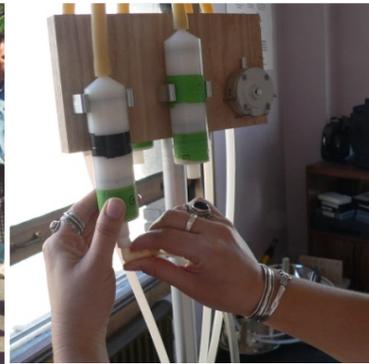




SILENT SPRING INSTITUTE



RESEARCHING THE ENVIRONMENT AND WOMEN'S HEALTH

Data Sharing Dilemmas in Personal Exposure Studies

The Silent Spring Institute Household Exposure Study

Julia G. Brody, PhD

February 2012

www.silentspring.org

Agenda

- Background: Household Exposure Study
- Online data: Privacy and consent issues
- Sharing individual data with participants
- Recommendations

Silent Spring Institute Household Exposure Study

Are **U.S. Homes**
a HAVEN for **TOXINS?**

KELLYN BETTS

The most comprehensive analysis to date shows that people are exposed to a wide variety of potentially toxic compounds in their homes.

ENVIRONMENTAL
Science & Technology

*Rudel et al.,
ES&T 2003*

Household Exposure Study

- 170 homes



Data

- > 100 analytes
- Indoor, outdoor air
- Dust
- Urine, some blood
- Observation, self-report
 - Weather
 - House characteristics
 - People and pets
 - Habits, hobbies, furnishings, belongings
 - Some health



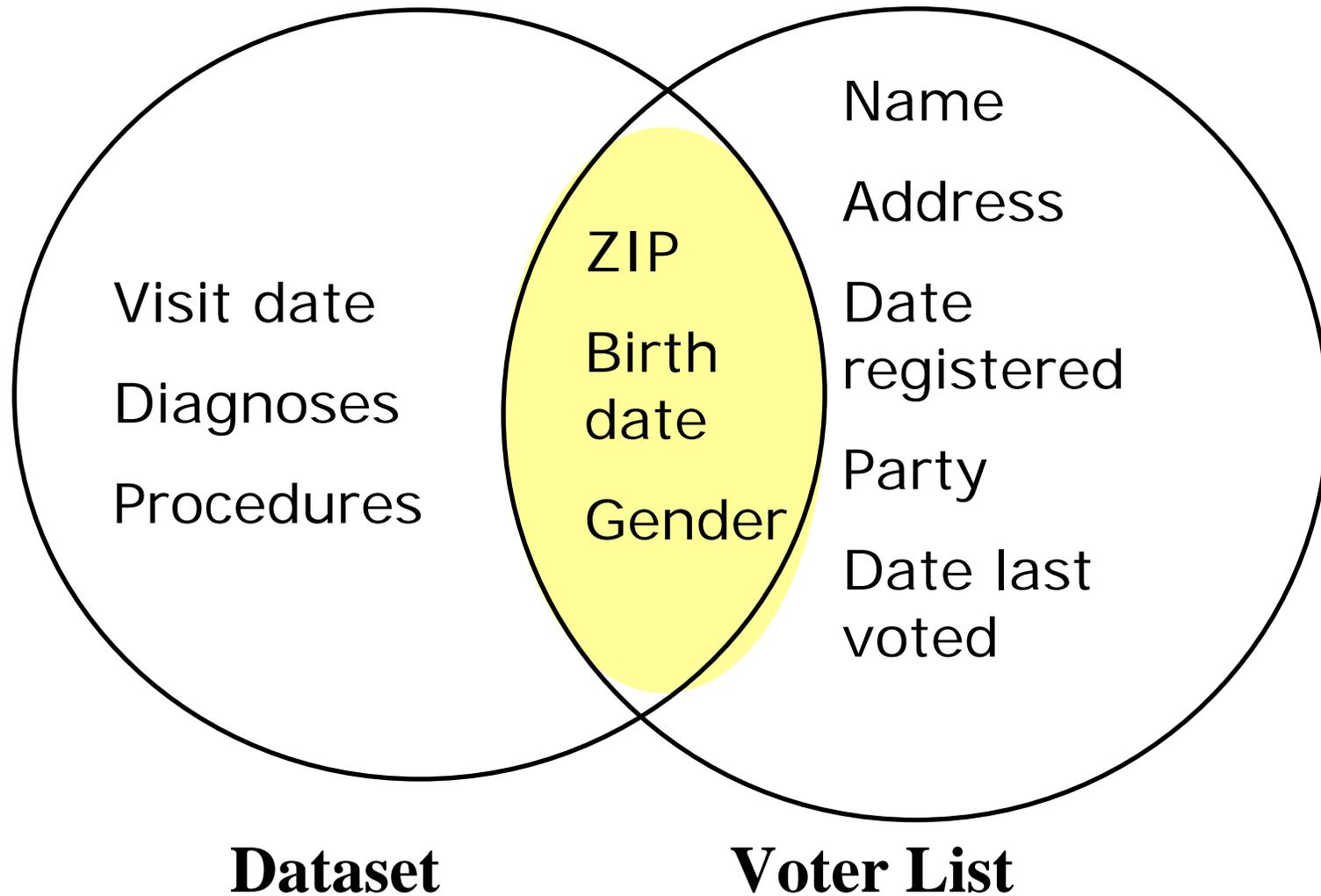
Community Values

- Right-to-know
- Science-power to solve ignored problems

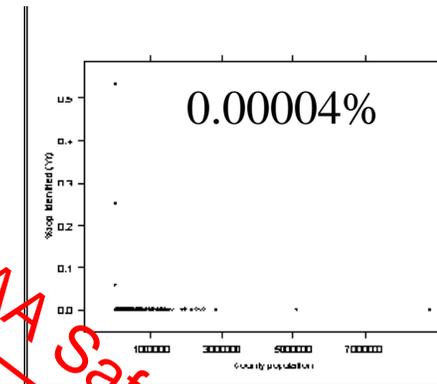
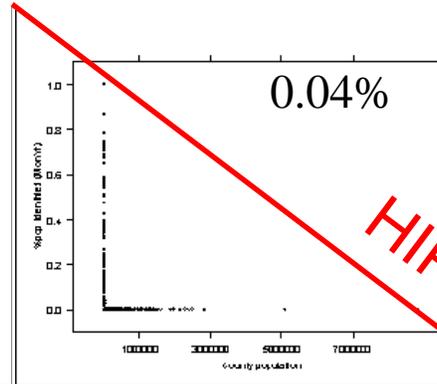
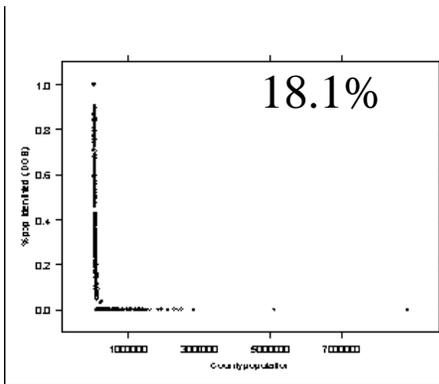


- **Privacy issues in online data sharing for environmental data**

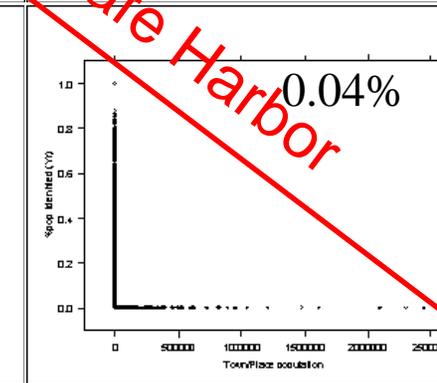
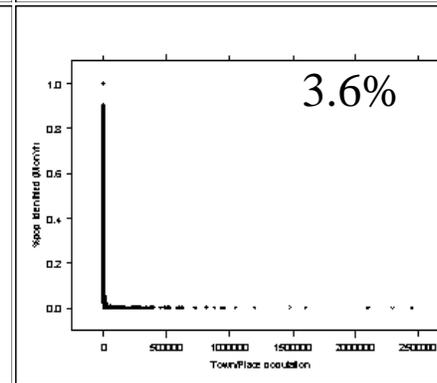
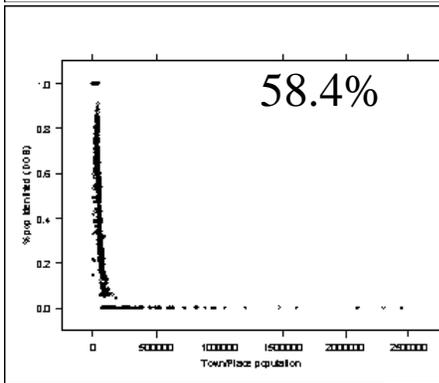
Privacy risks



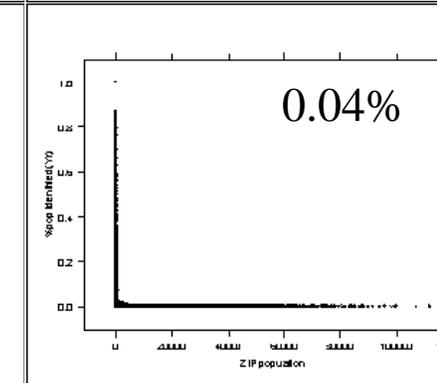
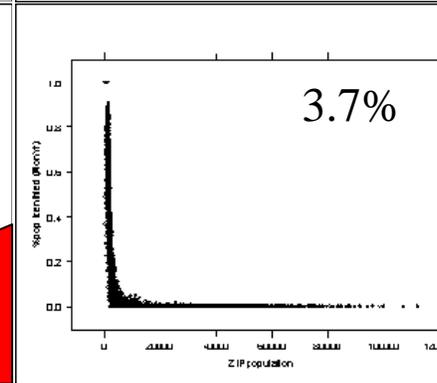
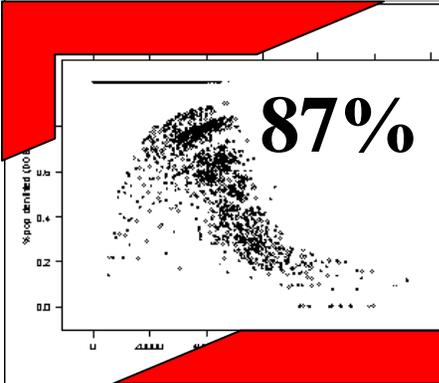
County



Town/
Place



ZIP
5-digit



Gender

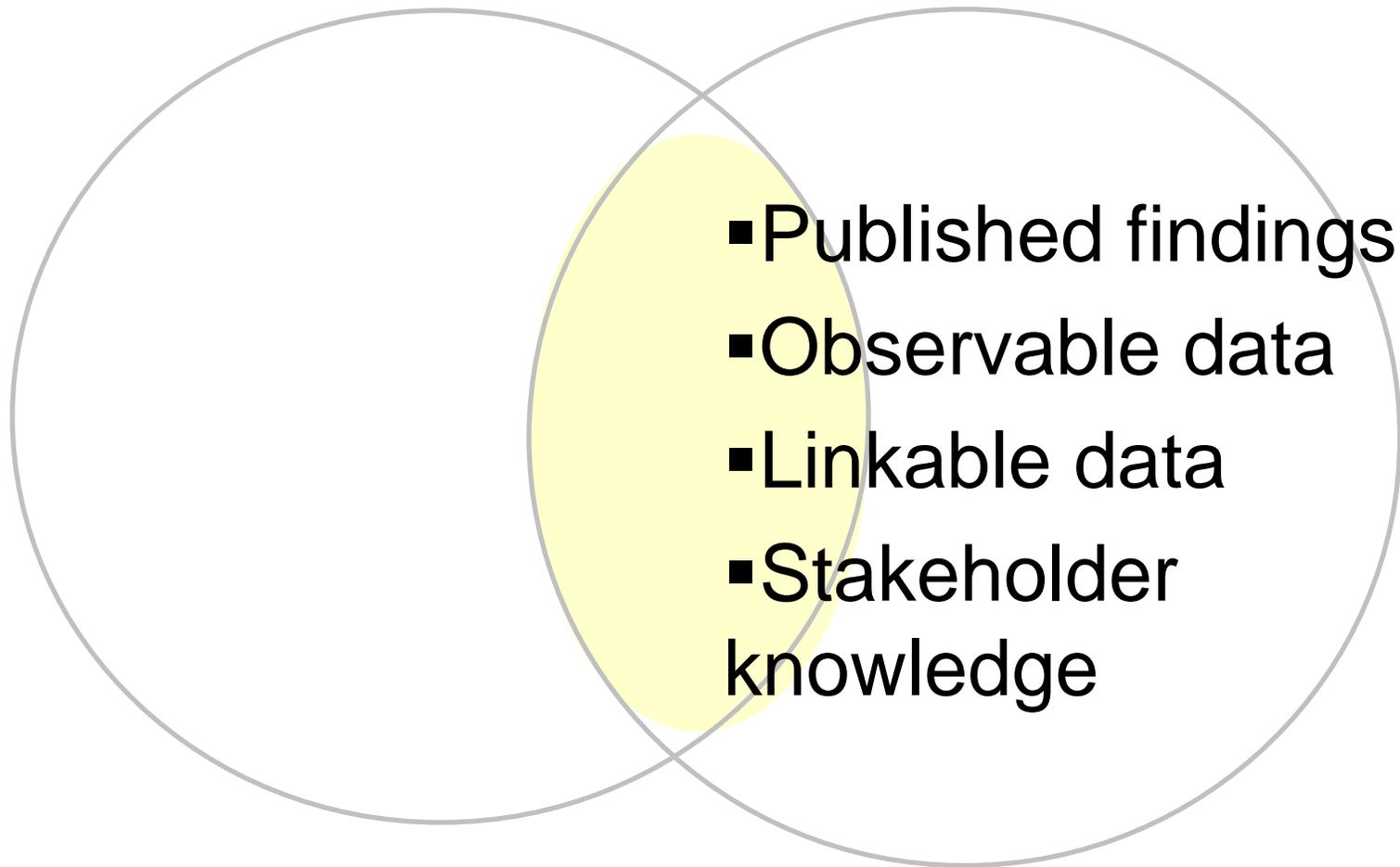
Date of Birth

Mon/Yr Birth

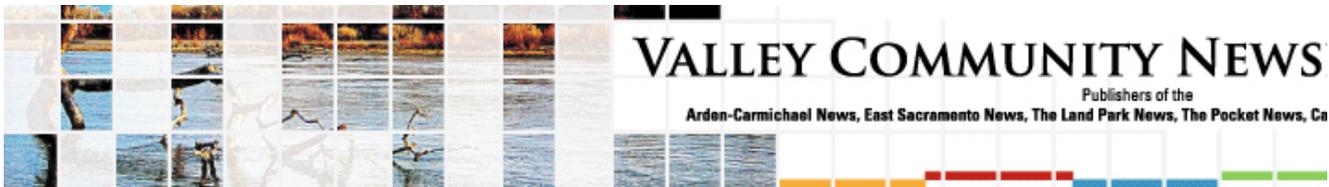
Year of Birth

HIPAA Safe Harbor

Sources of risks in enviro data?



Research Data



HOME ABOUT OUR PAPERS PLACE AN AD SUBSCRIPTION CALENDAR OF EVENTS MEET OUR STAFF CONTACT US

CDC to conduct national health survey in Sacramento County

Special to Valley Community Newspapers

Government workers will be ringing some doorbells in East Sacramento neighborhoods and throughout Sacramento County, but it won't be for the census. These surveyors will be recording data on America's physical health.



READY FOR THE NATION'S "CHECKUP." These portable units will be at Cal Expo in February and March to help collect data from Sacramento County residents about the nation's health. / Photo courtesy, Centers for Disease Control

The National Health and Nutrition Examination Survey (NHANES) is the most comprehensive survey of the health and nutritional status of the U.S. population.

Sacramento County is often chosen for marketing studies because it is a diverse community. The National Center for Health Statistics (a part of the Centers for Disease Control and Prevention) will conduct the surveys starting on Feb. 2 and running through April 1.

So, what is it?

For the last 50 years, the NHANES

DOWNLOAD OUR PAPERS

- ARDEN-CARMICHAEL NEWS
- EAST SACRAMENTO NEWS
- THE LAND PARK NEWS
- THE POCKET NEWS
- California
- THE VALLEY NEWS
- SPECIAL SECTIONS

VALCOMNEWS.COM ADVERTISING

A red square advertisement with the text "OUR LOCAL REALTORS" in white, bold, sans-serif font. Below this, in a smaller font, it says "VALLEY COMMUNITY NEWSPAPERS, INC.".

Humidity data is obtained from DHT11 sensor. Data manipulation is performed on the Arduino platform, and uploaded directly to Pachube.com via a Wiznet chipset based ethernet shield.

TAGS
[air quality](#) [arduino](#) [DHT11](#) [Dylos DC1100](#) [pm10](#) [pm2.5](#)

LOCATION NAME
The Peak, Hong Kong

LOCATION MAP

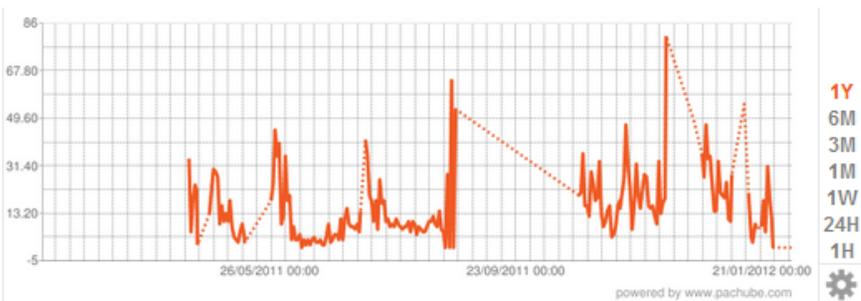

LATITUDE: **22.2707497532568** LONGITUDE: **114.149751663208** ELEVATION:

EXPOSURE: **Indoor** DISPOSITION: **Fixed** DOMAIN: **Physical**

EXPORT FORMATS
[JSON](#) [XML](#) [CSV](#)

CONTACT EMAIL:

DATASTREAMS
0 0 ug/m3



powered by www.pachube.com

FROZEN Updated on Wed, 25 Jan 2012 07:54:41 -0700 | Published by [ablusheep](#)

Indoor particle sensor

Feed from my Dylos DC1100 Pro, converted into approximate particle concentration (i.e. WHO standard microgram/m3) by applying correction factor.

The WHO recommended limits are:

PM2.5

- Short term (24 hour avg) = 25 ug/m3
- Long term (annual avg) = 10 ug/m3

PM10

- Short term (24 hour avg) = 50ug/m3
- Long term (annual avg) = 20 ug/m3

Correction factor is from "Air Quality Sensor Network for Philadelphia" by Arling, O'connor and Mercieca, Drexel University.

Humidity data is obtained from DHT11 sensor. Data manipulation is performed on the Arduino platform, and uploaded directly to Pachube.com via a Wiznet chipset based ethernet shield.

TAGS

[air quality](#) [arduino](#) [DHT11](#) [Dylos DC1100](#) [pm10](#) [pm2.5](#)

LOCATION NAME

The Peak, Hong Kong

Linkage in the world of ubiquitous computing

Exposure data: Potential harms

- Implications for health - insurability, employment
- Affect property values
- Reveal illegal behavior by a polluter
- Reveal personal behavior considered private (smoking, use of products restricted in the US)
- Trigger legal obligation or liability: reporting or remediation for a regulated substance; real estate disclosure
- Information pertinent to “toxic torts” or determination of responsible party status
- Create the link to other data in the dataset
- Reveal personal data of another party
- Reveal information about a place or group

Undefined terms in consent

- All **information that could identify you** will remain confidential to the **full extent of the law**.... Any record that includes your name or **personal identifying information** will be kept in locked file cabinets and access to these records will be restricted to researchers involved in this study.

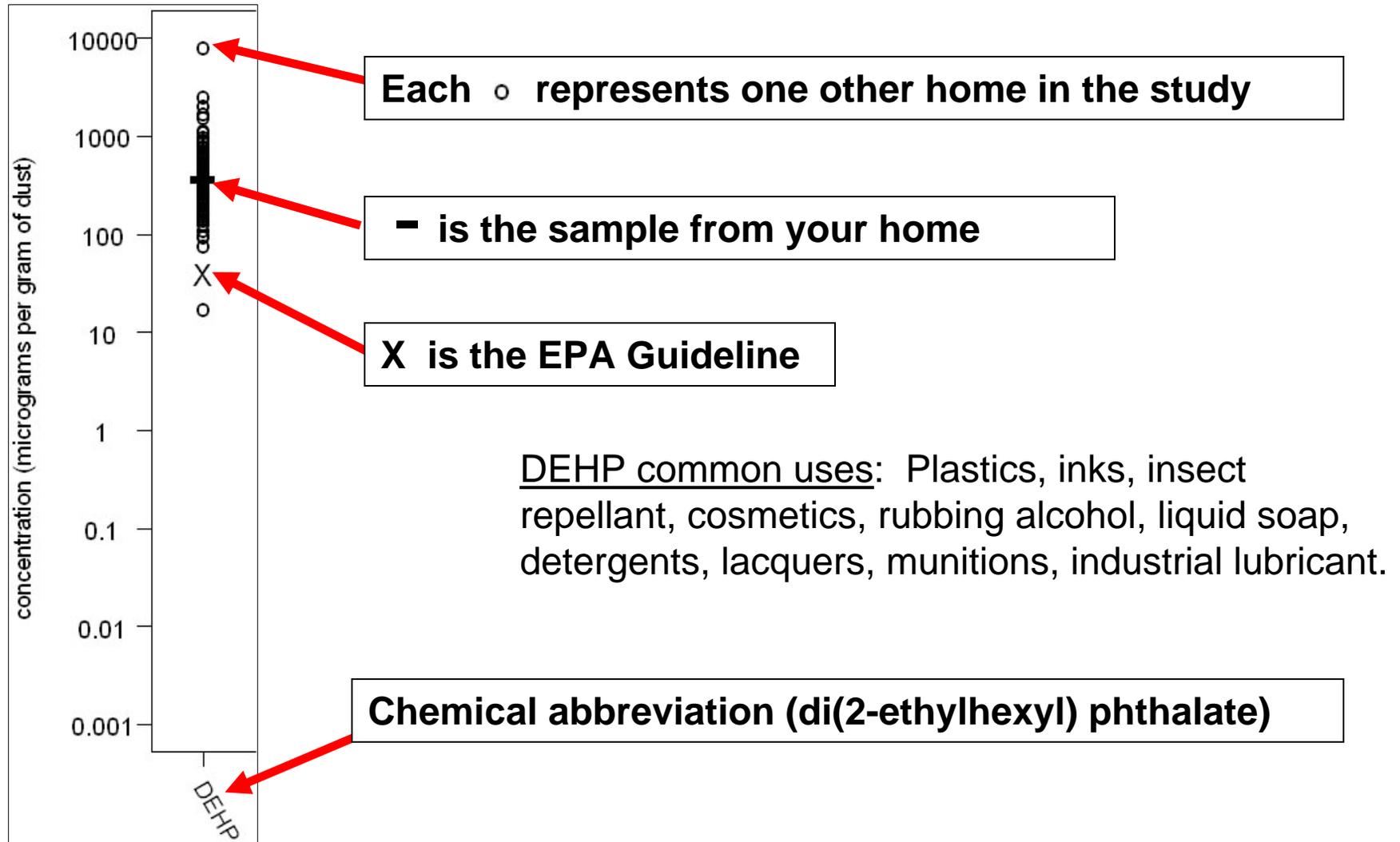
- **Sharing personal exposure data with study participants**

Individual report-back

- Multi-level
- Graphs and text
- What we know/don't know
- Actionable info: Community and individual exposure reduction



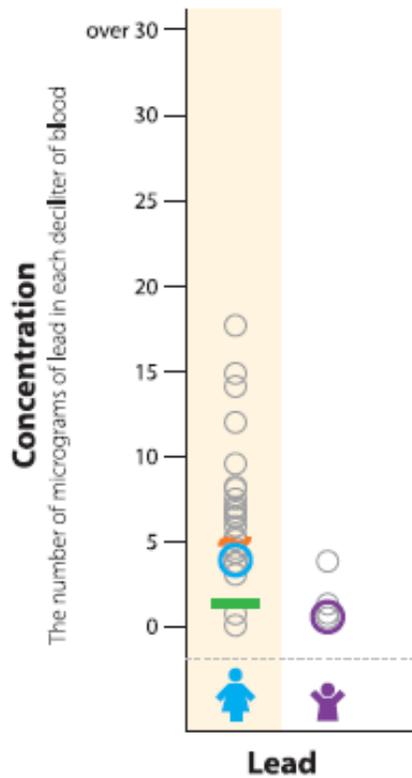
How to read your results



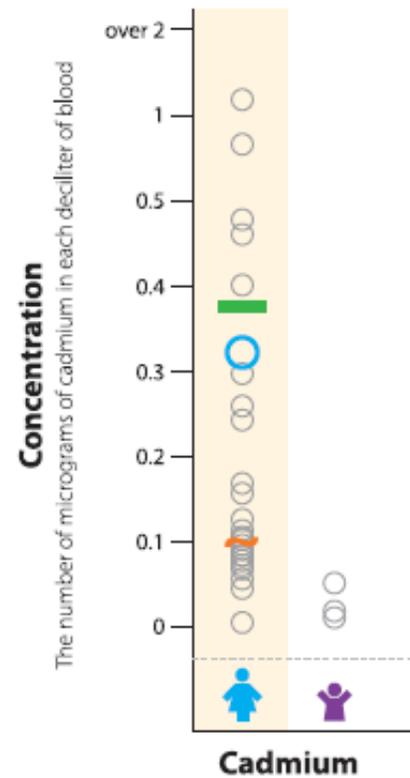
Part 1: Metals in Blood Results Chart

Participant number: 43

○ **Your level**  There is no blue circle if we did not find this chemical in your blood.
○ **Your baby's level**  There is no purple circle if we did not find this chemical in your baby's blood.
○ **Other people's levels** Each circle represents a person in the study.
█ **National average** The most common level in pregnant women.
~ **Level of health concern**



Your exact levels **3.85** **0.98**



Your exact level **0.326** **Not Found**

R. Morello-Frosch

Interviews with participants

- Participants wanted their results
- Increased trust in researchers
- Pride in contributing to science and health
- Learning, conceptual shifts about pollution
- Reflections on illnesses, “toxic trespass”
- Frustration at information gaps
- Evolving interpretations, brainstorming
- Motivation to reduce exposure
- Differences X community context

Recommendations: We Need...

- Technology solutions
 - Computer science tools to predict identifiability of environmental data
 - Tests of data-masking and auditing
- Guidelines
 - For truthful informed consent that is consistent with participant and community values and understanding
 - For data-user agreements
 - For individual report-back responsibilities
- New legal protections
 - To prevent forced disclosure, undue liability, discrimination
 - To discourage re-identification
- Training for IRBs, researchers



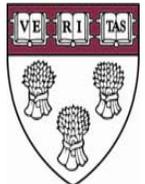
- [Silent Spring Institute](#)
Julia Brody, Laura Perovich, Ruthann Rudel



- [Harvard Data Privacy Lab](#)
Latanya Sweeney



- [Brown University](#)
Phil Brown



- [Harvard Environmental Law Clinic](#)
Shaun Goho



- [UC Berkeley](#)
Rachel Morello-Frosch



- [Communities for a Better Environment](#)
Jessica Tovar

A HEALTHIER FUTURE

View a brief introduction to Silent Spring Institute's research on the links between the environment and breast cancer, environmental health issues and the emerging field of green chemistry.

CLICK TO VIEW VIDEO



Silent Spring Institute researches the links between the environment and women's health, especially breast cancer.

Find us on Facebook

Explore our Science Review Database

MassHEIS: Massachusetts Health and Environment System

Today's Environmental Health News

DONATE NOW

FEATURED RESEARCH

Tests find new contaminants in Cape Cod's drinking water supply

President's Cancer Panel highlights everyday exposures to environmental pollutants and cancer

Oil refinery toxics found in air of nearby homes

Researchers call for better results reporting in breastmilk studies

Pollution from household and personal care products has been a blind spot for society, according to

MEDIA COVERAGE

Household Exposure Study highlighted by the NIEHS' Gwen Collman, The Environmental Factor

Director of Research, Ruthann Rudel, participates in review of soy infant formula, The Environmental Factor

Chemicals Found in Area Drinking Water, WCVB-TV

Silent Spring water tests reveal contamination, Cape Cod Times

NEW AT SILENT SPRING INSTITUTE

Massachusetts Environmental Trust funds Silent Spring Institute research by the sale of specialty license plates

Dinner honoree, Judi Hirshfield-Bartek, interviewed by The Boston Globe

Join the supporters of this year's Friends of Silent Spring Institute Dinner, May 6

DID YOU KNOW?

Of the 3,000 high-production

www.silentspring.org