Development and Outcomes of Returning Polycyclic Aromatic Hydrocarbon Exposure Results in the Washington Heights, NYC Community

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ABSTRACT: Report-back of research results (RBRR) is becoming standard practice for environmental health research studies. RBRR is thought to increase environmental health literacy (EHL), although standardized measurements are limited. For this study, we developed a report back document on exposure to air pollutants, Polycyclic Aromatic Hydrocarbons, during pregnancy through community engaged research and evaluated whether the report increased EHL. We used focus groups and surveys to gather feedback on the report document from an initial group of study participants (Group 1, n = 22) and then sent the revised report to a larger number of participants (Group 2, n = 168). We conducted focus groups among participants in Group 1 and discussed their suggested changes to the report and how those changes could be implemented. Participants in focus groups demonstrated multiple levels of EHL. While participant engagement critically informed report development, a survey comparing feedback from Group 1 (initial report) and Group 2 (revised report) did not show a significant difference in the ease of reading the report or knowledge gained about air pollutants. We acknowledge that our approach was limited by a lack of EHL tools that assess knowledge and behavior change, and a reliance on quantitative methodologies. Future approaches that merge qualitative and quantitative methodologies to evaluate RBRR and methodologies for assessing RBRR materials and subsequent changes in knowledge, attitudes, and behavior, may be necessary.

KEYWORDS: Report back, children's environmental health, environmental health literacy, polycyclic aromatic hydrocarbons

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Introduction

Guidelines and best practices for reporting back personal environmental exposure results continue to evolve. Often exposure measurements rely on novel analytic methods or contexts where human levels are not well elucidated or understood.[1] This uncertainty previously resulted in researchers not sharing participants' exposure levels with them. However, guidance from the National Academy of Sciences, National Conversation on Public Health and Chemical Exposures, and European and Canadian biomonitoring programs now encourage or require report back to research participants.[2,3] In addition, it has been shown that participants want to receive their results to understand how they compare with others in their study and other groups.[4-7] There are numerous ways of returning results, but each community and each exposure are different, thus the report-back of research results (RBRR) needs to be tailored to both communities and exposures.

Returning results provides the opportunity for participants and communities to learn more about environmental health, and/or how their environment can impact their health and the health of their community. This is the nexus of environmental health literacy (EHL).[8] Research has shown that not only do participants want their results, but that report back leads to participants learning about environmental health and consideration of possible exposure reduction strategies. These findings have been observed even in the face of uncertainty around the exposures.[9] In environmental justice communities comprised of individuals of lower socioeconomic status with high levels of contamination, participants are more likely to want their results and any available additional information on how

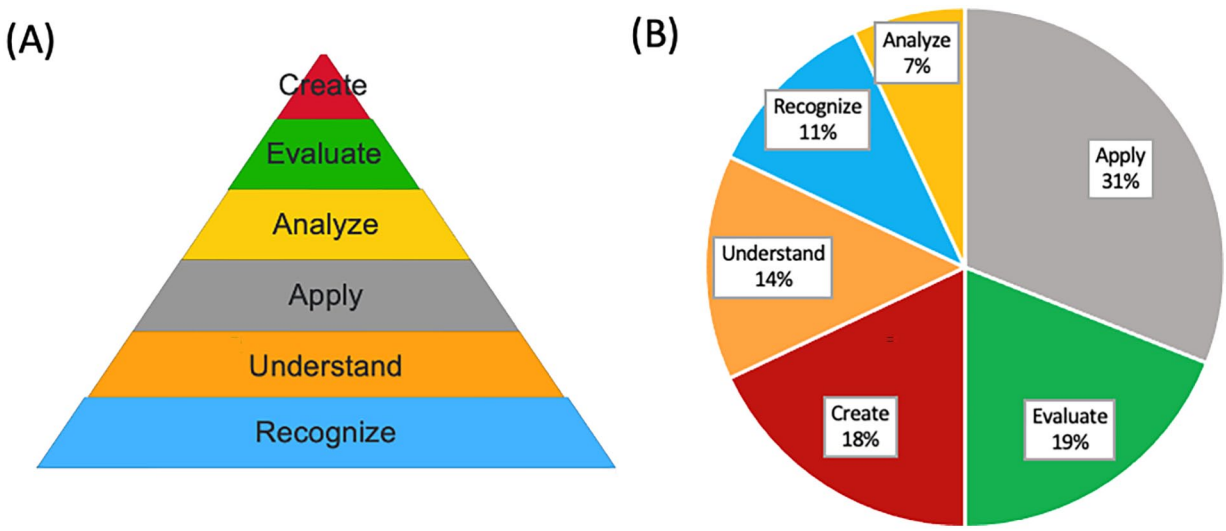

Figure 1. Environmental health literacy hierarchy: (A) EHL hierarchy as described by Finn and O'Fallon's environmental health literacy taxonomy (1) and (B) pie chart depicting the percent of focus group conversation related to each aspect of the EHL hierarchy.

to reduce exposures.[9] They also are willing to participate in community engaged research to better understand the exposures in their community.[10] Research that engages community members is critical for understanding the needs and desires of the community in which the research is taking place. This is not only good practice, but especially important while developing a report back document that needs to be culturally sensitive and meaningful to study participants and community members. By engaging the community to create a meaningful report, it allows for the participants to learn about environmental health and build EHL.

The connection between RBRR and EHL has been difficult to measure. The potential outcomes of EHL include: improving public health, increased research transparency, a mental model shift of where exposure sources are located (far away vs in home), reduction of exposures, and improvement of health outcomes for individuals and communities.[4,8,11] Finn and O'Fallon proposed an EHL hierarchy: recognize, understand, apply, analyze, evaluate, and create. This is similar to Bloom's taxonomy, which tracks increased comprehension of educational topics. Generally, individuals spend more time at the lower levels (recognize, understand, apply) of EHL before making their way to the higher levels (analyze, evaluate, create) (Figure 1A). However, there are few established methods for evaluating changes in EHL, or even evaluating the role of RBRR in building EHL.

RBRR is an important part of conducting environmental health research, and is now recognized as an ethical obligation.[2,12,13] However, RBRR must be conducted in a manner that makes the results accessible to the participants and done in a way to reduce harm. There is limited information on conducting RBRR for exposure assessments in pregnant individuals, particularly within culturally diverse communities.[4] Pregnancy is a sensitive time period for environmental exposures for both the fetus and pregnant person because of the rapid fetal development occurring.[14] Furthermore, it is well established that many chemicals can cross the placental barrier and even accumulate in the fetus. As a result, exposure studies during pregnancy are potentially assessing exposures to the pregnant person and the fetus, which can be confounded by differential risks to each. Additional challenges to overcome include reporting on data that may not have established health connections, or novel exposures that have limited information available to contextualize results or compare to other communities. To address these issues, the 2 main purposes of this research was to (1) develop a meaningful report back document on exposure to air pollutants during pregnancy through community engaged research and (2) evaluate whether the report increased EHL. To complete these aims, we worked with the Columbia Center for Children's Environmental Health's Fair Start Cohort. This cohort was created to study prenatal and early life environmental exposures on children's health outcomes in an urban population. All cohort participants completed a prenatal visit where they wore passive air monitoring wristbands to measure personal chemical exposure[15] and for this study we conducted focus groups and surveys in a subset of participants who received RBRR.

Methods

Study population: Fair start cohort

Recruitment of the Fair Start cohort at the Columbia Center for Children's Environmental Health (CCCEH) began in 2013 at New York Presbyterian Ambulatory Care clinics in New York City. Participants primarily reside in the neighborhoods of Northern Manhattan and the South Bronx and 94% self-identify as Hispanic. A prenatal visit was completed during the third trimester of pregnancy, which included wearing a passive sampling silicone wristband for 48 hours to evaluate exposure to 63 polycyclic aromatic hydrocarbons (PAHs).[16]

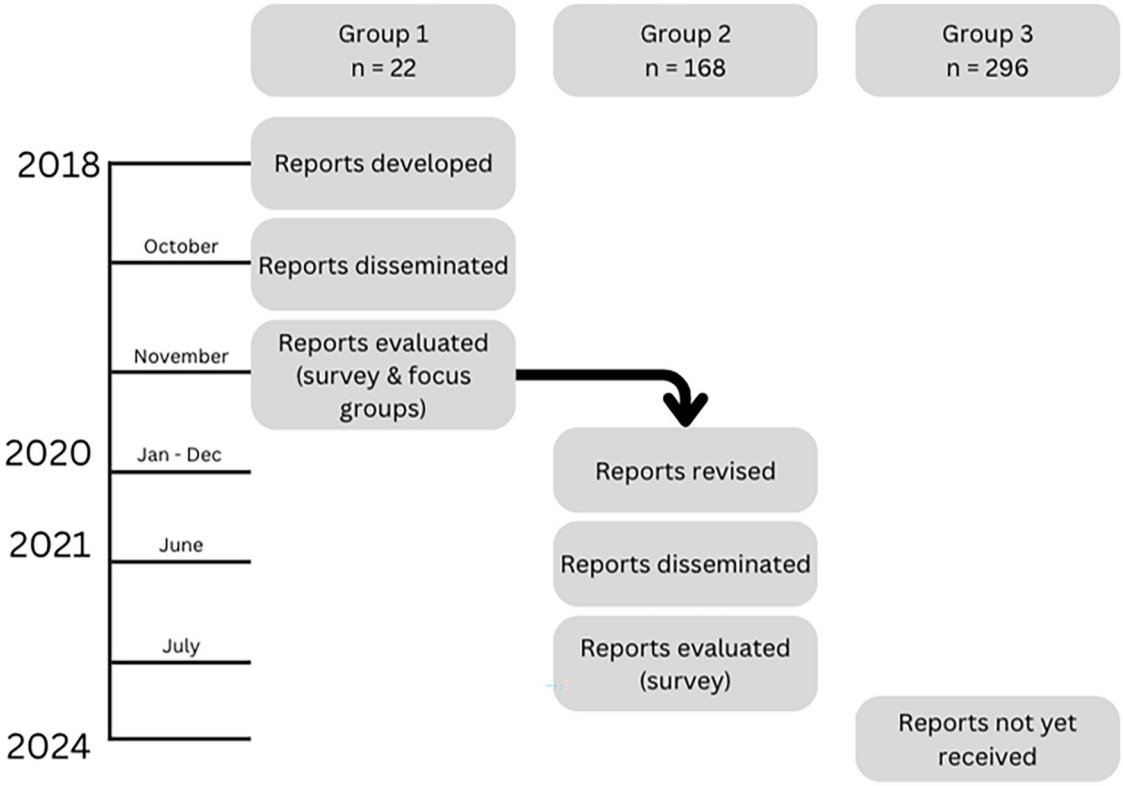

Figure 2. Flow chart of participants included in the study.

Recruitment into the Fair Start Cohort remains ongoing; the planned sample size is 1000 participants. During the consent process, all participants are given the option to receive their results from their wristband sampler; >99% have opted to receive their results. This study was approved by the Columbia University Irving Medical Center Institutional Review Board and participants provided informed consent prior to their prenatal visit.

Study population: Report back

A total of 190 participants from the Fair Start Cohort received a RBRR for the PAHs found in the wristbands they wore for 48 hours: Group 1 (n = 22) was included in the first round of report development and Group 2 (n = 168) received the revised version of the report. For Group 1, participants were contacted by a research worker and invited to the focus group. They were consented separately for focus group participation. We evaluated the demographics of these participants against the rest of the cohort, whose wristbands have not yet been analyzed for exposure (Group 3; n = 296) Figure 2. The group assignment was based on date of enrollment into the study such that Group 1 includes the initial participants, Group 2 includes all participants enrolled until March 2020, when we paused enrollment due to the COVID-19 pandemic and Group 3 includes everyone recruited once the COVID-19 pause was lifted. Table 1 summarizes those who participated in the report development, compared to the rest of the cohort.

To better understand whether differences between groups were due to differing group sizes or large sample sizes of multiple groups, or whether there were true differences between them, we conducted randomization tests. For each variable (maternal age, education, marital status, income, and ethnicity), we tested different sample sizes (one-half of the total number of samples, one-fourth of the total number of samples, with a minimum at n = 22) and randomly sampled the respective number of observations from each group. We then conducted either a Kruskal-Wallis or Fisher's exact test and denoted the *P*-value. This process was repeated 10 000 times and the median *P*-value was recorded. Results for this process can be seen in Table S1.

Preliminary report development

A previously developed report from a prior study using wristbands to assess exposure to PAHs was used as a template for the development of the report in the CCCEH cohort.[17] In that study, we developed the report with community liaisons as well as a Tribal Advisory Board. The report utilized best practices and recommendations from the Silent Spring Institute, particularly for how individual data points were graphed within the context of the study population.[18] For use in the Fair Start cohort, the report was reviewed and edited for cultural competency. CCCEH staff members who are from the local community reviewed the report for guidance on the results. Notably, the cohort had levels of naphthalene

Table 1. Participants in each phase of the report back.

CHARACTERISTIC	N	GROUP 1 N = 22[1]	GROUP 2 N = 168[1]	GROUP 3 N = 296[1]	*P*-VALUE[2]
Maternal age	482	31.0 (26.5,34.0)	28.0 (24.0,33.0)	30.0 (26.0,35.0)	0.006
Education	475				0.8
<High School		4 (18%)	39 (24%)	56 (19%)	
High School Diploma		11 (50%)	65 (40%)	126 (44%)	
2 or 4 y College Degree		7 (32%)	60 (37%)	107 (37%)	
Marital status	457				0.002
Never married		6 (27%)	76 (46%)	77 (29%)	
Married/Living w partner		12 (55%)	78 (47%)	166 (61%)	
Divorced/Separated		4 (18%)	11 (6.7%)	27 (10%)	
Income	442				0.2
0-20 000		7 (33%)	81 (52%)	143 (54%)	
>20,000		14 (67%)	74 (48%)	123 (46%)	
Ethnicity	482				0.017
Hispanic		21 (95%)	160 (97%)	262 (89%)	
Non-Hispanic		1 (4.5%)	5 (3.0%)	23 (7.8%)	
Unknown/Not reported		0 (0%)	0 (0%)	10 (3.4%)	

[1]Median (IQR); n (%).
[2]Kruskal-Wallis rank sum test; Fisher's exact test.

in their wristbands that were higher than that seen in other studies. The liaisons noted that naphthalene can be found in products used medicinally and culturally in the community. Many of the naphthalene-containing products are sent to the participants from family members outside the US. The liaisons flagged this exposure pathway as one that should be addressed within the cultural context. Additionally, the report template identified common sources of PAH exposure, such as grilling and use of wood stoves. Although grilling is less common in New York City and wood burning for heat is not prevalent, these sources remained in the report for participant knowledge on the recommendation of the liaisons. The report was then translated into Spanish. The first revision of the report was sent to the Group 1 participants (n = 22), along with an explanatory video, available with Spanish closed captioning, describing how to read and use the report.[19] The report consisted of: a cover letter describing the study and the use of a silicone wristband to collect exposure to 63 PAHs with links to videos describing PAHs; an infographic detailing common exposure sources of PAHs; a table describing PAHs of concern with associated health effects; and individual results in the context of the study population (Figure S1).

Secondary report development

The report was revised using qualitative and quantitative data from Group 1 focus groups and surveys (Figure S2). Specific details are provided in the Results. Upon developing the final version of the report, we did assess readability of the language. The report was uploaded to Readable (Horsham, England), which is a subscription service that assesses readability across 18 formulas for grade level and reading ease. The report received an "A" rating, based on elements of complexity, familiarity, legibility, and typography, with "A" being the highest rating. By using 18 formulas, which collected different information and outcomes, we were able to comprehensively assess the readability of the report, and appropriateness for the intended audience. The report was then translated to Spanish by native speakers, who ensured that the context of the report was maintained, rather than applying word-for-word translations. The translation was then checked by an independent translator. The revised report was tested again, using a survey with Group 2.

Focus group—Group 1

The report cover letter invited Group 1 participants to participate in 1 of 2 focus groups hosted in October of 2018. Research

staff called participants to verify they had received the report and confirm their preference for focus group date. Of the Group 1 participants, 14 attended a focus group (67%). One of the 14 attendees was the spouse of a participant who had passed away (unrelated to study participation) but expressed interest in attending. The purpose of the focus groups was to hear participants' opinions about, and reactions to, the report, along with suggestions for improvement. The focus groups were hosted in person at Columbia University and led by a moderator. Two notetakers were present to record participant observations, and 3 researchers attended each focus group to answer questions about the data in the report. In the first focus group, held in English, there were 8 participants and in the second focus group, held predominantly in Spanish, there were 6 participants. In the Spanish focus group, bilingual research staff translated questions and responses for Spanish speakers, although at times participants would understand responses in English and ask questions in Spanish or translate for each other. Focus groups were neither video nor audio recorded, but in some cases note-takers were able to capture quotes verbatim. Moderators asked participants to start by introducing themselves. Following introductions, participants were asked to describe their initial thoughts after reading the report, their prior knowledge of PAHs, how easy or difficult it was to read the report, and how/ if they planned on using this information going forward (Table S2). Following each focus group, the 2 notetakers combined their notes. Focus groups lasted approximately 2 hours each.

Thematic analysis to evaluate environmental health literacy

Notes from both focus groups were translated into English, combined into a single document, then coded and analyzed using NVivo (Version 12), a qualitative data analysis software. A codebook was generated based on Finn and O'Fallon's[8] Environmental Health Literacy taxonomy: recognize, understand, apply, analyze, evaluate, and create. Two authors independently reviewed the notes from the focus groups and assigned them to codes. This work was completed independently and then a comparison and reconciliation of discrepancies was completed by discussion of the same 2 authors. Any disagreements were brought to a third author for additional verification.

Surveys

Surveys were used to evaluate perceptions of the report, for example, how the participants liked the report, what was not understood, and what was missing. Additionally, participants were assessed for how they interacted with or planned to use their results. Two surveys were disseminated: 1 for the Group 1 participants and another slightly longer survey for the Group 2 participants, as described below.

Survey #1: Pilot testing the report

Prior to the focus groups and just after having received the report back, the Group 1 participants received a 10-question survey (Table S3), administered via Qualtrics (Qualtrics, Provo, UT) to gain further insight into their reaction to receiving their results and suggestions for improvement. Surveys were available in both English and Spanish and sent via a link in a text message by research staff. Those that did not complete the survey prior to the focus group were asked to complete the survey on an iPad upon arrival to the focus group. The survey asked questions on the amount of time participants spent reading the report, what they found the most versus least interesting, and how hard versus easy it was to understand the report. The survey had a 67% completion rate (n = 14), with all focus group participants completing the survey.

Survey #2: Evaluating the revised report

Using feedback from the Group 1 focus groups and survey, the report was modified and sent to Group 2 participants (n = 168). The survey for Group 2 participants contained all 10 questions from the first survey, plus an additional 7 questions on whether participants were glad to have received their results, their feelings after receiving their results and whether anything was surprising about their results (Table S3). Several survey questions were taken or adapted from Silent Spring's guidance on reporting back participant's health results.[18] Questionnaires were administered electronically via REDCap electronic data capture tools hosted at Columbia University.[20,21] Surveys were available in both English and Spanish. After receiving their report, all participants in Group 2 were sent a link via text message by research staff and asked to complete the survey. The survey had a 28% response rate (n = 47).

Data analysis

To determine if survey participants in Group 1 and Group 2 were reflective of the full cohort (Group 3), we utilized a Kruskal-Wallis rank sum test for continuous variables (age) and Fisher's exact test for categorical variables (education, marital status, income, and ethnicity). We chose not to include race as one of the characteristics of the groups because 87% of participants selected that they did not identify with a race.

To compare survey responses between Group 1 and Group 2, we utilized Fisher's exact test to look at differences between the groups. The significance level was set at alpha $< .05$ for all analyses. Further, to evaluate practical versus statistical significance due to large sample sizes, bootstrap randomizations of downsampling to smaller sample sizes were conducted at each sample size for a total of 10 000 bootstrap iterations, and the median *P*-value was reported.

Results

The differences between participants in Groups 1, 2, and 3 are summarized in Table 1. We did not find differences by education or income. Initial analyses' found differences by maternal age ($P < .006$), marital status ($P < .002$), and ethnicity ($P < .017$). While age was statistically significant different between groups, the average age of each group fell within a 3-year range, with participants in Group 1 being, on average, 3 years older than Group 2, and 1 year older than Group 3 participants. Group 1 was less likely to be never married, and more likely to be divorced or separated than Groups 2 and 3. Group 3 was less likely to be Hispanic than Groups 1 and 2, but overall, the range was 89% to 95% Hispanic ethnicity for each group. However, given the large sample sizes in 2 groups, we used bootstrap randomizations, at varying samples sizes, to assess whether the significance was driven by sample size rather than substantial differences between the groups. Even when group sizes were cut in half, still with over 100 samples in Group 3, *P*-values became non-significant. The bootstrap randomization tests show that the significance in *P*-values is driven by large sample sizes, not any substantial differences between the groups (Table S1).

Pilot testing and revising the report

The original report is shown in the Supplemental Information (Figure S1). During the focus group, participants were asked about ways to improve the report, with the moderator asking questions about the ease of finding information and other information that participants wanted. Table S1 includes the questions asked during the focus group. Participants in the focus groups were vocal about changes and improvements they wanted. Some changes were specific to the report format and visualization of the results. For example, participants said "the language and graphs were too academic" and wanted researchers to "make [the report] more relatable." Beyond these general requests, there were specific comments as well, including improvements to graphs, tables and figures, and contextual information. Table 2 summarizes the feedback that was received and changes that were made to the report. Participants noted several specific changes that they felt would increase their ability to read and understand the report. For example, participants noted that it was difficult to find their respective dot on the graph of exposure levels in the cohort, given that it was the same size and shape, with only the color differing (Figure 3). Participants suggested using a different shape. In the second version of the report individual results were visualized with the shape of a diamond.

While there are limited health guidelines or standards available to assess how exposure to PAHs impacts health, the first report utilized a table that described where PAHs were found in the environment and summarized health effects associated with PAHs, for example, "irritant," "cancer risk," or "no information available." As shown in Figure S1, the table used an "x" to indicate common environmental sources (eg, car exhaust, industrial pollution, etc.). During the focus group participants commented that the "x" made it appear that the PAH was not found in that medium. In the revised version the "x" was replaced by a check mark to make the association easier to read. Related to this feedback, participants requested to learn more about sources of exposure, or ways to reduce exposure. The original report included graphical representations of PAH sources; following the focus groups the report was rearranged so these graphics were moved to their own page to make them easier to see. The report also closed with ways to reduce exposure to give the report a more logical flow.

There were some changes that participants requested that were not able to be implemented. Participants asked to see how their individual and cohort PAH exposure levels compared to groups outside of New York City. Wristband samplers have been used to measure PAH in other groups in the United States, however the duration of wearing the sampler was different between the groups, and the wristbands were used for different purposes (eg, occupational exposure vs ambient exposure). After trying different display options (table, bar charts, bubble plots, and Venn diagram) the research team ultimately decided the comparisons available at the time were not accurately describing the differences in exposure duration and chose not to include them in the second version of the report. We continue to seek ways to visualize data within and between populations and groups.

Thematic analysis to evaluate environmental health literacy

In addition to using focus groups and surveys to improve the report, we also assessed whether the report improved the environmental health literacy (EHL) of the study participants. We utilized the EHL framework, outlined by Finn and O'Fallon[8] that highlights 6 levels of EHL: Recognize; Understand; Apply; Analyze; Evaluate; and Create (Figure 1A) with environmental health data. The focus groups were evaluated and coded using these levels of EHL. Figure 1B visually represents the number of codes that were assigned to each level of the hierarchy. The predominant themes were Apply, Evaluate, and Create with 31%, 19%, and 18% of discussion points coded to them, respectively. The theme of "Apply" is the third of 6 levels of EHL, while the latter 2 themes are located at the top of the EHL pyramid and represent a higher level of EHL. Given that the majority of discussion was in these realms of EHL, this demonstrate that participants were able to reach the highest level of the EHL pyramid during the focus groups and spent approximately 40% of the conversation on these topics. In other words, participants were able to move beyond the initial stages of recognize and understand, and scaffold their knowledge into more complex concepts. Below are descriptions of how each theme was addressed by focus group participants.

Table 2. Feedback from focus group on ways to improve report.

FOCUS GROUP N = 14		
ISSUE	SUGGESTION(S) IF APPLICABLE	CHANGES TO THE REPORT
Graph literacy		
Language and graphs were too academic.	It's better to use visuals demonstrating where the chemicals are found.	The report was edited to remove jargon, text was reduced, and the reading level was brought to an eighth grade reading level. Language on how to read results was additionally revised, and made much larger, enabling more intuitive instructions.
Participants struggled with the dot plot, citing difficulty finding their data point on the graph =	Suggestion for lines instead of dots on the graphic	For the graphs, the individual's data point was changed to a diamond shape, colored orange, while other data points were black dots.
Tables and figures		
Participants wanted to see more graphics for sources of exposure	List more information in the flow of the report, e.g., list the PAH infographic immediately after mentioning PAHs	The order of infographics was altered to fit the flow of information in the report. Previously, infographics were placed on the same page. In the revised report, the infographics were listed separately, in full size.
Participants said they barely understood the Types of PAHs table, stating it had too much information and was hard to follow. Additionally, the "X" was assumed to mean that a chemical was not found in their wristband.	Participants suggested using different colors and using lines to delineate between columns. Rather than using an "X" participants suggested using empty or checked boxes. Participants suggested alternating colors across rows to help define each row from the next.	In the revised report, this page included additional information in the header of the table, and added lines between the columns. Checked boxes were used in place of an X.
Environmental health literacy		
Broadly, participants wanted to know more about where the chemicals in their wristband were coming from.	By adding this information, participants felt the report would be more relatable.	The cover letter was substantially revised, both to reduce text, but also to include more accessible information about PAHs, including a link to a short video. The cover letter was followed by a full page infographic about PAHs and their sources.
In addition to wanting to learn more about PAHs, participants wanted clear examples of how they could reduce their exposure.		While information on exposure was originally provided, it was out of place, being shown as a halfpage, following the cover letter. In the revised report, this infographic was full page, and was the last page of the report.
Participants requested seeing their results in the context of other communities, not just New York City.	The wristband has been used in multiple other studies; participants were curious how their results compared to other urban, or rural, communities across the United States.	A challenge in addressing this request lies in the variability between other studies. The wristband provides a time-averaged concentration of chemicals. Therefore, it difficult to compare results across study types with different durations of time worn, different chemical analytes, etc. Future work will investigate options for inter- and intra-study comparisons.

Recognize. Here, we coded notes and comments that demonstrated that a participant was able to recognize PAHs. This is the first level of EHL, with EHL increasing as a person moves up the pyramid. Most focus group participants reported no prior knowledge of PAHs. One focus group participant mentioned car exhaust and boiler emissions as sources. However, as the conversation of the focus group went on, participants better understood that PAHs were common air pollutants generated through activities like cooking and motor vehicle exhaust through conversations around the importance of kitchen ventilation and concerns about idling buses outside of a participant's window.

Understand. This theme was assessed as reactions to the report, questions about the report, and participants demonstrating understanding at a broad sense of the connection between air pollution and their health. Initial reactions to the report included 1 participant stating, "I didn't know I was exposed to all this," another said it was "scary to get results like this," while another participant mentioned that the report made her aware of the risk. As participants discussed air pollution, they independently connected air quality to respiratory health, and pollutants acting as triggers for asthma. One participant commented that they heard about high rates of asthma in children from their child's pediatrician and others discussed the high rates of asthma in the neighborhood, within the context of their results.

Apply. Apply was coded as ways the participants understood the report, and then applied that information to themselves,

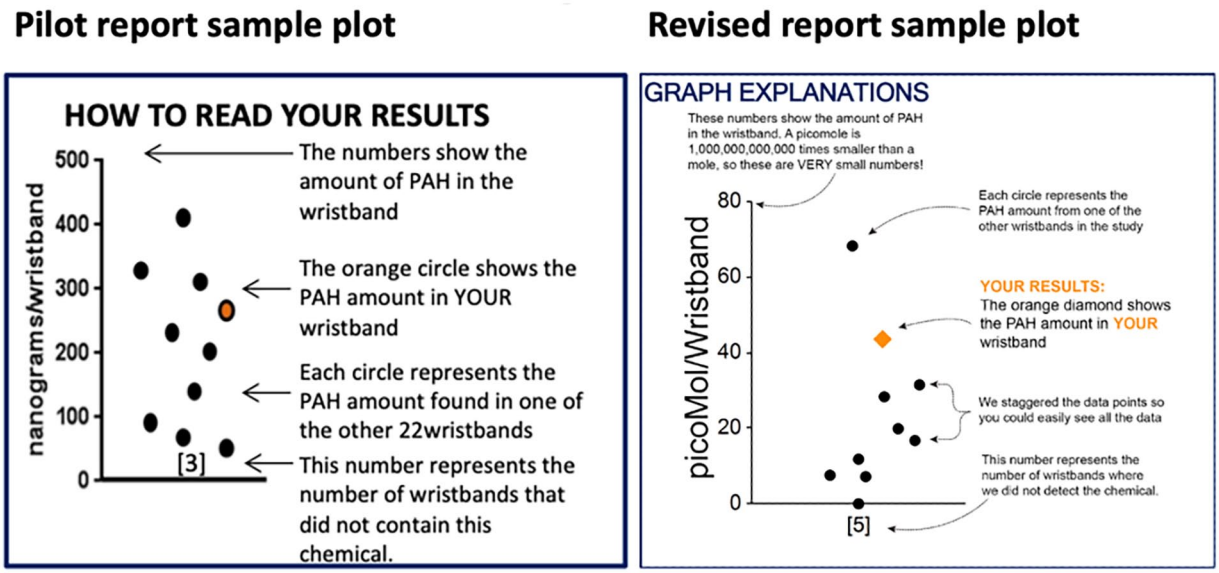

Figure 3. Comparison of plots between pilot report and revised report.

their family, or their community. Specifically, we evaluated ways that people discussed methods for avoiding exposure, including reducing air pollution and PAH exposure. This was the predominant theme across both focus groups with the most conversation dedicated to it (31%). At a broad level, participants discussed strategies for avoiding air pollution and ways to reduce exposure to PAHs, or more generally, air pollution exposure for themselves and their children. For example, participants dialogued about ways to increase ventilation, including opening windows and using a vent hood while cooking. One participant stated a desire to use an air purifier, yet noted that cost was prohibitive. Another mentioned purchasing new cleaning products to prevent asthma triggers in their home.

At the individual level, 1 participant asked what naphthalene was because her levels seemed high within the context of the 22 participants. Looking at the PAH sources table, she then mentioned that her mother is a smoker (naphthalene is found in cigarette smoke), so perhaps her levels made sense.

Analyze. As EHL increases, individuals can scaffold their existing knowledge to reach new conclusions. Here, we assessed how participants searched for additional information or discussed their experience participating in the research. For example, several participants indicated they had researched PAHs after receiving their report, and before attending the focus group. That is, "googled them." Other participants noted searching for tips to reduce exposure, and cooking and cleaning methods to reduce exposure. Participants suggested other options that, while not protective against PAH exposure specifically, are ways to reduce exposure to other pollutants, such as using a mattress protector. There was a larger discussion, led by the participants, regarding how PAHs might be associated with childhood development, specifically neurological development. Notably, participants commented that they have children or siblings that are on the autism spectrum and discussed the putative connections between exposure to environmental contaminants and health within this framing.

Evaluate. In the context of report development and improvement, this theme was adjusted to reflect recommendations participants made to improve the report. The main point of the focus group was to gather feedback to improve the report, so it is not surprising this was the second most prevalent theme. In addition to the recommendations in Table 2, participants noted that they would like to receive the reports earlier, and provided suggestions to use more graphics, simpler language, and include additional ways to reduce exposure.

At the community level, participants spoke about bringing the report to local Council Members to show them what is happening in the community, and to raise awareness of air quality and environmental contaminants. One participant noted that they were showing the report to their college professor, and using the results for a paper they were writing for class.

Create. The highest level of EHL, this theme involves relating the information from the report to other environmental concerns and global concerns. One participant stated "Industrialization in China compared to the U.S is 100 times worse and has made their air unbreathable. If we were to bring back factories and coal mining to the U.S., as this administration is currently pushing, we should really consider the effects that it will have on our air quality."This statement ties air pollution to policies and compares the policies in the U.S. to those in other countries. There was also a brief discussion amongst participants regarding the U.S. decision to not sign the Paris agreement and how important it is to vote in elections for policy makers who align with personal values. The Paris Agreement is an international treaty to reduce emissions and thus climate

Table 3. Summary of survey results for first and second questionnaire.

DISTRIBUTION	GROUP 1 N = 22 COUNT (%)	GROUP 2 N = 168 COUNT (%)	*P*-VALUE
Respondents	14 (64)	48 (29)	
Before you received the report, how much did you know about PAHs?			0.3
A lot of knowledge	0 (0)	1 (2)	
A little knowledge	5 (38)	12 (25)	
No knowledge	8 (62)	35 (73)	
How much did this report add to your knowledge of PAHs?			0.9
A lot	13 (93)	39 (81)	
Moderate amount	1 (7)	3 (6)	
A little	0 (0)	4 (8)	
None at all	0 (0)	2(4)	
How easy or difficult was it for you to find what your levels of PAHs were?			0.9
Easy	7 (50)	24 (50)	
Neutral	5 (36)	13 (27)	
Difficult	2 (14)	10 (21)	

change.[22] At the time of the focus groups, it was relatively new and frequently discussed in the media, likely resulting in participants discussing it during the focus group.

Overall, participants spoke about their desire to share the report with their community to spread awareness of the environmental exposures in the neighborhood. They linked their concerns regarding air pollution and health to the importance of participating in local elections. Specifically, 1 participant mentioned a desire to vote for politicians who care about these issues and would support regulation to decrease PAH levels.

Surveys

We utilized surveys to evaluate perceptions of the report, for example, how the participants liked the report, what was not understood, and what was missing. Additionally, we assessed how participants interacted with or planned to use their results. The baseline knowledge of PAHs before receiving their report (Question 4: Before you received the report, how much did you know about PAHs?) was similar between groups; 73% in Group 1, and 62% in Group 2 ($P = 0.3$; Table 3). Both groups indicated that the report added "a lot" to their knowledge about PAHs (93% and 81% respectively) indicating the report was useful in increasing knowledge.

Half of the participants in both Groups 1 and 2 found the report generally easy to use (eg, 50% of both Group 1 and Group 2 participants said the report was easy to read). Despite substantial changes to the report, we did not see an increase in participant reports of ease of use, or increased knowledge regarding PAHs after receiving the report, relative to Group 1.

Discussion

In this urban, primarily Hispanic (>90%) study population, participants received results from an individual level report back of prenatal exposure to PAHs. We used focus groups and surveys to evaluate the impact of the report back on EHL, and to improve the report.

Through focus groups, participants suggested changes to improve the readability of the report, including changing the layout and making the graphs and language easier to read. Using a thematic analysis of the focus groups notes, we found that participants reached all 6 levels of the EHL hierarchy and spent most of the discussion applying themes from the report back to their daily life with conversation around ways to reduce PAH exposure for themselves, their children, and their community. Interestingly, despite making the recommended changes, we found that participant increases in knowledge of PAHs, or ease of finding individual results was unchanged, as assessed via survey responses. However, in a previous analysis of the Group 2 questionnaire data, we did find differences in EHL within the group. As described previously, participants with a college degree were significantly more likely to be surprised by their results than those with less than a high school degree (OR = 5.60, $P \leq 0.05$) and those with higher naphthalene

levels were associated with lower odds of being surprised about receiving the results (OR = .37, $P = 0.02$).[23] The question "Were you surprised by anything in your results? (Q_#15)" was chosen as a measure of EHL because it demonstrates that participants were understanding and applying their results, each of which are a level in the EHL hierarchy by Finn and O'Fallon.[8] These findings suggest that the survey questions we asked may not be accurately, or comprehensively, assessing EHL.

This work supports the body of literature that RBRR should be standard practice in exposure assessment research.[1,2,9,24] The conversations from the focus groups demonstrate how giving participants their own exposure data increased awareness of both PAH exposure and additional environmental exposures. Our participants discussed utilizing the reports in several ways, including making changes in ventilation and cleaning practices. In an RBRR study of peripartum participants on exposure to per- and polyfluoroalkyl substances, participants similarly expressed a desire to reduce exposures, but had limited time and resources to do so.[4] In our study we saw similar barriers, with participants wanting to purchase air purifiers but not having the resources to do so. While our participants did not specifically identify time constraints, pregnancy and the peripartum period are a demanding time and ways to mitigate or reduce exposure that are inexpensive, and easy, should be prioritized. Further, our study and others noted that RBRR can empower study participants.[8,9,25-27] Here, our participants referenced plans to bring their reports to local politicians, and to discuss their results with friends and family. These actions are similar to what has been seen in other studies reporting back environmental exposures; RBRR can empower participants to make changes in their daily life based off the information they received.[11,17,28]

Increasing EHL represents more than increasing knowledge, but also empowering individuals and communities to make changes and advocate for lower environmental exposures.[8,25-27] Previous studies have found that personal exposure report back increased EHL at many different levels from individual, to family, to community.[9,11,24]

A prior study documented distinct individual changes that were enacted following RBRR. In a study utilizing the wristband samplers for PAH exposure in an adult Indigenous population, from which our report-back was based off of, participants discussed wanting to reduce their exposure after receiving their results.[17] Some of the ways they planned to do this was by switching to cleaner burning candles, burning candles for a shorter duration, and not using woodstoves as frequently. This group received the same exposure data (eg, samplers were assessed for 63 PAHs), but given the different community context received tailored strategies for reducing PAH exposure based on common exposure pathways due to cultural and geographic variables. From this we see how cultural sensitivity and planning is important in the report-back process, and regardless of the setting, participants want to find ways to reduce their individual exposure levels following report-back.

At the familial level, in a rural cohort near a Superfund site, parents of children aged 1 to 11 received results on blood lead and other metals in household water and soil samples. Interviews with parents revealed the vast majority of participants took action to reduce exposures in their home after receiving their results, including removing shoes when entering the home, laying down rocks to decrease exposure to soil, and decreasing the consumption of food known to be high in metals.[9] The exposures and type of community differ from ours but similarly demonstrates how parents are motivated to make changes in their home to reduce environmental exposures of their children, regardless of location or exposure.

Looking at community-level changes, a study in a town within an industrialized county of California took dust samples from homes and returned results to participants. Following RBRR, the researchers conducted interviews with a subset of the study population. They found that participants took legal and political action to address exposures from outdoor industrial emission sources.[24] Similarly, our participants expressed a desire to bring the report to local politicians and community leaders to influence community-level change. This demonstrates the potential for RBRR to shape actions and policies beyond the study population. This is particularly relevant for environmental justice communities, where pollution and exposure levels tend to be higher, necessitating large scale change beyond the individual and family units. In this way, RBRR can help empower people and leaders to advocate for their communities. These studies demonstrate the ways in which participants used information from the report to reach varying levels of the EHL taxonomy, and apply their EHL to themselves, their family, and their community.

There remain limited tools for assessing EHL, particularly tools that can evaluate EHL across the taxonomy. Here, we show that the RBRR strategies did enable participants to scaffold from low EHL (recognize) to high EHL (evaluate). However, this method of assessing EHL appears incomplete. Prior work on EHL has shown that tools that measure knowledge, as well as feelings and beliefs, may more completely encompass EHL.[29] In our study, we predominantly measured knowledge. However, evaluating changes in beliefs is also necessary. For example, a study that reported back results in the Navajo nation after a mine spill asked participants whether their feelings about the mine spill had changed after seeing their results.[30] Of the respondents, 55% said "No." Here, we found that despite revisions to the report to increase readability and comprehension, participants did not report an increase in self-rated perception of knowledge of PAHs. In other words, improving how factual knowledge is presented may not have a significant difference in participant knowledge or feeling about an exposure.

Thus, there is a need to investigate more comprehensive measures of EHL. There are few validated measures of EHL.[31] Lichtveld et al[32] developed a validated EHL survey with 4 scales, on different media-specific exposures and overall EHL.

The general EHL survey could be a good measure to use in RBRR and supplemented with the scale of an important exposure route. Dixon et al[33] created the validated Environmental Health Engagement Profile with 5 subscales to assess the way people engage with environmental health issues. There are scales that assess EHL within the domains of recognition and understanding.[34,35] Yet measuring EHL beyond factual knowledge alone is emerging as a valuable assessment.

Some limitations of this work include limited generalizability and lack of a baseline measure of EHL. Regarding generalizability, the report was modified for a primarily urban Hispanic cohort with monitoring completed during pregnancy. The language was modified to represent exposures during pregnancy, although the reports were initially designed for the public, independent of pregnancy status. Thus, while the reports may be specific to a pregnancy cohort, the suggested revisions were not pregnancy-specific. Finally, we did not have a baseline level of EHL. We initially began this study in 2018, with the goal of developing user-friendly reports. As we went through this process, we began to appreciate the role of RBRR in building EHL,[36] and expanded our study to incorporate an assessment of EHL. As a results, we relied on self-reported pre-post assessments of knowledge. In future, we recommend conducting an EHL assessment prior to RBRR.

Strengths of the study include the well-characterized exposure assessment, in depth qualitative focus group data and quantitative data from 2 versions of the report back. Previously, passive wristband samplers were considered a novel method of exposure assessment, however to date there have been more than 60 studies utilizing the wristbands on thousands of different participants[37] with many studies measuring PAHs.[16,17] As this number grows, we will be able to further modify the reports and incorporate PAH exposure data from other communities that used the passive wristband sampler. The request to provide comparison data sets came directly from the focus group participants, out of an interest to see how their community compared to others. This type of feedback is essential to continue improving the reports and to be responsive to the wants of the community while disseminating personal exposure results.

This study has demonstrated that engaging research participants in creating a report back document is essential to ensure it is easy to understand, culturally competent, and that it addresses the needs of the community in which it is to be used. In this study, we saw changes in EHL when assessing it through focus groups, but not surveys. Surveys can be helpful, yet our results suggested that our questions were not comprehensive. In the future more comprehensive methods for measuring EHL, and particularly for assessing the relationship between RBRR and EHL, are needed. Ideally methods that merge qualitative and quantitative methodologies to evaluate RBRR as well as methodologies for assessing RBRR materials and subsequent changes in knowledge, attitudes, and behavior are necessary for understanding and evaluating the impact of RBBR on the communities that receive them.

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CRediT Authorship Contribution Statement

Kylie W. Riley: Formal Analysis, Visualization, Writing – original draft. **Kimberly Burke**: Data curation, Formal Analysis. **Holly Dixon**: Data curation. **Darrell Holmes**: Data curation. **Lehyla Calero**: Data curation. **Michael Barton**: Data curation, Resources. **Rachel L. Miller**: Writing- review and editing. **Lisa M. Bramer**: Formal Analysis, Writing- review and editing. **Katrina M. Waters**: Funding acquisition, Writing- review and editing. **Kim A. Anderson**: Funding acquisition, Resources. **Julie Herbstman**: Conceptualization, Funding acquisition, Writing- review & editing. **Diana Rohlman:** Conceptualization, Methodology, Supervision, Writing- review & editing.

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Data Statement

Data will be made available on request.

Supplemental Material

Supplemental material for this article is available online.

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