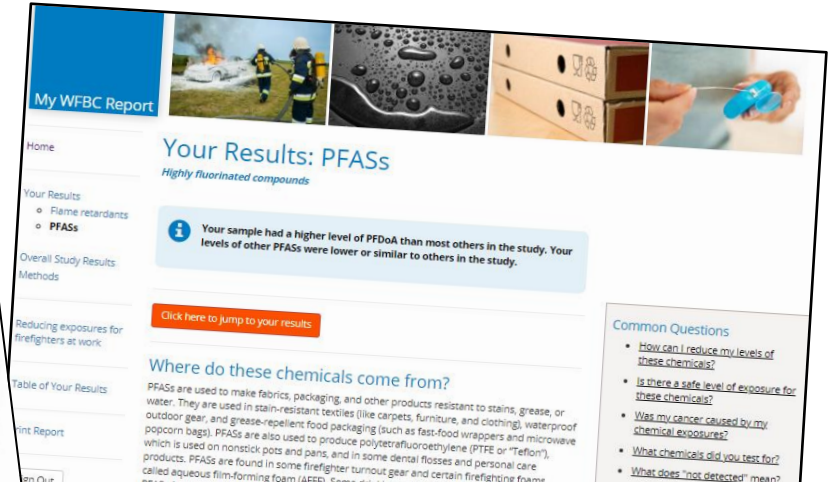
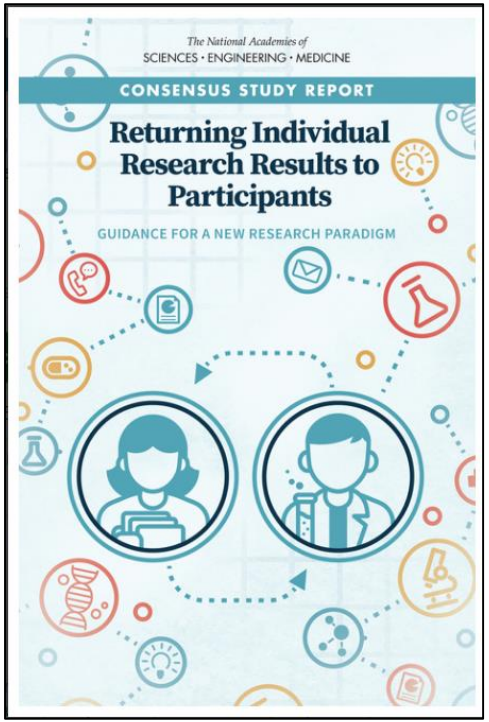
NASEM Guidance on PFAS Testing and Health Outcomes

Meeting 6, August 12, 2021





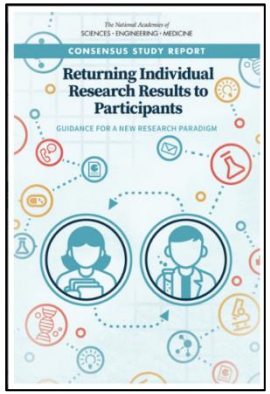
NASEM 2018 consensus report



- 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

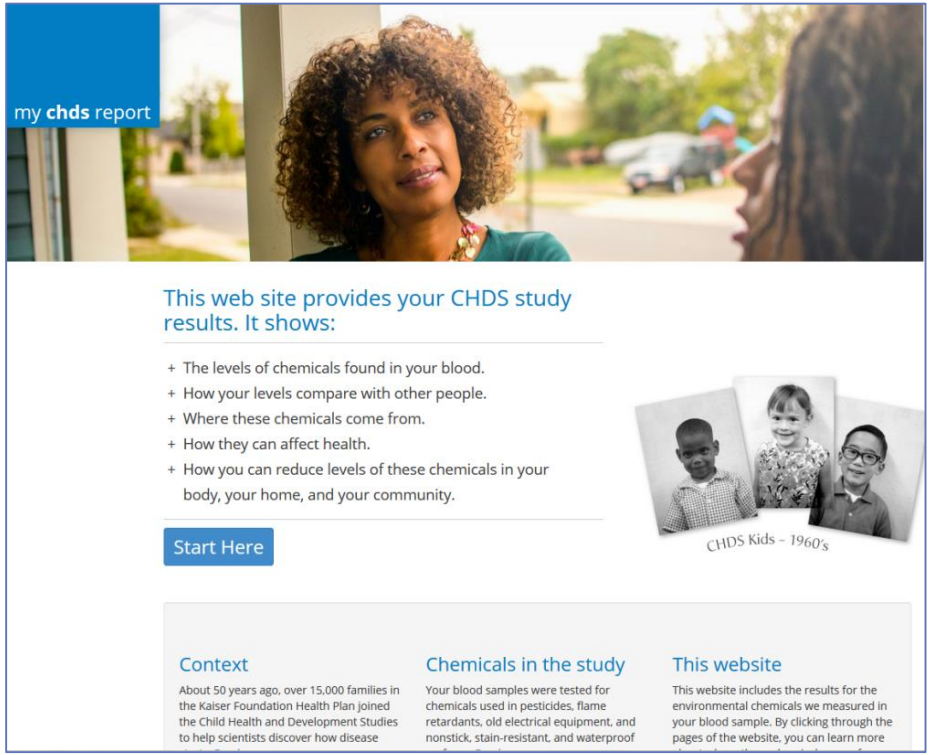
Results are more than a number

- 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?

Brody et al. 2007 AJPH

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)



Boronow et al. 2017 EHP

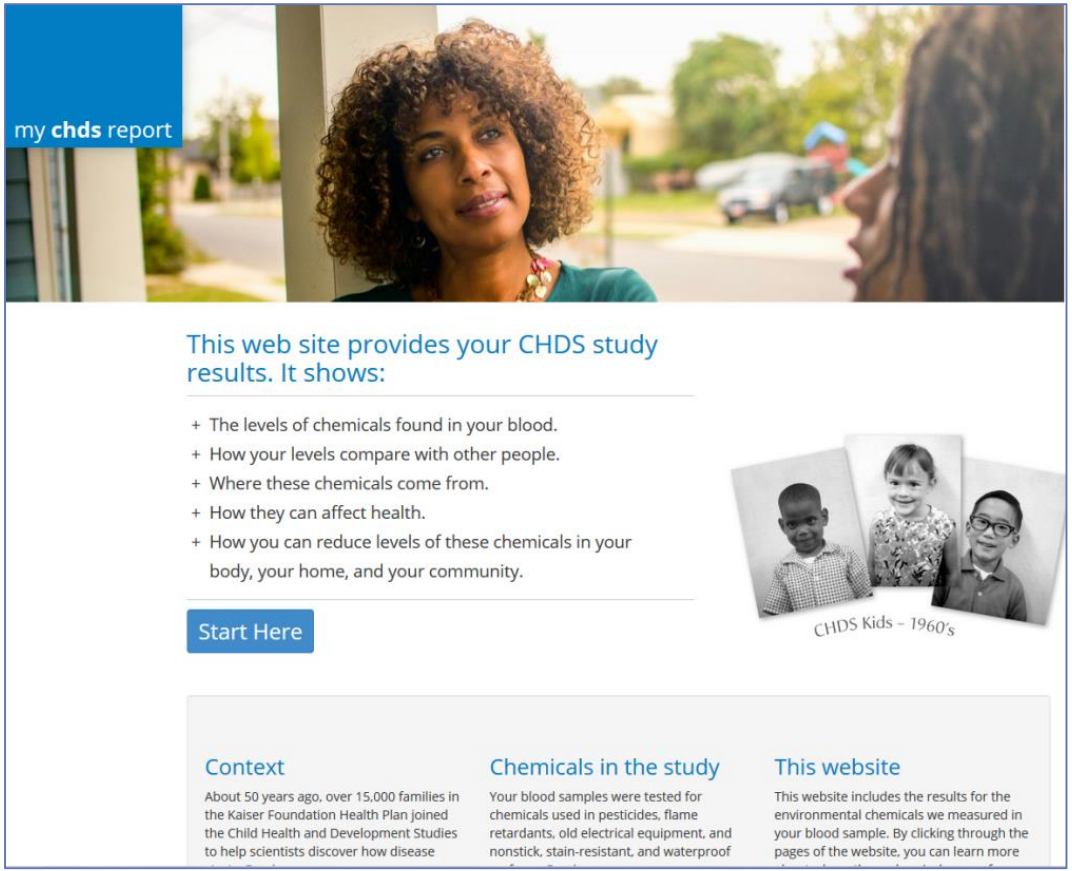
DERBI design basics

- 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

Boronow et al. 2017 EHP

DERBI Report Examples

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



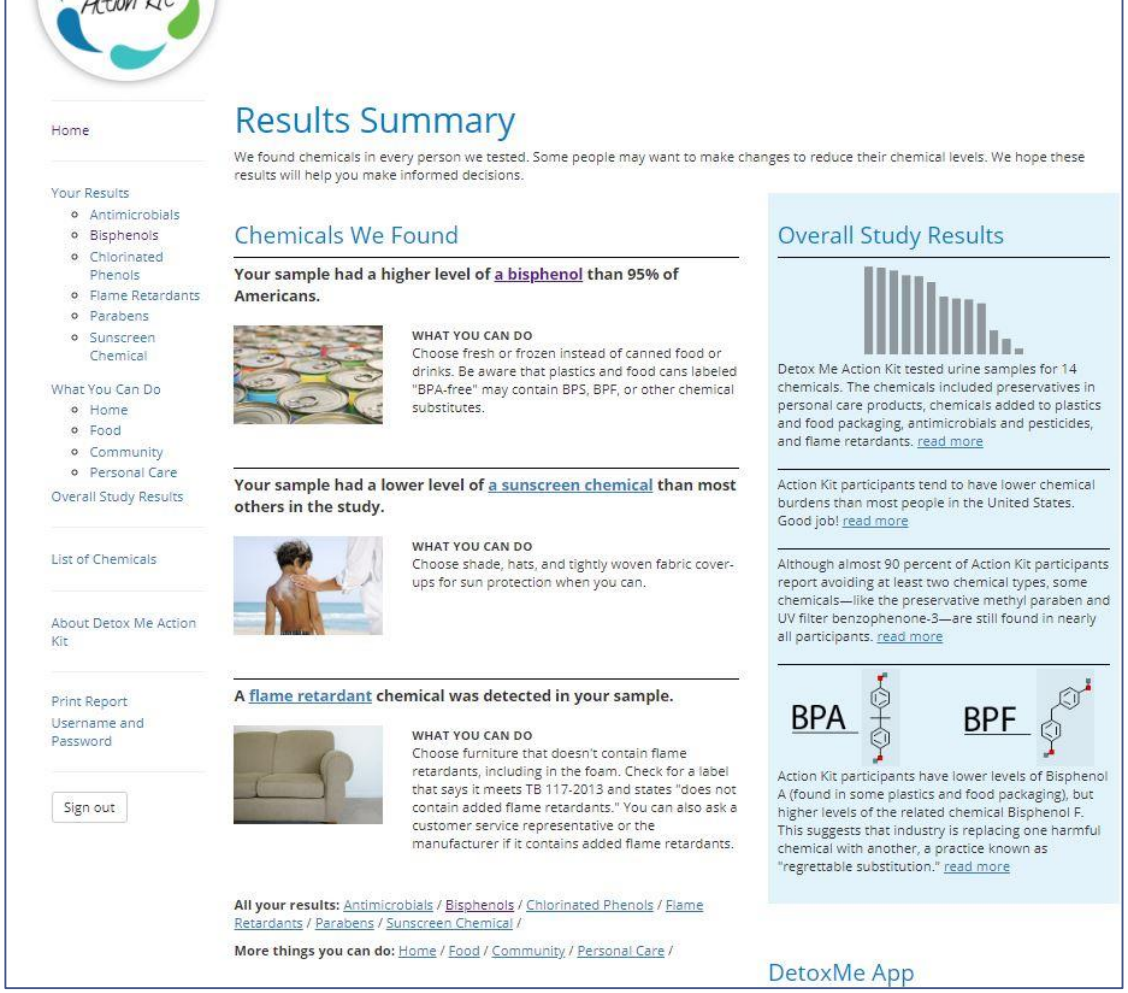
1. Welcome page
2. Individual login
   (no overt personal identifiers)
3. Summary page with main messages – "headlines" – about individual- and community-wide results

Child Health and Development Studies

Personalized summary page

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

From: Detox Me Action Kit biomonitoring study



Individual results page

Personal headline

Sources

Health effects

Exposure reduction

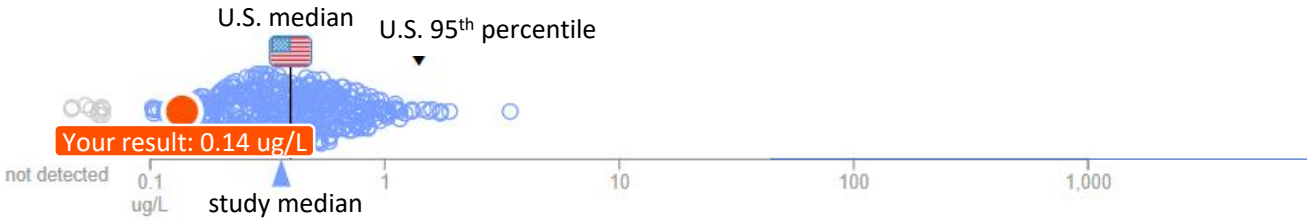
From: Women Firefighters Biomonitoring Collaborative

Scroll down to individual results graphs

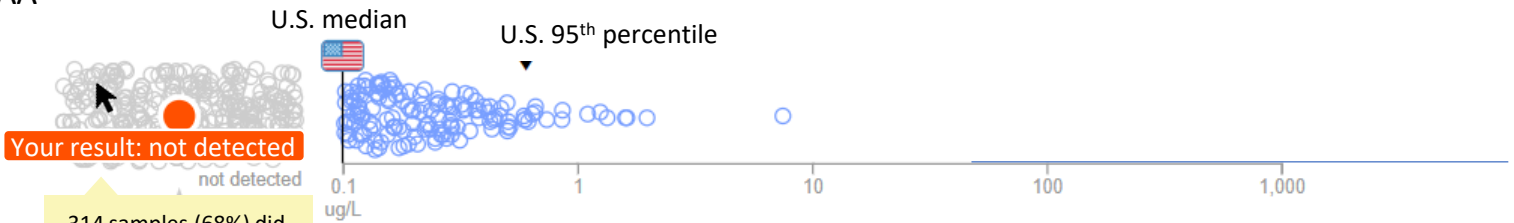
- Graphs use visual abilities to communicate “gist”

Hover to 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

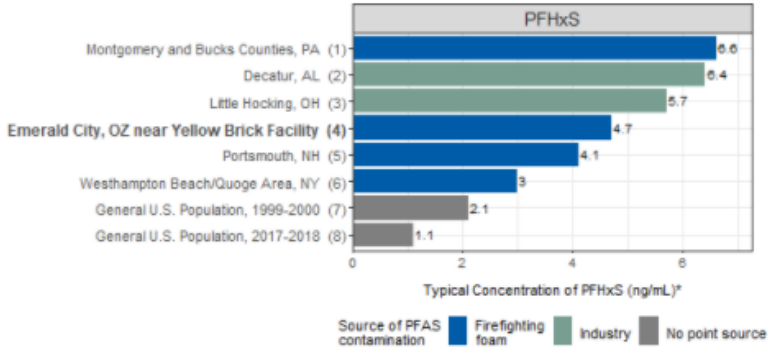
Community headlines on the summary page link to findings that provide context for personal results

Stakeholders asked for more detail.

Hypothetical example

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.

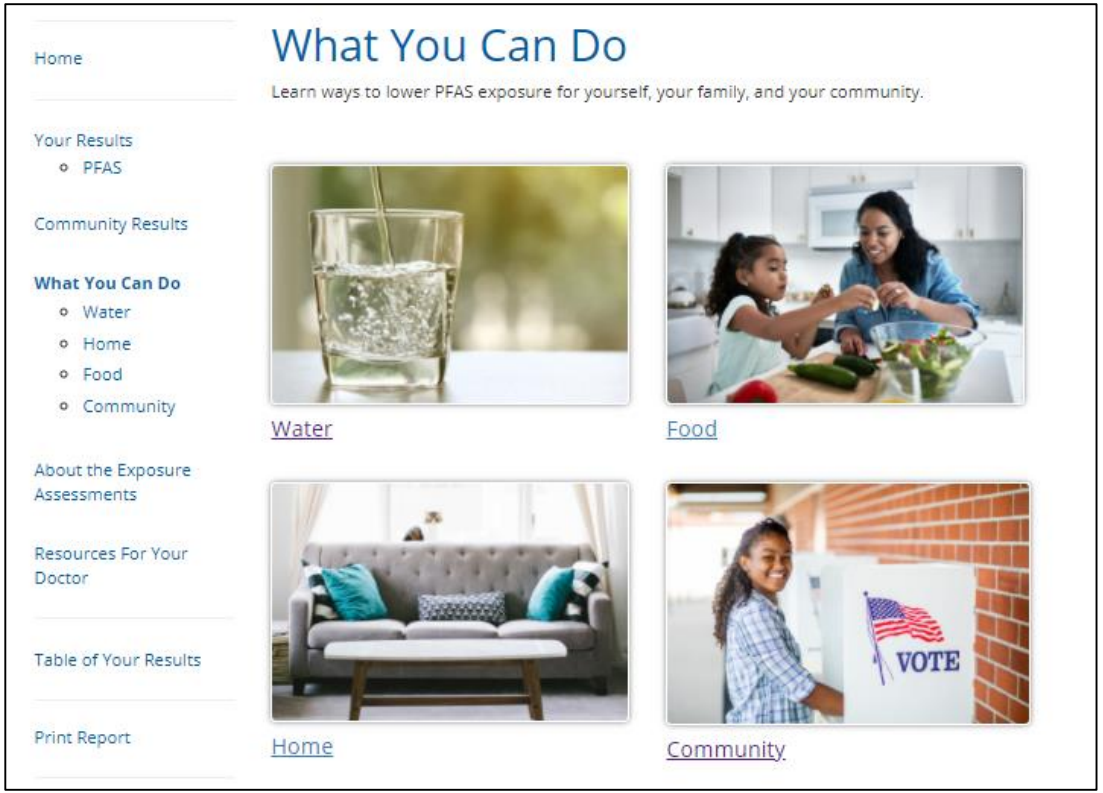
The PFHxS level in Emerald City is also similar to two communities where PFAS contamination came from an industrial source. However, Emerald City residents have much lower levels of PFOS and PFOA compared to communities that were impacted by industry.

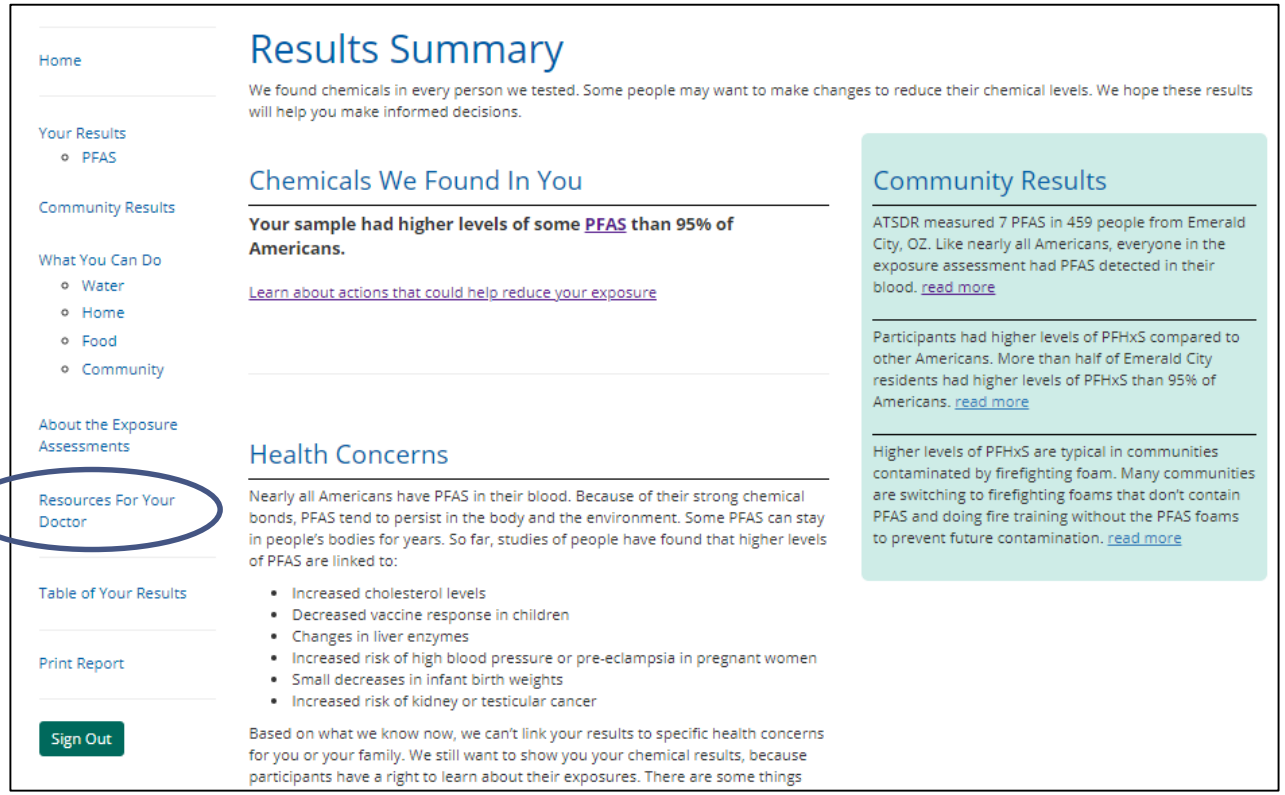
Show graphs for PFOS and PFOA

Show references

People value information to reduce exposure and protect health

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

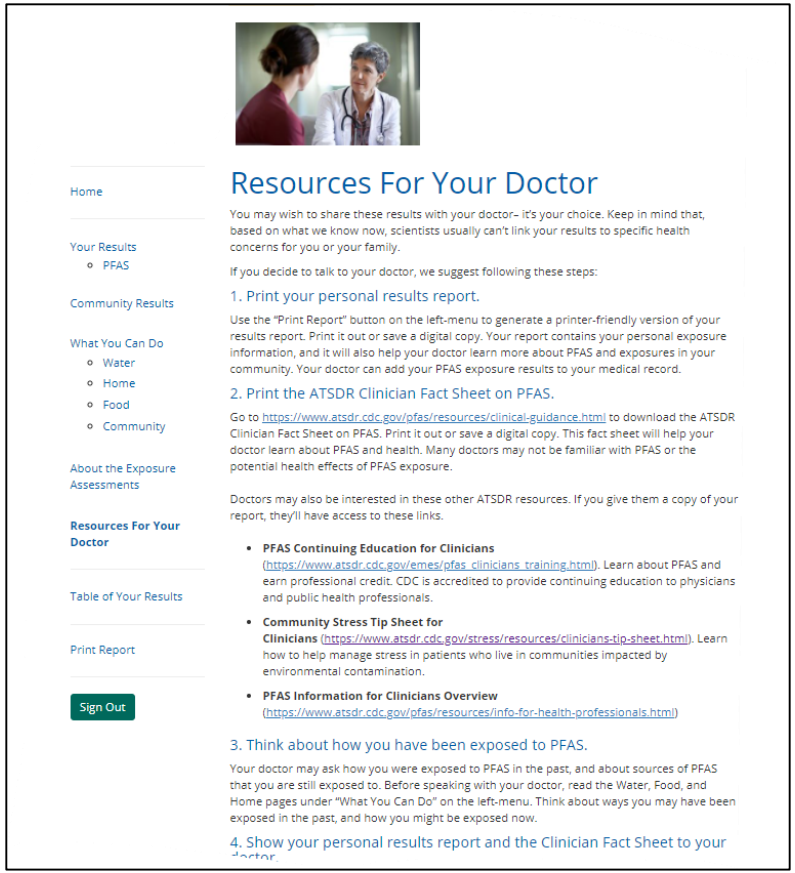




Hypothetical example

Resources to facilitate consultation with doctors

Hypothetical example – work-in-progress



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

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.

Doctors may also be interested in these other ATSDR resources. If you give them a copy of your report, they'll have access to these links.

- **PFAS Continuing Education for Clinicians** (https://www.atsdr.cdc.gov/emes/pfas_clinicians_training.html). Learn about PFAS and earn professional credit. CDC is accredited to provide continuing education to physicians and public health professionals.
- **Community Stress Tip Sheet for Clinicians** (https://www.atsdr.cdc.gov/stress/resources/clinicians-tip-sheet.html). Learn how to help manage stress in patients who live in communities impacted by environmental contamination.
- **PFAS Information for Clinicians Overview** (https://www.atsdr.cdc.gov/pfas/resources/info-for-health-professionals.html)

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

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 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

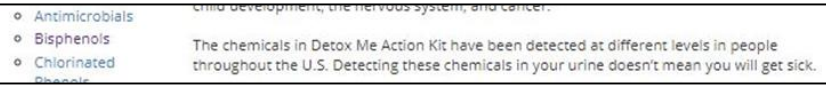
- How can I reduce my exposure to each of these chemicals?
- How do I get my water tested again?
- I already have water treatment, why am I still high in some chemicals?
- Is there a safe level of exposure for PFAS chemicals?
- Was my cancer or other illness caused by my chemical exposures?
- What does "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

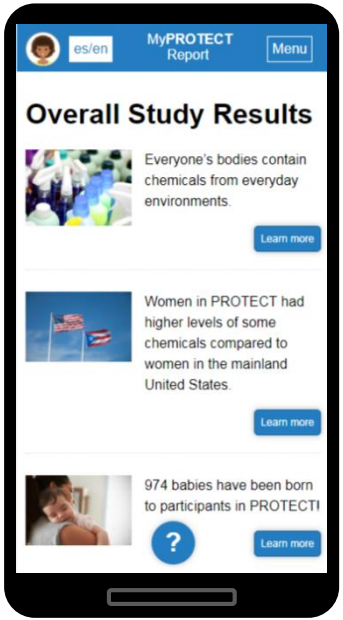
Reports support environmental health literacy and transparency about uncertainty

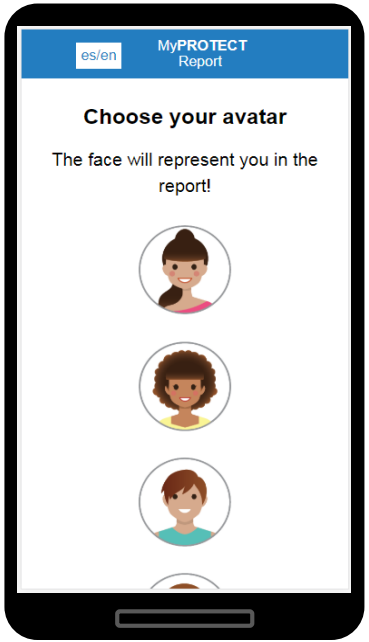
Chemicals in the study “have been detected at different levels in people throughout the U.S. Detecting these chemicals …doesn’t mean you will get sick.”

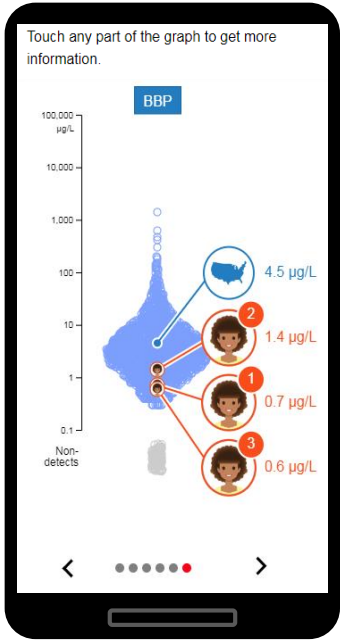


“Since we don’t do experiments on people, we often learn how chemicals may affect health by testing in animals or cells, similar to the way we test new drugs for safety.”

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

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

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

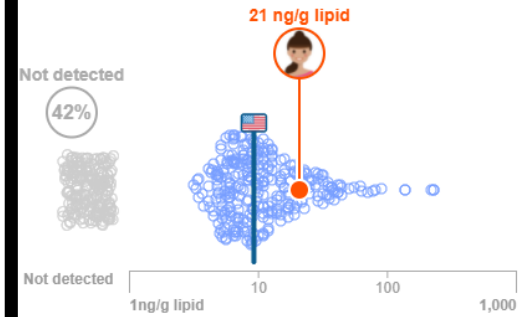
- Your result
- Typical U.S. woman 20-39 years old
- Other women in CIOB/ECHO
- Women in CIOB/ECHO who did not have the chemical detected in their sample

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

PBDE 153



Tap each part of the graph to learn more

PBDE 99

PBDE 47

PBDE 100

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
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