

A Qualitative Study of the Ethics of Community Scientists' Role in Environmental Health Research from the Perspective of Community Scientists and Institutional Review Board Staff

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BACKGROUND: Community engagement in research, including community scientists' (CSs) participation in environmental exposure assessments, promotes the bidirectional flow of information between communities and researchers and improves the development of interventions to reduce environmental health inequities. Nonetheless, institutional review boards (IRBs) with limited experience with CS research tend to struggle when reviewing protocols given CS participants' dual role as research participants and co-creators of data.

METHODS: We collected focus group data from 35 Latina housecleaners eliciting their bioethical reflections on their experience as CSs before and after participation in the collection of data about their exposures to chemical compounds in cleaning products. We shared findings from CS participants and collected impressions and challenges from IRB staff from five New York City biomedical research institutions. We used a modified approach to conventional content analysis to guide data analysis and combined deductive and inductive approaches to generate codes.

RESULTS: The CS participants emphasized their shared responsibility in the research process and bidirectional learning with the research team, which they saw as educating and empowering themselves and their broader community to create safer cleaning practices to improve the community's health and well-being. CS participants embraced the importance of sound science by their recognition that their community relied on the quality and accuracy of their work as CSs. Perspectives from IRB staff similarly recognized the value of participant engagement but emphasized the importance of disentangling CS activities as research participants from activities as research team members to better determine the appropriate mechanisms and authorities for assuring ethical protections.

DISCUSSION: Findings suggest that existing bioethical principles of beneficence, respect for persons, and justice, when interpreted by participants as inclusive of protections and benefits for both the CSs and their community's collective good, reflect the bioethical values of our CS participants. However, better guidance and training is needed for researchers, IRBs, and community collaborators to apply these values and respect and protect the full range of roles for community members participating in research. <https://doi.org/10.1289/EHP15824>

Introduction

Researchers, community stakeholders, as well as governmental and nongovernmental funders increasingly encourage the involvement of patients, community members, and community-based organizations in biomedical research to improve health outcomes, to focus funding on community priorities, and to allow for greater public engagement and learning through research.^{1,2} Community-engaged research approaches also challenge traditional approaches by democratizing roles and power dynamics between academic researchers and the communities in which their research is embedded.³ Community engagement (CE) promotes the bidirectional flow of information between communities and researchers, identifies

structural issues driving health risks, promotes better respect and understanding of community culture and norms, and facilitates development of health interventions that respond to social, economic, and environmental factors influencing health.^{3–7} When applied in research involving disproportionately impacted communities, it is an effective approach to improve health equity and increase environmental justice (EJ).^{2,8,9}

One important role that community members and patients have played in biomedical research is as community scientists (CSs), recruited by academic researchers in collaboration with community partners, to assist with research activities including environmental exposure assessments.¹⁰ With increased interest in understanding pathways through which a person's environment contributes to health, initiatives such as exposomics research have spurred increased development and use of lower-cost sensor technology for environmental monitoring, further expanding CS opportunities.^{11–13} Historically, a variety of terms have been used for CSs, and commonly in environmental health research, the term "citizen scientists" (CSs) to acknowledge that for many communities, use of the term "citizen" can be perceived as exclusionary.¹⁴

CSs have contributed to scientific knowledge through a variety of roles including through community-initiated data collection efforts that are independent or only loosely connected to research institutions. In these roles, community members use scientific processes to compile evidence related to community-identified environmental or health concerns.¹⁴ CSs may also be invited to participate in formal government-funded biomedical research studies initiated by academic researchers, where incorporating perspectives of community members or patients enhances researchers' ability to address important questions, such as in Patient Centered Outcomes Research Institute (PCORI) research.¹⁵ In community-based participatory research (CBPR), community

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members and academic researchers are coequal partners with an emphasis on promoting participation and empowering community stakeholders to play major roles in defining research questions, designing protocols, collecting data, disseminating findings, and translating research into tangible benefits for the participating communities.⁸

When CSs are involved in federally funded biomedical research, researchers and ethical review boards have been challenged in determining the appropriate processes for protecting CS participants and in developing procedures and training for ethical oversight, especially in studies utilizing CBPR approaches.^{4,7,16–19} Institutional review boards (IRBs) with limited experience reviewing CS protocols tend to struggle in their evaluation of studies in which participants take on roles that do not fit the standard hierarchical researcher–subject framework, but rather, have a collaborative approach.^{20–23} Historically, community members mostly participated in health research as individual “subjects” contributing data to researcher-designed studies that investigators could then generalize to broader populations.⁵ This researcher–subject relationship became the cornerstone of human research ethics, which in the United States takes the form of the Common Rule and its associated Belmont principles.²⁴ These principles assert that research procedures and participation of humans in research should *a*) maximize benefits and reduce risks (beneficence), *b*) be voluntary and provide special protection for those who lack the capacity to make such decisions themselves (respect for person), and *c*) fairly distribute the risks and benefits (justice).²⁵

Using this framework, the Common Rule has tended to evaluate the role of the investigator and study participant as a dichotomy, while CE research involving CSs often blurs the line between the two.^{5,26} This has led researchers to identify challenges with the current system of ethical oversight from the perspectives of researchers and stakeholder organizations engaged in CE research,^{5,21–23,26–29} which have informed the consensus development of broader ethical frameworks that also emphasize values such as transparency, respect for community assets, and accountability to communities (Table S1).^{30–32} Nonetheless, fewer studies have collected the perspectives of CSs,³³ including their understanding of the Belmont principles as a relevant ethical frame for their participation in research, or the perspectives of IRB staff responsible for reviewing these studies.^{34,35} This is a notable research gap given the focus of CE research on including the voice of the affected community.^{29,36}

We add to this ongoing bioethical discussion by contributing perspectives from CSs participating in the Safe and Just Cleaners (parent) study, which is a federally funded study that aims to document and reduce exposures to chemical components of household cleaning products among Latinx housecleaning workers in New York City (NYC).^{37,38} The Safe and Just Cleaners study uses a CBPR approach, having formulated the overall research questions jointly with our community partner Make the Road New York (MRNY). We use a variety of collaborative research approaches, including engaging community members in designing our research instruments; assisting with outreach and recruitment; administering surveys; and developing training, education, and policy initiatives to reduce exposures and improve housecleaners’ employment conditions. Throughout the parent study, the research team together with housecleaner participants, discussed and engaged with the overall principles of CBPR as shown in Table S1.^{37–39} One component of this research utilized housecleaners as CSs to assist with collection of exposure data related to the types of cleaning products workers used in their workplaces and their exposures to chemical components of these products during their cleaning tasks.

The origin of our interest in these bioethical issues emerged during the initial review of our grant application by the National Institutes of Health, when grant reviewers raised reasonable concerns regarding potential risks to immigrant housecleaners acting as CSs when collecting information at their workplaces, given their more precarious employment arrangement. Collaboratively, with input from our community partner and their housecleaner members, we discussed approaches to reduce risks, but this process also increased our interest in better documenting CS participants’ perspectives on these ethical issues as part of our research. With supplemental funding specifically designed to explore bioethical issues, we added a bioethical substudy, including collecting perspectives both from our CS participants as well as from IRB staff at several major biomedical research institutions in NYC.

The focus of this substudy was specifically on IRB review issues rather than the larger ethics of CBPR. We expected that the CS participants and IRB staff would frame the nature of the CSs risks and benefits differently. Specifically, in assessing beneficence, we anticipated the housecleaners CS participants would focus primarily on the potential benefits for themselves and their community from the research findings given the exposure risks they already face as precarious housecleaners, while the IRB staff would emphasize the potential risks to the CSs given the precariousness of their employment as immigrant housecleaners. To further explore this, we proposed the following research questions: *a*) How do CS participants reflect on their experience being CSs with a focus on the ethical dimensions of this work and if they perceive the framework of the Belmont principles of beneficence, respect for person, and justice applied to them both as individual CS participants and as co-creators of data intended to benefit their larger community as well as themselves? and *b*) How do IRB staff interpret these same ethical principles when assessing how their biomedical institutions protect immigrant housecleaners and other CS participants, considering their dual role as individual research participants and as co-creators of data to improve their communities’ health?

Methods

Participants

The Safe and Just Cleaners study previously collected survey data from 402 Latinx immigrant housecleaners, inquiring about the frequency of use and type of cleaning products used and other working conditions, between August 2019 and February 2020.³⁷ Survey participants were subsequently invited to attend ongoing monthly discussions and training sessions organized by our community partner and to participate in a variety of leadership roles, including becoming a CS and assisting with the study’s exposure assessment activities. Thirty-five of these CS housecleaners also took part in the bioethics substudy. Detailed demographic data on participants were drawn from their previous survey data, which was complete for all participants with no missing data responses (Table 1).

IRB staff participants were recruited as a convenience sample by emailing the membership list from the New York Regional IRB Consortium, a group of 17 staff from 16 biomedical IRBs at academic medical centers who meet periodically to share information. Of the 17 members contacted, 11 indicated interest in participating but only eight stated they were available to participate on the selected focus group (FG) date. Of the eight, six signed into the virtual FG and one lost connectivity and was not able to participate beyond the introductions. The five staff members who participated came from five different IRBs all of which were in Manhattan but otherwise were similar to other consortium members with respect to the types of biomedical protocols their IRB reviewed. The

Table 1. Characteristics of community science participants in the Safe and Just Cleaners bioethics substudy, August 2021–May 2022 (*n* = 35).

	Exposure assessment activity participant (<i>n</i> = 9)	Smartphone App activity participant (<i>n</i> = 28)	Total participants ^a (<i>n</i> = 35)
Years working as a housecleaner in the US [<i>n</i> (%)]			
1–4 years ^b	4 (44%)	12 (43%)	15 (43%)
5–9 years	3 (33%)	5 (18%)	8 (23%)
10–15 years	1 (11%)	9 (32%)	9 (26%)
>15 years	1 (11%)	2 (7%)	3 (9%)
Mean age ± SD	49 ± 9.9	50 ± 7.4	49 ± 8.2
Mean years living in the US ± SD	15 ± 8.8	18 ± 9.9	17 ± 9.8
Educational attainment [<i>n</i> (%)]			
Primary school	2 (22%)	6 (21%)	8 (23%)
High school	2 (22%)	13 (46%)	14 (40%)
Certificate of high school equivalency	1 (11%)	1 (4%)	2 (6%)
Some college	4 (44%)	8 (29%)	11 (31%)
Comfort speaking English [<i>n</i> (%)]			
Comfortable	3 (33%)	3 (11%)	6 (17%)
More or less comfortable	4 (44%)	9 (32%)	12 (34%)
Not comfortable	2 (22%)	16 (57%)	17 (49%)
Total earning per month [<i>n</i> (%)]			
\$500 or less	2 (22%)	8 (29%)	10 (29%)
>\$500 to \$1,000	2 (22%)	10 (36%)	11 (31%)
>\$1,000 to \$1,500	4 (44%)	5 (18%)	8 (23%)
>\$1,500 to \$2,000	1 (11%)	2 (7%)	3 (9%)
>\$2,000	0	1 (4%)	1 (3%)
Refused	0	2 (7%)	2 (6%)
Primary family wage earner [<i>n</i> (%)]	5 (55%)	8 (29%)	13 (37%)

Note: Data based on participants responses on the Safe and Just survey administered between August 2019 and February 2020. Exposure assessment, community science exposure assessment laboratory cleaning simulation; SD, standard deviation; SP, smartphone community science activity.

^aTwo participants were engaged in both the Exposure assessment and the SP activity.

^bNo participant had worked <1 year.

participation of the IRB staff was facilitated through a co-investigator (I.W.) who was a member of this consortium.

Community Scientists' Activities

The study included CS participants who were involved in at least one of two CS activities. The first CS activity (*n* = 28; conducted between August 2021 and May 2022) called the smartphone (SP) activity, aimed to supplement our previous survey data that collected information on the number and type of cleaning products participants used in the kitchen and bathroom. For the SP activity, CSs collected “real-time” information by photographing the cleaning products they used at the workplace, which were almost always provided by the client.³⁷ The overall goal for collecting this data, together with the previously collected survey data, was to prioritize the most commonly used cleaning products for a future in-depth exposure assessment laboratory study. During at least four cleaning workdays over the course of 2 weeks, CS participants completed a brief Spanish language survey on their smartphone about their use of cleaning products and uploaded photographs they took of the products used that day.

For the second CS activity (*n* = 9; conducted in May 2022), called the exposure assessment activity, we piloted our study's exposure assessment data collection protocol using a retrofitted bathroom and kitchen built within our laboratory at the Icahn School of Medicine at Mount Sinai. While the cleaners carried out their normal cleaning activities using products previously prioritized as most common, they wore sensors that collected personal exposures for volatile organic compounds, and we video-recorded their

cleaning process. We also demonstrated skin exposure by placing fluorescent tracer dye with water in an empty cleaning product bottle, instructed the cleaners to apply the contents as they would when using their usual cleaning products, and used UV light to document where products deposited on cleaners' skin.

Data Collection Procedures

Each CS participant was invited to attend two focus groups (FG), one following a CS training session (pre-FG) and one within a month after completing the CS data collection (post-FG). We conducted four rounds of FGs for the SP activity and one round for the exposure assessment activity in Spanish via videoconference for a total of 10 FGs with six to nine participants in each FG. The FGs were facilitated by a bilingual co-investigator (I.C.) and observed by others (S.B., J.C., and A.G.).

We defined the Belmont principles of beneficence, respect for persons, and justice for our CS FG participants by adapting the language of the Belmont definitions²⁴ for this specific study context and then asked participants to reflect on their understanding of these principles given their experiences as part of the research. For this study, we defined beneficence as research that maximizes possible benefits and minimizes possible harms. We defined respect for persons to mean that all people are individuals with the right to make decisions for themselves and that people who may have limited decision-making ability should be protected. We defined justice for them as the idea that no one person or group should be burdened if participating in a research study and that everyone deserves to benefit from the research.

We converted these concepts into simple language in Spanish, which was developed collaboratively with our community partner organization staff who were familiar with CS participants. We designed a semistructured guide with open-ended questions that could elicit a wide array of experiences with the concepts of each principle, drawing on the expertise of the research team member (I.W.) who had extensive experience as an IRB staff member in a biomedical institution. The pre- and post-FGs used similar prompts but post-FG follow-up prompts explored workers' reflections on having completed the activity. FGs lasted ~45 min and took place between August 2021 and May 2022.

We held a single IRB staff FG in October 2022 that was co-facilitated by the CS FG facilitator (I.C.) and the co-investigator that was an IRB staff member and was a regular member of the New York Regional IRB Consortium (I.W.). The FG was conducted by videoconference and was observed by two other investigators (S.B. and J.C.). We designed a semistructured guide for the 90-min FG. We first provided examples of CS environmental health research activities, including our own research and a study that used high school students as CSs to collect information about home radon exposures,⁴⁰ to set a tone about various approaches to CS research. We summarized examples of risks and benefits for CSs participating in those studies, including some of the reflections from our study's pre- and post-FGs. Then, we asked the FG participants to reflect, from their perspectives as IRB staff, on the risks and the benefits for the community members who are serving as CSs. We then explored FG participants' reflections on their IRB's approach to assessment of CS risks and benefits, data integrity, conflict of interest, and recommendations. The full FG facilitators' guides for both the CS and IRB FG can be found in the supplemental material (“Supplemental material 1”).

Analysis

We used a modified approach to conventional content analysis to guide data analysis.⁴¹ The conventional approach aims to answer

research questions through participants' perspectives by designing questions and a coding scheme of transcribed data that centers on their descriptions of experiences.⁴¹ We modified this method by beginning the analytical process by note-taking/memoing and facilitating discussions among the team conducting the analysis prior to initiating the design of the coding scheme. Additionally, we combined deductive and inductive approaches to generate codes. We describe our analytical process in the following to promote transparency and trustworthiness of our data.⁴²

For the 10 CS FGs, bilingual team members, both from the academic and community organization collaborators, attended some or all of the CS FGs (I.C., S.B., J.C., A.G., and D.F.) conducted in Spanish. Following each FG, team members debriefed and took notes on our impressions. One author (J.C.) listened to and summarized the FG recordings. Two other authors (S.B. and I.C.) read the summaries and added their own notes and reflections. Two authors (J.C. and S.B.) extracted quotes from the transcripts exemplifying each code and organized them on an Excel spreadsheet. These three authors (J.C., S.B., and I.C.) then held several meetings to discuss content and developed a coding scheme that initially drew on the Belmont principles deductively but then focused on participants' understanding of the Belmont principles, creating inductive codes under each principle. Examples of codes under beneficence included benefits such as "health of cleaners will improve" and "becoming aware/reflecting about their work" and risks such as "fear of not being accurate" and "fear of being observed by the client." For respect for persons, example codes included "choosing to volunteer" and "speaking freely"; and for justice, examples of codes included "being valued" and "participation enthusiasm/contributing to study." We shared summaries of these findings with the rest of the authors (H.H., A.G., and D.F.) who had been involved in the study design and who interacted with CSs during the CS data collection activities. Using Excel software, two authors (J.C. and S.B.) extracted quotes from the transcripts exemplifying each code. The Excel spreadsheet was then reviewed by three authors (I.C., S.B., and J.C.), and we achieved consensus on coding, exemplary excerpts, and excerpt translation into English.

We adapted this process above to the single FG for IRB staff conducted in English. Four of the co-investigators (I.W., I.C., S.B., and J.C.) attended the FG and held a debrief discussion and drafted notes following the FG. One author (S.B.) reviewed all of the notes, listened to the recording, generated a summary which was shared and commented on by the other three, and transcribed the recording using Otter.ai software pro version. Based on this discussion, one author (S.B.) developed a document listing codes, such as "challenges in assessing unfamiliar research procedures," "defining participant role as research participant or research team member," "role of the IRB in ethical decisions that do not involve human participants," and "advantages of community engaged research," and exemplary excerpts. Two other authors (I.W. and I.C.) read this document and discussed content with S.B. to achieve consensus.

Focus group data collection was approved by the City University of New York IRB (number 2022–0290 for the IRB FG and number 2016–1506 for the CSs FGs). CS participants received incentive payments for participating in the bioethics FGs distinct from their payments for participating in the CS activities. IRB FG participants received a coffee shop gift card. All FG participants gave verbal informed consent to participate.

Results

We present findings from the CS FGs followed by the IRB FGs. The main themes for our CS FGs mirrored participants' understanding of the Belmont principles. IRB FG findings focused

more on challenges that IRB staff perceived in reviewing CS protocols.

Community Scientists' Reflections

Beneficence. When our participants reflected on the principle of beneficence, participants emphasized the benefits of safer cleaning products and practices for their own health, for the health of their community, and for improving the overall environment. One participant explained, "We are trying to create an eco-friendly world where our health suffers less" (SP_GRP1_Post-FG).

Many felt that their role as a CS conferred additional benefits by enhancing their learning process. For example, the CS activities allowed them to reflect on their working conditions and become more self-aware, which helped them to assimilate knowledge to use in their own individual circumstance. One SP CS participant described how taking photos of the cleaning product labels made her pay more attention to what was on the labels and what might be harmful. Similarly, following the fluorescent dye activity that showed how the cleaning products remained on their clothing and skin after a simulated cleaning task, one participant described how this reinforced the importance of protective equipment and safer cleaning practices as follows:

You saw how those liquids remain on your clothes, on your skin, because I didn't use gloves there and that's when I realized how important it is to use gloves. So, for me it was a great learning experience. (Exposure assessment_post-FG)

Given their belief in the importance of the data being collected, participants expressed feelings of pride in their role as trained CSs. One SP activity participant explained, "it is more like we are an active part of the investigation. So now we are your eyes" (SP_GRP4_Pre-FG).

Participants also recognized that they may never be the direct beneficiaries of our findings but viewed their participation in the scientific process as giving them an opportunity to act on their own values to achieve a healthier future for their community. As one participant explained:

It's the ethics of fighting for ourselves and [...] for those who come after us, so that the science is better [...] Well, so that they can see how chemicals [cleaning products] can be improved. (Exposure assessment_Pre-FG)

Some participants described how the activity led to positive client interactions, such as this SP CS participant who shared information with her client about safer cleaning practices that she had learned during her CS training. She described how the client responded, "Next time we will choose products that are not as toxic" (SP_GRP3_Post-FG). Similarly, another participant described how the experience of being a CS empowered her sense of confidence to initiate discussions about the use of safer products with clients:

This helps us to have a foundation with which to sometimes face employers [...] we have the knowledge and it gives us the power. For example, I can tell them I have taken a course [part of the training provided to CSs] and the truth is it's something with which you can fall back on a lot and we make ourselves be respected more than anything. (SP_GRP4_Pre-FG)

When prompted to also reflect on potential harms of participating as a CS, most described instead the risks that they faced from housecleaning work. A few participants, prior to engaging in the SP activity, raised the concern that their clients might react negatively to their taking pictures of the cleaning products. This concern stimulated a discussion about how they might use this opportunity to begin a discussion with their clients about choosing safer products. The FG also became a forum for participants to discuss strategies to avoid potential client conflict. One worker described her plans as follows:

In my case if they see me using the phone to take photos, it's going to be a problem, but I'm going to try to do it and if I can't do it in their [the clients'] homes, then I will go to the supermarket and the same products that I use in their homes I'm going to take a picture of them, because I know what products I use. (SP_GRP4_Pre-FG)

Another member of the same FG responded to this comment by pointing out that perhaps this could be one way of gauging whether their clients cared about their health, "I see it as another experiment, [. . .], to see who we are working with and how they might mistreat us" (SP_GRP4_Pre-FG).

Respect for persons. Many CSs shared that when they agreed to participate, they felt uncertain of the full details to which they were committing. While our explanation of their rights during the consent process was important, several participants emphasized the importance of the trust that had been established with the research team during previous study activities. One participant described, "You gave me the opportunity to withdraw [from the study], so it's not mandatory. That is one of the things that made me feel safer, and the way you expressed it" (Exposure assessment_Post-FG).

In addition, they recognized that being a CS was a voluntary activity that involved their active and willing participation to generate good data and that was what they agreed to. One participant explained as follows:

You can't pressure me, because then I'm not going to do it well, because I would no longer be focused on what I'd be doing. So, I would prefer to withdraw and leave without any problem, but no one can force anyone. (SP_GRP2_Pre-FG).

Participants also underscored the importance of feeling accompanied by the research team, which allowed them to ask questions during the process. One CS described, "And really the way you explain to us, the patience, the kindness with which you teach us. So, it makes us stronger or at least it has helped me a lot in my work" (SP_GRP2_Pre-FG). Accompaniment also reduced their anxiety about making mistakes, which they feared might reduce the soundness of the data. One participant shared, after taking advantage of one-on-one assistance sessions with a research team member, "Once you started [providing support], that's where the worry disappeared" (SP_GRP1_Post-FG).

Justice. When we probed further into the principle of respect for persons, participants' comments aligned more with the principle of justice. For example, participants described how the study in general and their involvement as CSs made them feel important, especially as immigrant housecleaners. As one participant explained, "It feels important because there is value in [housecleaning] work. It [CS research] gives importance to such hard work" (SP_GRP1_Post-FG). Other participants emphasized that, as immigrant workers, they often felt invisible working in unregulated jobs where they were unfairly excluded from societal benefits, including participating in research studies. One participant shared, "It is a privilege that you are thinking of immigrant

women, since in this country we do not have many privileges" (SP_GRP1_Post-FG). Also, as collaborators, they perceived reciprocity and mutual respect between themselves and the research team, characteristics that are part and parcel of the equitable distribution of benefits and illustrate equal treatment of individuals. As one participant explained, "As long as you continue researching, we are there ready to support you. What happens? We are helping each other" (SP_GRP3_Pre-FG).

Finally, participants underscored that the material support we provided, in terms of stipend payments and the flexibility offered in the timing and modality of our training sessions, made it possible for them to participate as low wage workers and mothers. For example, our training sessions occurred virtually in the evenings and allowed them to participate using their smartphones either from home, in transit from work to home, or sometimes even while they were at work. They also acknowledged the importance of being compensated for their lost work time, which was especially necessary for those participating in the laboratory-based exposure assessment, which required a day of lost earnings. This CS conveyed the spirit and practice of the ethical principles when she said:

We volunteer for this study, we support the study, you learned from us, we learned from you. And on top of that, we get paid well. I think that's very important to me. (Exposure assessment_Post-FG)

IRB Staff Reflections

Though the FG facilitators probed on the applicability of the Belmont principles to CS activities, the IRB FG discussions centered mainly on challenges for IRBs in reviewing protocols, which include CS activities, particularly related to disentangling the dual role of CSs who sometimes are engaged as research participants and other times as part of the research team. They expressed that the benefits and risks were similar whether an activity was done as a member of a research team or as a research participant, but it was only the IRB's responsibility to assess beneficence if the CS activity is considered research participation. For example, they agreed that learning about the scientific process was a benefit for all CS participants, irrespective of their role. The participants all agreed, however, that their responsibility for ethical review should be limited to research activities where CSs would be considered research participants. Though, as one participant made clear, "Does that mean they [CSs who are part of a research team] don't have rights, and you shouldn't respect them? [. . .] but they're not under the Human Subjects regulations." (IRB_Participant_5). This same participant went on to explain further:

[Investigators] want to throw anything that is a little bit weird or a little bit risky and involves people to the IRB, but we're terrible at everything except [human subject] research, [. . .], we might have an opinion. So, if we throw this into the regulations, we get the wrong answer some of the time.

In explaining why they might get the "wrong" answer, this same participant further explained that IRBs were less familiar with the types of activities involved:

We know the risks of an MRI [. . .] but when you get to these social emotional risks, reputational risks, we are doing this based on gut feeling and not so much on data about how risky these procedures actually are, or the interventions actually are [. . .]. We're gonna have a long conversation at the board meeting and probably make a poorly based decision based on this gut feeling.

Irrespective of whether a CS was acting as a research participant or a research team member, the IRB FG participants acknowledged the responsibility of research institutions to provide protection against any harms. According to another participant:

[My institution] kind of takes the more conservative approach in terms of protecting our investigators. We very much look at the risk to our investigator, like when they're going out and doing community research or anything like that [...] so I think the same thing here [referring to CS participants], like I'd be interested to see, like how we can expand on that. (IRB_Participant_4)

IRB FG participants suggested that sometimes researchers try to classify CS participants as research participants because that involves fewer bureaucratic obstacles, such as the challenges of paying nonuniversity-based research personnel. One participant shared, "We say no, they're not [research participants], we consider them researchers. And they fight us on it. Oftentimes, it comes down to an issue, payment, it's easy to pay a research participant" (IRB_Participant_3).

Another challenge raised was how to address the likelihood that many CS participants come from "vulnerable" populations, given how they more often live in communities disproportionately impacted by environmental exposures. As explained by one participant, "I would also worry about [...] if something happened to them [such as a car accident] who's accountable for that? You know, they're immigrants. So there's issues with that" (IRB_Participant_1).

Lastly, participants pointed out that though dual roles are challenging to disentangle, it is important to keep the two roles distinct. They recommended that participation as a research participant and researcher should occur as separate aspects of a study and should not be combined to avoid conflicts of interest. CSs should fully understand that they enter into the role of data collector voluntarily—as they do for the role of study participant. A FG participant commented that it is important to avoid "either coercion or undue influence [...] So saying, you may have this benefit [for example learning new skills], but oh, no, you don't have this benefit if you don't agree to be a [research] subject. So is that really penalizing?" (IRB_Participant_3).

One participant, who was more familiar with participatory action research because of previous experience during graduate training, emphasized the importance of involving CSs in research as they can enhance the relevance of the study aims and the integrity of the scientific process. That participant suggested that "this type of work [...] it's better science, better data you're getting, and it's biased in a good way, [...] being able to contextualize what's actually happening. Better than maybe an outside researcher" (IRB_Participant_3). This participant also suggested that IRBs could play an important role assisting investigators to resolve challenges.

Finally, participants suggested that better guidelines could help IRBs determine which CS roles should be considered as research participants and which as members of the research team. Once the roles are determined, then further guidance could help institutions, researchers, and IRBs understand their responsibility to protect CSs when contributing either as research participants or as part of a research team. For example, one participant suggested that many CS activities would be classified as minimal risk or exempt under the new Common Rule, which provides "a lot of freedom that we don't normally take [such as] you can waive elements of informed consent" (IRB_Participant_5).

Discussion

In this study, we explored bioethical values and experiences of Latinx immigrant housecleaners participating as CSs in environmental exposure data collection activities within a CBPR project. The CS participants emphasized their shared responsibility in the research process and bidirectional learning with the research team, which they saw as educating and empowering themselves and their broader community to create safer cleaning practices and improve health and wellbeing. In their role as CSs, they felt valued and supported in contrast to how they more commonly felt disrespected and devalued as housecleaners and immigrants. CS participants embraced the importance of sound science by their recognition that their community relied on the quality and accuracy of their work as CSs. Perspectives from biomedical IRB staff similarly recognized the value of CS engagement, but rather than focusing on the challenges of applying the Belmont principles to research participants engaged in CS, they emphasized the importance of disentangling activities performed as research participants from activities performed as members of the research team to better determine the appropriate mechanisms and authorities for assuring ethical protections.

Our findings also suggest that existing bioethical principles of beneficence, respect for persons, and justice reflect the bioethical values of our CS participants but only when they are interpreted as inclusive of protections, benefits, and justice not only for themselves as individual participants but also for their community's collective good. While our study was limited to one cohort of CS participants all experiencing a similar set of environmental exposures and therefore might not reflect the wide range of environmental health data collection scenarios CSs experience, our findings complement previous research. Bromley et al.,⁵ based on interviews with university- and community-based researchers conducting CBPR research, similarly found that despite the expanded roles played by participants and communities, the core Belmont principles were meaningful ethical guides as researchers "stroved to extend respect, mitigation of harm, and just treatment to communities and groups."⁵ Martineau et al.²⁹ and others^{5,17,23,26–28} have emphasized the importance and challenges of implementing a holistic ethical approach that integrates the Belmont principles for the ethical conduct of human "subject" research and sound science with principles of responsible community collaboration, emphasizing the need for support and guidance to achieve sustained, respectful, reciprocal, accountable, and transparent community partnerships. Taken together, these findings support and highlight the benefits of CS not only to improve biomedical research but also to build informed community leadership and sustained community capacity to achieve health equity as reflected in the values expressed by several professional organizations and research teams who promote CS (see Table S1).^{30–32}

CE approaches have positively influenced research to focus more clearly on interventions aimed at building community power to reduce structural determinants of health, including environmental racism and other forms of environmental injustices.^{32,43} A systematic review of environmental health research that incorporated approaches with EJ communities found that when community members hold formal leadership roles, including as CSs, research projects were more likely to result in structural changes to improve health equity.⁴⁴ Our participants' emphasis on feeling respected and accompanied as CSs, an aspect of ethical CS research also emphasized by others,¹⁵ contributed to their stated growth and empowerment to change their exposure conditions. Their understanding of the Belmont principles emphasized the importance of accompaniment to reduce these barriers, which mirrors a finding from one of the few other studies that interviewed CSs about their experience.³³

Nonetheless, sometimes researchers less familiar with appropriate methods for CE research demonstrate only symbolic efforts to build capacity and leadership among participants recruited as CSs, which has been pejoratively referred to as “tokenism.”⁴⁵ Other times, lower income and immigrant communities may face challenges in fully participating in CS environmental health projects due to time constraints and accessibility barriers to the types of technology being used. As environmental health research evolves, tokenism and accessibility barriers could impede the efficacy and diffusion of newer forms of technology, such as wearable and other low-cost sensors, to the most highly impacted communities. With less access to the benefits from such research, accessibility barriers could potentially widen rather than reduce environmental health inequity.^{18,44}

Gilbert⁴⁶ similarly underscored these issues by suggesting that “dignity” should be added to the Belmont principles arguing that “respect for person” alone is not sufficient if participants and communities do not gain the tools and knowledge resulting from studies to exercise their agency to effect changes in their communities.^{23,46} This sense of dignity emerged in our findings and reflects the challenges we encountered in disentangling the workers’ reflections on the Belmont principles of “respect for persons” from “justice.” Workers emphasized how the capacity building they received in the larger parent project along with respect and accompaniment promoted by our research team empowered them to exercise their rights to ask their clients to use safer cleaning products, and this was an important project benefit for them and their community.

Our study was limited to a small number of IRB staff members in one city, most of whom had limited prior experience with CE and CS research apart from one participant who had experience from a prior stage in their career. This may have influenced their perspectives. Also, IRB members, rather than the staff, may be more familiar with CE research, given the recent emphasis on these approaches by funders, and therefore, IRB members may have had different perspectives from the IRB staff. Nonetheless, our findings from IRB staff mirror those of a more systematic study of biomedical IRB chairs, funded by the Patient Centered Outcomes Research Institute (PCORI), which aimed to better understand ethical challenges of including patients as part of biomedical research teams.^{34,47} IRB chairs felt that they had significant responsibility to protect both patients and their institutions when patients are involved in non-traditional research roles. Reflecting themes raised in our study, they *a*) expressed discomfort in considering study participants in nontraditional roles other than as human “subjects,” *b*) felt less familiar with some of the research methods used when “subjects” participated in nontraditional roles, and *c*) raised concerns about adequate training of participants in nontraditional roles and protection against conflict of interests.⁴⁷

To reduce some of these challenges, researchers such as Morello-Frosch et al.²⁵ have suggested a “post-Belmont ethic” to encourage and democratize community collaboration in the production of scientific knowledge by reducing barriers to data access and communication and emphasizing the role of biomedical research in harm prevention at both the individual level and at the community level.²³ One specific application of such an ethic is reflected in a new proposed framework to counter IRBs hesitancy to report back individual environmental measurements when there is uncertainty in the clinical relevance. This framework emphasizes how well-designed report-backs can improve environmental health literacy and enhance individual and community engagement in actions to reduce exposures.⁴⁸ At the same time, it will be important to increase the capacity of researchers, institutions, and ethics boards through improved training and support processes to guide ethical oversight for CE research and to better protect and promote

the full range of roles for community members participating in research as has already been implemented in several research centers.^{20,49,50}

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