

Supplementary Information for:

Perceived Risks, Benefits and Interest in Participating in Environmental Health Studies that Share Personal Exposure Data: A U.S. Survey of Prospective Participants

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Section 1: Hypothetical Scenarios and Data Sharing Types

| Scenarios | |
|-----------|--|
| 1A | <p>Women Needed for the Smallville Breast Cancer Study!</p> <p>As a resident of Smallville, Indiana, you may have heard the recent news reports about breast cancer in your community. Researchers are recruiting women from Smallville and the neighboring town of Woodbridge for a study of the possible causes of the high rate of breast cancer in your town over the past several years.</p> <p><i>What is the study about?</i> The study will investigate differences in the levels of chemicals such as pesticides, chemicals in cleaning products, and industrial chemicals. The levels in homes and in people in Smallville will be compared to the levels in Woodbridge.</p> <p><i>What is involved?</i> If you agree to participate in the study, the research team will call to arrange a one-time visit to your home. At the visit, the researchers will conduct a survey including questions about your personal information and background, your job, your health history and your family's health history. The study team will ask for your permission to access the Smallville Health Information Exchange to get data from your electronic medical record to track changes in your health going forward. All of the health care providers in Smallville currently participate in the Health Exchange. The research team will collect environmental samples (dust and water) from your home, and you will be asked to provide a urine sample for chemical testing.</p> <p><i>Will I get results?</i> You will have the opportunity to receive your chemical testing results and the results for your home.</p> <p><i>Who is conducting the study?</i> Researchers at the National Environmental Health Center, a government agency, are conducting this study.</p> |
| 1B | <p>Women Needed for the Smallville Breast Cancer Study!</p> <p>As a resident of Smallville, Indiana, you may have heard the recent news reports about breast cancer in your community. Researchers are recruiting women from Smallville and the neighboring town of Woodbridge for a study of the possible causes of the high rate of breast cancer in your town over the past several years.</p> <p><i>What is the study about?</i> The study will investigate differences in the levels of chemicals such as pesticides, chemicals in cleaning products, and industrial chemicals. The levels in homes and in people in Smallville will be compared to the levels in Woodbridge.</p> <p><i>What is involved?</i> If you agree to participate in the study, the research team will call to arrange a one-time visit to your home. At the visit, the researchers will conduct a survey including questions about your personal information and background, your job, your health history and your family's health history. We will contact you by phone every two years to get updated information about your health. The research team will collect environmental samples (dust and water) from your home, and you will be asked to provide a urine sample for chemical testing.</p> <p><i>Will I get results?</i> You will have the opportunity to receive your chemical testing results and the results for your home.</p> <p><i>Who is conducting the study?</i> Researchers at the National Environmental Health Center, a government agency, are conducting this study.</p> |
| 1C | <p>Women Needed for the Smallville Water Study!</p> <p>As a resident of Smallville, Indiana, you may have heard about the recent discovery of unsafe chemicals at the city water treatment plant. Before the contamination was detected, residents connected to the city water supply were exposed to chemicals in their tap water.</p> <p><i>What is the study about?</i> The purpose of the study is to measure current levels of chemicals in homes and to investigate possible health effects from exposure to the contaminated water.</p> <p><i>What is involved?</i> If you sign up for the Smallville Water Study, the research team will call to arrange a one-time visit to your home. At the study visit, the researchers will conduct a survey, which will include questions about your personal information and background, your job, your health history and your family's health history. The study team will ask permission to access the Smallville Health Information Exchange to get data from your electronic medical record to track changes in your health going forward. All of the health care providers in Smallville currently participate in this Exchange. The research team will also collect environmental samples (dust and water) from your home, and ask you to provide a urine sample for chemical testing.</p> <p><i>Will I get results?</i> You will have the opportunity to receive your chemical testing results and the results for your home.</p> <p><i>Who is conducting the study?</i> Researchers at the National Environmental Health Center, a government agency, are conducting this study.</p> |

| | |
|-----------|--|
| 2A | <p>Help researchers learn about kids' exposure to pollution!</p> <p>Kids aged five to 13 years old are being recruited from across the US for a study to learn about the levels of everyday chemicals in our children's bodies, with a focus on hormone disruptors.</p> <p><i>What is the study about?</i> The purpose of this study is to learn about kids' everyday exposures to certain types of pollution. There are many kinds of chemical pollutants. Hormone disruptors are chemicals that mimic or disrupt natural hormones in our bodies. The research team wants to find out whether the levels of hormone disrupting chemicals are different in different communities.</p> <p><i>What is involved?</i> If you agree to participate in the study, you will complete a one-time survey with questions about your and your child's personal information and background, your child's health history and your family's health history. The research team will also ask about characteristics of your home, your neighborhood, and your family's everyday activities. Your child will be asked to provide biological samples (blood and urine) for chemical testing and genetic analyses.</p> <p><i>Will I get results?</i> You will have the opportunity to receive the chemical testing and genetic testing results for your child.</p> <p><i>Who is conducting the study?</i> Researchers from Southwestern University are conducting the study.</p> |
| 2B | <p>Help researchers learn about kids' exposure to pollution!</p> <p>Kids aged five to 13 years old are being recruited from across the US for a study to learn about the levels of everyday chemicals in our children's bodies, with a focus on hormone disruptors.</p> <p><i>What is the study about?</i> The purpose of this study is to learn about kids' everyday exposures to certain types of pollution. There are many kinds of chemical pollutants. Hormone disruptors are chemicals that mimic or disrupt natural hormones in our bodies. The research team wants to find out whether the levels of hormone disrupting chemicals are different in different communities.</p> <p><i>What is involved?</i> If you agree to participate in the study, you will complete a one-time survey with questions about your and your child's personal information and background, your child's health history and your family's health history. The research team will also ask about characteristics of your home, your neighborhood, and your family's everyday activities. Your child will be asked to provide biological samples (blood and urine) for chemical testing and genetic analyses.</p> <p><i>Will I get results?</i> You will not receive any individual results from the study of the samples from your child.</p> <p><i>Who is conducting the study?</i> Researchers from Southwestern University are conducting the study.</p> |
| 2C | <p>Help researchers learn about kids' exposure to pollution!</p> <p>You're being contacted because you have a child between the ages of five and 13 years old and you live in one of three communities in California, Michigan and New Jersey that are eligible for the Everyday Chemical Exposures study. Researchers have been collecting air and dust samples from schools and outdoor play areas in your community. Now, they want to learn more about kids' exposures to chemicals in homes.</p> <p><i>What is the study about?</i> The purpose of this study is to learn about the kids' everyday exposures to certain types of pollution. There are many kinds of chemical pollutants. Hormone disrupting chemicals are chemicals that mimic or disrupt natural hormones in our bodies. The research team wants to find out whether the levels of hormone disrupting chemicals are different in different communities.</p> <p><i>What is involved?</i> If you agree to participate in the study, the research team will call to arrange a one-time visit to your home. At the visit, you will complete a survey including questions about your and your child's personal information and background, your child's health history and your family's health history. The research team will also ask about characteristics of your home, your neighborhood, and your family's everyday activities. The researchers will collect samples of the air and dust in your home to be sent for chemical testing, along with the samples from schools and outdoor play areas in your community. The air and dust samples from your home will be collected in your child's bedroom.</p> <p><i>Will I get results?</i> You will have the opportunity to receive the chemical testing results for your home.</p> <p><i>Who is conducting the study?</i> Researchers from Southwestern University are conducting the study.</p> |
| 3 | <p>Get personalized feedback about your exposure to everyday chemicals!</p> <p>Volunteers from across the United States are being recruited to participate in a study of a new survey tool that estimates your degree of exposure to certain types of chemicals in and around your home.</p> <p><i>What is the study about?</i> The purpose of the study is to test out a tool that gives you feedback about your possible exposure to certain types of chemicals based on (1) information you tell us about your everyday activities and (2) an estimate of the air quality in your area. The researchers will use the information from this study to develop better strategies to help people learn about and reduce their personal exposures to chemicals.</p> <p><i>What is involved?</i> If you agree to participate in the study, you will be asked to complete a one-time survey including questions about your personal information and background, your history of breast cancer, your</p> |

| | |
|--|--|
| | <p>opinions about causes of breast cancer, and questions about environmental health topics. Next, we'll ask how often you use certain types of personal care and household products. We will give you directions to use your device's camera to scan the Universal Product Code (UPC) on the products that you use most frequently. You can also type in the UPC codes manually if you can't use the product scanner. Finally, we will ask you to enter the zip code for the area where you live, so that we can access the current air quality forecast in your area.</p> <p><i>Will I get results?</i> After you complete the self-assessment, you will receive a personal exposure report. Your report will include rating (high, medium, low) that compares your possible exposure to certain types of chemicals from consumer products and air pollution to the possible exposures of others who used the tool. You'll also get some tips on how you can try to reduce your possible exposures to these types of chemicals.</p> <p><i>Who is conducting the study?</i> Researchers from Southwestern University are conducting the study.</p> |
|--|--|

| Data Sharing Types | Scenarios | |
|---|------------|--|
| No Sharing | 1A, 1B, 1C | <i>What am I agreeing to?</i> If you participate in this study, your chemical testing and survey information will be stored for future research by the research team. You will receive a newsletter once a year with general updates about the studies being done. |
| | 2A & 2B | <i>What am I agreeing to?</i> If you participate in this study, your child's chemical testing, genomic data and survey information will be stored for future research by the research team. You will receive a newsletter once a year with general updates about the studies being done. |
| | 2C | <i>What am I agreeing to?</i> If you participate in this study, your chemical testing and survey information will be stored for future research by the research team. You will receive a newsletter once a year with general updates about the studies being done. |
| | 3 | <i>What am I agreeing to?</i> If you participate in this study, your product use information, survey information, and your personal exposure report will be stored for future research by the research team. You will receive a newsletter once a year with general updates about the studies being done. |
| Sharing in Publicly-Accessible Database | 1A, 1B, 1C | <i>What am I agreeing to?</i> If you participate in this study, your chemical testing and survey information will be stored for future research. Your data will be made freely available in a public, unrestricted database that anyone can use. This public information will not be labeled with your name or other information that could be used to easily identify you. You will receive a newsletter once a year with general updates about the studies being done. |
| | 2A & 2B | <i>What am I agreeing to?</i> If you participate in this study, your child's chemical testing, genomic data and survey information will be stored for future research. Your child's data will be made freely available in a public, unrestricted database that anyone can use. This public information will not be labeled with your child's name or other information that could be used to easily identify you or your child. You will receive a newsletter once a year with general updates about the studies being done. |
| | 2C | <i>What am I agreeing to?</i> If you participate in this study, your chemical testing and survey information will be stored for future research. Your data will be made freely available in a public, unrestricted database that anyone can use. This public information will not be labeled with your name or other information that could be used to easily identify you. You will receive a newsletter once a year with general updates about the studies being done. |
| | 3 | <i>What am I agreeing to?</i> If you participate in this study, your product use information, survey information, and your personal exposure report will be stored for future research. Your data will be made freely available in a public, unrestricted database that anyone can use. This public information will not be labeled with your name or other information that could be used to easily identify you. You will receive a newsletter once a year with general updates about the studies being done. |
| Sharing in Controlled-Access Database | 1A, 1B, 1C | <i>What am I agreeing to?</i> If you participate in this study, your chemical testing and survey information will be stored for future research. Your data will be shared with other researchers in one or more "controlled-access" databases. This means that |

| | | |
|--|--------------------|---|
| | | only researchers who apply for and get permission to use the information for a specific research project will be able to access the information. Your data will not be labeled with your name or other information that could be used to easily identify you. You will receive a newsletter once a year with general updates about the studies being done. |
| | 2A & 2B | <i>What am I agreeing to?</i> If you participate in this study, your child's chemical testing, genomic data and survey information will be stored for future research. Your child's data will be shared with other researchers in one or more "controlled-access" databases. This means that only researchers who apply for and get permission to use the information for a specific research project will be able to access the information. The data will not be labeled with your child's name or other information that could be used to easily identify you or your child. You will receive a newsletter once a year with general updates about the studies being done. |
| | 2C | <i>What am I agreeing to?</i> If you participate in this study, your chemical testing and survey information will be stored for future research. Your data will be shared with other researchers in one or more "controlled-access" databases. This means that only researchers who apply for and get permission to use the information for a specific research project will be able to access the information. Your data will not be labeled with your name or other information that could be used to easily identify you. You will receive a newsletter once a year with general updates about the studies being done. |
| | 3 | <i>What am I agreeing to?</i> If you participate in this study, your product use information, survey information, and your personal exposure report will be stored for future research. Your data will be shared with other researchers in one or more "controlled-access" databases. This means that only researchers who apply for and get permission to use the information for a specific research project will be able to access the information. Your data will not be labeled with your name or other information that could be used to easily identify you. You will receive a newsletter once a year with general updates about the studies being done. |
| Sharing in Publicly-Accessible Database with Zip Code in Controlled-Access Database | 3 | <i>What am I agreeing to?</i> If you participate in this study, your product use information, survey information, and your personal exposure report will be stored for future research. Your data will be made freely available in a public, unrestricted database that anyone can use. This will include basic information such as your race, ethnic group, and sex; your opinions about causes of breast cancer and your responses to questions about environmental health topics; your product use information; your personalized exposure report; and some variables that we will obtain from the 2010 US Census report to describe your community (such as median household income in your area). Your zip code will be shared with other researchers in a "controlled-access" database. This means that only researchers who apply for and get permission to use the information for a specific research project will be able to access this information. Neither the public information nor the data in the controlled-access database will be labeled with your name or other information that could be used to easily identify you. You will receive a newsletter once a year with general updates about the studies being done. |

Section 2: Survey questions

Part 1

1. Imagine that you would be eligible to participate in this study. Based on the information you've just read, would you tell these researchers you are interested in participating in their study? If you want to look back at the study description before you give your answer, please click the "Review study description" button below.

[Review study description](#)

[Hide study description](#)

2. Would you tell these researchers you are interested in participating in their study?

Yes

No

3. Do you think there are any benefits to the study?

Yes

No, I don't think there are any benefits

4. If Do you think there are any benefits to the study? Yes Is Selected

In your opinion, what do you think are the benefits of this study? Please list any benefits in the boxes below.

1

2

3

4

5

5. If Do you think there are any benefits to the study? Yes Is Selected

If you would like to look at the study description again, click the "Review study description" button below

[Review study description](#)

[Hide study description](#)

6. If In your opinion, what do you think are the benefits of this study? Please list any benefits in th... 2 Is Not Empty

When considering participation in this study, how important were these benefits to you? Please enter a number to rank the importance of each item in the list below [filled in with participants answers to question 4]. A ranking of "1" indicates the benefit that was most important to you.

7. Do you think there are any risks to the study?

Yes

No, I don't think there are any risks

8. If Do you think there are any risks to the study Yes Is Selected

In your opinion, what do you think are the risks of the study? Please list any risks in the boxes below.

- 1
- 2
- 3
- 4
- 5

9. If Do you think there are any risks to the study? Yes Is Selected

If you would like to look at the study description again, click the "Review study description" button below

Review study description

Hide study description

10. If In your opinion, what do you think are the risks of the study? Please list any risks in the boxes... 2 Is Not Empty

When considering participation in this study, how important were these risks to you? Please enter a number to rank the importance of each item in the list below. [filled in with participants answers to question 8]. A ranking of "1" indicates the risk that was most important to you.

11. What about this study mattered to you when you were deciding whether you would be interested in participating? For each study feature in the list below, please indicate how it impacted your decision:*

| | This feature of the study made me... | | | | |
|---|--------------------------------------|-------------------------------------|----------------------------|-------------------------------------|---------------------------------|
| | Much less likely to participate | Somewhat less likely to participate | Did not impact my decision | Somewhat more likely to participate | Much more likely to participate |
| The researchers | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The study procedures | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I can receive my results | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The purpose of the study | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| My data will be saved for future research | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Note: Depending on the type of data sharing described in the vignette, other features listed in this table could include: (1) My data will be shared publicly or (2) My data will be shared with other approved researchers. For the vignettes in group 2, features were described as relevant as 'my child's results' and 'my child's data'. Scenario 2B included the feature 'I will not receive my child's results'. In all tables, order of presentation of study features was randomized.*

12. If Would you participate in this study? Yes Is Selected

Please tell us in your own words why you would be interested in participating in this study:

13. If Would you participate in this study? No Is Selected

Please tell us in your own words why you would not participate in this study:

Part 3

In the study scenarios we described, we asked you to give consent for your data to be shared and used to answer future research questions. What types of data would you be willing to have stored and shared for future research in a controlled-access scientific database? How about in a publicly-accessible database? Please indicate your choice in the drop-down list for each type of data listed below. [Note: order of presentation of items in table was randomized]

| | I would allow this type of data to be shared in... | | | |
|--|--|------------------------------------|--|--|
| | A controlled-access database (1) | A publicly-accessible database (2) | Both controlled-access and publicly-accessible databases (3) | I would not allow this type of data to be shared (4) |
| Health history (3) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Age (4) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Race and ethnicity (5) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Date of Birth (6) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Address (7) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Location - GPS coordinates (8) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Location - zip code (9) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Genetic data (10) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Chemical testing results for samples from your body (11) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Opinions & beliefs (12) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Information about the personal care and cleaning products you use (13) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Characteristics of your home (14) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Your usual activities in your home (15) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Chemical testing results for samples from your home (2) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Have you ever participated in a research study where environmental samples (for example, dust, air or water samples) were collected from your home? We're asking about samples specifically collected for a research study, not for other purposes such as a home inspection.

- ☐ Yes (1)
- ☐ No (2)

Have you ever participated in a research study where you were asked to provide biological samples (any sample from your body)?

- ☐ Yes (1)
- ☐ No (2)

Table S1: Vignette sets

| Set | Scenario | Sharing |
|-----|----------|---------|
| 1 | 1C | NS |
| | 2C | PD |
| | | |
| 2 | 1B | CD |
| | 3 | NS |
| | | |
| 3 | 1B | NS |
| | 2C | CD |
| | | |
| 4 | 2B | PD |
| | 3 | CD |
| | | |
| 5 | 1C | PD |
| | 2B | NS |
| | | |
| 6 | 1A | CD |
| | 2A | PD |
| | | |
| 7 | 1C | CD |
| | 3 | PD |
| | | |
| 8 | 1A | PD |
| | 2A | NS |
| | | |
| 9 | 2C | ND |
| | 3 | C_P |
| | | |
| 10 | 1B | PD |
| | 2B | CD |
| | | |
| 11 | 1A | NS |
| | 2A | CD |

NS = No sharing; PD = Publicly-accessible database; CD = Controlled-access database; C_P = Zip code in controlled-access, rest of data in publicly-accessible database. Each participant saw one vignette set. Order of presentation of vignettes within in a set was randomized.

Table S2. Modified Poisson Regression Results Showing Associations Between Experimentally Manipulated Study Features, Demographic Characteristics and Prior Donation of Environmental or Biological Samples and Proportion Interested in Participating.

| Vignette Pair | Factor | Level | RR | 95% CI |
|--|----------------------------------|---|-------------|--------------|
| Model 1 (N = 437) | | | | |
| 1A & 1B <i>Smallville Studies</i> | EMR access | No (health questionnaire) | REF | |
| | | Yes | 0.9 | (0.84, 0.97) |
| | Data sharing type | Controlled-access | REF | |
| | | None | 0.96 | (0.89, 1.04) |
| | | Public-access | 0.92 | (0.85, 1.01) |
| | Age | < 35 | 0.89 | (0.71, 1.11) |
| | | 35 to < 65 | 0.96 | (0.89, 1.04) |
| | | ≥ 65 | REF | |
| | Education | No college degree | REF | |
| | | College degree | 0.97 | (0.89, 1.05) |
| Prior enviro/bio sample donation | No | REF | | |
| | Yes | 1.02 | (0.95, 1.1) | |
| Model 2 (N = 412) | | | | |
| 1A & 1C <i>Smallville Studies</i> | Purpose | Follow-up after municipal water contamination | REF | |
| | | Investigation of breast cancer cluster | 0.99 | (0.91, 1.08) |
| | Data sharing type | Controlled-access | REF | |
| | | None | 0.94 | (0.85, 1.04) |
| | | Public-access | 0.92 | (0.83, 1.02) |
| | Age | < 35 | 0.65 | (0.43, 0.99) |
| | | 35 to < 65 | 0.99 | (0.9, 1.08) |
| | | ≥ 65 | REF | |
| | Education | No college degree | REF | |
| | | College degree | 0.9 | (0.82, 0.99) |
| | | Prefer not to answer | 0.53 | (0.13, 2.26) |
| | Prior enviro/bio sample donation | No | REF | |
| | | Yes | 0.96 | (0.88, 1.05) |
| Model 3 (N = 369) | | | | |
| 2A & 2B <i>Children's Everyday Exposure</i> | Personal results | Receive overall results only | REF | |
| | | Receive personal and overall results | 1.17 | (1.03, 1.34) |
| | Data sharing type | Controlled-access | REF | |
| | | None | 0.9 | (0.77, 1.05) |
| | | Public-access | 0.94 | (0.81, 1.1) |
| | Age | < 35 | 0.95 | (0.72, 1.25) |
| | | 35 to < 65 | 0.86 | (0.76, 0.98) |
| | | ≥ 65 | REF | |
| | Education | No college degree | REF | |
| | | College degree | 1.08 | (0.89, 1.31) |
| | | Prefer not to answer | 1.44 | (1.16, 1.77) |
| | Prior enviro/bio sample donation | No | REF | |
| | | Yes | 1.01 | (0.89, 1.15) |
| Model 4 (N = 348) | | | | |
| 2A & 2C <i>Children's Everyday Exposure</i> | Sample type | Biological | REF | |
| | | Environmental | 1.2 | (1.09, 1.32) |
| | Data sharing type | Controlled-access | REF | |
| | | None | 0.89 | (0.8, 1) |

| Vignette Pair | Factor | Level | RR | 95% CI |
|---------------|------------------|----------------------|------|--------------|
| | | Public-access | 0.92 | (0.83, 1.02) |
| | Age | < 35 | 1.07 | (0.99, 1.17) |
| | | 35 to < 65 | 0.87 | (0.8, 0.95) |
| | | ≥ 65 | REF | |
| | Education | No college degree | REF | |
| | | College degree | 1.04 | (0.92, 1.18) |
| | | Prefer not to answer | 1.32 | (1.14, 1.52) |
| | Prior enviro/bio | No | REF | |
| | sample donation | Yes | 0.99 | (0.9, 1.08) |

Model 5 (N = 267)

| | | | | |
|---|-------------------|--|------|--------------|
| <i>3^a Exposure Reduction</i> | Data sharing type | Controlled-access | REF | |
| | | None | 0.98 | (0.89, 1.09) |
| | | Public-access | 0.98 | (0.89, 1.08) |
| | | Most data public-access, zip code in controlled-access | 0.99 | (0.9, 1.09) |
| | Age | < 35 | 0.95 | (0.79, 1.16) |
| | | 35 to < 65 | 1.01 | (0.94, 1.09) |
| | | ≥ 65 | REF | |
| | Education | No college degree | REF | |
| | | College degree | 1.05 | (0.94, 1.18) |
| | Prior enviro/bio | No | REF | |
| | | sample donation | 1.01 | (0.94, 1.08) |

bio = biological, EMR = electronic medical record, enviro = environmental, RR = risk ratio

^aIn group 3, only the type of data sharing varied, so there was no vignette pair.

Table S3. Modified Poisson Regression Results Showing Associations Between Experimentally Manipulated Study Features and Proportion Interested in Participating --Sensitivity Analysis Including Second-viewed Vignette.

| Vignette Pair | Factor | Level | RR | 95% CI |
|--|-------------------|--|------|--------------|
| Model 1 (N = 866) | | | | |
| 1A & 1B <i>Smallville Studies</i> | EMR access | No (health questionnaire) | REF | |
| | | Yes | 0.91 | (0.87, 0.96) |
| | Data sharing type | Controlled-access | REF | |
| | | None | 0.98 | (0.92, 1.03) |
| | | Public-access | 0.88 | (0.82, 0.94) |
| Model 2 (N = 861) | | | | |
| 1A & 1C <i>Smallville Studies</i> | Purpose | Follow-up after municipal water contamination | REF | |
| | | Investigation of breast cancer cluster | 1.08 | (1.01, 1.16) |
| | Data sharing type | Controlled-access | REF | |
| | | None | 0.95 | (0.88, 1.02) |
| | | Public-access | 0.9 | (0.83, 0.98) |
| Model 3 (N = 800) | | | | |
| 2A & 2B <i>Children's Everyday Exposure</i> | Personal results | Receive overall results only | REF | |
| | | Receive personal and overall results | 1.2 | (1.07, 1.35) |
| | Data sharing type | Controlled-access | REF | |
| | | None | 0.89 | (0.79, 1.01) |
| | | Public-access | 0.76 | (0.66, 0.88) |
| Model 4 (N = 836) | | | | |
| 2A & 2C <i>Children's Everyday Exposure</i> | Sample type | Biological | REF | |
| | | Environmental | 1.24 | (1.14, 1.35) |
| | Data sharing type | Controlled-access | REF | |
| | | None | 0.85 | (0.77, 0.93) |
| | | Public-access | 0.83 | (0.75, 0.91) |
| Model 5 (N = 588) | | | | |
| 3 ^a <i>Exposure Reduction</i> | Data sharing type | Controlled-access | REF | |
| | | None | 0.9 | (0.83, 0.99) |
| | | Public-access | 0.91 | (0.84, 0.99) |
| | | Most data public-access, zip code in controlled-access | 0.91 | (0.84, 0.99) |

EMR = electronic medical record, RR = risk ratio

^a In group 3, only the type of data sharing varied, so there was no vignette pair.

The results of the sensitivity analysis were largely similar to the main analysis of the first viewed vignette presented, with the following exceptions. For the Smallville and Exposure Reduction studies, estimates for public vs restricted-access sharing were reduced by 7-14% and became significant, indicating that individuals viewing a public sharing scenario immediately after viewing a “no sharing” or “restricted-access” scenario had a stronger negative reaction than those viewing public sharing first. This is consistent with our hypothesis that there were carry-over effects and with McGuire et al.’s (2011) finding that many participants in genetic studies who initially agreed to public sharing chose more restrictive options when they were subsequently presented (McGuire, et al., 2011). The experience of evaluating one description of how data will be shared (rather than comparing different descriptions) is more relevant to the real experience of potential participants considering a research study. For the Exposure Reduction study, the estimate for no sharing vs restricted-access sharing was reduced by 9% and became statistically significant (compared to essentially null in the model restricted to the first vignette). We are cautious to place much weight on this change, given the limitations of the “no sharing” condition described in the text (i.e., that the description stated that information would be stored for future research by the study team, but did not specify that direct identifiers would be kept separately from the data). The association between study purpose (breast cancer cluster vs. water contamination) and IIP in the Smallville studies increased by 6% and became statistically significant. Given that people sign up for the AOW because they are interested in breast cancer studies, their interest in the breast cancer study (when viewed as the second vignette) may have been

enhanced by having just read about a study *not* focused on breast cancer (either the Children's Everyday Exposure study or the Exposure Reduction study). Again, the experience of evaluating one study description at a time (rather than comparing different descriptions in close succession) is ultimately more representative of the experience of AOW members and potential research participants in general.

McGuire, A. L., Oliver, J. M., Slashinski, M. J., Graves, J. L., Wang, T., Kelly, P. A., . . . Hilsenbeck, S. G. (2011). To share or not to share: A randomized trial of consent for data sharing in genome research. *Genet Med*, 13(11), 948-955. doi: 10.1097/GIM.0b013e3182227589

Figure S1

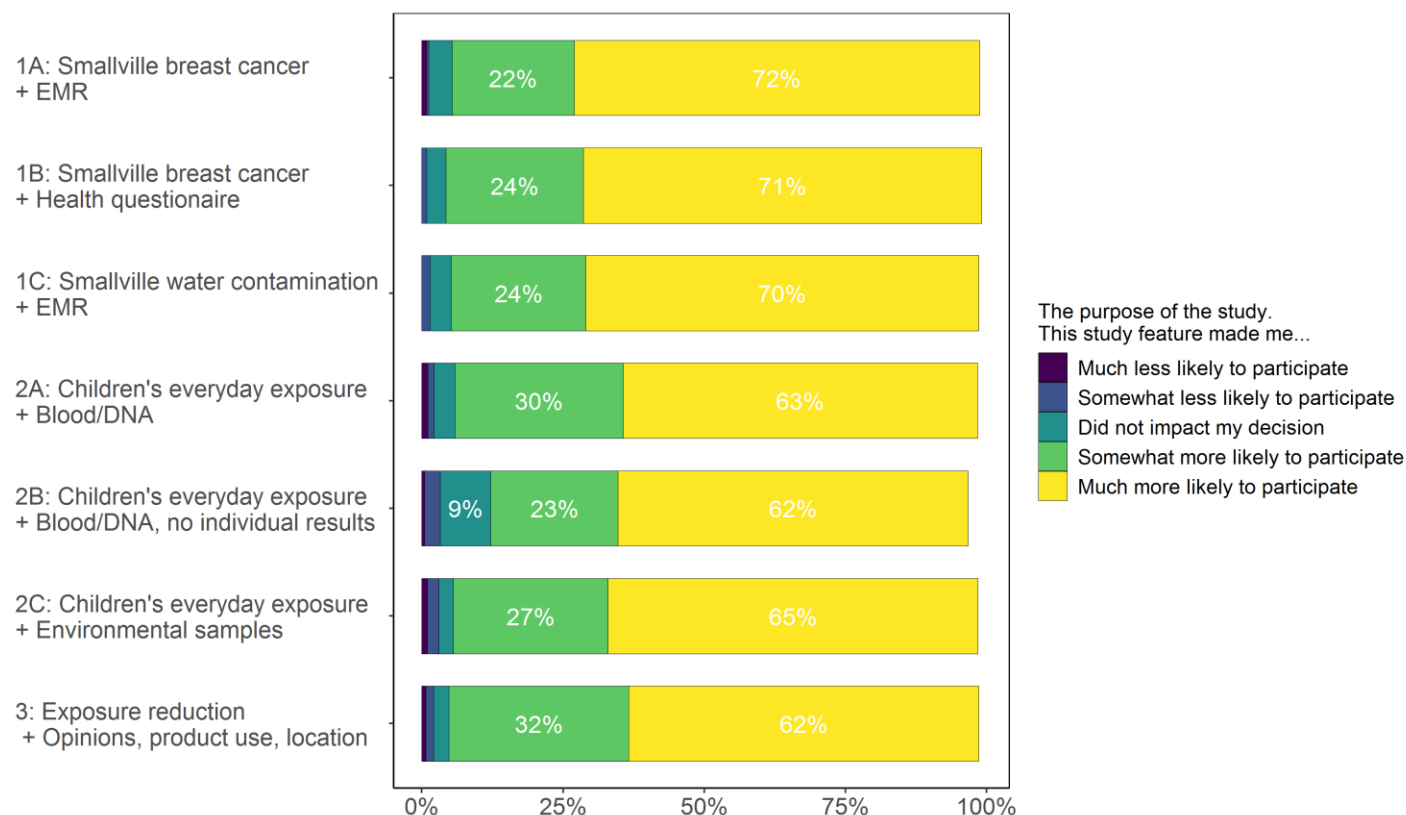


Figure S1. Influence of study purpose on decision to participate in a hypothetical environmental health study. Percentage selecting each response computed based on the total number of participants who could have answered the question (N = 1,575). Bars that do not sum to 100% reflect participants who did not answer the question.

Figure S2

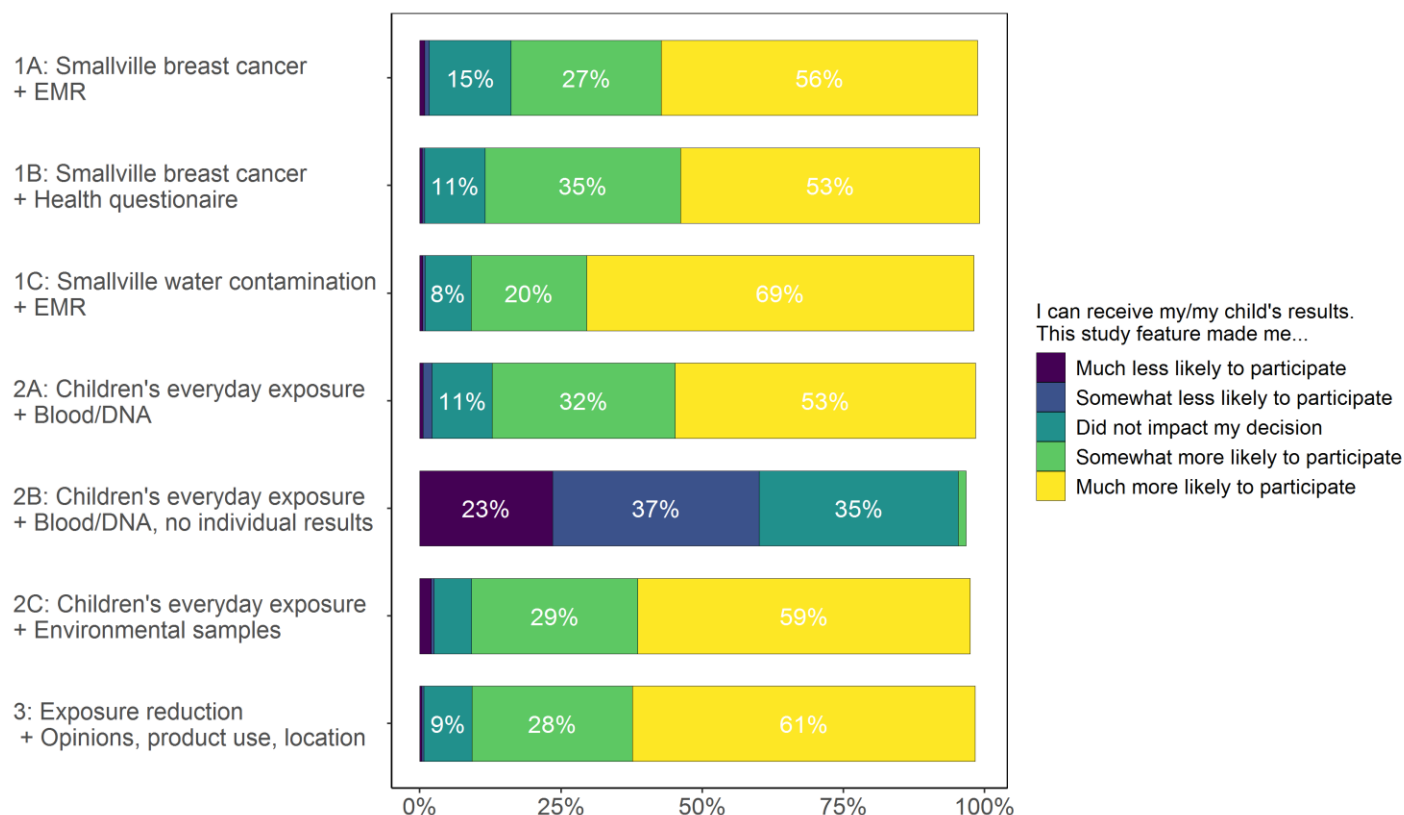


Figure S2. Influence of receiving individual results on decision to participate in a hypothetical environmental health study. Percentage selecting each response computed based on the total number of participants who could have answered the question (N = 1,575). Bars that do not sum to 100% reflect participants who did not answer the question. Note, for scenario 2B, the statement was ‘*I will not receive my child's results.*’