

Right-to-Know, Right-to-Act

Why Report Back on Exposures in EH Studies?

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Why report back?

1. Justice – “right thing to do” – builds trust
2. Learning – for participants *and* researchers
3. Action – to promote health

“a lab of our own”



Brody et al., 2005 EHP

SilentSpring.org

Household Exposure Study



- 120 homes
- 89 EDCs
- Air, dust, urine

Rudel et al. 2003, ES&T

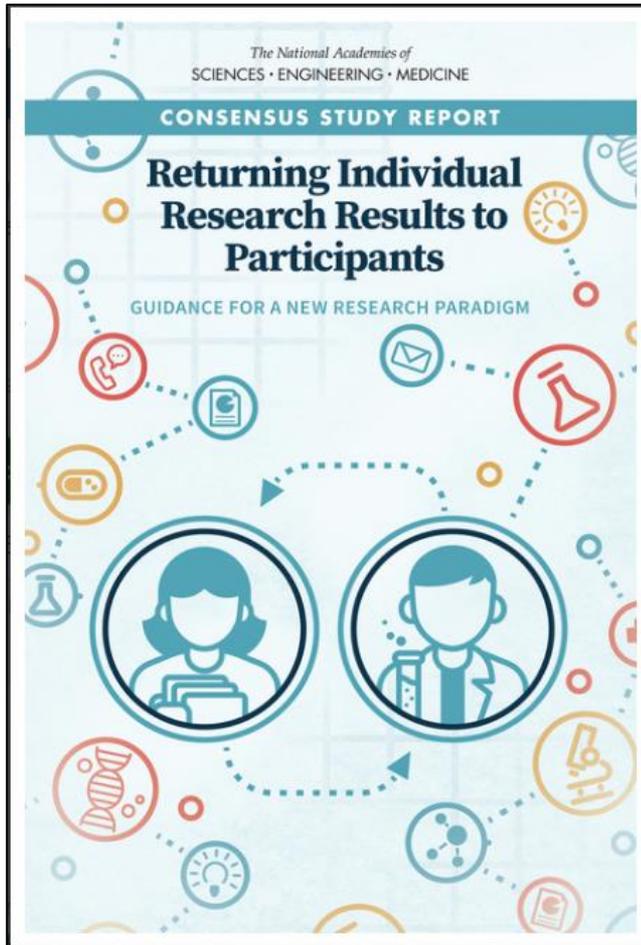
CBPR values

- Collaboration to address community issues, build capacity
- Mutual respect, open communication
- Knowledge is power
- Co-learning
- Co-ownership of data



Schulz et al. 1998 ARPH

NASEM consensus report



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

NASEM 2018

“Let me get this straight: You have found something, you do not know the cause or solution? Thank you for doing the right thing morally and ethically for sharing this information with us.”

Hernick et al., 2011, EHP

Personalized results are more than a number

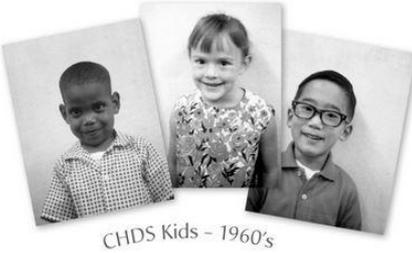


my chds report

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	Chemicals in the study	This website
About 50 years ago, over 15,000 families in the Kaiser Foundation Health Plan joined the Child Health and Development Studies	Your blood samples were tested for chemicals used in pesticides, flame retardants, old electrical equipment, and	This website includes the results for the environmental chemicals we measured in your blood sample. By clicking through the

Learning

- The “exposure experience”

a new embodied knowledge of invisible pollution



*Altman et al., 2008,
J Health & Social Behavior*

Conceptual shifts: Pollution is personal

- Chemicals of health concern are in people
- Many sources
- I'm high/low compared to others, benchmarks
- I can make changes, but ...
- Reflections on family illness, “toxic trespass”
- My data contributes to science that can help

For researchers

- Report-back creates opportunities to discover unknown exposure sources
- Builds trust, supports recruitment and retention
- By empowering people with knowledge, ... contributes to public health impact of research

Ohayon et al. 2017, Env. Research

Brainstorming about action

- “I appreciate learning about my chemical exposure so I can make improvements.”
- “I had no idea that house dust had environmental toxins, wow...I should really dust more often!”
- “I’m going to go out and buy my sister, who has young children, a new ceramic pan to cook.”

Action

People use their results

- Personal choices
- Medical settings
- Community decisions



Examples: *Brody 2009 AJPH; Emmett 2009, JOEM; Adams 2011, JHSB; Perovich 2018, AJPH*

Local and national campaigns



Tweets **4,234** Following **2,212** Followers **1,124** Likes **7,986**

Following

pfoaprojectny

@pfoaprojectny1 Follows you

Pics reflect my family's pfoa blood levels, and this page is a sharing of my never ending search for knowledge. Opinions are solely mine.

📍 Hoosick Falls, NY

📅 Joined June 2016

Tweet to

Message

👤 25 Followers you know



Tweets Tweets & replies Media

★ Pinned Tweet



pfoaprojectny @pfoaprojectny1 · Dec 5

An important educational documentary on #PFAS #PFOA every community should see, with a focus on small towns and how citizen advocacy is absolutely essential. Please share to spread awareness and inform the next town sadly to deal! @Badwater2018 @vpytko



Everything You Need to Know About PFAS
This video is about PFAS contamination in Hoosick Falls, NY; Merrimack, NH; and Oscoda and Rockford/Belmont, Mich.

youtube.com

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Rob Allen @RobAllenHF ×

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NY Water Project @nywat... ×

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Trends for you · Change



Joseph Allen

@j_g_allen

Follow

I'm 'BPA-Free' (and loaded with BPS).
Just like your kid's sippy cup?

#DetoxMeActionKit @SilentSpringIns 1/



6:18 AM - 9 Sep 2017

6 Retweets 16 Likes

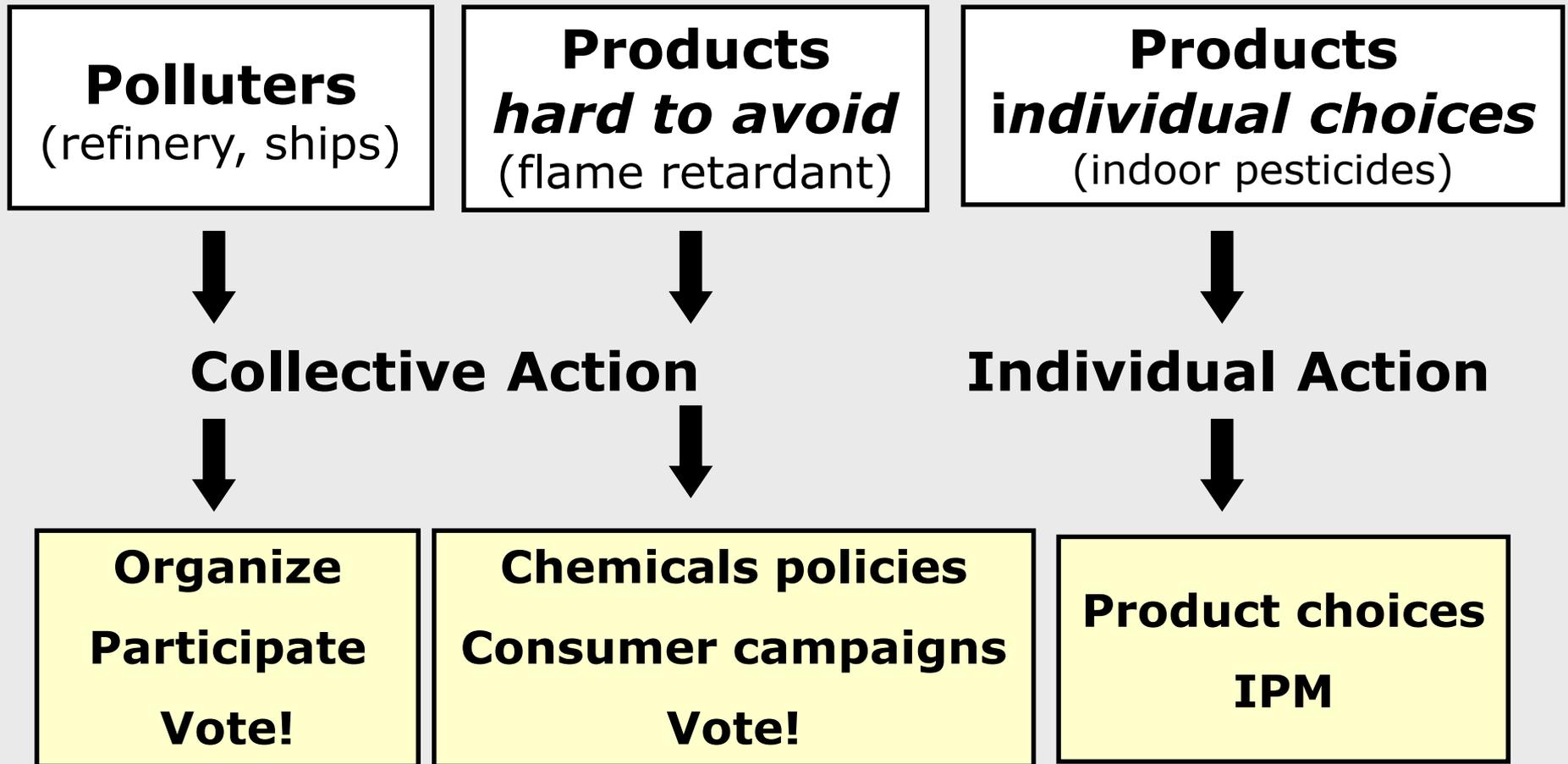


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Tweet your reply

Foundation for environmental health literacy



Brody et al. in Finn and O'Fallon, eds,
2018 Environmental Health Literacy

es/en

MyPROTECT Report



Welcome to MyPROTECT Report

- + View your MyPROTECT study results
- + Learn about the chemicals in the study
- + Reduce chemicals in your home and community

[Get started](#)

es/en

MyPROTECT Report

Choose your avatar

The face will represent you in the report!





Detox Me

BY SILENT SPRING INSTITUTE



Detox Me free smartphone app walks you through simple, *research-based tips on how to reduce harmful chemicals.*

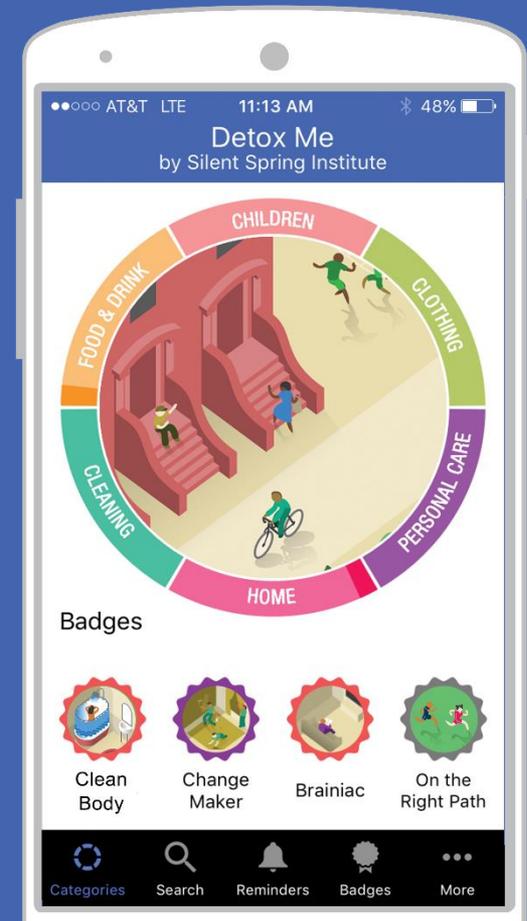


- **Track** your progress and get reminders.
- **Scan** product barcodes to find relevant tips.
- **Share** tips with friends, family.

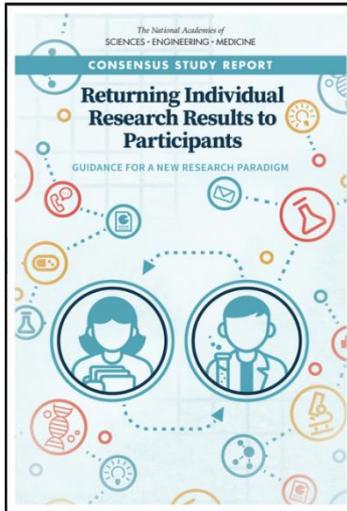


www.detoxmeapp.org

Also in Spanish!



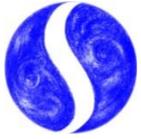
NASEM Take-Aways



NASEM 2018

- Potential harms are overstated and benefits under-appreciated
 - Benefits to participants extend beyond clinic and beyond actionable results
 - For researchers: a vital key to the trust that underlies participation
- Calls on NIH and academic institutions to create new supports
 - QA/QC standards outside of CLIA, communications expertise, \$\$
- Encourages researchers and IRBs to routinely report-back, starting *now*

Personal Exposure Report-Back Ethics (PERE) Study



- Silent Spring Institute - Julia Brody, Ruthann Rudel, Erik Haugsjaa, Katherine Boronow, Jennifer Ohayon

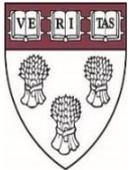


- Northeastern SSEHRI - Phil Brown

- UC Berkeley - Rachel Morello-Frosch



- Harvard Environmental Law & Policy Clinic - Wendy Jacobs, Shaun Goho



- Harvard Human Computer Interaction Group - Krzysztof Gajos, Ken Arnold



- Participating studies, including CDC Green Housing Study, Child Health and Development Studies, BCERP ELLA Study, Women Firefighters Biomonitoring Collaborative, PROTECT



Supported by NIEHS, NSF, CA Breast Cancer Research Program