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

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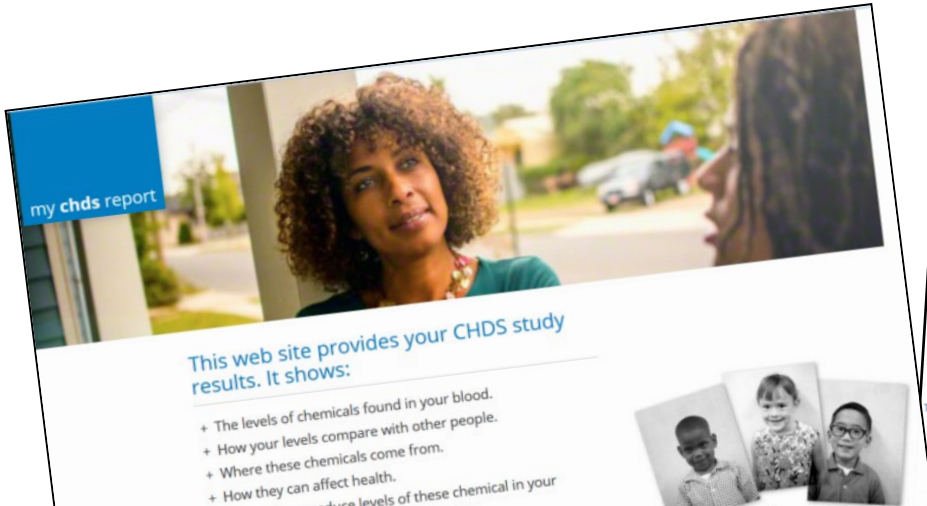
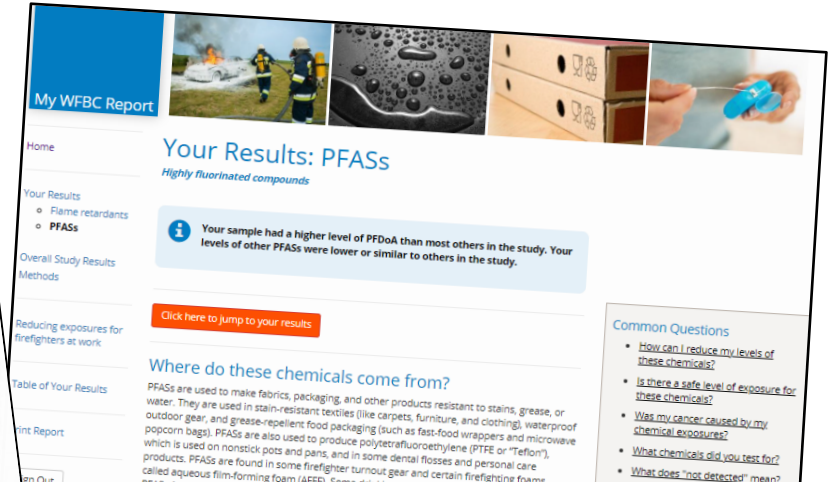




Early ethics questions: Returning environmental exposure results when health effects are uncertain

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

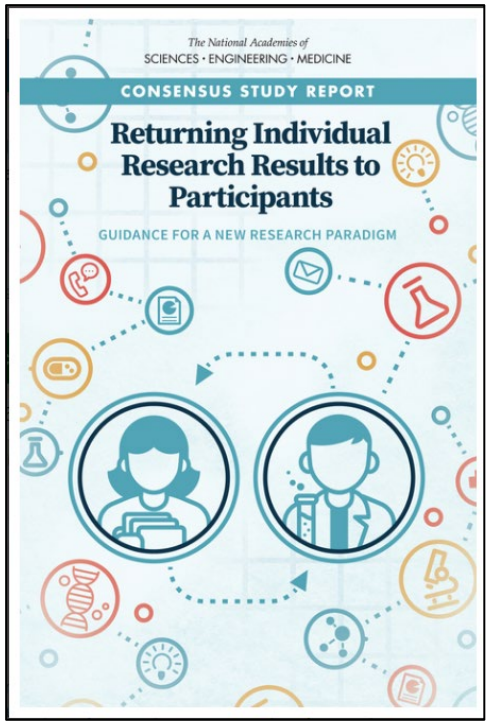
> *Goho, S. 2016.* ***The Legal Implications of Report-Back in Household Exposure Studies.*** *Environ Health Perspectives, doi:10.1289/EHP187.*

- 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

- 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

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

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?

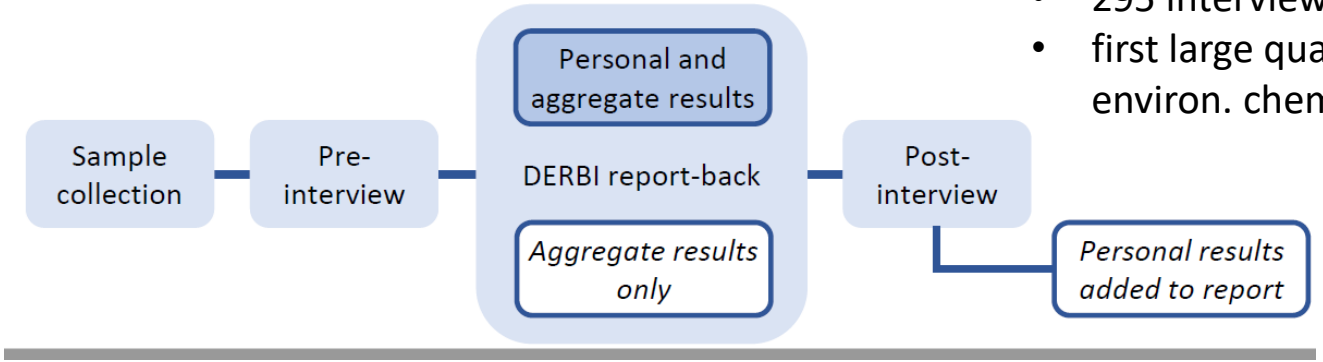
How have people responded to personal reports?

- 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*

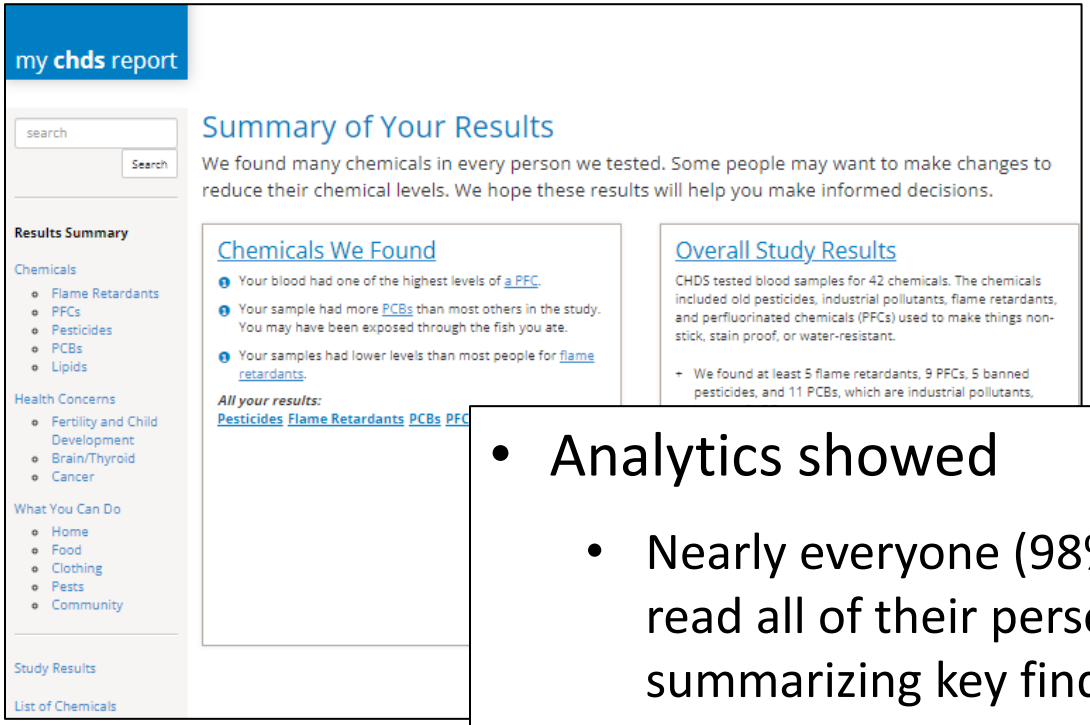
Experiment: Personal reports draw more engagement

- 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

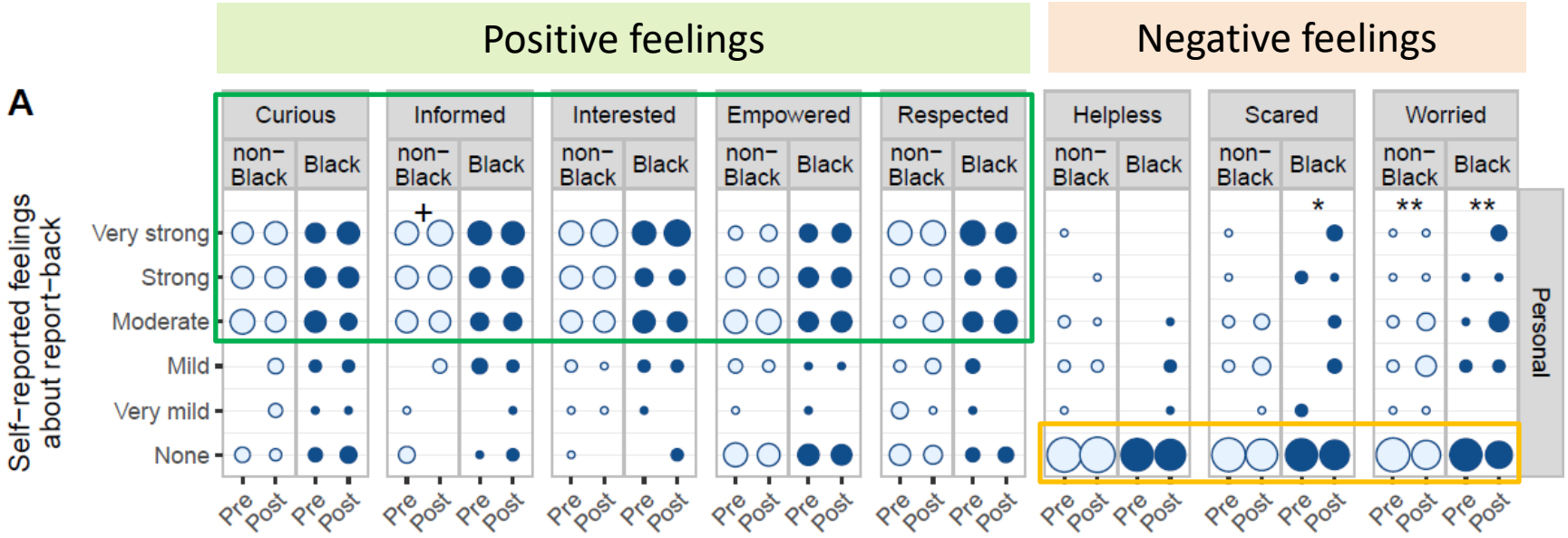
Brody et al., EHP, 2021. In collaboration with the Child Health and Development Studies



- 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



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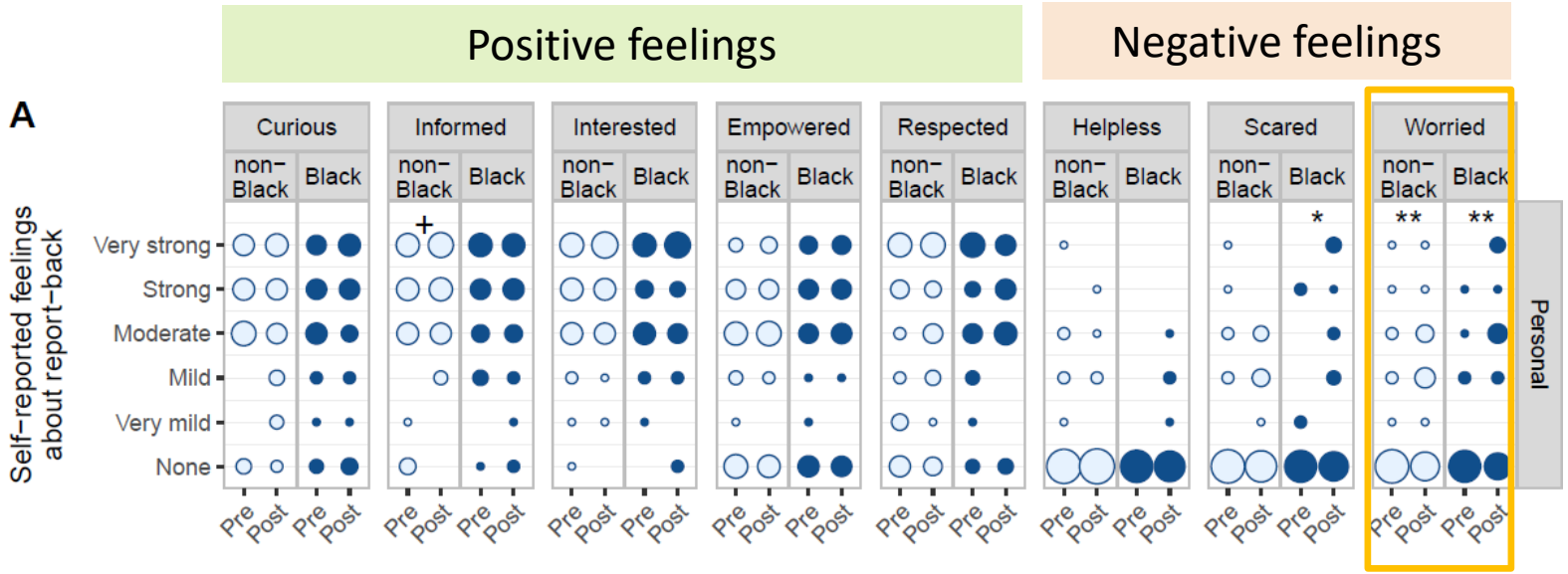

- Moderate increases in worry -- may motivate action
- Among Black participants, increased worry - associated with high exposure
- Would we see similar effect for group with genetic vulnerability?

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

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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, AJPH; 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

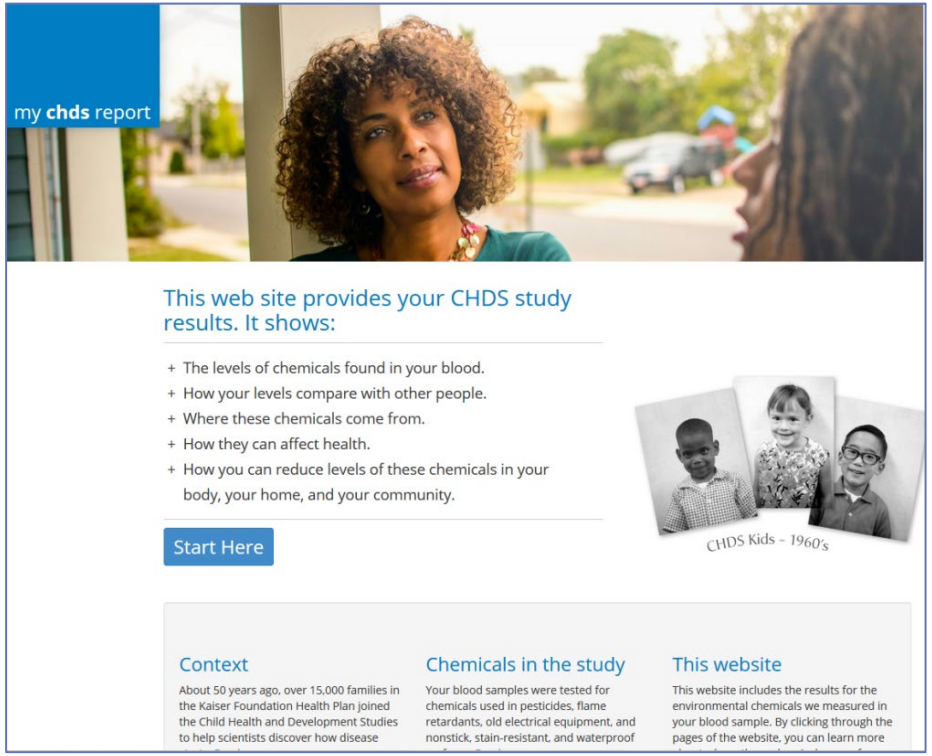
Participants want to know…

“What, so what, now what?”

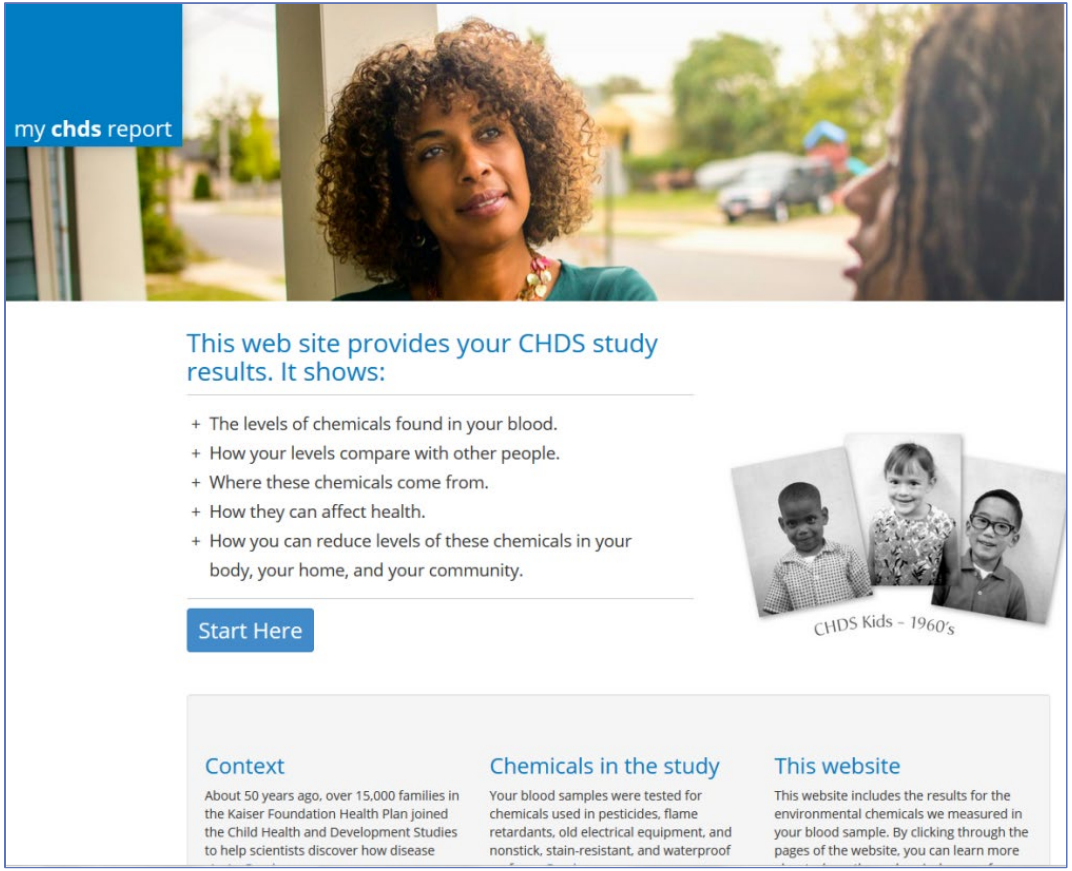
– Dr. Maida Galvez

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



Boronow et al. 2017 EHP



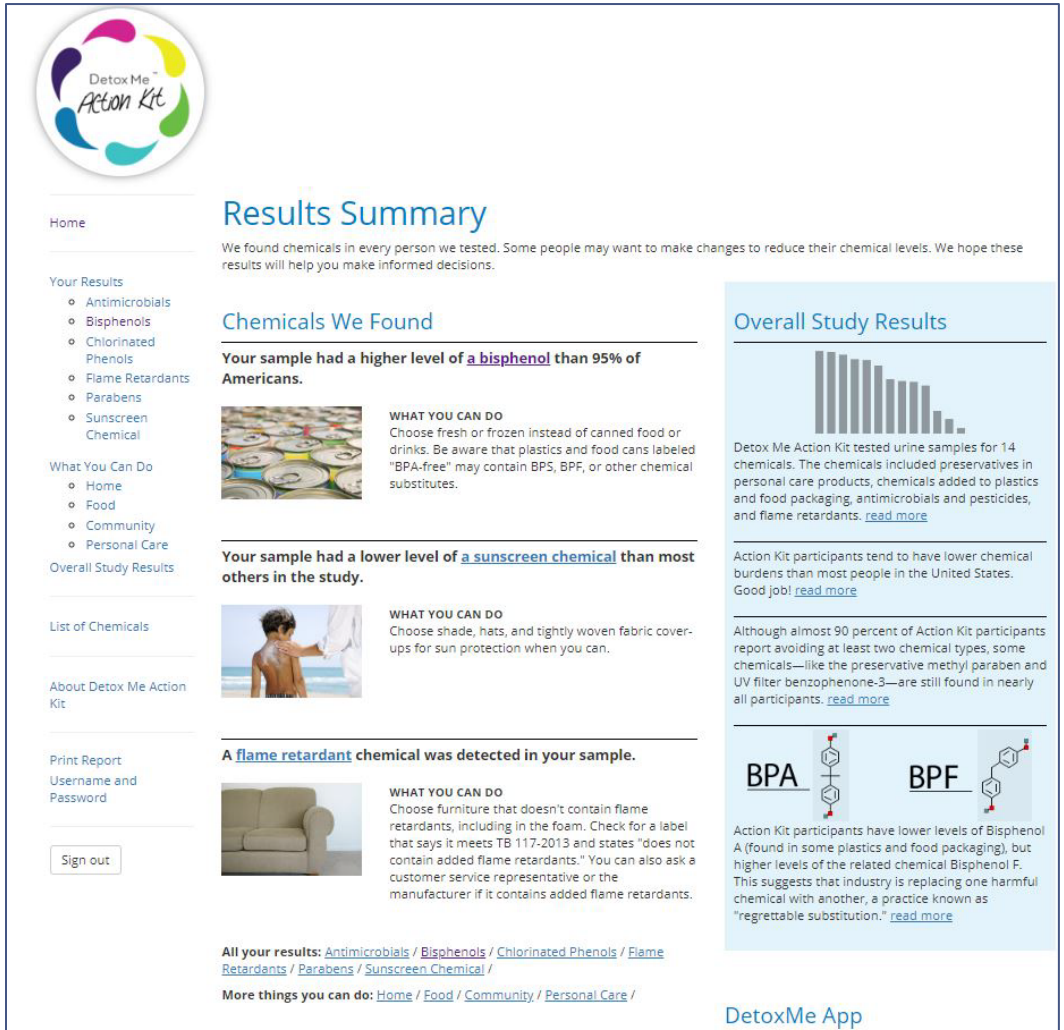
From: Child Health and Development Studies

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

Personalized summary page

- "Headlines" about individual and community results
- Suited to G X E because info can be integrated
- Links to detail

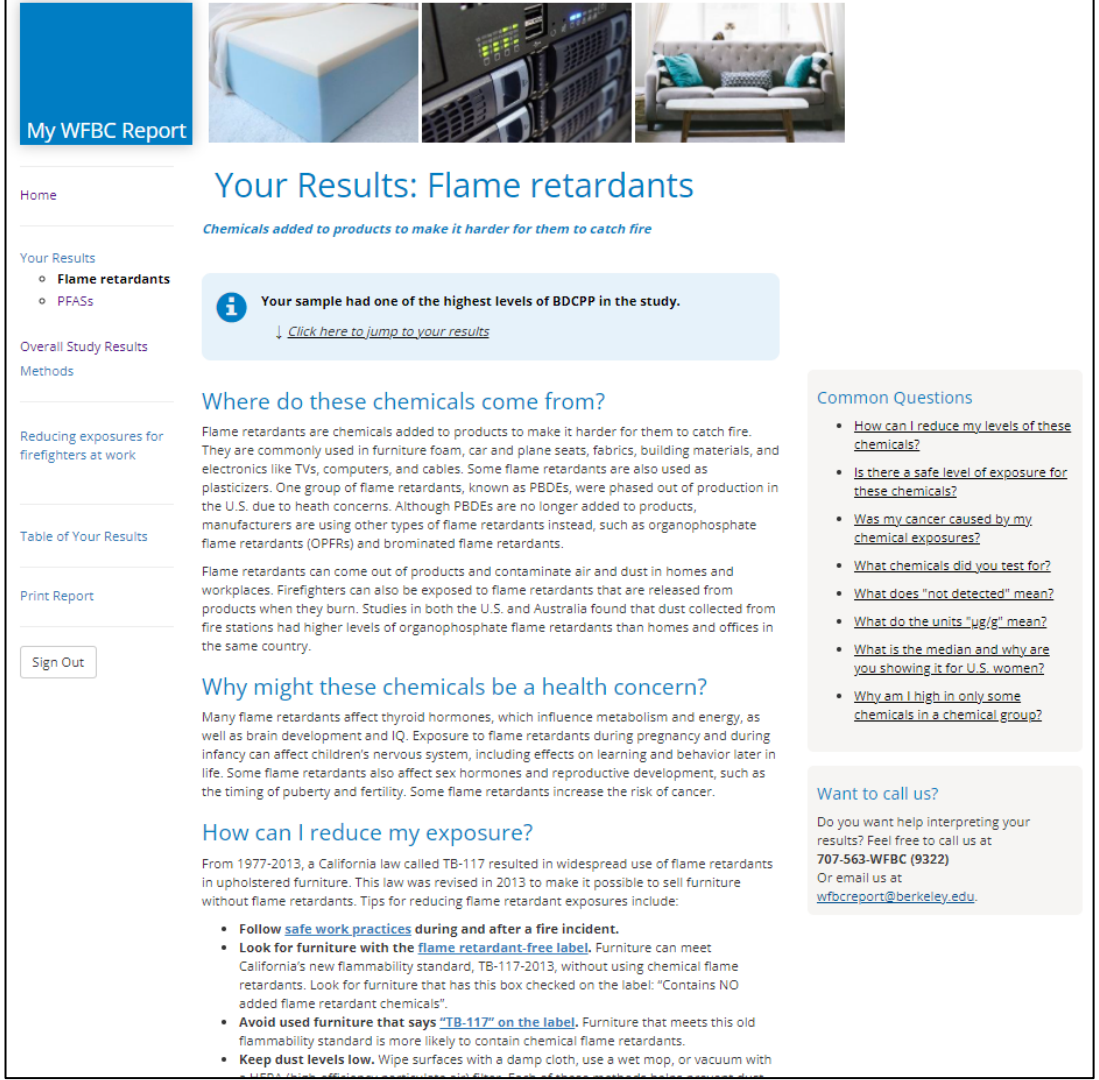
From: Detox Me Action Kit Study



“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



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

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."

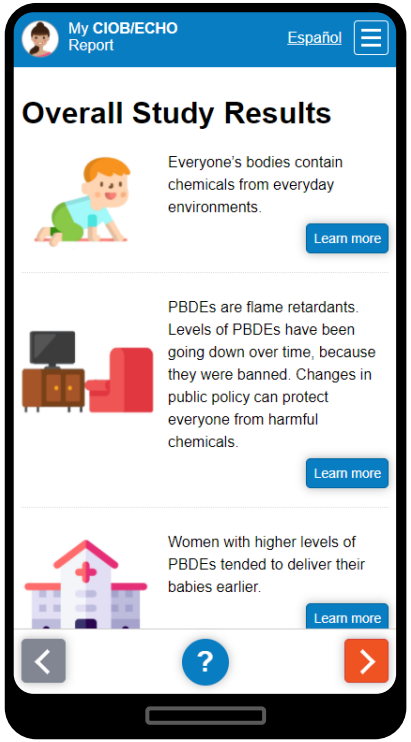
"So far, studies of people have found that higher levels of PFAS are linked to:

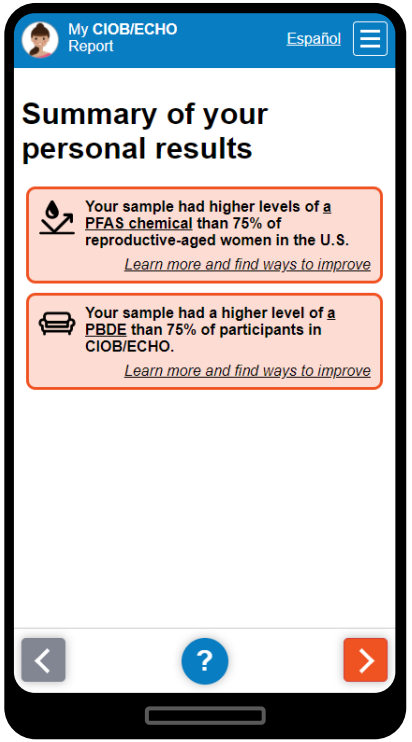
- Increased cholesterol levels
- Decreased vaccine response in children …

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





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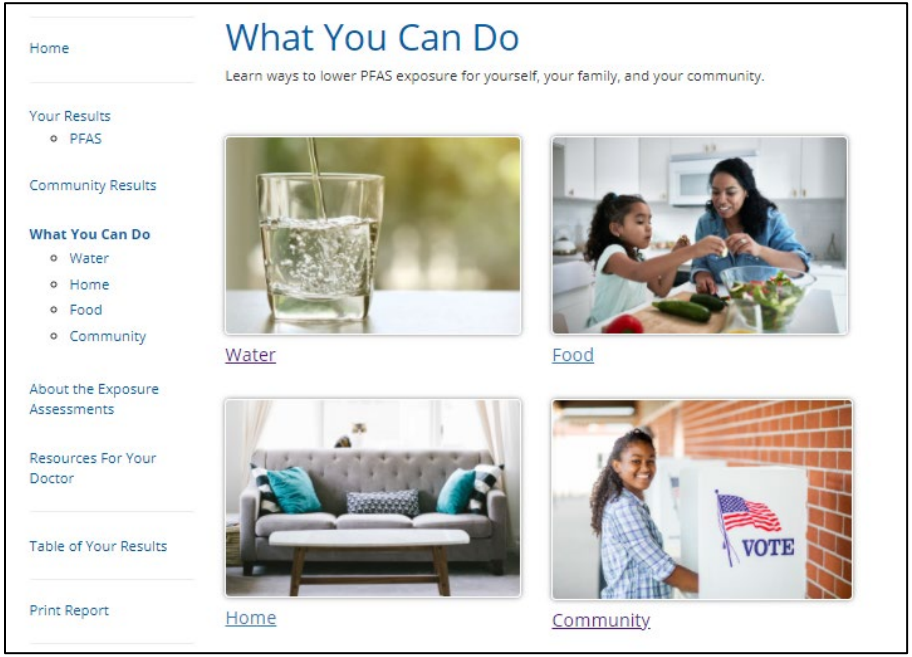
People value information to reduce exposure and protect health

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



Study participant views on collective action

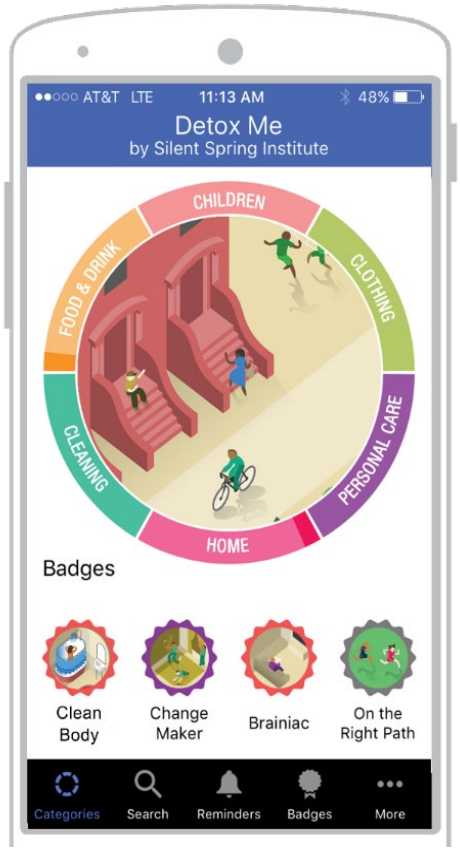
- Focus groups of peripartum moms:
  - Motivated to act despite time burdens
  - Asked for action tips to be time-conscious
  - Built new ideas on their other experiences of civic participation
  - Expressed willingness to share knowledge with their network
  - Were wary of advocating exposure reduction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

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