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Outcomes from Returning Individual versus Only Study-Wide Biomonitoring Results in an Environmental Exposure Study Using the Digital Exposure Report-Back Interface (DERBI)

Julia Green Brody,[1] Piera M. Cirillo,[2] Katherine E. Boronow,[1] Laurie Havas,[3] Marj Plumb,[4] Herbert P. Susmann,[5] Krzysztof Z. Gajos,[6] and Barbara A. Cohn[2]

[1]Silent Spring Institute, Newton, Massachusetts, USA
[2]Public Health Institute, Oakland, California, USA
[3]Participant Advisory Council, Child Health and Development Studies, Public Health Institute, Oakland, California, USA
[4]Plumbline Coaching and Consulting, Omaha, Nebraska, USA
[5]Department of Biostatistics, School of Public Health and Health Science, University of Massachusetts Amherst, Amherst, Massachusetts, USA
[6]Computer Science, Harvard John A. Paulson School of Engineering and Applied Sciences, Cambridge, Massachusetts, USA

Background: Study participants want to receive their biomonitoring results for environmental chemicals, and ethics guidelines encourage reporting back. However, few studies have quantitively assessed participants' responses to individual exposure reports, and digital methods have not been evaluated.

Objectives: We isolated effects of receiving personal results vs. only study-wide findings and investigated whether effects differed for Black participants.

Methods: We randomly assigned a subset of 295 women from the Child Health and Development Studies, half of whom were Black, to receive a report with personal environmental chemical results or only study-wide (aggregate) findings. Reports included results for 42 chemicals and lipids and were prepared using the Digital Exposure Report-Back Interface (DERBI). Women were interviewed before and after viewing their report. We analyzed differences in website activity, emotional responses, and intentions to participate in future research by report type and race using Wilcoxon rank sum tests, Wilcoxon-Pratt signed ranks tests, and multiple regression.

Results: The personal report group spent approximately twice as much time on their reports as the aggregate group before the post-report-back interview. Among personal-report participants ($n=93$), 84% (78) viewed chemical group information for at least one personal result highlighted on their home page; among aggregate-report participants ($n=94$), 66% (62) viewed any chemical group page. Both groups reported strong positive feelings (curious, informed, interested, respected) about receiving results before and after report-back and mild negative feelings (helpless, scared, worried). Although most participants remained unworried after report-back, worry increased by a small amount in both groups. Among Black participants, higher post report-back worry was associated with having high levels of chemicals.

Conclusions: Participants were motivated by their personal results to access online information about chemical sources and potential health effects. Report-back was associated with a small increase in worry, which could motivate appropriate action. Personal report-back increased engagement with exposure reports among Black participants. https://doi.org/10.1289/EHP9072

Introduction

Many environmental health studies assess exposures by testing for chemical levels in biospecimens, including blood, urine, or other tissues, and participants in these studies nearly always want to know their own results. A consensus statement from the National Academy of Sciences Engineering and Medicine recommended the return of individual biomonitoring results (known as report-back) for both ethical and practical reasons (National Academies of Sciences, Engineering and Medicine 2018). Offering results respects the autonomy of participants and, by educating them about environmental chemicals and health, it empowers them to make informed personal choices and contribute to public health decisions at the community and national levels (Brody et al. 2014; National Academies of Sciences, Engineering and Medicine 2018). By showing respect for and engaging with participants, report-back builds trust in the research enterprise and supports recruitment and retention in studies (National Academies of Sciences, Engineering and Medicine 2018; Ohayon et al. 2017).

Past research shows that when results are returned with contextual information about chemical sources, health effects, and strategies to reduce exposure, participants in many different communities and across the socioeconomic spectrum appreciate their reports and learn from them (Adams et al. 2011; Altman et al. 2008; Brody et al. 2014; Giannini et al. 2018; Hernick et al. 2011; Perovich et al. 2018; Ramirez-Andreotta et al. 2016a; Tomsho et al. 2019). Participants want their results even when the health implications are uncertain (Adams et al. 2011; Hernick et al. 2011; National Academies of Sciences, Engineering and Medicine 2018), and they generally understand that their chemical levels cannot be linked to specific instances of disease (Altman et al. 2008). After receiving reports, they are motivated to reduce their exposures (Adams et al. 2011; Altman et al. 2008; Brody et al. 2014) and sometimes become active in community-level change (Adams et al. 2011; Brody et al. 2009). In studies using community-engaged methods, report-back supports values of co-ownership and co-learning, and partnering with community members to design study reports improves quality and relevance (Brody et al. 2007; Dunagan et al. 2013).

To better understand the distinctive effects of receiving individual results in comparison with nonpersonalized study communications, we undertook the MyCHDSReport Study in a subset of women born 1959–1967 in the second generation of the Child Health and Development Studies (CHDS) who participated in a home visit. We compared outcomes from receiving a report with both personal chemical levels and aggregate study results vs. receiving a report with only the aggregate results. In addition, this sample was designed to comprise approximately half participants

Address correspondence to Julia Green Brody, Silent Spring Institute, 320 Nevada Street, Suite 302, Newton, MA 02461 USA. Email: brody@silentspring.org

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who identified themselves as Black/African American. Analyzing effects in this group is an important inquiry because the history of structural racism and research exploitation differentially affects the experience of Black people as research participants (Muhammad et al. 2018). Finally, this study is the first to evaluate personal report-back using an interactive, web-based report created with the Digital Exposure Report-Back Interface (DERBI) (Boronow et al. 2017). Digital reports offer a more flexible experience in comparison with paper reports by making it easier for participants to navigate to the type and amount of information they wish to see by following links to layered information. In addition, by automating report preparation, DERBI makes it practical to personalize reports in large studies in order to highlight and summarize notable findings for each participant.

In this overview paper, we describe the community-based participatory research process for report design and analyze participants' engagement with the report, their emotional responses, and their interest in future research participation. We tested whether participants who received personal results had responses that differed from those of participants who received only aggregate results. Recognizing the need to examine racism in research and society (Payne-Sturges et al. 2021), we evaluated whether report-back outcomes differed by race. We prioritized emotional responses, because researchers who are reluctant to report personal results have cited concerns about causing extreme anxiety or panic (Ohayon et al. 2017).

Methods

Collaborative Framework

This study was a unique collaboration of the CHDS at the Public Health Institute, Silent Spring Institute, in Newton, Massachusetts, and the CHDS Participant Advisory Council (PAC). The CHDS PAC is a racially diverse multigenerational council of approximately 12 cohort members that meets several times a year and that served as the community partner for this study. The CHDS was responsible for recruitment, project implementation, and survey data collection; Silent Spring was responsible for building the MyCHDSReport website and qualitative data collection; and the CHDS PAC assisted in the design of study materials, facilitated recruitment, and participated in data interpretation. We worked together to design research questions, develop content for MyCHDSReport, and analyze data.

Study Population

The CHDS is a large, multigenerational cohort that enrolled more than 15,000 families residing in the East Bay, California, area from 1959 to 1967 (van den Berg et al. 1988), and it maintains ongoing follow-up. Daughters born into the CHDS were in their 40s and 50s at the time of this study. During the period 2010–2013, the daughters were invited to participate in in-person study visits as part of two adult follow-up studies, the Three Generations Study (3Gs) or the Disparities in Health Study. Among the women who donated blood, a subset of 150 women who had mothers who identified as Black/African American and 150 who did not were randomly selected for assays of environmental chemicals. Participants subsequently provided self-reported race, which we used in our analyses. (For brevity, we refer to participants who chose Black/African American as one of their races as Black participants and to those who chose non-Hispanic White, Hispanic, Asian, or multiple races and did not choose Black/African American as non-Black.) In all but one case, the mother's race aligned with the participant's self-reported race. Report-back of these results became the basis for MyCHDSReport Study. Of the 300 blood sampling participants, 5 were deemed ineligible (4 who indicated at the time of blood draw that they did not wish to receive their assay results and 1 whose assays failed), leaving 295. Eligible participants closely resembled the original CHDS population based on a comparison of maternal characteristics measured at index pregnancy (including age, race/ethnicity, parity, education, health behavior, family income, and infant birth outcomes) (Table S1). The only significant difference between the CHDS as a whole and the study sample was the intentionally greater proportion in the current study of participants whose mothers identified as Black.

Blood Sampling

Trained examiners conducted in-home visits to collect biological samples, including blood samples collected using a serology protocol adapted from the National Health and Nutrition Examination Survey (NHANES) National Examination Management Services, Inc., standard operating procedures (CDC 2011). Briefly, the examiner put on gloves, prepared and labeled the blood collection equipment and then asked the participant to sit upright, identified an appropriate vein, applied a tourniquet, and cleansed the site with alcohol to perform the venipuncture. Three 10-mL vacutainer tubes, a red top, a green top (with heparin) and a red top, were drawn in succession. Care was taken to explain the procedure to the participant beforehand, to avoid drawing blood from an unsuitable vein, and to dispose of needles and blood supplies in appropriate puncture-resistant sharps containers. Blood samples were placed in a protective biostorage cannister inside a Styrofoam shipper containing polar foam or gel packs for same-day transfer or overnight shipping to the Children's Environmental Health Laboratory at the University of California Berkeley where they were processed. At the laboratory, the liquid portion of both red-top vacutainers was transferred into two 15-mL Falcon tubes of equal volume and centrifuged for 15 min at 4°C at 1,200 *g*. The plasma layer was transferred into cryovials to form nine aliquots of various volumes for storage at −80°C. Blood clots in each vacutainer were halved and transferred to four cryovials and stored at −80°C. The green-top vacutainer was inverted 10 times to mix the sample. Two 200-uL aliquots of whole blood were withdrawn into cryovials for storage, and then the remaining sample was transferred into a 15-mL Falcon tube and centrifuged for 15 min at 4°C at 1,200 *g*. From the plasma fraction four aliquots of various volumes were transferred into cryovials for storage at −80°C. The buffy coat was transferred to two cryovials in equal amounts, and the red blood cells were divided into two equal aliquots and transferred into cryovials for storage at −80°C. All cryovials were labeled using cryo-safe labels and immediately transferred to freezers for storage.

Serum samples were then shipped on dry ice to the Environmental Chemical Laboratory at the California Department of Toxic Substances Control for chemical assay. Samples were analyzed using the following methods, as summarized here and with details published previously. Two hydroxy-PBDE metabolites were analyzed using a Prominence ultrafast liquid chromatography system (UFLC) (Shimadzu Corporation) coupled to AB Sciex 5500 Qtrap System (AB Sciex LLC), as described in Petropoulou et al. (2014), and 5 additional PBDEs were included in an organochlorine method for 17 PCBs and 7 organochlorine pesticides as described in Whitehead et al. (2015). This method used an Agilent 7890A gas chromatograph coupled to an Agilent 7000 triple quadrupole mass spectrometer (Agilent Technologies). Chromatographic conditions included pulsed splitless injection (20 psi for 1 min) at 250°C, a constant helium carrier gas flow of 1 mL/min, and a 30-m DB-5ms column with 0.25-mm diameter and 0.25-μm film thickness (Agilent Technologies). The gas chromatography (GC) oven program was initiated at 90°C, held for 1 min, ramped at 50°C/min to 150°C, held for 1 min, ramped at 8°C/min to 225°C, held for 6.5 min, ramped at

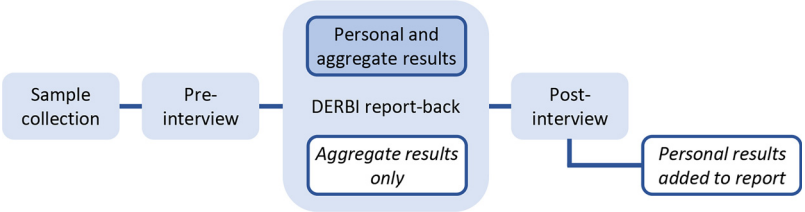

Figure 1. Participants in the MyCHDSReport study completed two interviews, before and 3-4 wk after receiving access to a report with environmental chemical assay results. Participants were randomized to receive a report with their personal chemical levels and aggregate study results, or aggregate results only. Participants in the aggregate results only group gained access to their personal results after completing the postinterview.

14°C/min to 310°C, and finally held for 6 min. The mass spectrometer was operated in electron impact ionization mode using multiple ion detection, source temperature of 250°C, ionization energy of 70 eV, and mass resolution of 1.2 amu. The transfer line temperature was 280°C. Multiple reaction monitoring was used for quantitation of analytes. Sample concentrations were interpolated from linear external calibration curves with 1/x weighting. MassHunter Quantitation Analysis Workstation (version B.06.00; Agilent Technologies) program was used for sample quantitation. Eleven per- and polyfluoroalkyl substances (PFAS) were analyzed using a Symbiosis Pharma system with Mistral CS Cool (Spark Holland) coupled to an AB Sciex 4,000 Qtrap system (AB Sciex LLC), as described in Wang et al. (2011).

For lipids, total cholesterol and triglyceride levels were measured by the Boston Children's Hospital as previously described (Allain et al. 1974), and the Phillips formula was used to calculate total lipid content (Phillips et al. 1989). Total cholesterol, triglycerides, high-density lipoprotein cholesterol (HDL-C), and low-density lipoprotein cholesterol (LDL-C) concentrations were assessed simultaneously using enzymatic analysis on the Roche P Modular system with reagents and calibrators from Roche Diagnostics, using assays approved by the Food and Drug Administration for clinical use (Allain et al. 1974). A preliminary reaction was used to correct for endogenous glycerol during the measurement of triglycerides (Stinshoff et al. 1977). Serum total lipids were calculated using the enzymatic summation formula: $\text{total lipids} = (2.27 \times \text{total cholesterol}) + \text{triglycerides} + 62.31$ (Phillips et al. 1989).

Study Design

Participants were asked to complete two interviews, before and approximately 3–4 wk after they received access to their study report. Between the interviews, they were asked to log into MyCHDSReport to view their chemical assay results (MyCHDSReport is described below). Participants were randomized to either of two conditions, Personal Results (PR) group or Aggregate Results (AR) group. They received login information for their report immediately after the pre–report-back interview (hereafter, "preinterview"). Both groups received information about the study-wide results, including the distributions of chemical levels for all participants along with interpretive and contextual information. The PR group also received their individual chemical results. The AR group initially received only the overall study results and then received their individual results after the post–report-back interview (hereafter, "postinterview) (Figure 1). Participants did not know which group they were in until after they were preinterviewed when they opened their report. The PR and AR reports differed only in the omission of personal results from the AR reports.

The sample was further stratified to two types of surveys: a qualitative, semi-structured telephone interview with primarily open-ended questions or a quantitative, structured telephone interview with fixed-response choices (Figure 2). Sixty-eight participants were randomly assigned to qualitative interviews and 227 to structured interviews. Both surveys encompassed similar broad areas—attitudes about environmental exposures, receiving results reports, and participation in CHDS; knowledge and behaviors related to chemical exposures; and communications with social networks. Both interview types included one overlapping section of structured questions about behaviors related to highly fluorinated compounds (PFAS), because this was a topic of emerging concern (Boronow et al. 2019). We report here on website activity for participants in both interview types and on the emotional response and future participation sections of the structured interviews.

Structured Interviews

The structured interviews were administered via computer-assisted telephone interview (CATI) by the Survey Research Group division of the Public Health Institute, Sacramento, California. Verbal consent to participate in the study was received before both the pre- and postinterviews began. Eligible participants were called a maximum of 40 times per interview before they were considered a passive refusal. After individuals were called 20 times, incentives were employed to encourage participation. If the interviewer was unable to reach the participant after 20 call attempts, the participant was mailed a USD $5 incentive letter. For the second interview, if a participant still hadn't completed the interview 2 wk after being mailed the $5 incentive, she was mailed a recruitment invitation that was handwritten on a notecard by a PAC member. To begin the second interview, participants were asked whether they had viewed their MyCHDSReport. If not, the interview was rescheduled for a later time to allow an opportunity to view the report before the interview. Second interviews were conducted 3–4 wk after the first interview and only when the participant said she had viewed her report. This timing allowed a period for participants to view their reports and consider them and was practical for the study team. Completed interviews took approximately 30 min.

The first section of interview questions investigated participants' emotions about receiving their personal results. Participants were asked to rate eight feelings they might have about getting their results: interested, helpless, respected, worried, empowered, curious, scared, or informed. Participants could answer that they did not have the feeling or could rate the feeling as very mild, mild, moderate, strong, or very strong. The order of the feeling questions was randomized. For analysis, responses were scored on a scale of 0 (if they said they did not have the feeling) to 5 (if the participant indicated the feeling was very strong). This question format was a novel approach to quantifying emotional responses to report-back. The list of feelings represented topics reported in qualitative studies and discussed in ethics documents. "Interested," "curious," and "informed" represented a domain of feelings related to the potential for report-back to influence environmental health literacy (Altman et al. 2008; Brody et al. 2014; Ramirez-Andreotta et al. 2016a). "Helpless" and "empowered" tapped the theoretical benefit of report-back for addressing power imbalances by sharing

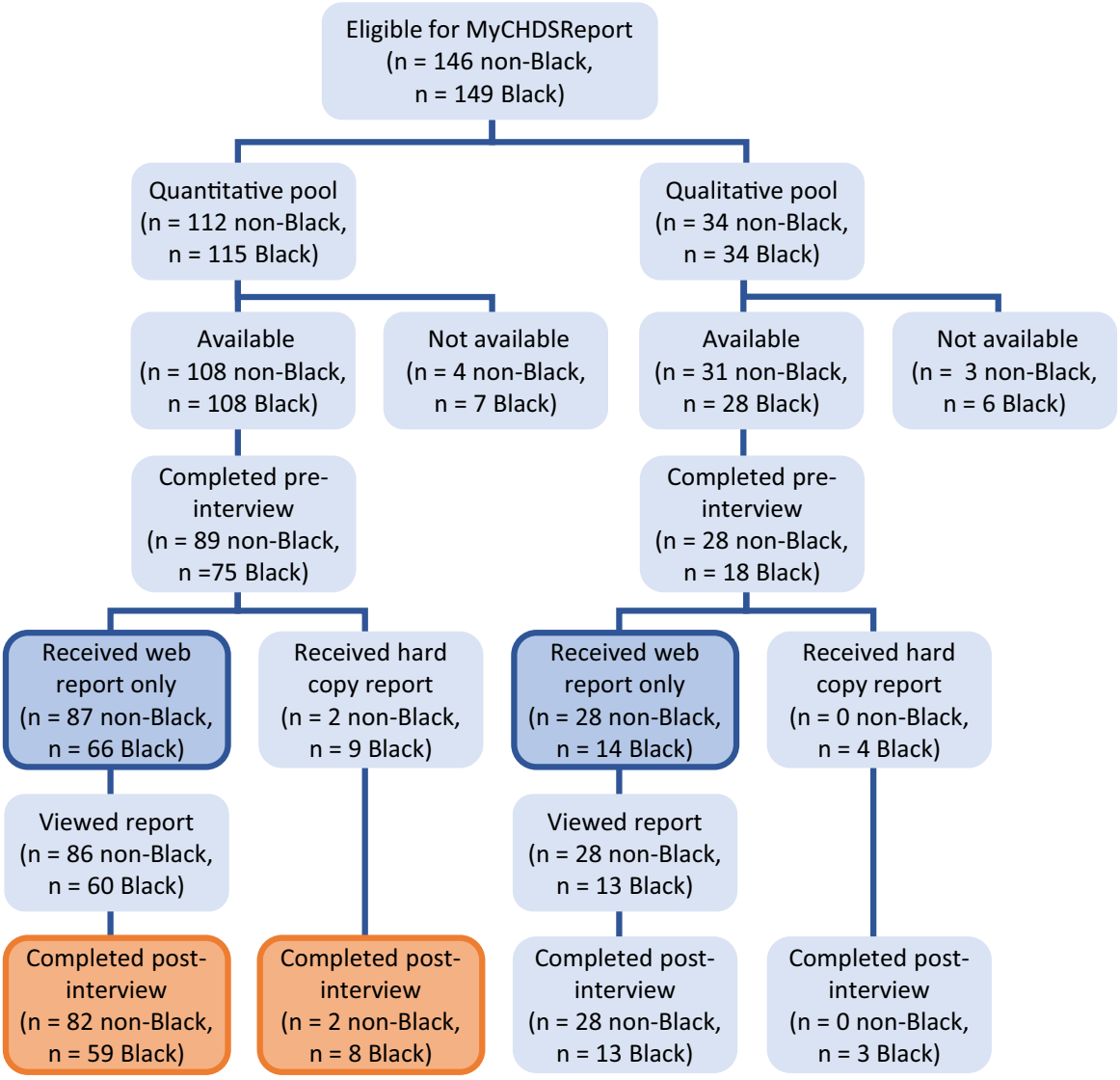

Figure 2. Participants in the MyCHDSReport study were randomly assigned to a quantitative or qualitative interview. "Not available" participants include those who were deceased, too ill, or lacked valid contact information. Analysis of web analytics includes women in both study groups who received the web report only (darker-blue boxes). Analysis of emotions and interest in future research participation is limited to women in the quantitative group who completed both interviews (orange boxes). Five participants in the quantitative pool and one participant in the qualitative pool who completed the postinterview but did not view their online report and did not receive a hard copy report are excluded from the "Completed postinterview" counts.

expert information (Morello-Frosch et al. 2009), although empowerment may be more likely in place-based studies where study participants can join together with local organizations (Brown et al. 2012). Feelings of being "respected" have been reported from qualitative interviews, an outcome that relates to the ethical conduct of research and may influence recruitment and retention in studies (Adams et al. 2011; Brody et al. 2014; Hernick et al. 2011; Perovich et al. 2018). Qualitative studies have found that participants did not become overly worried or scared, but these possible outcomes have been a recurring concern of researchers (Ohayon et al. 2017). We anticipated that participants would generally feel interested, respected, empowered, curious, and informed about receiving their reports and that these feelings would increase more among those receiving individual than aggregate results. We anticipated that feeling worried, scared, and helpless would be in the lower range of responses and generally remain low after receiving individual results. We anticipated higher levels of concern if participants learned they had unusually high levels of a chemical.

The final section of interview questions asked about participants' willingness to participate in future CHDS studies, such as take a phone survey, give additional biological samples, or invite their children or grandchildren to participate in a study. The survey questions relied on here are shown in Supplemental Material, Survey Questions.

MyCHDSReport

Most participants received their results by logging into the MyCHDSReport secure website using a unique code that was provided at the end of the preinterview (the code was shared verbally, by text message, by email, or by multiple routes, at each participant's request). Reports included blood levels of 42 chemicals, including 7 brominated flame retardants, 11 PFAS, 7 organochlorine pesticides, and 17 PCBs, as well as lipid measurements.

MyCHDSReport was created using DERBI, a scalable software framework for generating personalized reports with

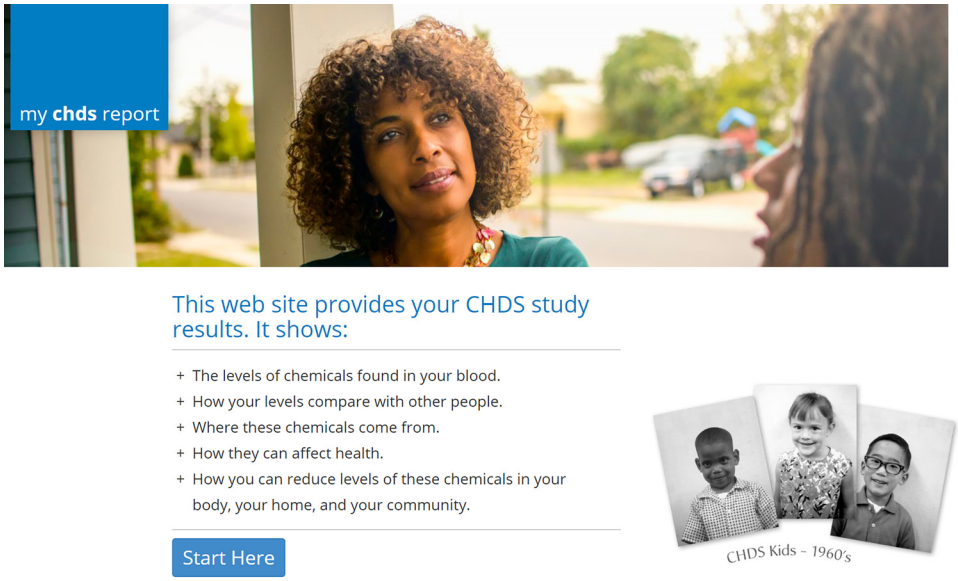

Figure 3. Participants are first directed to the "welcome page" when accessing their MyCHDSReport. From this page, participants log into their personal report using a unique password. This illustration is from "My CHDS Report" (sample report) on the MyCHDSReport website (http://derbidemo.com). © 2014 Child Health and Development Studies (CHDS), Silent Spring Institute. Reprinted with permission.

individual biomonitoring levels (Boronow et al. 2017). Reports were user-centered and encouraged interest and engagement by providing useful and readily accessible contextual information. The development and characteristics of DERBI reports are described in detail in Boronow et al. (2017) and briefly here in the application to CHDS. An example MyCHDSReport is accessible at http://derbidemo.com.

MyCHDSReport began with a "welcome page" that reminded participants about the study and introduced the contents of their report (Figure 3). After logging in with a personal password and consenting to receive their report, participants saw a summary page with highlights from the report. In the PR report, the "Chemicals We Found" section of the summary page included "headlines" about notable individual findings—high or low levels of a compound or group of compounds. An individual headline might read, "Your sample had more PCBs than most others in the study." In the AR report, this section gave a brief description of each chemical group that was measured. In both report types, each chemical group name was hyperlinked to a corresponding chemical page with information about sources of exposure, potential health impacts, and strategies for reducing exposure. Chemical results were shown after the contextual information.

Results were presented graphically, using strip plots that showed an individual's chemical level in relation to the study distribution (an example report can be viewed at http://derbidemo.com and major report features are illustrated in Boronow et al. 2017, "Figure 1"). The AR report showed the same graphs without the marker denoting a participant's personal level. The graphs also showed means for U.S. White and Black women ages 40–59 in NHANES. NHANES comparisons for pesticides, PBDEs, and PCBs were weighted arithmetic means of pooled serum concentrations from the 2007–2008 cycle (CDC 2015), and comparisons for PFAS were calculated as geometric means of individual serum concentrations from the 2011–2012 cycle specifying appropriate sample weights and survey design. In addition to graph legends, interpretive text appeared when users held their cursors over different parts of the graphs.

The "Overall Study Results" section contained information about the study group as a whole and about broader research results from CHDS. For example, one of the highlights in both PR and AR reports was, "The chemicals in people have changed across the generations. CHDS mothers have higher levels than the daughters for the older chemicals." One goal of the "Overall Study Results" was to help participants understand how their personal results contributed to new scientific findings.

Other sections of the PR and AR reports included "What You Can Do," which organized exposure reduction tips across all the chemical groups by topic area (such as "Home," "Food," or "Community"), and the "Health Concerns" section, which highlighted the primary ways that the chemicals in the study might affect health. Reports included phone and email contact information to reach the research team with questions.

The report (including text and photographs) was drafted by Silent Spring Institute, and content was reviewed by the CHDS and the CHDS PAC. The PAC members commented on multiple drafts, reviewing content individually and in small groups at the PAC meetings. The prototype web-based report was usability tested by four metro-Boston residents similar in age to the CHDS daughters and then by a CHDS daughter.

Web Analytics

MyCHDSReport recorded participant activity on the website so that we could analyze user behavior. Every event on the website was recorded with a participant identifier and time stamp. To accommodate participants without Internet access, we provided the option for participants to receive a print copy of the MyCHDSReport in the mail on request. Participants also had the option to print a version of the report from the website for the convenience of those who preferred viewing results on paper or wanted to save a printed copy. If a participant requested a printed copy of their MyCHDSReport, verbal consent was obtained over the phone before results were mailed.

Analysis

The analysis of website activity included participants from both the structured and qualitative interview groups who were not mailed a hard copy of the report. The analysis of how participants felt about receiving their results and their intentions to participate in future research was restricted to the structured interview

participants who completed both pre- and postinterviews and included those who received a hard copy of the report. Five participants were excluded because they received only a web report and their analytics data showed that they had not logged into their report prior to the postinterview, despite giving a verbal confirmation that they had done so. We examined the differences between Personal Results (PR) and Aggregate Results (AR) participants in website activity, how they felt about getting results and their intentions to participate in future research before and after viewing the MyCHDSReport, and we evaluated the effect of having high chemical levels on the emotional response to report-back. We expected PR participants to spend more time in their reports, and we anticipated that having high chemical levels in comparison with others in the study or national samples would be associated with higher levels of concern after receiving personal results. We analyzed differences by race in the effect of report type or headlines. Our null hypothesis was "no difference" by race. However, the history of structural racism in research and society and our commitment to preparing results reports tailored to participants' needs led us to examine the possibility of differential effects by race. All analyses were performed using R (version 4.1.1; R Development Core Team).

Participant characteristics. Education was categorized into less than a bachelor's degree (high school or less, Associate's degree, technical or vocational training) or at least a bachelor's degree (bachelor's, master's, doctoral, or professional degree). Self-reported race/ethnicity was categorized as Black if the participant chose Black/African American as one of her races (multiple races could be selected).

Frequency of "high" exposure results. To evaluate whether participants' emotional responses to the report depended on whether they had higher levels of a chemical compared with those of others in the study, we calculated summary variables representing the number and types of results headlines that a PR participant received on the first page of her MyCHDSReport. Participants received a "high" headline for a chemical group if they met one of three criteria: a serum level above the 95th percentile in the study for one or more chemicals, a serum level above the 75th percentile for multiple chemicals, or serum levels above the median in over 75% of chemicals in a group. Participants who had serum levels above the 95th percentile for five or more PCBs and 4,4′-DDE received a headline that highlighted common dietary sources for both groups of chemicals, and this headline was counted as two high headlines ("high" for PCBs and "high" for pesticides). Participants received a "low" headline for a chemical group if they had serum levels below the median for every chemical in the group. Participants could also receive a headline that their cholesterol level exceeded a health guideline.

We calculated the total number of "high" headlines about chemical groups that each participant received. We did not include the cholesterol headline because it conveys information that many participants would already know. We also created a variable indicating whether or not a participant received at least one "highest" headline. The "highest" headlines were a subset of "high" headlines that read, "Your blood had some [one] of the highest levels of [chemical group]" and corresponded to being above the 95th percentile for one or more chemicals in a group (not including the combined PCBs and pesticides headline). We hypothesized that a "highest" headline could be perceived by participants as having greater urgency than the other types of "high" headlines.

Web analytics. We calculated summary variables for website activity from the analytics data. For each participant, website events were categorized as occurring before or after the postinterview, based on the time of that interview. We calculated cumulative time on the site based on event timestamps. Events more than 30 min apart were treated as separate sessions on the website, and the time between sessions was excluded from the cumulative time calculation. We used Wilcoxon rank sum tests to compare time spent on the site by PR and AR participants and Fisher's exact tests to compare how likely the groups were to visit different sections of the report. Within each report group we performed similar analyses to examine differences between non-Black and Black participants in website activity. We used logistic regression to test for associations between viewing a page type and race, report type, and education. We first tested the hypothesis that report type could modify the relationship between race and pages viewed by including the interaction between race and report type. In the absence of a significant interaction ($\text{alpha} = 0.05$), we subsequently ran the regression with the main effects only. We calculated the odds ratios (OR) as $\exp(\beta)$. We also used multiple regression to test for associations between time spent online before the postinterview and race, report type, and education. For the regression model only, minutes online were square-root transformed to reduce right skewness. We first tested the hypothesis that report type could modify the relationship between race and time online by including the interaction between race and report type. In the absence of a significant interaction, we subsequently ran the regression with the main effects only.

Structured survey analysis. Statistical analysis of each structured survey question was restricted to participants who gave an answer at both the pre- and postinterview for that question (i.e., did not respond "do not know" or choose not to answer). We used Wilcoxon rank sum tests to test for differences between PR and AR participants at baseline. Within each report group, we used exact Wilcoxon-Pratt signed-rank tests to test whether paired differences (before and after visiting the MyCHDSReport) differed from zero. Wilcoxon's original approach to handling tied values (zero differences) drops them prior to ranking, such that the test is essentially performed on the subset of data that excludes the tied values. The Pratt method, in contrast, assigns ranks to the zero differences and then drops those ranks prior to testing and leaves the ranks of the nonzero differences unchanged (Pratt 1959). Because of the high proportion of zero differences in our data (Figure S1), we elected to use the Pratt method, as implemented in the R package coin (version 1.4.1).

Within each report group we further stratified by race and used exact Wilcoxon-Pratt signed-rank tests to test for changes in feelings and intentions separately among participants who were Black and non-Black. The results from the stratified analysis suggested the possibility that race modified the relationship between report type and changes in certain feelings after report-back. To confirm these findings, we ran linear mixed effect models to test the three-way interaction between race, report type, and interview (pre- or post-). In addition to the three-way interaction, all component simple and two-way effects were specified as fixed effects, and participant was specified as a random effect. From these models we sought only to evaluate the significance of the three-way interaction term using Type III Sum of Squares and Satterthwaite's method for computing the denominator degrees of freedom and F-statistics. Mixed model analysis was conducted using the lmerTest package in R (version 3.1.3; R Development Core Team).

We used multiple regression to test for associations between predictor variables and postinterview emotions scores in the PR group. Predictors included headlines (number of high headlines or any highest headline), race, education, and preinterview emotions score. Including the preinterview score as a covariate

adjusts for variation in emotion prior to report-back. We first tested the hypothesis that race modified the relationship between headlines and feelings at the postinterview by including the interaction between race and headlines. In the absence of a significant interaction, we ran the regression with the main effects only.

The study was reviewed and approved by the institutional review board of the Public Health Institute. Informed consent was obtained from all participants, and we have complied with all federal guidelines governing the use of human participants.

Results

Study Participation

Twenty eligible participants (7%) were not available to participate in this study: 4 were deceased, 2 were too ill, and 14 lacked valid contact information. Of the not-available participants, 13 (65%) were Black and 7 (35%) were non-Black. Participation rates for interviews were high, though lower for Black women, particularly at the preinterview stage. For structured interviews, 164 (76%) of available cohort daughters completed the preinterview, including 89 (82%) of non-Black daughters and 75 (69%) of Black daughters. Among preinterview participants, 84 (94%) of non-Black and 67 (89%) of Black women completed the postinterview (Figure 2). Similar proportions in the PR and AR groups [76 (68%) and 75 (71%), respectively] completed both interviews. For the semistructured interviews, 46 (78%) of available cohort daughters completed the preinterview, including 28 (90%) of non-Black daughters and 18 (64%) of Black daughters. Among these preinterview participants, all 28 (100%) non-Black participants and 16 (89%) Black participants completed the postinterview. We were unable to reach 38 (14%) of available cohort members by phone after many calls, and this was the primary reason for nonparticipation at the preinterview. Five participants in the structured-interview group and one in the semistructured group did not view their reports before their postinterview; these participants are excluded from the calculation of the postinterview participation rates above and from the paired pre- and postinterview analysis among the quantitative group. A total of 195 participants across both interview types completed the first interview and received only a web report (no hard copy report) and were therefore eligible for inclusion in the web analytics (Figure 2).

Participant Characteristics

Our analyses included 197 unique participants: 141 (72%) were in both the web analytics sample and the structured survey sample, 46 (23%) were only in the web analytics sample, and 10 (5%) were only in the structured survey sample. Because the two analysis samples were highly overlapping and the characteristics of the two groups were similar, we report here on the combined 197 participants (Table 1).

Participants were ages 49–56 y (median = 53 y) in 2015 when interviews began. Participants had a range of educational attainment with 91 (46%) having a bachelor's or higher degree. 86 (44%) had children under 18 y old in their household. Among the available group, those who participated in the study did not differ from those we were unable to recruit in education level (Fisher's exact test: $p = 1$; one nonparticipant missing education data is excluded) or having children at home (Fisher's exact test: $p = 0.50$).

Although recruitment was designed to be balanced by race, among the available group Black women were less likely to participate than non-Black women (Fisher's exact test: $p < 0.001$), yielding 81 (41%) participants who were Black and 116 (59%) who were non-Black. Of the non-Black participants, 98 (84%) were non-Hispanic White, 9 (8%) were Hispanic, 4 (3%) were Asian, and 5 (4%) were mixed race and not Black.

Table 1. Characteristics of women in the MyCHDSReport study ($n = 197$).

Characteristic	Response level	Number (%)
Black/African American race	No	116 (59)
	Yes	81 (41)
Education	Less than high school	6 (3)
	High school	77 (39)
	Vocational-Technical	9 (5)
	Associate	14 (7)
	Bachelor's	60 (30)
	Master's	22 (11)
	Doctorate	4 (2)
	Professional	5 (3)
Household members under age 18 y	None	111 (56)
	One or more	86 (44)
Lipid headline	No	121 (61)
	Yes	76 (39)
Number of "high" chemical headlines	0	6 (3)
	1	51 (26)
	2	45 (23)
	3	77 (39)
	4	18 (9)
Any "highest" headline	None	88 (45)
	One or more	109 (55)

Note: Of the 116 non-Black/African-American participants, 98 (84%) were non-Hispanic White, 9 (8%) were Hispanic, 4 (3%) were Asian, and 5 (4%) were mixed race and not Black.

Results reports included 1–4 headlines per participant, with 147 (75%) participants receiving 3–4 headlines. About half of participants [109 (55%)] had at least one "highest" headline, and 95 (48%) received 3–4 "high" or "highest" headlines.

Alternative Report-Back Format

A small number of participants from both survey groups ($n = 15$) requested a hard copy of the MyCHDSReport. Among participants who completed the preinterview, Black participants [13 (14%)] were significantly more likely to request a hard copy in comparison with non-Black participants [2 (2%)] (Fisher's exact test: $p < 0.001$). In addition, 51 of 187 participants (27%) who logged into their web report clicked on the button "Print Report," which loaded a PDF version of the report suitable for printing or saving.

Activity in the Web-Based Reports

A total of 210 (76%) of available participants completed the preinterview and received access to MyCHDSReport, including 195 who received only online access to the report and 15 who were mailed a hard copy of the report. Among those who received only the online report, 187 (96%) logged into MyCHDSReport before the postinterview. Login rates were identical in the PR group and AR group. Among those who logged into their report, 91 (98%) in the PR group and 90 (96%) in the AR group spent at least 1 min on the site. (We estimate that 1 min is sufficient time for a participant to read all of her personal headlines.) More non-Black participants logged into their report for any length of time than Black participants [114 (99%) vs. 73 (91%); Fisher's exact test: $p = 0.009$].

Before the postinterview, participants in the PR group who logged into their report ($n = 93$) were more likely to visit at least one chemicals page in comparison with participants in the AR group ($n = 94$) [78 (84%) vs. 62 (66%); Fisher's exact test: $p < 0.01$]. In the PR report, individual chemical results were located on the chemical pages, which included flame retardants, PFAS, pesticides, PCBs, and lipids. Participants in the AR group were more likely to visit the "Overall Study Results" in comparison with those in the PR group [50 (53%) vs. 31 (33%); Fisher's exact test: $p < 0.01$]. More PR than AR participants visited pages related to health [52 (56%) vs. 45 (48%); Fisher's exact test:

$p = 0.31$] and exposure reduction actions [47 (51%) vs. 38 (40%); Fisher's exact test: $p = 0.19$], although these differences were not statistically significant.

We further tested whether race, report type, and education were associated with viewing each page type (Figure 4A; Table 2; Table S2). We did not find any significant interactions between race and report type with viewing each page type, so we report here on the regression models including main effects only. Unsurprisingly, AR report recipients were less likely to view a "Chemical" page [OR = 0.34; 95% confidence interval (CI) = 0.16, 0.69] and more likely to view the "Overall Study Results" (OR = 2.52; 95% CI = 1.35, 4.79) in comparison with PR report recipients. Black participants were less likely to view a "Chemical" page (OR = 0.3; 95% CI = 0.14, 0.6) and the "Overall Study Results" (OR = 0.34; 95% CI = 0.17, 0.66) than non-Black participants, independent of report type. There were no associations between race or report type and likelihood of visiting a "Health" page or "Actions" page. We also found that participants with a bachelor's degree were more likely to view several page types, including "Actions" (OR = 3.17; 95% CI = 1.73, 5.92), "Chemical" (OR = 2.15; 95% CI = 1.04, 4.61) and "Overall Study Results" (OR = 2.32; 95% CI = 1.24, 4.39), than participants without a bachelor's degree.

After logging in for the first time, 53 (57%) PR participants navigated directly from the summary page to a chemical page that was highlighted in their personal headlines. This pattern of navigation did not differ between non-Black and Black participants [33 (58%) vs. 20 (56%); Fisher's exact test: $p = 0.83$]. Before the postinterview, 53 (57%) PR participants viewed all of the chemical pages highlighted in their personal headlines; however, a greater proportion of non-Black than Black participants viewed all of their headlines [39 (68%) vs. 14 (39%); Fisher's exact test: $p = 0.009$]. A total of 78 (84%) out of all PR participants viewed the corresponding chemical group page for at least one of her headlines. This rate was also higher among non-Black participants [51 (90%) vs. 27 (75%); Fisher's exact test: $p = 0.08$], although the difference was not statistically significant.

Participants in the AR group received access to their personal reports after their postinterview, so we were interested in comparing online time for both groups after the preinterview and again after the postinterview. We limited this analysis to 182 participants ($n = 89$ PR, $n = 93$ AR) who completed both interviews. Before the postinterview, participants in the PR group spent more time on the report [median = 19.5 min, interquartile range (IQR) = 10.4–38.1] than the AR group (median = 11.6 min, IQR = 5.2–27.6) ($W = 5{,}187.5$, $p = 0.003$). After the postinterview, 61 (66%) participants in the AR group opened their reports again, receiving their personal results for the first time, whereas only 19 (21%) in the PR group went back to the report. When considering total time on the report (before and after the postinterview combined), participants in the two groups spent a similar amount of time on their report (PR median = 21.5 min, IQR = 10.6–42.4; AR median = 21.8 min, IQR = 8.1–51.1; $W = 4{,}163$, $p = 0.9$).

We next examined differences in time online by race after stratifying by report type (Figure 4B; Table S3). Before the postinterview, among the PR group, median time online was 3.1 min greater for non-Black (median = 21.5 min, IQR = 12.3–41.8) than for Black participants (median = 18.4 min, IQR = 7.76–29.1) ($W = 1{,}145$, $p = 0.09$). The difference by race in time online before the postinterview was stronger in the AR group: median time online was 8.3 min greater for non-Black participants (median = 15.2 min, IQR = 5.67–32.3) than for Black participants (median = 6.9 min, IQR = 3.1–20.0) ($W = 1{,}372$, $p = 0.008$). We did not find a significant interaction between race and report type on square-root transformed minutes online before the postinterview. In the regression without the interaction, we found significant main effects for race ($\beta = -1.08$; 95% CI = −1.74, −0.42) and report type ($\beta = -0.84$; 95% CI = −1.48, −0.20), but not

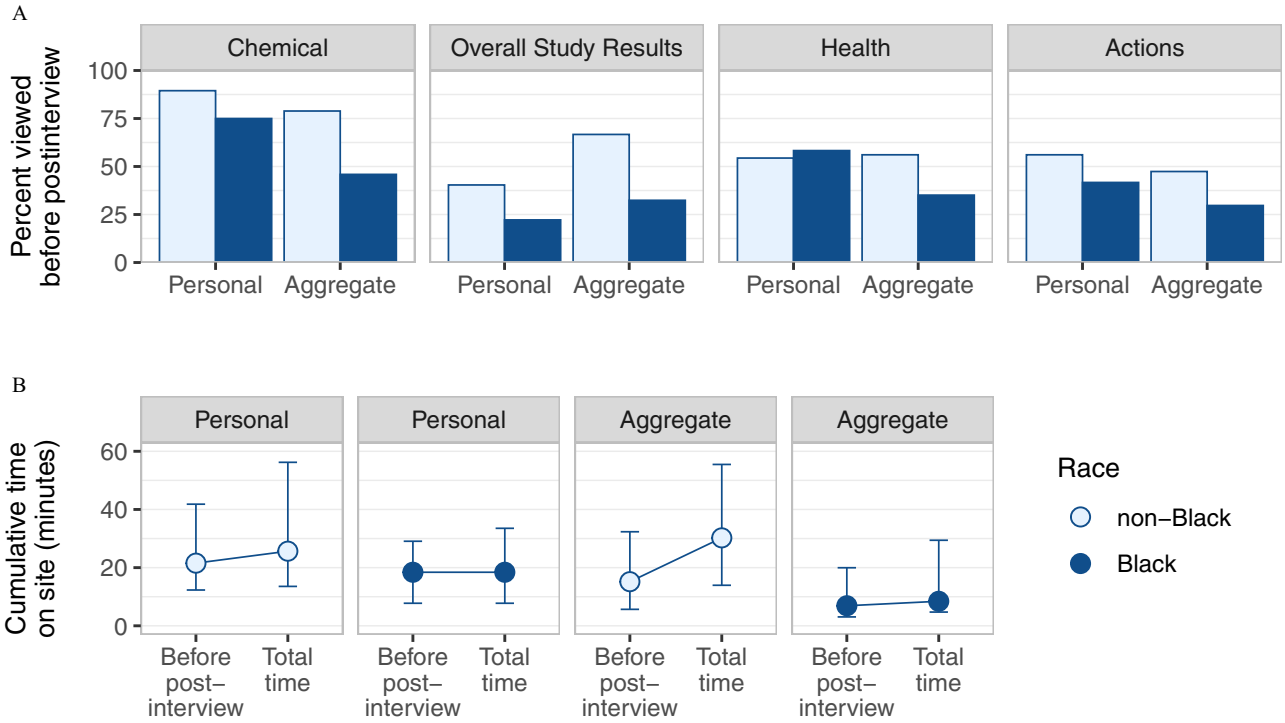

Figure 4. Participant activity on the MyCHDSReport website among non-Black ($n = 114$) and Black ($n = 73$) participants who opened their reports. Participants received a report containing their personal chemical levels or aggregate results only. (A) Frequency of visits to each type of page. (B) Cumulative time spent on the website (median and interquartile range) before and after the postinterview. Participants in the aggregate results group received access to their personal results after completing the postinterview. Summary data are available in Table S2 (A) and Table S3 (B).

Table 2. Odds ratios from logistic regressions evaluating whether education, race, and report type were associated with viewing each of four page types in the web-based results report ($n = 187$).

Page type	Variable	Odds Ratio (95% CI)
Chemical	Intercept	7.04 (3.39, 15.92)***
	Bachelor's degree or more (ref: no bachelor's degree)	2.15 (1.04, 4.61)*
	Black race (ref: non-Black race)	0.30 (0.14, 0.60)***
	Aggregate report (ref: personal report)	0.34 (0.16, 0.69)**
Overall study results	Intercept	0.46 (0.25, 0.84)*
	Bachelor's degree or more (ref: no bachelor's degree)	2.32 (1.24, 4.39)**
	Black race (ref: non-Black race)	0.34 (0.17, 0.66)**
	Aggregate report (ref: personal report)	2.52 (1.35, 4.79)**
Health	Intercept	1.25 (0.71, 2.21)
	Bachelor's degree or more (ref: no bachelor's degree)	1.33 (0.74, 2.40)
	Black race (ref: non-Black race)	0.74 (0.40, 1.35)
	Aggregate report (ref: personal report)	0.72 (0.40, 1.29)
Actions	Intercept	0.72 (0.40, 1.29)
	Bachelor's degree or more (ref: no bachelor's degree)	3.17 (1.73, 5.92)***
	Black race (ref: non-Black race)	0.60 (0.32, 1.13)
	Aggregate report (ref: personal report)	0.63 (0.34, 1.16)

Note: Models initially included the interaction between race and report-type. No significant interactions were found (alpha = 0.05), so we report regression results with main effects only. No other covariates were included in the models. We calculated the odds ratios as $\exp(\beta)$. Two-tailed p-values are derived from Wald tests. CI, confidence interval. $^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$.

level of education ($\beta = 0.31$; 95% CI = −0.34, 0.96). After the postinterview, among the AR group, more non-Black participants reopened their report than Black participants (84% vs. 38%; Fisher's exact test: $p < 0.001$) and received their personal results for the first time. Among the PR group participants who had already received their personal results, non-Black and Black participants reopened their reports at similar rates (24% vs. 17%; Fisher's exact test: $p = 0.60$). When considering total time on the report (before and after the postinterview combined), non-Black participants spent more time online than Black participants, and this difference was greater in the AR group (non-Black median = 30.2 min, IQR = 13.9–55.5; Black median = 8.4 min, IQR = 4.7–29.4; $W = 1{,}478.5$, $p = 0.0005$) than in the PR group (non-Black median = 25.7 min, IQR = 13.6–56.2; Black median = 18.4 min, IQR = 7.76–33.5; $W = 1{,}201$, $p = 0.03$) (Figure 4B).

Feelings about Receiving Results

Participants reported positive feelings—interested, respected, curious, and informed—about receiving their results reports. Between 68% and 93% of participants reported moderate, strong, or very strong levels of each positive feeling before and after receiving results reports in the PR and AR groups (Table S4). Somewhat fewer participants (57% to 69%) felt at least moderately empowered. At the same time, levels of negative feelings—helpless, worried, and scared—were low, with 72% to 96% of participants reporting not having the feeling or very mild or mild levels in both groups at both time points for each feeling. There were no differences in levels between the report groups at the preinterview, as would be expected from randomized assignment to the PR or AR group. Feelings of worry increased a small but significant amount between the pre- and postinterviews, and the increase was greater in the PR group than the AR group (Table S4). Feeling scared increased slightly in the PR group and feeling helpless increased slightly in the AR group. Levels of positive feelings did not change.

We next examined levels of feelings (Figure 5) and pre- to postinterview changes in feelings (Table 3) after stratifying by report type and race. Feelings of worry increased a small but significant amount between the pre- and postinterviews in non-Black participants in the PR and AR groups, and in Black participants in the PR group. There was no change in worry among Black participants in the AR group. At the postinterview, seven participants in the PR group (two non-Black and five Black) reported strong or very strong levels of worry; all of these participants had three to four high headlines and no low headlines. In addition, feeling scared increased slightly among Black participants in the PR group but not among any other subgroup. As before, levels of positive feelings did not change between the pre- and postinterviews. Using linear mixed effects models, the three-way interaction between race, report type, and interview (pre-/post-) was significant for feeling worried but not for any other feelings (Table S5). This finding supports the observation from the stratified analysis that the effect of report type on change in worry differs by race.

As would be expected, personal reports with more headlines about "higher" chemical levels were associated with greater concern in the postinterviews. Although the effects were small in absolute magnitude, they were greater among Black than among non-Black participants. We detected a significant interaction between race and number of "high" chemicals headlines with feeling scared and feeling worried (Table 4). Among Black participants, each additional "high" chemicals headline was associated with a 0.94 point (95% CI = 0.24, 1.64) higher level of feeling scared and 1.23 point (95% CI = 0.46, 2.00) higher level of feeling worried at the postinterview. The marginal effects were not significant among non-Black participants (Scared: $\beta = -0.03$, 95% CI = −0.46, 0.39; Worried: $\beta = 0.3$, 95% CI = −0.16, 0.76). We also detected a significant interaction between race and having any "highest" headline with feeling worried: among Black participants, having any "highest" headline was associated with a 1.96 point (95% CI = 0.78, 3.14) higher level of feeling worried at the postinterview, in comparison with a 0.27 point (95% CI = −0.73, 1.26) higher level among non-Black participants. There was no significant interaction between race and having any "highest" headline with feeling scared at the postinterview: among all participants, having any "highest" headline was associated with a 0.86 point (95% CI = 0.18, 1.55) higher level of feeling scared. Having more headlines about "higher" chemical levels was not associated with levels of any positive feelings at the postinterview. However, having a bachelor's degree or higher was associated with feeling slightly less informed at the postinterview in comparison with those without a bachelor's degree (Model 1: $\beta = -0.61$, 95% CI = −1.14, −0.08; Model 2: $\beta = -0.57$, 95% CI = −1.09, −0.06).

Intent to Participate in the CHDS in Future

Intentions to participate in future surveys or donate biological samples (blood, urine, or saliva) were very high before and after receiving results in both PR and AR groups, with 79%–91% of each group reporting being "very likely" to participate in each activity (Table S6). Intentions for future participation did not change after report-back in either the PR or AR group (Table S6), nor were any changes detected after further stratifying by race (Table S7, Figure S2).

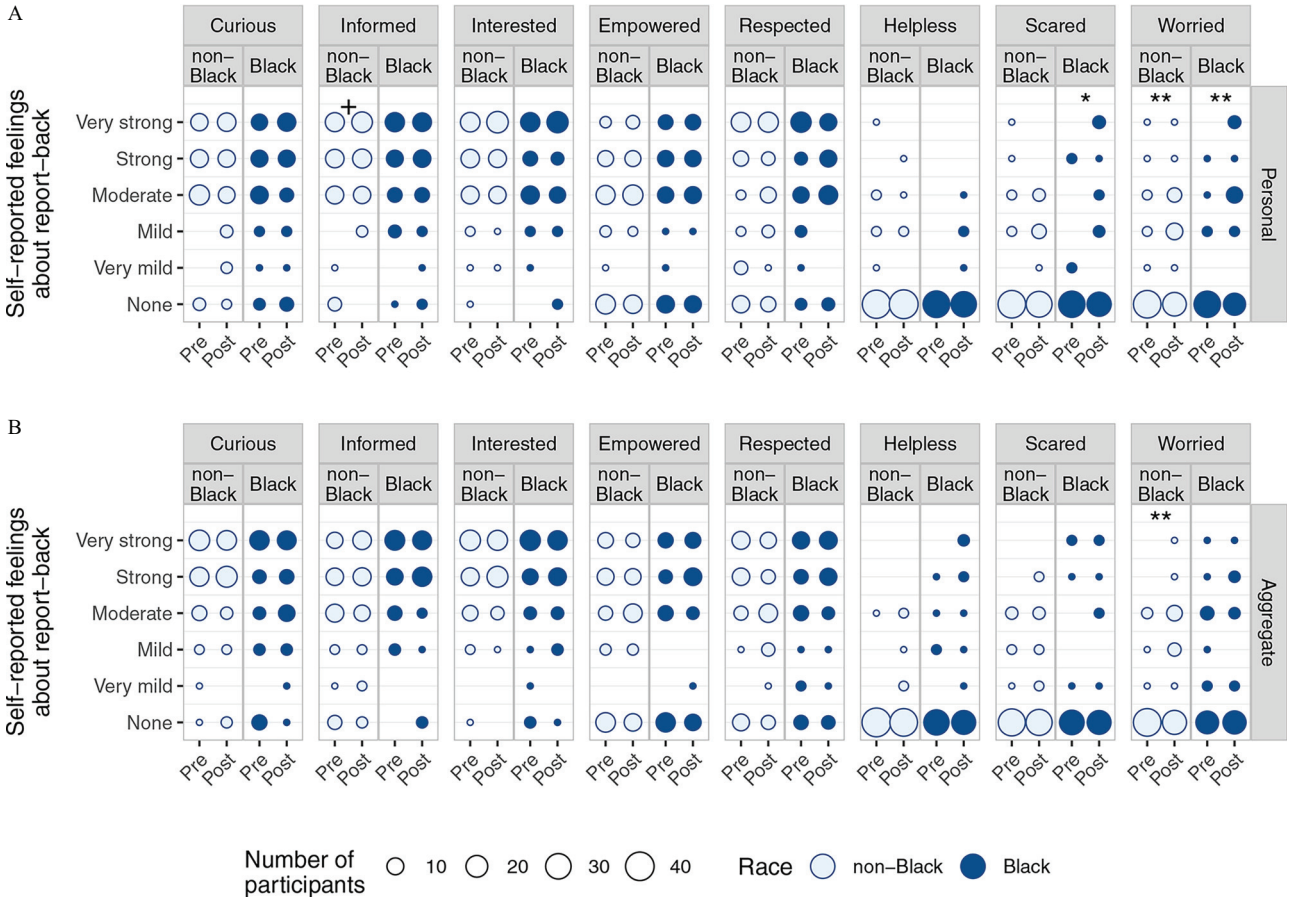

Figure 5. Feelings about receiving results before and after viewing MyCHDSReport among non-Black and Black participants who (A) received a report with their personal chemical levels or (B) who received aggregate results only. Symbols indicate *p*-values from Wilcoxon-Pratt signed-rank tests comparing feelings about getting results at the preinterview and postinterview, stratified by report type and race: $+ < 0.1$; $^{*}<0.05$, $^{**}<0.01$. Summary data are available in Table 3.

Participants were also asked about their willingness to recruit a child or grandchild to participate in a future study about breast cancer and the environment. An elevated number of "do not know" and "not at all likely" responses were nearly all attributable to participants who had no household members under age 18 y, suggesting that participants without children were using these categories to indicate that the question did not apply to them. Thus, we restricted this analysis to participants who had at least one household member under age 18 y and found that willingness to recruit a child or grandchild to participate was similar to levels of other intentions (Table S6).

Discussion

This study of women in their 40s and 50s who were biomonitored for flame retardants, PFAS, organochlorine pesticides, and PCBs in blood is the first test of returning results using personalized web-based reports created with DERBI. Participants showed strong interest in receiving results, with nearly all opening their report, and 98% of participants who opened their web-based personal results report spent enough time online to read their personalized summary headlines. The study design compared participants who initially received both personal and aggregate (study-wide) results with those who initially received only aggregate results. Participants who received personal results were more active on the reports, spending twice as much time viewing the report as those who received aggregate reports. Thus, they had greater opportunity to learn about the information in the report. Participants who received personal results tended to navigate from the summary page directly to more information about chemicals highlighted in their personal results headlines, which included descriptions of exposure sources, potential health effects, and tips for exposure reduction, as well as detailed graphs of their exposure results. However, personal results participants were less likely to visit the "Overall Study Results" section, suggesting an opportunity in future reports to draw more attention to big-picture findings and information about how their research participation contributed to science. A small group of participants preferred to receive print reports, so studies still need to make this option available.

When asked how they felt about receiving their results, participants in both groups reported feeling interested, respected, curious, and informed, both before and after receiving reports. Negative feelings—helpless, worried, and scared—were low, both before and after receiving results, scoring between not having the feeling and having mild negative feelings. Feelings of worry were more sensitive to the information in the report among Black participants: levels of worry increased among personal, but not aggregate, report recipients and worry after report-back was greater when personal results included headlines about chemical levels that were high in comparison with others. In contrast, among non-Black participants, worry increased in both report-type groups, and worry after report-back was not strongly associated with having high headlines. In general, few participants exceeded "moderate" levels of worry after report-back. However, for these participants, a "help line" to reach the study team can provide access to additional information and support, and

Table 3. Feelings about receiving results (frequency distribution and mean and standard deviation) stratified by race before and after participants received a report with personal chemical results and aggregate study results, or aggregate results only.

		Personal report								Aggregate report							
		non-Black participants				Black participants				non-Black participants				Black participants			
Feeling	Value	Pre	Post	Z	p	Pre	Post	Z	p	Pre	Post	Z	p	Pre	Post	Z	p
Curious	Mean (SD)	3.5 (1.4)	3.5 (1.5)	0.43	0.68	3.4 (1.5)	3.4 (1.8)	−0.89	0.38	4 (1.2)	3.9 (1.3)	−0.28	0.79	3.3 (2)	3.7 (1.3)	−0.83	0.42
	5	10 (25%)	12 (30%)	—	—	8 (24%)	11 (33%)	—	—	17 (40%)	15 (36%)	—	—	14 (42%)	13 (39%)	—	—
	4	11 (28%)	10 (25%)	—	—	9 (27%)	9 (27%)	—	—	14 (33%)	18 (43%)	—	—	5 (15%)	6 (18%)	—	—
	3	15 (38%)	9 (22%)	—	—	10 (30%)	5 (15%)	—	—	7 (17%)	4 (10%)	—	—	4 (12%)	9 (27%)	—	—
	2	0 (0%)	4 (10%)	—	—	2 (6%)	2 (6%)	—	—	2 (5%)	2 (5%)	—	—	3 (9%)	3 (9%)	—	—
	1	0 (0%)	3 (8%)	—	—	1 (3%)	1 (3%)	—	—	1 (2%)	0 (0%)	—	—	0 (0%)	1 (3%)	—	—
	0	4 (10%)	2 (5%)	—	—	3 (9%)	5 (15%)	—	—	1 (2%)	3 (7%)	—	—	7 (21%)	1 (3%)	—	—
Informed	Mean (SD)	3.5 (1.6)	4 (1)	−1.71	0.091	3.8 (1.3)	3.7 (1.4)	0.76	0.46	3.2 (1.6)	3.6 (1.5)	−1.42	0.16	4.1 (1)	3.9 (1.4)	0.34	0.73
	5	13 (31%)	16 (38%)	—	—	13 (39%)	12 (36%)	—	—	9 (22%)	13 (32%)	—	—	15 (45%)	13 (39%)	—	—
	4	12 (29%)	13 (31%)	—	—	9 (27%)	10 (30%)	—	—	11 (27%)	12 (29%)	—	—	9 (27%)	14 (42%)	—	—
	3	11 (26%)	10 (24%)	—	—	6 (18%)	6 (18%)	—	—	12 (29%)	9 (22%)	—	—	6 (18%)	2 (6%)	—	—
	2	0 (0%)	3 (7%)	—	—	4 (12%)	2 (6%)	—	—	2 (5%)	2 (5%)	—	—	3 (9%)	1 (3%)	—	—
	1	1 (2%)	0 (0%)	—	—	0 (0%)	1 (3%)	—	—	1 (2%)	2 (5%)	—	—	0 (0%)	0 (0%)	—	—
	0	5 (12%)	0 (0%)	—	—	1 (3%)	2 (6%)	—	—	6 (15%)	3 (7%)	—	—	0 (0%)	3 (9%)	—	—
Interested	Mean (SD)	3.8 (1.2)	4.1 (1)	−0.79	0.44	3.8 (1.1)	3.9 (1.4)	−0.43	0.69	4 (1.1)	4.2 (0.8)	−0.86	0.40	3.8 (1.6)	4 (1.2)	0.62	0.54
	5	14 (34%)	18 (44%)	—	—	13 (39%)	17 (52%)	—	—	17 (42%)	16 (40%)	—	—	16 (48%)	14 (42%)	—	—
	4	12 (29%)	11 (27%)	—	—	6 (18%)	4 (12%)	—	—	12 (30%)	18 (45%)	—	—	8 (24%)	11 (33%)	—	—
	3	11 (27%)	10 (24%)	—	—	11 (33%)	8 (24%)	—	—	8 (20%)	5 (12%)	—	—	4 (12%)	4 (12%)	—	—
	2	2 (5%)	1 (2%)	—	—	2 (6%)	2 (6%)	—	—	2 (5%)	1 (2%)	—	—	1 (3%)	3 (9%)	—	—
	1	1 (2%)	1 (2%)	—	—	1 (3%)	0 (0%)	—	—	0 (0%)	0 (0%)	—	—	1 (3%)	0 (0%)	—	—
	0	1 (2%)	0 (0%)	—	—	0 (0%)	2 (6%)	—	—	1 (2%)	0 (0%)	—	—	3 (9%)	1 (3%)	—	—
Empowered	Mean (SD)	2.2 (1.8)	2.5 (1.8)	−0.76	0.45	2.6 (1.9)	2.8 (1.9)	−0.37	0.73	2.5 (2)	2.6 (1.8)	−0.57	0.58	2.3 (2.1)	2.9 (2)	−1.40	0.16
	5	3 (7%)	5 (12%)	—	—	6 (18%)	7 (21%)	—	—	8 (19%)	6 (14%)	—	—	7 (21%)	8 (24%)	—	—
	4	8 (19%)	8 (19%)	—	—	8 (24%)	8 (24%)	—	—	10 (24%)	9 (21%)	—	—	5 (15%)	11 (33%)	—	—
	3	13 (31%)	15 (36%)	—	—	8 (24%)	9 (26%)	—	—	6 (14%)	13 (31%)	—	—	7 (21%)	4 (12%)	—	—
	2	3 (7%)	2 (5%)	—	—	1 (3%)	1 (3%)	—	—	3 (7%)	3 (7%)	—	—	0 (0%)	0 (0%)	—	—
	1	1 (2%)	0 (0%)	—	—	1 (3%)	0 (0%)	—	—	0 (0%)	0 (0%)	—	—	0 (0%)	1 (3%)	—	—
	0	14 (33%)	12 (29%)	—	—	10 (29%)	9 (26%)	—	—	15 (36%)	11 (26%)	—	—	14 (42%)	9 (27%)	—	—
Respected	Mean (SD)	2.8 (2.1)	3.2 (1.9)	−0.98	0.34	3.6 (1.6)	3.4 (1.5)	1.01	0.34	3.1 (2)	3 (1.6)	1.10	0.28	3.1 (1.9)	3.4 (1.8)	−0.18	0.86
	5	14 (35%)	15 (38%)	—	—	15 (44%)	9 (26%)	—	—	12 (30%)	9 (22%)	—	—	10 (31%)	11 (34%)	—	—
	4	7 (18%)	5 (12%)	—	—	4 (12%)	9 (26%)	—	—	11 (28%)	6 (15%)	—	—	6 (19%)	10 (31%)	—	—
	3	2 (5%)	8 (20%)	—	—	8 (24%)	12 (35%)	—	—	6 (15%)	13 (32%)	—	—	7 (22%)	4 (12%)	—	—
	2	2 (5%)	4 (10%)	—	—	3 (9%)	0 (0%)	—	—	1 (2%)	5 (12%)	—	—	1 (3%)	1 (3%)	—	—
	1	5 (12%)	1 (2%)	—	—	1 (3%)	0 (0%)	—	—	0 (0%)	1 (2%)	—	—	2 (6%)	1 (3%)	—	—
	0	10 (25%)	7 (18%)	—	—	3 (9%)	4 (12%)	—	—	10 (25%)	6 (15%)	—	—	6 (19%)	5 (16%)	—	—
Helpless	Mean (SD)	0.4 (1.1)	0.3 (0.9)	0.72	0.50	0 (0)	0.3 (0.7)	−2.00	0.12	0.1 (0.5)	0.2 (0.7)	−1.60	0.22	0.3 (1)	0.9 (1.7)	−1.39	0.14
	5	1 (2%)	0 (0%)	—	—	0 (0%)	0 (0%)	—	—	0 (0%)	0 (0%)	—	—	0 (0%)	3 (9%)	—	—
	4	0 (0%)	1 (2%)	—	—	0 (0%)	0 (0%)	—	—	0 (0%)	0 (0%)	—	—	1 (3%)	2 (6%)	—	—
	3	2 (5%)	1 (2%)	—	—	0 (0%)	1 (3%)	—	—	1 (2%)	2 (5%)	—	—	1 (3%)	1 (3%)	—	—
	2	2 (5%)	2 (5%)	—	—	0 (0%)	2 (6%)	—	—	0 (0%)	1 (2%)	—	—	2 (6%)	1 (3%)	—	—
	1	1 (2%)	0 (0%)	—	—	0 (0%)	1 (3%)	—	—	0 (0%)	2 (5%)	—	—	0 (0%)	1 (3%)	—	—
	0	36 (86%)	38 (90%)	—	—	31 (100%)	27 (87%)	—	—	41 (98%)	37 (88%)	—	—	29 (88%)	25 (76%)	—	—
Scared	Mean (SD)	0.5 (1.2)	0.6 (1.1)	−0.98	0.37	0.3 (1)	1.1 (1.8)	−2.34	0.017	0.4 (1)	0.6 (1.2)	−1.04	0.33	0.5 (1.4)	0.7 (1.5)	−0.38	0.68
	5	1 (2%)	0 (0%)	—	—	0 (0%)	4 (12%)	—	—	0 (0%)	0 (0%)	—	—	2 (6%)	2 (6%)	—	—
	4	1 (2%)	0 (0%)	—	—	2 (6%)	1 (3%)	—	—	0 (0%)	2 (5%)	—	—	1 (3%)	1 (3%)	—	—
	3	2 (5%)	4 (10%)	—	—	0 (0%)	2 (6%)	—	—	4 (10%)	4 (10%)	—	—	0 (0%)	2 (6%)	—	—
	2	2 (5%)	6 (15%)	—	—	0 (0%)	3 (9%)	—	—	2 (5%)	2 (5%)	—	—	0 (0%)	0 (0%)	—	—
	1	0 (0%)	1 (2%)	—	—	2 (6%)	0 (0%)	—	—	1 (2%)	2 (5%)	—	—	1 (3%)	1 (3%)	—	—
	0	34 (85%)	29 (72%)	—	—	30 (88%)	24 (71%)	—	—	35 (83%)	32 (76%)	—	—	27 (87%)	25 (81%)	—	—
Worried	Mean (SD)	0.5 (1.2)	1.1 (1.4)	−2.91	0.002	0.3 (0.9)	1.5 (1.9)	−3.01	0.002	0.3 (0.8)	1 (1.5)	−3.12	0.002	0.9 (1.5)	0.9 (1.6)	0.16	0.93
	5	1 (2%)	1 (2%)	—	—	0 (0%)	4 (12%)	—	—	0 (0%)	1 (2%)	—	—	1 (3%)	1 (3%)	—	—
	4	1 (2%)	1 (2%)	—	—	1 (3%)	1 (3%)	—	—	0 (0%)	1 (2%)	—	—	1 (3%)	3 (9%)	—	—
	3	2 (5%)	6 (15%)	—	—	1 (3%)	8 (24%)	—	—	3 (7%)	8 (19%)	—	—	5 (16%)	3 (9%)	—	—
	2	2 (5%)	9 (22%)	—	—	2 (6%)	2 (6%)	—	—	1 (2%)	5 (12%)	—	—	1 (3%)	0 (0%)	—	—
	1	1 (2%)	1 (2%)	—	—	0 (0%)	0 (0%)	—	—	1 (2%)	1 (2%)	—	—	2 (6%)	2 (6%)	—	—
	0	34 (83%)	23 (56%)	—	—	30 (88%)	19 (56%)	—	—	37 (88%)	26 (62%)	—	—	22 (69%)	23 (72%)	—	—

Note: These data are presented graphically in Figure 5. Statistical results (Z statistic and p-value) are shown for paired Wilcoxon-Pratt signed-rank tests for changes in feelings after report-back. Feelings are rated from "not having the feeling" (0) to "very strong" (5). Feelings data are available from 151 participants; 20 participants have incomplete feelings data. The number of participants missing data for each feeling is as follows: curious (3), informed (2), interested (4), empowered (0), respected (5), helpless (3), scared (4), worried (2). —, not applicable.

researchers may also wish to reach out proactively to participants with exceptionally high levels of a chemical. Small increases in worry may be viewed as a positive outcome because moderate levels of worry have been shown to motivate appropriate actions in other domains of preventative health (reviewed in Sweeny and Dooley 2017). Future research should confirm that moderate worry similarly motivates action to reduce exposure to environmental chemicals. In this study population, which included 54% with less than a 4-year college education, education was not associated with emotional response to report-back, with the exception that more-educated participants felt less "informed" after receiving their personal reports in comparison with participants without

Table 4. Multiple regression models evaluating mutually adjusted associations between participant characteristics and report headlines with levels of eight emotions after receiving individual-level report-back.

	Model 1: Number of "high" headlines			Model 2: Any "highest" headlines		
Feeling	Variable	Coefficient (95% CI)	R^2	Variable	Coefficient (95% CI)	R^2
Curious ($n=73$)	Intercept	1.88 (0.50, 3.26)*	0.09	Intercept	2.44 (1.27, 3.60)*	0.07
	Preinterview emotion level	0.25 (−0.01, 0.52)	—	Preinterview emotion level	0.29 (0.03, 0.55)*	—
	Bachelor's degree or more (ref: no bachelor's degree)	0.26 (−0.49, 1.02)	—	Bachelor's degree or more (ref: no bachelor's degree)	0.19 (−0.56, 0.94)	—
	Black race (ref: non-Black race)	−0.19 (−1.00, 0.61)	—	Black race (ref: non-Black race)	0.00 (−0.76, 0.76)	—
	Number of "high" chemical headlines	0.24 (−0.18, 0.67)	—	Having any "highest" headline	−0.18 (−0.96, 0.60)	—
Informed ($n=75$)	Intercept	3.62 (2.67, 4.57)*	0.19	Intercept	3.51 (2.70, 4.31)*	0.20
	Preinterview emotion level	0.30 (0.12, 0.48)*	—	Preinterview emotion level	0.30 (0.12, 0.47)*	—
	Bachelor's degree or more (ref: no bachelor's degree)	−0.61 (−1.14, −0.08)*	—	Bachelor's degree or more (ref: no bachelor's degree)	−0.57 (−1.09, −0.06)*	—
	Black race (ref: non-Black race)	−0.42 (−0.97, 0.14)	—	Black race (ref: non-Black race)	−0.47 (−1.00, 0.05)	—
	Number of "high" chemical headlines	−0.14 (−0.42, 0.15)	—	Having any 'highest' headline	−0.32 (−0.85, 0.21)	—
Interested ($n=74$)	Intercept	3.79 (2.51, 5.08)*	0.03	Intercept	3.77 (2.62, 4.92)*	0.03
	Preinterview emotion level	0.01 (−0.24, 0.27)	—	Preinterview emotion level	0.01 (−0.25, 0.26)	—
	Bachelor's degree or more (ref: no bachelor's degree)	0.37 (−0.23, 0.96)	—	Bachelor's degree or more (ref: no bachelor's degree)	0.36 (−0.22, 0.95)	—
	Black race (ref: non-Black race)	−0.09 (−0.71, 0.53)	—	Black race (ref: non-Black race)	−0.09 (−0.68, 0.49)	—
	Number of "high" chemical headlines	0.00 (−0.32, 0.32)	—	Having any "highest" headline	0.08 (−0.53, 0.68)	—
Empowered ($n=76$)	Intercept	2.48 (1.14, 3.82)*	0.06	Intercept	2.24 (1.22, 3.26)*	0.06
	Preinterview emotion level	0.25 (0.01, 0.49)*	—	Preinterview emotion level	0.23 (0.00, 0.47)	—
	Bachelor's degree or more (ref: no bachelor's degree)	−0.19 (−1.05, 0.66)	—	Bachelor's degree or more (ref: no bachelor's degree)	−0.15 (−1.00, 0.70)	—
	Black race (ref: non-Black race)	0.29 (−0.61, 1.20)	—	Black race (ref: non-Black race)	0.20 (−0.66, 1.06)	—
	Number of "high" chemical headlines	−0.18 (−0.66, 0.31)	—	Having any "highest" headline	−0.24 (−1.13, 0.65)	—
Respected ($n=74$)	Intercept	1.68 (0.48, 2.88)*	0.37	Intercept	2.27 (1.31, 3.24)*	0.35
	Preinterview emotion level	0.46 (0.28, 0.64)*	—	Preinterview emotion level	0.48 (0.30, 0.66)*	—
	Bachelor's degree or more (ref: no bachelor's degree)	−0.49 (−1.19, 0.20)	—	Bachelor's degree or more (ref: no bachelor's degree)	−0.58 (−1.27, 0.12)	—
	Black race (ref: non-Black race)	−0.39 (−1.10, 0.31)	—	Black race (ref: non-Black race)	−0.25 (−0.93, 0.43)	—
	Number of "high" chemical headlines	0.24 (−0.13, 0.60)	—	Having any "highest" headline	−0.07 (−0.77, 0.62)	—
Helpless ($n=73$)	Intercept	−0.19 (−0.76, 0.39)	0.11	Intercept	0.18 (−0.24, 0.60)	0.07
	Preinterview emotion level	0.23 (0.00, 0.47)	—	Preinterview emotion level	0.26 (0.02, 0.50)*	—
	Bachelor's degree or more (ref: no bachelor's degree)	−0.03 (−0.41, 0.35)	—	Bachelor's degree or more (ref: no bachelor's degree)	−0.08 (−0.47, 0.30)	—
	Black race (ref: non-Black race)	−0.05 (−0.46, 0.36)	—	Black race (ref: non-Black race)	0.07 (−0.32, 0.47)	—
	Number of "high" chemical headlines	0.17 (−0.03, 0.37)	—	Having any "highest" headline	0.05 (−0.35, 0.45)	—
Scared ($n=74$)	Intercept	0.73 (−0.40, 1.85)	0.14	Intercept	0.21 (−0.55, 0.96)	0.13
	Preinterview emotion level	0.15 (−0.15, 0.45)	—	Preinterview emotion level	0.19 (−0.11, 0.49)	—
	Bachelor's degree or more (ref: no bachelor's degree)	−0.15 (−0.84, 0.54)	—	Bachelor's degree or more (ref: no bachelor's degree)	−0.31 (−0.98, 0.36)	—
	Black race (ref: non-Black race)	−2.45 (−4.78, −0.12)*	—	Black race (ref: non-Black race)	0.31 (−0.36, 0.98)	—
	Number of "high" chemical headlines*Race	0.98 (0.17, 1.79)*	—	Having any "highest" headline	0.86 (0.18, 1.55)*	—
	Number of "high" chemical headlines (non-Black race)	−0.03 (−0.46, 0.39)	—	—	—	—
	Number of "high" chemical headlines (Black race)	0.94 (0.24, 1.64)*	—	—	—	—
Worried ($n=75$)	Intercept	0.31 (−0.92, 1.53)	0.17	Intercept	0.88 (0.00, 1.77)*	0.16
	Preinterview emotion level	0.10 (−0.23, 0.44)	—	Preinterview emotion level	0.22 (−0.12, 0.55)	—
	Bachelor's degree or more (ref: no bachelor's degree)	0.17 (−0.58, 0.93)	—	Bachelor's degree or more (ref: no bachelor's degree)	−0.05 (−0.79, 0.69)	—
	Black race (ref: non-Black race)	−2.54 (−5.11, 0.02)	—	Black race (ref: non-Black race)	−0.79 (−2.04, 0.47)	—
	Number of "high" chemical headlines*Race	0.93 (0.04, 1.82)*	—	Having any "highest" headline*Race	1.70 (0.14, 3.25)*	—
	Number of "high" chemical headlines (non-Black race)	0.30 (−0.16, 0.76)	—	Having any "highest" headline (non-Black race)	0.27 (−0.73, 1.26)	—
	Number of "high" chemical headlines (Black race)	1.23 (0.46, 2.00)*	—	Having any "highest" headline (Black race)	1.96 (0.78, 3.14)*	—

Note: Models initially included the interaction between race and headlines. In the presence of a significant interaction (alpha = 0.05), marginal effects of headlines are reported for each race group. In the absence of a significant interaction, we ran the regression with the main effects only. No other covariates were included in the models. Two-tailed p-values are derived from t-tests. —, not applicable; CI, confidence interval.
*$p < 0.05$.

a bachelor's degree. In this group, the reports may have made participants more aware of how much they did not know about chemicals and health.

Black CHDS members were less likely than others to log into their reports and visited fewer pages, but these differences were less pronounced in the group who received personal exposure results, suggesting that offering personal results may help to respectfully engage members of the Black community in research and increase the benefits to them.

A systematic literature review of barriers and facilitators for underrepresented groups in research identified several factors that may play a role in Black participants' spending less time viewing their report and in their lower participation rate in the study (George et al. 2014). Barriers include competing time demands influenced by the effects of structural racism on working conditions, family caretaking responsibilities, and limited financial resources. In addition, many of the reviewed studies identified mistrust as a barrier stemming from racist research abuses in the past, and this effect was also highlighted recently (Payne-Sturges et al. 2021). Mistrust was frequently associated with believing that research will benefit only white people or the research institution (George et al. 2014), a belief that could lead Black people to think that results reports will not be relevant and helpful to them. Future research to understand the barriers specifically to engaging with personal results reports could include interviews with participants who spent little time on their reports. To learn about participants who were not reachable for interviews, another approach would be to offer results without asking for interview participation and observe whether people access their report.

Past research on facilitators of participation by underrepresented groups supports our inference that offering personal results can encourage participation and engagement. George et al. (2014) found that receiving information about personal health and about the study were considered benefits of being in a study and that learning about the research process could reduce distrust. DERBI reports cover these topics, but participants did not know this until they opened the report. Future research could evaluate alternative dissemination strategies that help participants anticipate the benefits from their report. Researchers also could test additional CBPR methods, for instance, further engaging a participant advisory council (as in this study) or other trusted community leaders or organizations, or returning results in health care settings or community meetings (Brody et al. 2009; Perovich et al. 2018). Of particular importance, researchers can address the mistrust and concerns of participants who identify as Black by responding to the inequitable chemical exposures discovered in their studies. A recent commentary in this journal calls on researchers to investigate the role of racism in exposure inequalities (Payne-Sturges et al. 2021). In biomonitoring studies where participants receive their personal results, scientists and participants can partner in powerful ways to influence public policies that drive exposures, as illustrated in an earlier study by some among this team of authors (Brody et al. 2009). The success of these efforts most directly addresses the expectations of members of the Black community that research will not have benefits for them.

A benefit of digital report-back is that it can offer different experiences for different users; however, Black participants in our study were more likely to opt for a print report in comparison with non-Black participants. Smartphone report formats may improve accessibility in future studies, because phones are an important means for accessing the Internet in low-income communities, and people who are Black or Hispanic, younger, or less educated are more likely to be smartphone-dependent (Pew Research Center 2021).

This investigation is the first study, as far as we know, to compare randomized groups receiving individual results vs. only study-wide, aggregate results, a design that strengthens our ability to infer that the experience in the individual report-back group is specifically due to receiving individual results. Other strengths of our study include the large number of participants and strong response rate in our structured, quantitative survey in comparison with earlier studies (Giannini et al. 2018; Tomsho et al. 2019), and the representation of Black and non-Black participants across a range of education levels. However, a limitation of our study is that the CHDS is a highly engaged cohort in which the second-generation participants were enrolled at birth and have participated along with their mothers over many years, and engagement is enhanced by having a PAC and a newsletter. Thus, future research is needed to evaluate whether our findings are generalizable to studies with less-extensive engagement practices. A related limitation is that attitudes toward future participation were strongly positive at the outset, limiting the opportunity to observe an effect of report-back.

Our results are consistent with previous reports that participants want to receive their results and can benefit from them (Brody et al. 2014; National Academies of Sciences, Engineering and Medicine 2018). Although researchers often anticipate that returning personal chemical-exposure results will generate undue worry or panic (Ohayon et al. 2017), the National Academy of Sciences Engineering and Medicine consensus report concluded that these concerns are overstated and that returning results builds trust with study participants and enables them to better protect their health (National Academies of Sciences, Engineering and Medicine 2018). Our results add new evidence that emotional responses are positive. Other studies have supported the value of report-back by showing that participants generally understand and learn from their results (Altman et al. 2008; Brody et al. 2014; Giannini et al. 2018; Perovich et al. 2018; Tomsho et al. 2019), although research is still needed to keep improving methods to return results and advance environmental health literacy, including the ability to take health-protective actions.

Future studies are needed to better understand report-back in other research contexts that pose different challenges. DERBI reports are tailored to each study, and the CHDS content is most relevant to report-back for persistent chemicals. Different messages would be needed for chemicals that have a short half-life in the body, for example, to explain the potential for temporal variation in results and highlight strategies to reduce exposure. We anticipate that report-back experiences in studies of short-lived chemicals may be more positive, because previous studies show strong interest by participants in "actionability" of their results (Brody et al. 2014; Perovich et al. 2018; Ramirez-Andreotta et al. 2016b), and chemicals with short half-lives offer more opportunity for exposure reduction. Studies of short-lived chemicals will typically have considered temporal variability in their sampling plan, for example by collecting composites or repeated samples, to create reliable exposure measurements. When multiple samples were collected from an individual, report-back can visually communicate temporal variation by showing the samples separately or, in some instances, it may be appropriate to reduce variability by reporting the median.

Other types of report-back outcomes beyond those assessed here should also be quantified, including effects on participants' environmental health literacy and behavior change. We did not investigate participant concerns about security or privacy risks in the online reports, although the potential for data breaches in research has been a concern of potential study participants (Udesky et al. 2020). DERBI does not contain any personally identifiable information.

Report-back in this study reflects guidance from the National Academies of Sciences, Engineering and Medicine Consensus Report (National Academies of Sciences, Engineering and Medicine 2018) and a researcher handbook based on earlier exposure biomonitoring studies (Dunagan et al. 2013). Researchers can use these documents to guide choices for studies that differ from the CHDS in various ways. For instance, in studies of exposed communities, report-back should not normalize high exposures by limiting benchmarks to within-community comparisons. In very small studies, comparisons to external benchmarks, such as NHANES, are more appropriate than comparisons to the study distribution. When a government health guideline exists, results should be reported in relation to this level, with possible exceptions when researchers believe the standard does not reflect current science. Ethics guidelines call for rapid notification of participants whose results exceed a clinical health guideline, and studies may also contact participants about results that are extreme outliers even in the absence of a known clinical implication. Extreme outliers suggest an unusual—and likely modifiable—exposure scenario. The National Academies of Sciences, Engineering and Medicine report extensively addresses concerns about laboratory quality assurance and quality control practices and calls on the research community to develop new practices that facilitate reporting back results from academic and other laboratories that are not certified under the Clinical Laboratory Improvement Amendments for clinical health results (National Academies of Sciences, Engineering and Medicine 2018). Results should not be reported if there is reason to believe that laboratory practices were inadequate or the chain of custody cannot be documented, so samples may be misidentified. Otherwise, the National Academies of Sciences, Engineering and Medicine report recommends, and we concur, that individual results should be offered to study participants in nearly all circumstances as an ethical obligation to promote autonomy and increase the benefits of research to them. In CHDS, participants made their own decisions, through informed consent, whether to receive their results.

In this study of blood levels of 42 persistent chemicals, individual report-back motivated study participants to spend more time learning about environmental chemicals, including information on the chemicals' sources and health effects and how to reduce exposures. The personalized headlines successfully directed participants to navigate to the information most important to each individual, based on her results. The slight increase in worry associated with report-back may appropriately motivate actions to reduce exposures, a possibility that warrants further study. The high level of engagement with personal results reports suggests that report-back can contribute to environmental public health by improving environmental health literacy.

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