What do we Owe Participants? Ethics and Practice of Environmental Health Data Report-Back

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Harvard Chan NIEHS Center
for Environmental Health
Science Communications Hub



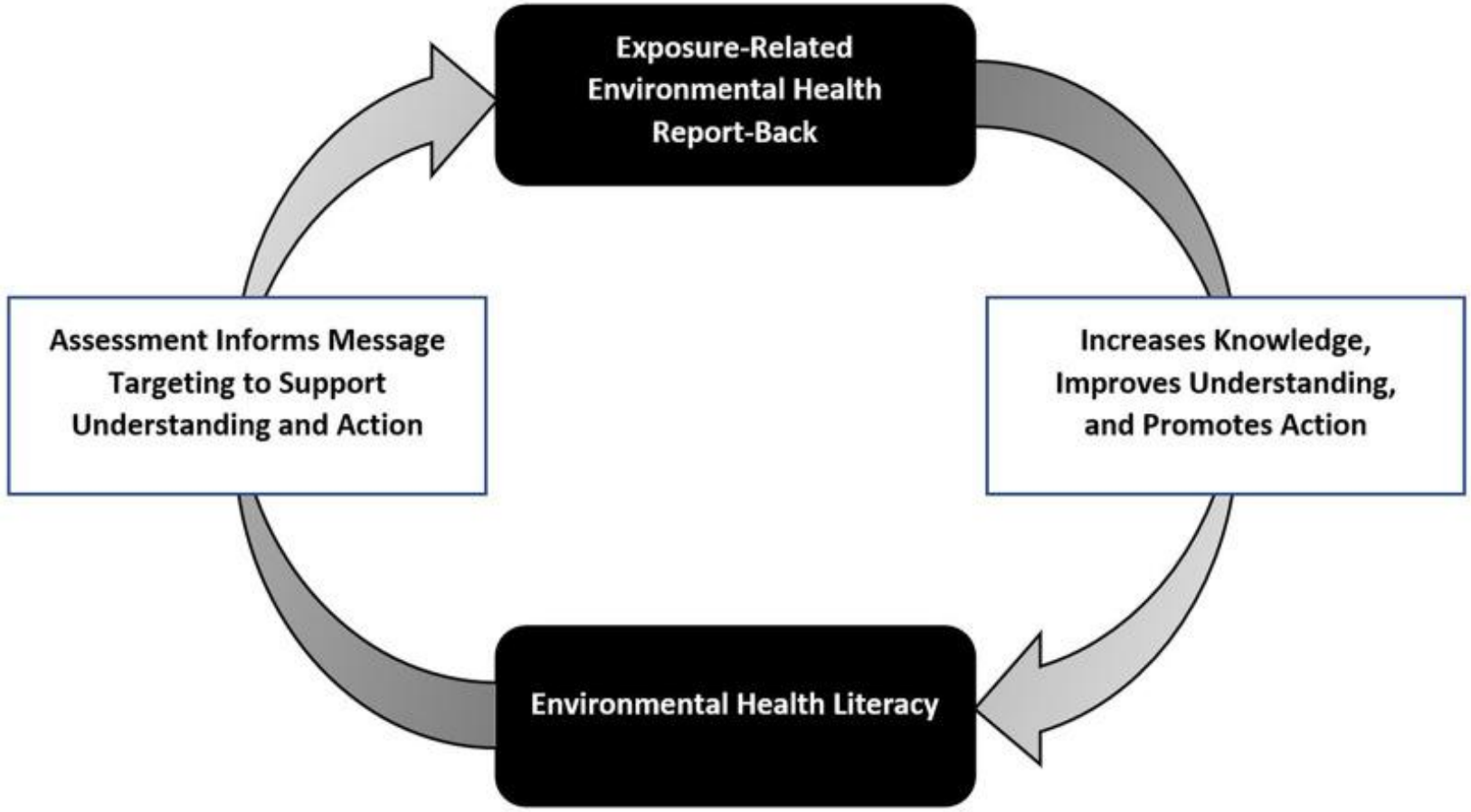
Today's Workshop Objectives

1. Describe key ethical arguments for returning environmental health results to study participants
2. Identify practical and ethical considerations that shape how results are returned, including uncertainty, data quality, potential barriers, and participant preferences

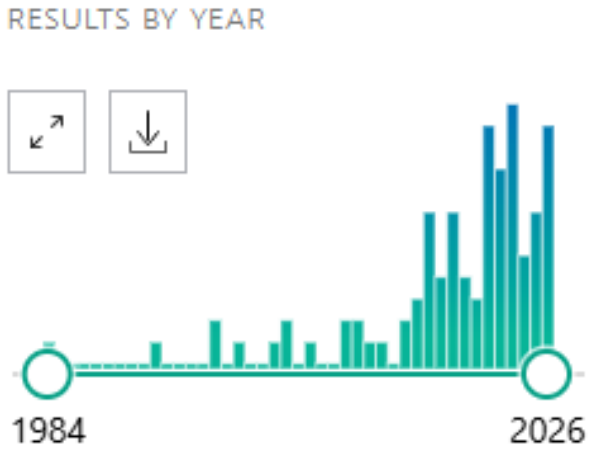
Outline

- Data report-back and environmental health literacy (EHL)
- Ethical concerns with report-back
- The Exposure Experience
- Biomonitoring frameworks
- The role of community context
- Activity

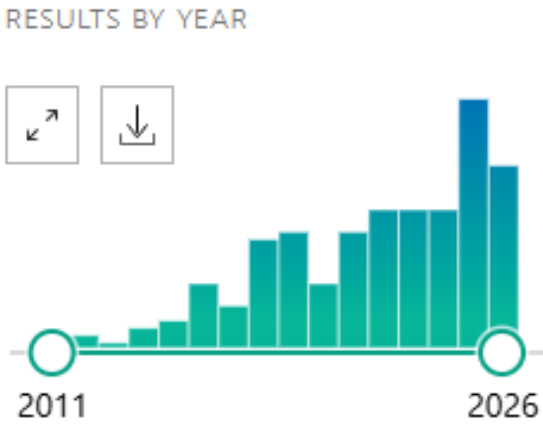
Data Report Back & EHL



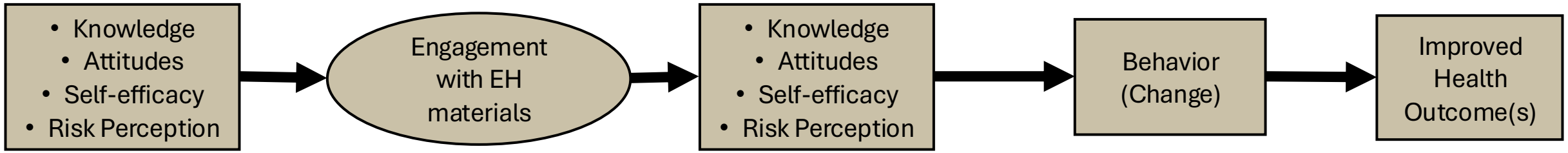
(Figure: Hoover, 2023)



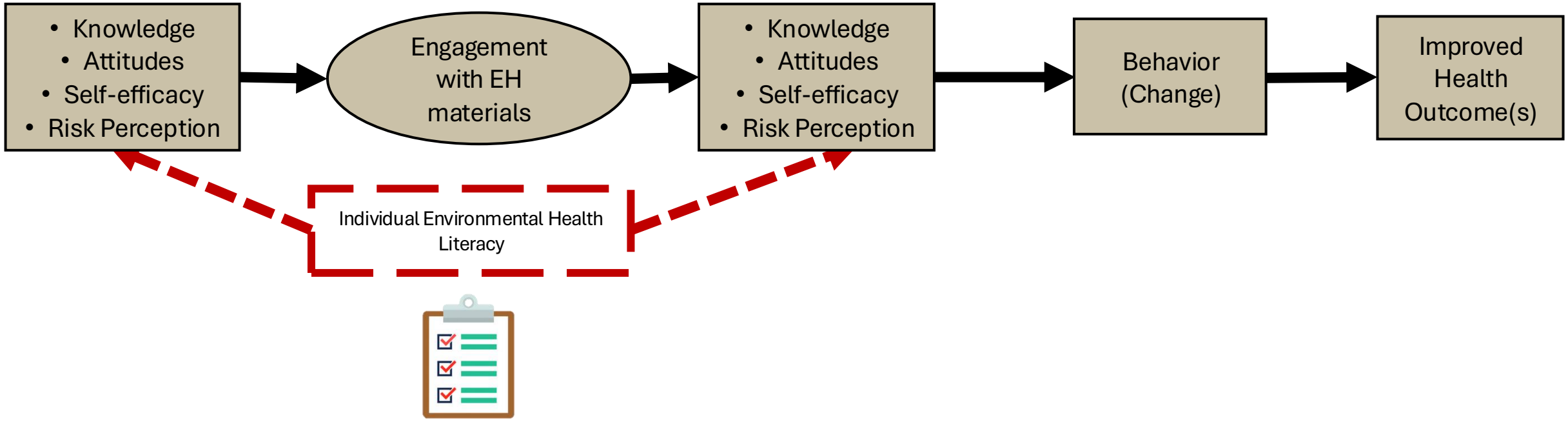
“report-back” AND “environment*”



“environmental health literacy”


• Knowledge
• Attitudes
• Self-efficacy
• Risk Perception
Engagement with EH materials
• Knowledge
• Attitudes
• Self-efficacy
• Risk Perception
Behavior (Change)
Improved Health Outcome(s)

“What is the Impact of our Message(s)?”



(Icons: Freepik, 2023)

What ethical concerns do you have about report-back of environmental health data?

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Cost-prohibitive solutions

Lack of health-based thresholds

Best approach for communication of results

Property value/real estate disclosures

Uncertainty in dose/response relationship

Exposure to mixtures

Undue distress

Burden on individual for systemic challenges

Timing of return

Lag in exposure and potential health effects

Limited capacity/agency for participants to reduce exposures

Limited/incomplete characterization of potential exposure

Resources to 'do it well'

Historical Precedent - IRB

- Institutional Review Boards (IRBs) discouraged return of research results to individuals (Botkin et al., 2018)
- Exceptions with unexpected findings with medical significance:
  - Duty to warn
  - Duty to rescue



Genomic Sequencing & Community Based Participatory Research

Genome Sequencing

- Whole-genome sequencing
- Framework 1: Research aims/results vs. incidental findings
  - "(*a*) research results on the genes and variants under study,
  - (*b*) **secondary findings** when there is a roster of additional genes and variants deliberately analyzed for potential communication to the research participant, and
  - (*c*) **incidental findings** that are beyond the research results and are not deliberately ascertained for potential communication" (Wolf & Green, 2023)
- Framework 2: Ancillary care
  - What have participants entrusted to researchers
  - Strength of researchers' responsibilities
  - Context: broad ask at consent to watch for health outcomes
  - Should/could/should not be reported (Beskow & Burke, 2011)

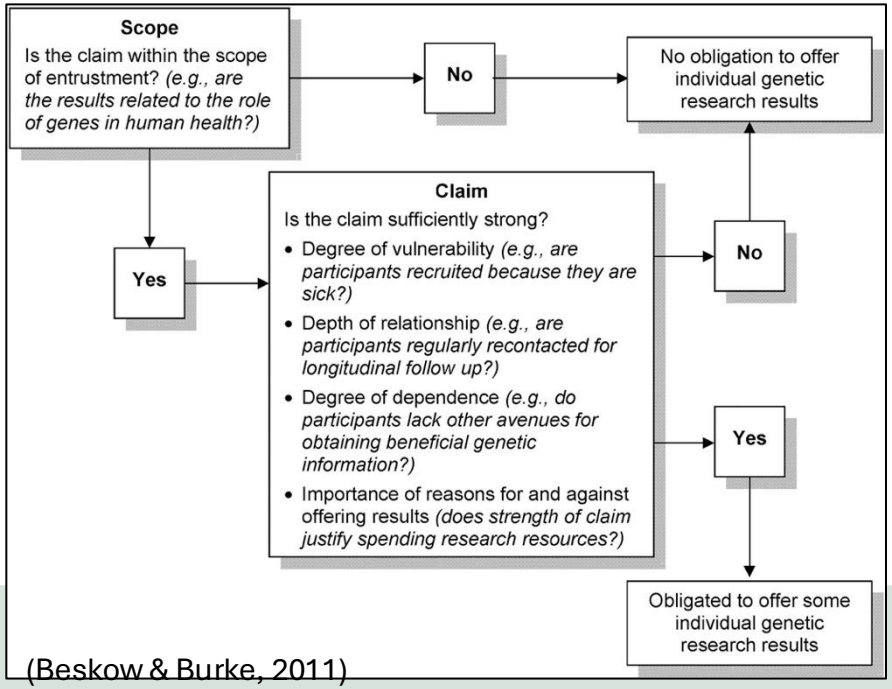
CBPR

- Co-ownership of data
- Co-learning
- Data democratization and knowledge sharing

Genomic Sequencing & Community Based Participatory Research

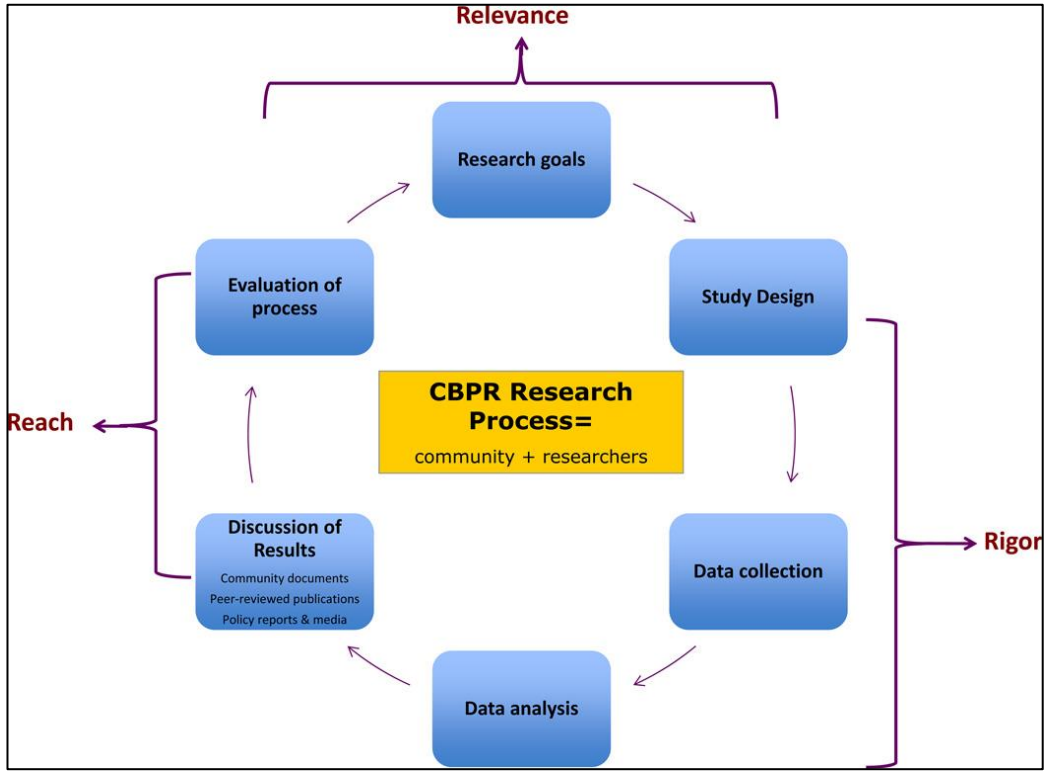
Genome Sequencing

MUST offer	May be obligated to offer depending on context	May CHOOSE to offer
• Duty to rescue – Results that clearly indicate a high probability of a serious condition for which an effective intervention is readily available	• See Figure 2	• By designing the study to assess participant understanding and use of genetic information • As an enticement to participate (with caution)



(Beskow & Burke, 2011)

CBPR



(Balazs & Morello-Frosch, 2013)

“The Exposure Experience”

▸ J Health Soc Behav. Author manuscript; available in PMC: 2009 Dec 1.

Published in final edited form as: J Health Soc Behav. 2008 Dec;49(4):417–435. doi: 10.1177/002214650804900404

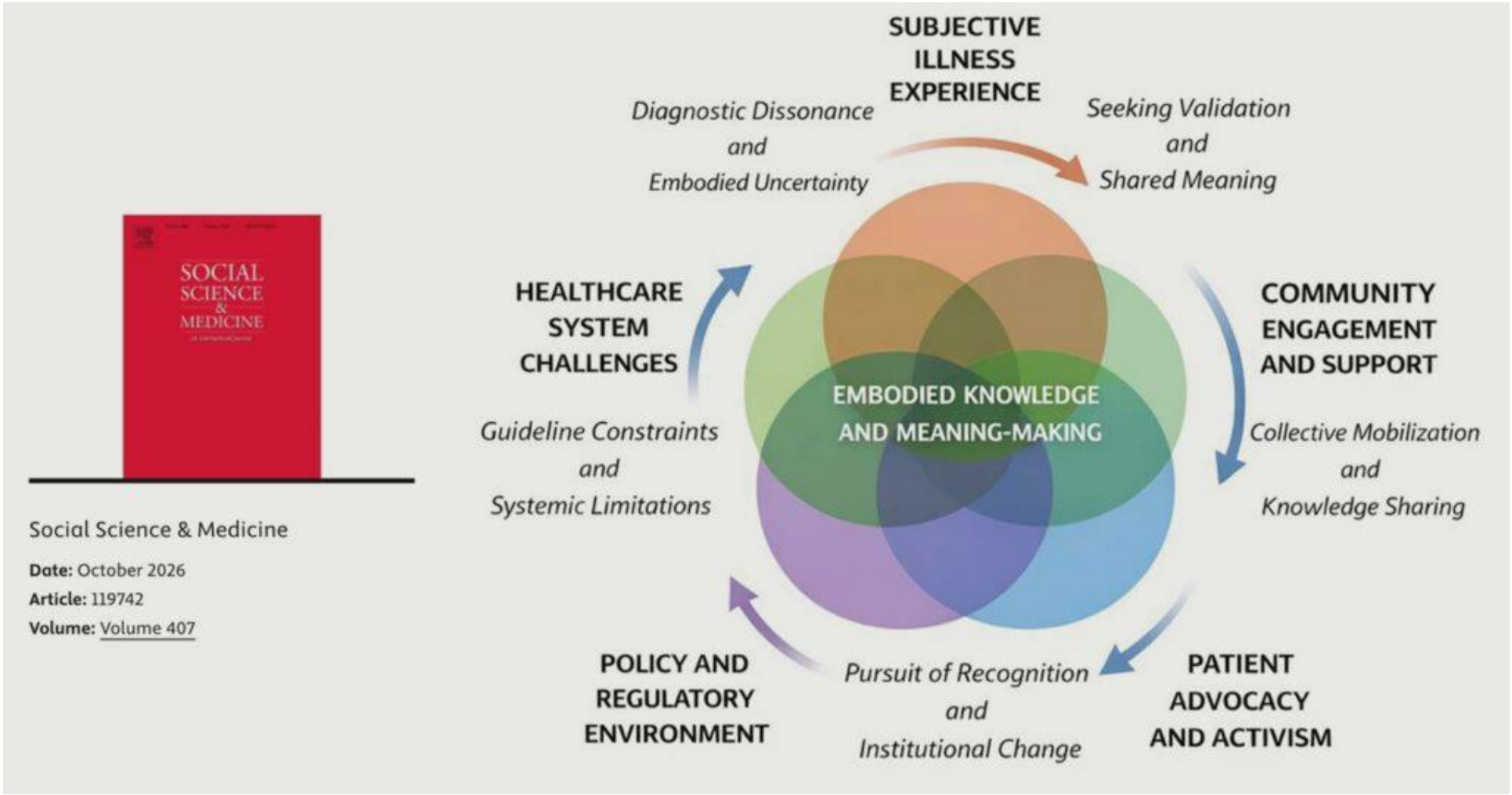
Pollution Comes Home and Gets Personal: Women's Experience of Household Chemical Exposure*

Rebecca Gasior Altman [1], Rachel Morello-Frosch [2], Julia Green Brody [3], Ruthann Rudel [4], Phil Brown [5], Mara Averick [6]

- 89 chemicals assessed in 120 homes, biological samples for potential associations with breast cancer via air, dust, urine samples
  - Electronics, carpets, cleaning products, personal care products, etc.
- Assessed ‘how people assign meaning to their results’
- Interviewed 25 participants within 6 months of receiving results

The Illness Experience

- Medical sociology
- How do people feel, make sense of, seek information related to illness, how is their experience embedded in context



(CanLyme, 2026)

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Participant Responses

1. Chemicals can be found both in the home and in human samples
2. Most homes have chemicals
3. Homes contain a wide variety of chemical compounds
4. Banned substances (e.g., DDT) are still detected
5. Multiple sources for chemicals found in biospecimens or household testing
6. Questions regarding lack of health-based guidelines for chemical exposures and/or product safety testing

Participant-Identified Information Gaps

1. Do these results indicate a problem?
2. What is ‘acceptable’ for exposure levels?
3. Where are the chemicals coming from?
4. What should I do?
5. What are the scientists’ assessment of my results?

“Every home also has corn flakes in the kitchen; but that doesn’t tell me anything”

Biomonitoring Technology Outpaces Communication Practices

Biomarkers of exposure

Biomarkers of effect

Biomarkers of susceptibility

(EPA, 2026)

Biomonitoring Technology Outpaces Communication Practices

Biomarkers of exposure

- Individuals' exposure to certain chemicals
- Individuals' exposures over time
- Variability across groups

Biomarkers of effect

Biomarkers of susceptibility

(EPA, 2026)

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- Indicate individual change in biologic function from an exposure
- More closely related to potential health impact vs. biomarker of exposure

Biomarkers of susceptibility

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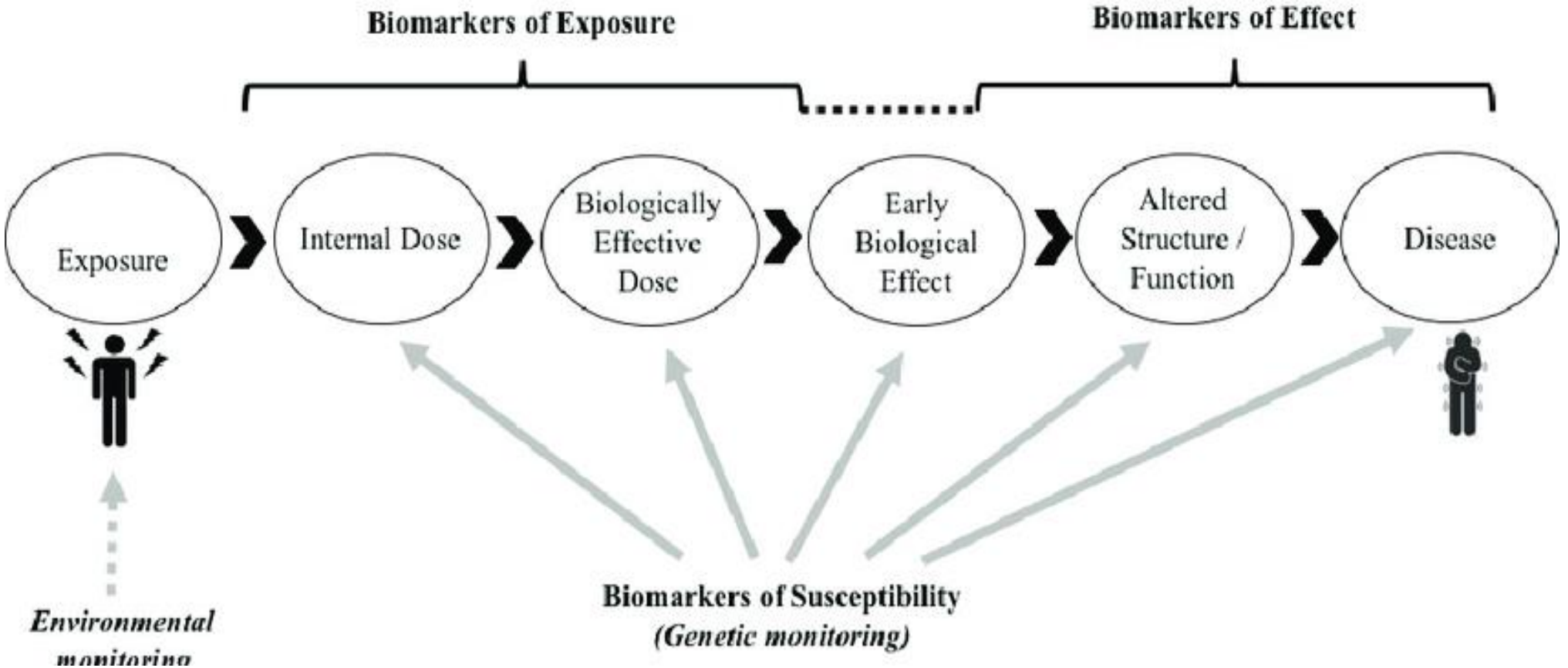
- Indicate individual change in biologic function from an exposure
- More closely related to potential health impact vs. biomarker of exposure

Biomarkers of susceptibility

- Factors that make individuals more sensitive/prone to impact from an exposure

(EPA, 2026)

Exposure Disease Continuum



(Emerce, 2019)

Biomonitoring Technology Outpaces Communication Practices



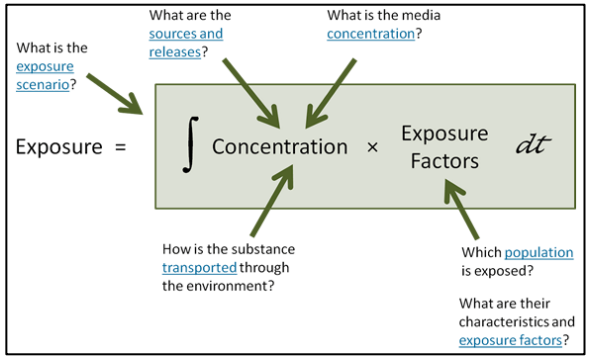


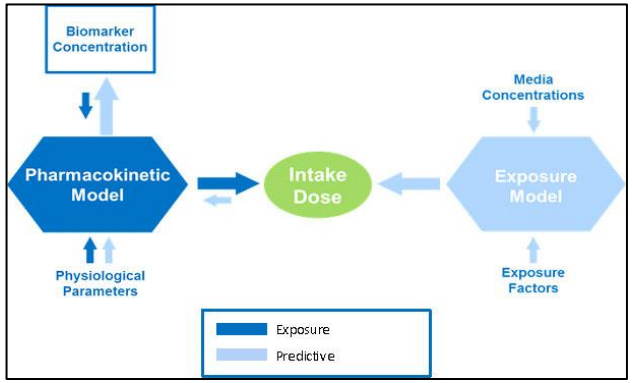
3 general approaches to Exposure assessment

1. Point of Contact Measurement
    1. Exposure measured at point of contact with human body
    - (+) measurement happens while the event happens – can measure concentration + timing of contact

2. Scenario Evaluation
    1. Exposure is estimated by separately considering exposure concentration and the timing of contact; information later integrated

3. Reconstruction
    1. Exposure estimated from dose after exposure has occurred
        1. Dose is reconstructed from internal indicators (excretion concentrations, body burden, biomarkers of exposure)



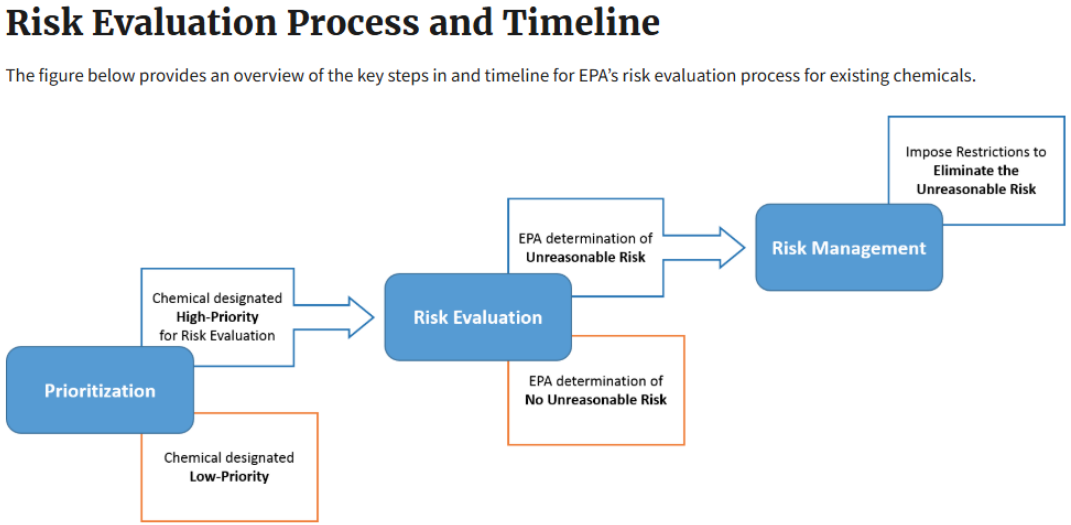


An Ethical Quandary

- Toxic Substances Control Act (TSCA)
  - 1976 “unreasonable risk of injury to health or the environment”
  - Manufacturers notify EPA before making or importing new chemicals in commerce
  - Exceptions:
    - Food and Drug Administration: foods, additives, drugs, cosmetics
    - Bureau of Alcohol, Tobacco, Firearms, and Explosives: Tobacco/tobacco products
    - Nuclear Regulatory Commission: radioactive materials

According to TSCA:

- ~86,000 chemicals registered for use in the United States
- ~42,000 chemicals actively used in United States commerce
- ~700 new chemicals added per year



- 38 chemical risk evaluations ongoing or completed
- ~3 years/evaluation

(EPA, 2026)

3 Frameworks for Communicating Biomonitoring Results

Environ Health. 2009 Feb 28;8:6. doi: 10.1186/1476-069X-8-6

Toxic ignorance and right-to-know in biomonitoring results communication: a survey of scientists and study participants

Rachel Morello-Frosch [1,✉], Julia Green Brody [2], Phil Brown [3,4], Rebecca Gasior Altman [4], Ruthann A Rudel [2], Carla Pérez [5]

- Explored what information on report-back existed for researchers and communities
- Reviewed reports, publications, guidelines
- Interviewed 26 individuals
  - Scientists engaging in report back
  - Community members involved in biomonitoring

"None of these chemicals come with a return address"

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Framework 1: Clinical Ethics

Orientation: biomedical
Right-to-know emphasis: weak
Communication strategy: individual results provided only if clinical relevance is understood
Protocol development: Participant confidentiality trumps other considerations, developed by medical experts, no communication or results sharing across participants

Central tension: uncertainty for many exposures and at low levels

"None of these chemicals come with a return address"

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Framework 2: Community-Based Participatory Research

Orientation: prevention
Right-to-know emphasis: strong, also affords participants right not-to-know
Communication strategy: participants informed of right to know at recruitment; aggregate and individual level results provided with explanation of scientific uncertainties
Protocol development: Joint with scientific and community members; participants allowed to share results in some instances

Central tension: attempt to address lay-expert dichotomy via dissemination can stigmatize "contaminated" communities

"None of these chemicals come with a return address"

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Framework 3: Citizen-Science Data Judo

Orientation: advocacy (advocacy biomonitoring)

Right-to-know emphasis: strong

Communication strategy: report-back aggregate and individual level results; supports precautionary individual action

Protocol development: developed by scientists, participants encouraged to share results and disseminate findings for broader public

Central tension: challenges to traditional IRB protocols related to confidentiality

"None of these chemicals come with a return address"

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Central Issues in Reporting Exposure Data

1) Providing background information to make individual results meaningful
2) Developing report-back protocols and contention among researchers regarding individual vs. aggregate communication of results
3) Factors affecting how results are reported
4) Addressing varying levels of literacy
5) IRB requirements, standards of confidentiality, and individual report-back

"None of these chemicals come with a return address"

Belmont Report Framing

Beneficence

- "Investigators have an obligation to promote and safeguard the well-being of research participants" (Botkin et al., 2018)
- Ethical practice of promoting good for participants
- Health of participants prioritized before research interests

Non-Malfeasance / "do no harm"

- Avoid causing harm to participants

Justice

- "there should be fairness in the distribution of the benefits and burdens of research" (Botkin et al., 2018)
- How can we more openly provide access to benefits of participating in research

Autonomy / Respect for Persons

- Participants should have the option to decide whether they want to receive back their results

Context and Process Matter

▸ J Health Soc Behav. Author manuscript; available in PMC: 2012 Jan 1.

Published in final edited form as: J Health Soc Behav. 2011;52(2):180–196. doi: 10.1177/0022146510395593

Disentangling the Exposure Experience: The Roles of Community Context and Report-back of Environmental Exposure Data

Crystal Adams [1], Phil Brown [1], Rachel Morello-Frosch [2], Julia Green Brody [3], Ruthann Rudel [3], Ami Zota [4], Sarah Dunagan [3], Jessica Tovar [5], Sharyle Patton [6]

'…use illness experience as an analog to ask, "How do people experience, understand and respond to a concrete physical presence of potentially harmful pollutants?" '

1. In the context of uncertain EH results, how does community context contribute to the exposure experience
2. How does report-back process impact the exposure experience?

- CBPR approach, involvement at every step
- Expertise of local knowledge contributes to exposure experience (rejected Information Deficit model)

2 Different Contexts

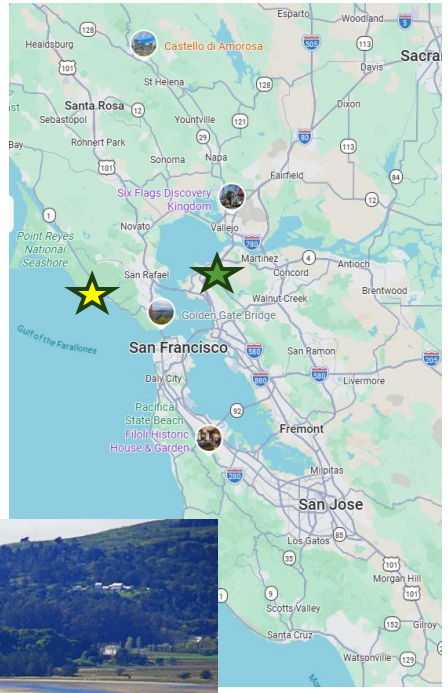
Richmond

- Chevron Richmond Oil Refinery
- Longstanding EJ challenges
  - 61% Latino, 18% African-American
  - 50% have incomes below 200% of the poverty line
  - High cancer and respiratory impacts from industrial air pollution

Bolinas

- 20 miles west of Richmond
- “Reclusive enclave…[with] a long history of environmentalism”
  - Commonweal (environmental organization)
- 91% White

2 Different Contexts



(Google, 2026)

Richmond ★



(Center for Land Use Interpretation, 2026)

Bolinas ★



(John Weiss, 2024)

Approach

- 2006: indoor and outdoor air and dust collected
- Documented household characteristics
- Interviewed participants on individual behaviors and expectations of the study
- Assessed samples for 150+ chemicals
  - Industry and transportation
  - Endocrine disrupting chemicals

Process

First Home Visit

- Informed consent
- Air and dust samples collected
- Participants interviewed about product use, household characteristics, study expectations, and experience with activism
- Participants offered option to receive individual sampling results

Results packets delivered (mail or hand-delivered)

Second Home Visit: Results Report-back

- Team member reviewed results packet and answered questions
- Exposure reduction information provided

Third Home Visit: Follow-up interviews

- Second informed consent
- Participants interviewed about report-back process and experience participating in the study

Chemical Findings

- Richmond had higher concentrations of industrial and transportation pollutants vs. Bolinas
- Vanadium and nickel concentrations highest in the state
  - Oil combustion and refining
  - Marine shipping
- $PM_{2.5}$ in Richmond homes were above California's ambient air quality standard
- Flame retardants (PBDEs) at very high levels in both Richmond and Bolinas
  - California furniture flammability standard

Community Context and the Exposure Experience

1. Expectations and Learning
   - Bolinas expected “clean bill of health”
   - Richmond anticipated pollution from nearby industry
   - Both surprised by indoor results

2. Trust is Affected by Community Context
   - Low trust with industry and government officials
   - High trust towards local environmental organizations
   - Bolinas more focused on chemical regulation
   - Richmond focused on regulation of industrial polluters

3. Action is Affected by Community Context
   - Broad interest in using results to get government officials to increase regulation of toxics
   - Interested in using results to foster community-level actions

Report Back and the Exposure Experience

- Participants felt they were contributing to science and a sense of ownership over the findings
- High levels of trust in the research team from time taken to communicate with participants
- Expectations of clear-cut answers on exposures were not met, led to shift in perspective on science and uncertainty

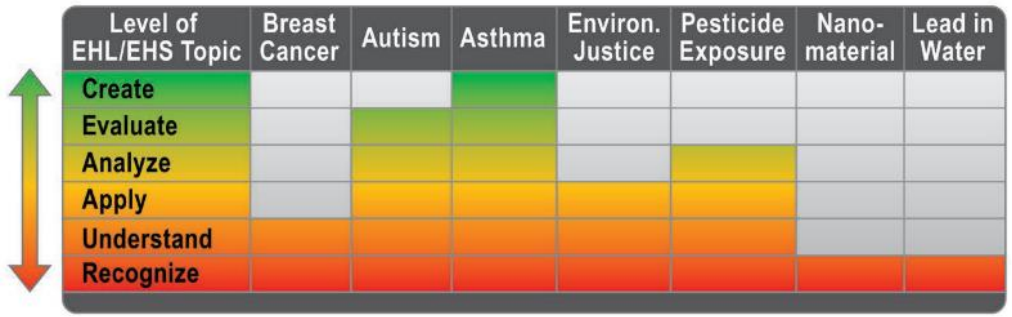


Figure 2. Conceptual model of environmental health literacy adapted from Bloom (1956), representing the potential for different levels of EHL across various environmental health science topics.

(Finn & O'Fallon, 2017)

Takeaways for EH Report-Back

- Preparation for communication starts well before data are collected
- We must work with participants/audience to tailor messages for them
- Uncertainty is not *necessarily* a reason to avoid report-back
- Support for results interpretation makes a difference

What ethical concerns do you have about report-back of environmental health data?

Cost-prohibitive solutions

Lack of health-based thresholds

Best approach for communication of results

Property value/real estate disclosures

Uncertainty in dose/response relationship

Exposure to mixtures

Undue distress

Burden on individual for systemic challenges

Timing of return

Lag in exposure and potential health effects

Limited capacity/agency for participants to reduce exposures

Limited/incomplete characterization of potential exposure

Resources to 'do it well'

Should we do report back?

2008	Pollution comes home and gets **personal women's experience** of household chemical exposure
2009	Toxic ignorance and right-to-know in biomonitoring results communication: a survey of scientists and study participants
2009	**Participant experiences** in a breastmilk biomonitoring study: a qualitative assessment
2010	Participatory testing and reporting in an environmental-justice community of Worcester, Massachusetts: a pilot project
2011	Disentangling **the Exposure Experience**: The Roles of Community Context and Report-Back of Environmental Exposure Data
2011	**Sharing unexpected biomarker results** with study participants
2016	The **legal implications** of report back in household exposure studies

How can we do report back well?

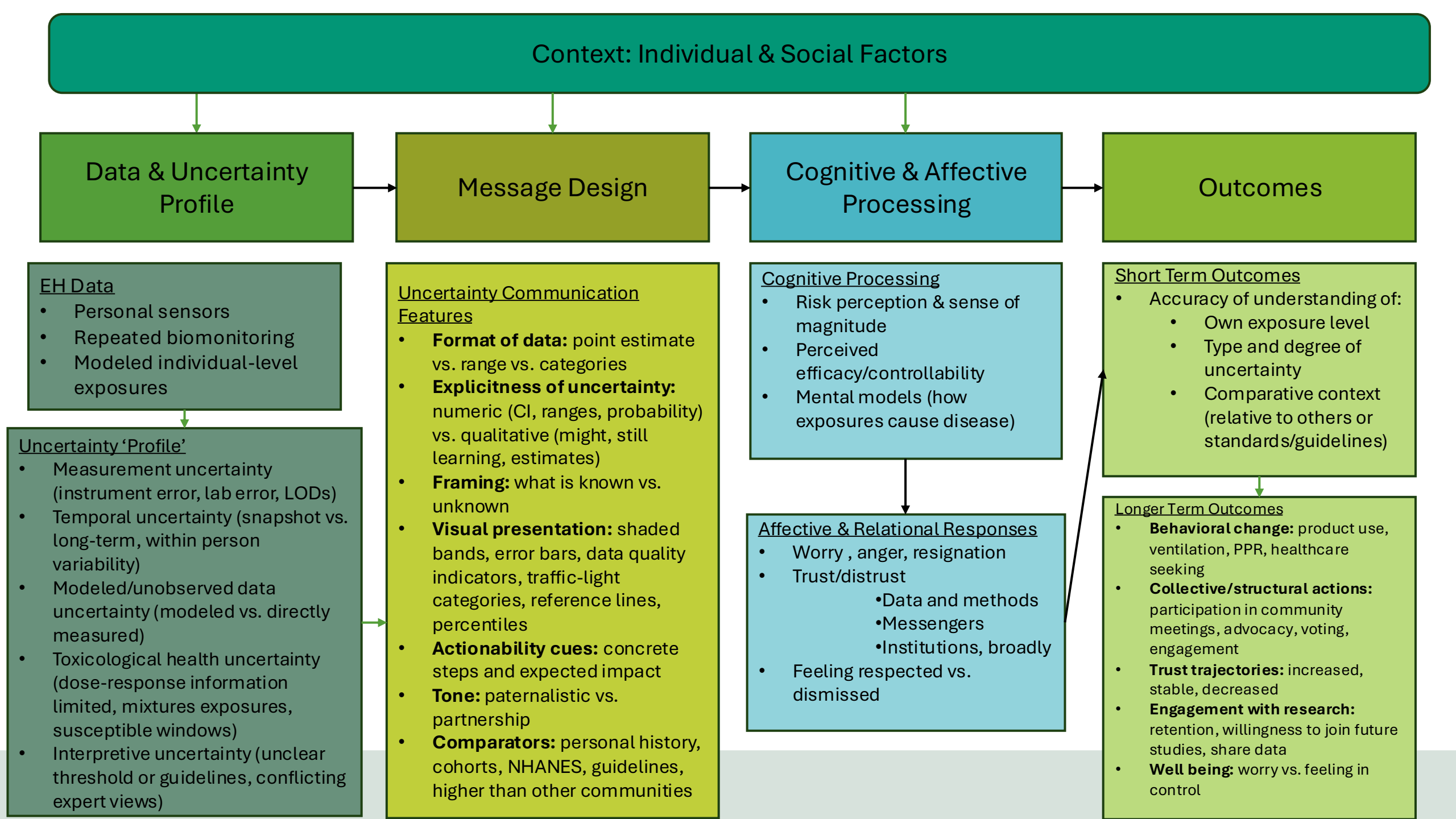
2016	Improving environmental health literacy and justice through environmental **exposure results communication**
2015	Community engagement **and data disclosure** in environmental health research
2017	**Making air pollution visible:** A tool for promoting environmental health literacy
2018	**Communicating environmental exposure results** and health information in a community-based participatory research study.(Report)
2018	**Community reporting** of ambient air polychlorinated biphenyl concentrations near a Superfund site
2018	**Reporting to parents on children's exposures** to asthma triggers in low-income and public housing, an interview-based case study of ethics, environmental literacy, individual action, and public health benefits
2016	Improving environmental health literacy and justice through environmental **exposure results communication**

Facets to Consider

- Respect participants' desires
  - Opt in/opt out
  - Include them in the development process to meet their communication goals

- Support your participants
  - Literacy/numeracy/graphicacy demands low
  - Provide support for Data Evaluability
  - Multiple opportunities for conversation of results

- Navigate the Exposure Experience
  - Provide space for feedback and feelings from results
  - 'Uncertainty profile'


Context: Individual & Social Factors
Data & Uncertainty Profile
Message Design
Cognitive & Affective Processing
Outcomes
EH Data
• Personal sensors
• Repeated biomonitoring
• Modeled individual-level exposures
Uncertainty 'Profile'
• Measurement uncertainty (instrument error, lab error, LODs)
• Temporal uncertainty (snapshot vs. long-term, within person variability)
• Modeled/unobserved data uncertainty (modeled vs. directly measured)
• Toxicological health uncertainty (dose-response information limited, mixtures exposures, susceptible windows)
• Interpretive uncertainty (unclear threshold or guidelines, conflicting expert views)
Uncertainty Communication Features
• Format of data: point estimate vs. range vs. categories
• Explicitness of uncertainty: numeric (CI, ranges, probability) vs. qualitative (might, still learning, estimates)
• Framing: what is known vs. unknown
• Visual presentation: shaded bands, error bars, data quality indicators, traffic-light categories, reference lines, percentiles
• Actionability cues: concrete steps and expected impact
• Tone: paternalistic vs. partnership
• Comparators: personal history, cohorts, NHANES, guidelines, higher than other communities
Cognitive Processing
• Risk perception & sense of magnitude
• Perceived efficacy/controllability
• Mental models (how exposures cause disease)
Affective & Relational Responses
• Worry , anger, resignation
• Trust/distrust
•Data and methods
•Messengers
•Institutions, broadly
• Feeling respected vs. dismissed
Short Term Outcomes
• Accuracy of understanding of:
• Own exposure level
• Type and degree of uncertainty
• Comparative context (relative to others or standards/guidelines)
Longer Term Outcomes
• Behavioral change: product use, ventilation, PPR, healthcare seeking
• Collective/structural actions: participation in community meetings, advocacy, voting, engagement
• Trust trajectories: increased, stable, decreased
• Engagement with research: retention, willingness to join future studies, share data
• Well being: worry vs. feeling in control

Activity: “Could we report this back?”

- From a research project you are working on or did work on, identify **one specific result** that could potentially be shared with participants (individual, household, community, study-wide)
  - What result would we report, and how?
  - How might participants benefit from receiving the information?
  - What is our biggest concern or hesitancy about reporting it?
  - What is uncertain about what we are reporting?