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Clinical Research FORUM Analysis, Advocacy, Action.

Participant engagement to develop report-back materials for personal air monitoring

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Abstract

Background: Studies that measure environmental exposures in biological samples frequently provide participants their results. In contrast, studies using personal air monitors do not typically provide participants their monitoring results. The objective of this study was to engage adolescents who completed personal air sampling and their caregivers to develop understandable and actionable report-back documents containing the results of their personal air sampling. Methods: Adolescents and their caregivers who previously completed personal air sampling participated in focus groups to guide the development of report-back materials. We conducted thematic analyses of focus group data to guide the design of the report-back document and convened experts in community engagement, reporting study results, and human subjects research to provide feedback. Final revisions to the report-back document were made based on follow-up focus group feedback. Results: Focus groups identified critical components of an air-monitoring report-back document to include an overview of the pollutant being measured, a comparison of individual personal sampling data to the overall study population, a guide to interpreting results, visualization of individual data, and additional information on pollution sources, health risks, and exposure reduction strategies. Participants also indicated their desire to receive study results in an electronic and interactive format. The final report-back document was electronic and included background information, participants' results presented using interactive maps and figures, and additional material regarding pollution sources. Conclusion: Studies using personal air monitoring technology should provide research participants their results in an understandable and meaningful way to empower participants with increased knowledge to guide exposure reduction strategies.

Introduction

Wearable sensors that measure personal exposure to air pollution represent a paradigm shift in exposure assessment and epidemiologic research. In contrast to stationary air monitoring, these devices provide users their individual-level information regarding exposure and can identify specific locations and activities associated with increased exposures, including being indoors, in transit (car, bus, and walking), and other settings [1,2]. Wearable air pollution monitors can also be linked to spatiotemporal geolocations and paired with other sensors to capture physiologic (e.g., heart rate variability and lung function) and physical activity (e.g., accelerometer) data, thereby connecting personal exposure data with individual health indicators [3]. As the reliability and accuracy of low-cost air monitoring devices continue to improve their use is expected to become widespread in research studies and by citizen-scientists who seek information regarding personal pollutant exposures [4].

While personal air monitors will provide new opportunities to researchers, the individuallevel data they measure requires novel human subject considerations. In contrast to stationary air monitoring or statistical prediction models to estimate air pollution exposure, personal air monitors provide individual level and actionable information. Participants in studies that measure environmental exposures and chemicals in biospecimens report a desire to receive their results, and researchers agree that participants have a right to their individual results [5–8]. Effective report back of biomonitoring results also increases participants' engagement with research, and guidelines for providing individual results to participants in biomonitoring studies are now available [9–11]. Biomonitoring studies have also demonstrated that engaging with communities and research participants in the development of report-back materials is critical to effectively develop report-back materials that are appropriate and specific to the study objectives and population [5,12]. There are critical differences, however, between biomonitoring studies and personal air monitoring and, to our knowledge, studies involving children and adolescents using personal air monitors have not examined participants' desire to receive their exposure results nor considered best practices to return these results using an understandable and actionable approach.

Therefore, the objective of this study was to engage with participants and caregivers enrolled in the Ecological Momentary Assessment and Personal Particle Exposure (EcoMAPPE), a panel study of adolescents' personal exposure to ultrafine particles (UFPs) and respiratory health, to determine appropriate methods to provide personal air monitoring results to research study participants. In addition, we applied qualitative research methods to identify the perceived benefits, concerns, and desired content and format for reporting personal air monitoring results back to participants and their caregivers.

Materials and Methods

Overview of Report-Back Development

We employed an iterative, participant-engaged approach to develop personal air monitoring report-back materials that included focus groups of adolescent study participants who completed a study of personal air sampling and their caregivers. In addition, we sought input from an expert panel of researchers experienced in community-engagement, reporting study results, and human subjects research regulatory affairs. Following the initial development of materials, we reconvened our focus groups prior to making final changes to the materials.

Study Population

We enrolled a subset of adolescents (n = 8) who participated in the EcoMAPPE study and their caregivers (n = 8) to participate in separate focus groups for this study. Briefly, the EcoMAPPE study enrolled 118 adolescents aged 13-17 years to complete personal air monitoring and respiratory health assessments [13]. Personal exposure to UFPs (particulate matter < 100 nm in aerodynamic diameter) was measured during a one-week sampling campaign using the Personal Ultrafine Particle Counter (PUFP C200, EnMont LLC, Cincinnati, OH, USA), a wearable condensation particle counter with a built-in global positioning system (GPS) [14]. The PUFP measures UFP concentrations per cm^3 of air every 1 s over concentrations of $0 - 2x10^5$ particles/cm³ (p/cc) with an accuracy of ± 10%. EcoMAPPE participants were instructed to wear the PUFP C200 for 3 h each day of sampling (the maximum battery life of the PUFP on a full charge). Additional details regarding the EcoMAPPE study and results have been described elsewhere [3,13].

We recruited adolescent focus group participants by stratifying the EcoMAPPE study population by self-reported race (White/ non-White) and gender (male/female) and randomly contacting participants among each strata to ensure focus group participants were not the single representative of their race and gender. Recruitment was conducted by providing information about the study to the participant and caregivers by email with follow-up by phone. Caregivers of interested adolescents were also enrolled to form two focus groups of eight participants each. The size of each focus group was intentionally limited to eight to allow hands-on design and to encourage discussion. Ethical approval to conduct this research was obtained from the Cincinnati Children's Hospital Institutional Review Board. Prior to participating in the focus groups, all caregivers and adolescents provided written informed consent and assent, respectively.

Adolescent and Caregiver Focus Groups

We employed a qualitative approach to facilitate interactive discussion and co-design of report-back materials, with particular attention to content, design features, and communication strategies. Separate (adolescent and caregiver) in-person focus groups were semi-structured and designed to elicit meaningful qualitative feedback regarding their interest in receiving study results, perceived benefits and concerns, content, format, and delivery methods for reporting results back to participants and caregivers following personal air pollution monitoring. Adolescent and caregiver focus groups were scheduled to last one hour and facilitated by one qualitative researcher (AP and EH, respectively) and one member of the research study team. Focus groups were audio-recorded and transcribed verbatim.

Focus group guides were designed prior to meeting by the qualitative methodologists with additional input from the study team. Participant and caregiver focus group guides were similar, though the adolescent focus group guide included additional time for rapport building and activities to encourage participation. In both focus groups, participants were asked to describe the EcoMAPPE study to gain a better understanding of the words that they used to explain the research. Participants in the adolescent focus group were asked to design their own report-back materials, including drawing out an example of their own personal air pollution monitoring periods with relevant information to explain this to someone who had not participated in the study. Participants then did a "gallery walk" of the examples and wrote down the elements that they liked from each example. Participants also discussed how they would change their own map based on what others had drawn. In each of the focus groups, participants were provided examples of report-back documents that contained information about UFPs and prototype interactive graphs where users could toggle between different sampling days and asked to provide feedback on the materials including questions they had and suggestions for improvement.

Expert Panel Review

We solicited feedback from a panel of four external experts in academia not involved with the EcoMAPPE study and with experience in community-engaged research, environmental health, personal exposure result reporting, and institutional review boards. Prior to a virtual meeting, the expert panel was provided with an electronic draft of the report-back materials developed following the initial focus groups of participants and caregivers. During a virtual semi-structured meeting, the expert panel reviewed all sections of the draft report-back material with the study team and provided suggestions for revisions that included changes to the language, figures, maps, colors, and information provided.

Repeat Focus Group

After revising the report-back document based on feedback from the expert panel, we reconvened the caregiver and adolescent focus groups in the summer of 2021 (Fig. 1). Due to the COVID-19 pandemic, the second focus groups were conducted virtually with separate sessions for adolescents and caregivers. In both focus groups,

Your Personal EcoMAPPE Results

This report is best viewed on a desktop or laptop computer-interactive plots and maps may not be viewable on a mobile device.

Thank you for participating in the EcoMAPPE Study! The purpose of the study was to understand how one type of air pollution—ultrafine particles (UFPs) affects your health.

This report summarizes the measurements recorded while you were participating in EcoMAPPE and using the personal UFP sensor. Please keep in mind that the results you see in this report were measured during your participation from August, 26 2020 through September, 2 2020.

The levels of air pollution you breathe change frequently depending on where you are and what you are doing—so the levels of air pollution you
experience now may be different from the levels that are in this report. You can think of this report as a snapshot of your UEP exposure.

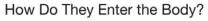
What Are Ultrafine Particles?

We measured ultrafine particles in this study. UFPs are just one type of particulate air pollution. To understand them, here is what you need to know:

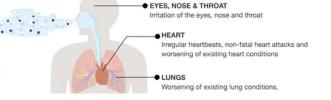
- Particulate matter (PM) is a mixture of solid and liquid droplets mixed with the air you breathe.
- Particulate matter comes in many sizes and shapes, and can be made up of different things including dust, dirt, smoke, metals, pollen, or liquid droplets.

Some particles are big enough or dark enough for you to see. Smoke in the air is an example of particulate matter that you can see with your eyes. Other particles are so small that you cannot see them without a very powerful microscope.

Ultrafine particles (UFP) are smaller than 100 nanometers in size – this is about 900 times smaller than a grain of sand! Ultrafine particles can remain suspended in the air for a long time because they are very small and lightweight.



Particulate matter enters the body when we breathe. Mucus membranes in your nose and throat can remove most of the larger particles, but ultrafine particles can continue deep down into the lungs and beyond because they are so small. The smaller the particle, the harder it s for the body to clear them. What Are the Health Risks?



 Dates the participant completed personal sampling

 Clarification that personal exposures change frequently

Information regarding ultrafine particles

Fig. 1. Introduction to the report-back document.

participants were provided a copy of the revised electronic reportback document followed by a guided discussion to elicit feedback on the presentation, content, readability, and usability of the report. Final revisions to the report-back document were made based on this feedback.

Focus Group Analysis

We conducted a thematic analysis of the transcribed focus groups. Two members of the research study team and one data analyst external to the study made up the analysis team. All three analysts independently read the data line by line and recorded inductively derived open code (i.e., *in vivo* codes) for each relevant section of text in the data. The three data analysts reviewed codes together and came to consensus with the external team member providing feedback regarding assumptions and biases held by the research study team members. This process resulted in the development of a codebook that included examples of themes and subthemes. One research team member (AP) assigned the codes to themes and subthemes using inductive coding. The synthesized data were shared with the rest of the analysis team for feedback. Data and coding were organized using ATLAS.ti qualitative data analysis software.

Report-Back Document Development

Based on focus group input, we designed the report-back document to be electronic and interactive. We developed a digital HTML report using R (4.1.1) and R Markdown (2.11) which incorporated instructional images and interactive plots and maps. Participant UFP sampling data were aggregated to 5-second median values for visualization, and the R packages "highcharter" (0.9.4) and "mapdeck" (0.3.4) were used to produce interactive plots and maps [15,16]. Standalone, instructional images were also included in the interactive report to provide background information on the personal sampler, UFPs, pollution sources, and reduction strategies.

Results

Focus Group Results

We enrolled a total of eight adolescents who participated in the EcoMAPPE study and one corresponding caregiver to provide their input on the report-back documents during focus group sessions. Adolescent participants were, on average, 14.4 years of age (range: 13–16 years) and one-half (n = 4) were female. Participants self-reported race included Black/Bi-racial (n = 2), White (n = 4), and more than one race (n = 2) and 25% (n = 2) reported having current asthma. Enrolled caregivers were, on average, 49 years of age, primarily female (n = 6), and White (n = 6). Five themes were derived from the coded focus group data and include: 1) feasibility and acceptability of the study, 2) visualizing data, 3) what participants want to know, 4) problems with the "black box," and 5) utilization of the app (i.e., electronic report-back document).

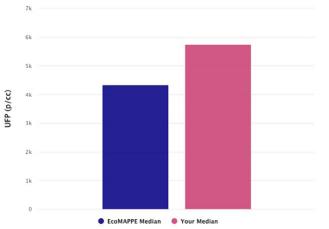
When the focus group participants were asked to draw an example of how they would visualize their personal air pollution time periods, the prompt provided was "Think of an example of one of the times you wore the sensor. Using the paper in front of you sketch out a map of the time-period." They were then asked to explain their map to the person next to them and adjust based on that conversation – what did they need to add or change to make the map understandable? The drawings from the adolescent focus groups revealed their preferences for the information included in

How Did Your Levels of Ultrafine Particles Compare to Others Who Participated in the EcoMAPPE Study?

Scientists are measuring ultrafine particles in cities around the world to understand the normal amount of ultrafine particles inside and outside. In one study, the average outdoor level of UFPs in cities was 44,000 particles / cm³ of air.

Because the Environmental Protection Agency has not established clean air quality standards for UFPs, we are showing you how your exposure compares to all other EcoMAPPE participants. The bar chart below shows your median UFP exposure and the median UFP exposure of all EcoMAPPE participants. The median represents the middle of a data set—half (50%) of the data is lower than this value and half of the data is higher than this value. The median is also referred to as the 50th percentile.

- A total of 118 adolescents participated in this study.
- The median concentration recorded by all participants was 4,340 particles/cm³
- Your median UFP concentration was 5,750 particles/cm³ and was higher than the median level recorded by all EcoMAPPE participants.
- Your median ranks in the 60th percentile, meaning that 60 percent of EcoMAPPE participants had a median UFP concentration lower than you.



 General information regarding levels in other studies

> Background information to interpret overall personal exposures to other participants' levels in the study

Fig. 2. Comparison of participant's median ultrafine particle exposure to the overall study median exposure.

report-back materials and how they would communicate that information. All participants drew the places that they went while in the study and many had some indication of travelling to and from each place. All participants indicated the level of pollution of each location using either color or density of dots or a combination of both. Two participants provided a key that indicated how the colors corresponded with the level of pollution and one of these participants provided a graph that indicated change in pollution as they traveled to and from different locations.

Report-Back Document

Participants provided feedback on the visualization of the data on the mockup report-back materials. They shared which colors were better for visualizing the level of exposure to UFPs. One participant said, "when you're in one spot and there are bigger [dots] and smaller [dots] that might be hard to see but with the color you can understand it a little better." They also asked that that the report-back materials "map out the timeline" and the "direction we were traveling." They also preferred illustrations to words, when possible and said things like, "it needs to be something that's not childish but it still needs to be fun and catch attention." Participants said they would "open it [the report-back document] up on my phone because I don't actually have a computer with me and then go look at it on the computer because it's easier."

Based on this feedback from participants, caregivers, and experts, we produced a single web page to be provided electronically via email to the study participants and their caregivers. The HTML report-back document was composed of 1) an introduction to the materials including an overview of UFPs (Fig. 1), 2) a comparison of their median exposure compared to the entire study population (Fig. 2), 3) a guide to understanding the personal sensor and results (Fig. 3), 4) visualization of their personal sampling data

using an interactive map and time-series of data corresponding to each day of personal sampling (Fig. 4), and 4) information on sources of UFPs, potential health risks, and strategies to reduce exposure (Fig. 5).

A key component to the report-back document included a statement that personal exposures change frequently based on many factors (Fig. 1). This point was emphasized by the expert panel as critical for the participants to recognize. Following a reminder of their dates of participation, the report-back document provides background information on UFPs, routes of exposure, and potential health risks. Language included in this section was informed by the focus group participants and the expert panel feedback from the expert panel. The first data provided to the participants are their overall median exposure levels recorded during the week of personal sampling (Fig. 2). Following discussion in the focus groups and expert panel, we determined a bar chart was the most informative approach to present this data. Prior to providing their overall median exposures, a brief definition of median is provided. Importantly, caregivers expressed a desire to place the overall levels of exposure in the context of other studies. Therefore, a general statement regarding outdoor exposure levels in other studies is also provided.

Prior to reporting the results of individual real-time sampling data, a summary of the PUFP sensor is provided (Fig. 3). Then, an informative guide to understand the maps and time-series data is presented (Fig. 3) so that participants can interpret their personal sampling data. This includes a color scale, which represent UFP exposure categories ordered from low (green; < 25K p/cc) to high (red; > 100K p/cc). As shown in Fig. 4, instructions for how to interact with their personal particle data is provided. Participants can explore the map of their personal exposures by zooming in and out and panning across the locations of each measurement. Participants can also rotate the map to visualize the locations in

Your UFP Monitoring Device

We gave you the PUFP C200 to measure your personal UFP exposure. The device records the number of ultrafine particles in the air and your GPS location every second.

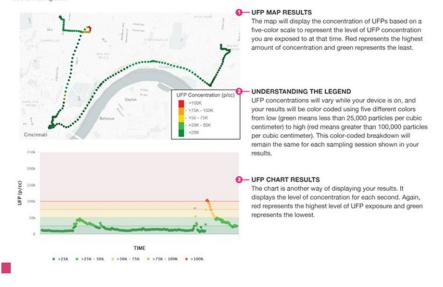
The PUFP measures particles in the air by cubic centimeter, or cm3, which is a unit of volume that corresponds the amount of air in a cube that measures 1cm x 1cm x 1cm. Your air pollution exposure is reported as the number of ultrafine particles per cubic centimeter (p/cc). For more information on the sensor, visit: https://www.enmont.com/products



Overview of personal sampling device

Understanding Your Results

The results in this report are displayed by 'sampling session', which represent each time you operated the sensor. During your participation, you recorded 8 sampling sessions beginning on August, 26 2020 and ending on September, 2 2020. You might not have a map for all of the sampling sessions in this report. If the PUFP did not record GPS location during a sampling session, a map will not be shown. You may also notice some gaps between points on the UFP charts due to missing data.



Guide to interacting with their individual sampling data

Fig. 3. Guide to understanding the personal air sensor and results.

3D. Maps and corresponding time-series plots also display additional information when the user places their cursor or taps on a data point. For the maps, the UFP concentration is displayed. Likewise, the UFP concentration, date and time of the measurement, and a vertical bar highlighting the data point are displayed while hovering on the time-series plot. Separate tabs corresponding to each sampling period are available so that participants can visualize the results of their sampling by day of participation. The report-back document concludes with additional information regarding indoor and outdoor sources of UFPs and potential strategies to reduce exposures (Fig. 5).

Discussion

To our knowledge, previous studies of personal air pollution exposure have not examined participants' desire to receive their results nor considered best practices to return these results using an understandable and actionable approach. In this study, we engaged adolescents who completed personal air sampling for UFPs, their caregivers, and academic experts to co-design report-back materials that is appropriate and specific to the study population – a critical component to developing report-back documents [5,12]. Using this approach, we identified key components to the report-back document including background information about UFPs and the device that was used to measure their exposure, providing a summary of individual results compared to others, an interactive visualization of their personal monitoring results, and information on sources of exposure, reduction strategies, and health risks. Importantly, our report-back document was created as an HTML document based on our participants desire to receive their data in electronic format. In addition to being the preferred method of adolescents to receive their study results, an electronic document provides some additional benefits compared to a written or printed report. For example, we were able to embed interactive maps and figures into the electronic HTML document which allows the viewer to zoom in to specific locations and times of interest. In addition, electronic documents may enhance readability for adolescents as information can be tabulated of separate pages or links to decrease the overall length of the document. Finally, electronic documents may be generated and distributed in shorter time frames allowing for results to be provided with smaller delays from the time of data collection to dissemination.

In response to participants in biomonitoring studies desire to receive their results, guidelines for providing biomonitoring results back to study participants are now available [9,10]. There are, however, important differences between biomonitoring studies and data collected by personal air monitors at a high resolution over time that necessitated this study. For example, biomonitoring studies typically collect a limited number of biospecimens (e.g., blood, urine) to assess the presence of chemicals with varying half-lives. Frequently, months or years may pass from the time of sample collection to return of biomonitoring results due to the time required to perform laboratory assays. In contrast, personal air monitors measure individuals' exposure with high temporal resolution (e.g., every 1 s) and can be combined with Bluetooth or other technology to facilitate immediate data transfer to the study participant

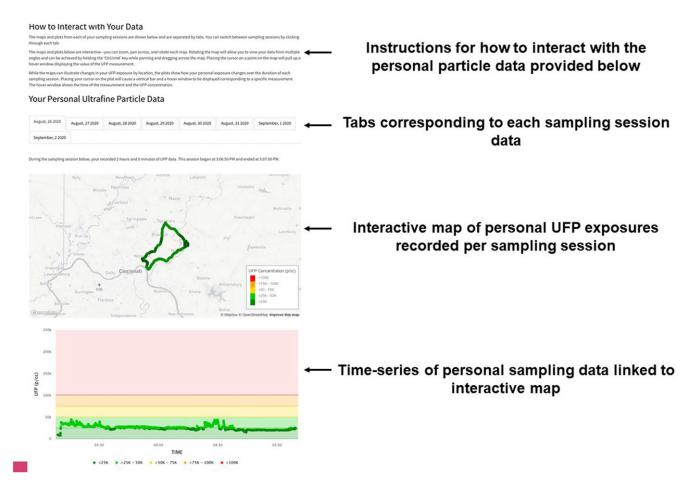
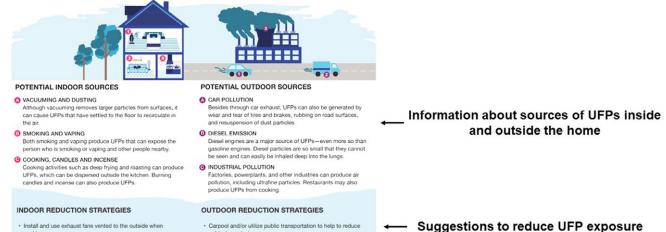


Fig. 4. Interactive map and time series of personal air monitoring results for each day of personal sampling.

What Causes Changes in Ultrafine Particle Levels?

Air pollution, including UFPs, come from many sources both inside and outside your home. As you participate in your normal daily activities, including going to and from school, sports practices, playing outside, or spend time inside your home, you are exposed to different levels of UFP. This section outline ion sources of UFPs and ways you can reduce or avoid them



- · Install and use exhaust fans vented to the outside when
- Install and use exclusit rans vehicle to the outside when cooking.
 Refrain from burning candles or incense inside your home.
 Change filters on central HVAC systems and air purflers according to manufacturer's directions.
 Using a vaccum with a HEPA filter can help capture the UFPs. Operating a HEPA air purfler in your home can also reduce the parathesis of the manufacture in explose in our home can also reduce the number of fine and ultrafine particles in your home.
- **Ouestions?**

If you have any questions about your personal data or the informtion within this report, please contact Dr. Patrick Ryan.

Fig. 5. Additional information regarding sources of ultrafine particles and strategies to reduce personal exposure.

ehicular emissions.

vehicular emissions. Reduce physical activities near traffic areas or try to avoid these places during peak hours. A void outdoor activities if not necessary when and where air pollution levels are high. Visit airnow.gov to type in your zip code and view the current air quality in your location.

or researcher. This temporal resolution, when combined with GPScaptured location, provides a unique opportunity to identify places, activities, and times with elevated personal exposures. Thus, personal air monitoring provides the user actionable information to raise awareness and guide behavioral changes to reduce exposure [17,18]. These behavioral changes offer the potential to significantly reduce overall exposure to air pollution given that short term but high air pollution events contribute a disproportionate percentage of individuals' total daily exposure [14,19–24]. Furthermore, behavioral modifications to reduce exposures, including modifying cycling and pedestrian routes, can significantly reduce personal UFP, black carbon, and particulate matter (PM) exposures [25,26].

Providing study participants their individual results may also lead to increased trust in science, environmental health literacy, individual empowerment, and motivation to reduce environmental exposures [9]. Engaging participants by providing them the results of their research provides opportunity to progress from recognizing the relationship between exposure and health, to actively reducing exposure and improving health [12]. Reporting results to participants also facilitates a collaborative research approach where participants not only provide data but also receive feedback. This engagement can enhance recruitment and retention, detect novel sources of exposure, and identify new research topics [6,27].

In addition to engaging with participants through focus groups, our study had several additional strengths including the input of experts experienced in community-engaged research, human subjects' research, and personal air sampling but not associated with the EcoMAPPE study. These researchers provided external perspective and suggestions on our report-back materials prior to our second focus groups. Our focus on UFPs, an air pollutant hypothesized to be more toxic than larger particles but whose human health effects are understudied [28-32], has also allowed us to develop reports of exposure to a pollutant with unknown health effects. Finally, we provided the participants with interactive maps and corresponding time-series data enabling them to identify specific times and locations where their personal exposures were elevated or decreased. Future research will examine whether providing participants their individual results increase their knowledge and awareness of environmental health, air pollution, and motivates changes in behavior to reduce air pollution exposures.

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Disclosures. The authors declare that they have no actual or potential conflicts of interest.

Ethics approval and consent to participate. The Cincinnati Children's Hospital Medical Center Institutional Review Board approved this study. All participants provided consent and assent prior to participation. All authors have reviewed and approved the manuscript for publication. Examples of reportback materials and code are available upon request.

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