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# From Crowdsourcing to Extreme Citizen Science: Participatory Research for Environmental Health

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## Keywords

participatory research, citizen science, community-engaged research, environmental sensors, crowdsourcing, health policy

## Abstract

Environmental health issues are becoming more challenging, and addressing them requires new approaches to research design and decision-making processes. Participatory research approaches, in which researchers and communities are involved in all aspects of a research study, can improve study outcomes and foster greater data accessibility and utility as well as increase public transparency. Here we review varied concepts of participatory research, describe how it complements and overlaps with community engagement and environmental justice, examine its intersection with emerging environmental sensor technologies, and discuss the strengths and limitations of participatory research. Although participatory research includes methodological challenges, such as biases in data collection and data quality, it has been found to increase the relevance of research questions, result in better knowledge production, and impact health policies. Improved research partnerships among government agencies, academia, and communities can increase scientific rigor, build community capacity, and produce sustainable outcomes.

## INTRODUCTION

The involvement of citizen scientists (individuals conducting research who have not been formally trained as scientists) and communities in environmental health research has increased rapidly in the past decade, along with the emergence of environmental monitoring technologies, the utilization of mobile devices to collect data, and the growth of online data sharing. Citizens<sup>1</sup> have become increasingly involved in research owing to multiple factors, including the improved accuracy and reduced cost of environmental sensors, an increased emphasis on and realization of the benefits of community participation, and the tightening of research budgets, which in some instances may necessitate the involvement of the public,<sup>2</sup> especially when collecting large volumes of data.

These changes have spurred a new approach to environmental health research that is increasingly reliant on community participation and involvement, fostering greater data accessibility and public transparency in a research project's decision-making processes. These approaches are variously called community-engaged research, community-based participatory research, participatory action research, and citizen science, among other terms, but for the purposes of this review we designate these approaches collectively as "participatory research." The National Advisory Council for Environmental Policy and Technology (NACEPT) of the US Environmental Protection Agency (EPA) has noted that all these concepts have a common emphasis on "openness, democratization of science, and the mobilization of diverse people and communities" (45, p. 1).

Despite its benefits, some researchers have raised concerns about whether participatory research approaches produce data that can be defended as scientifically accurate and valid (25, p. 231). Here we review various concepts of participatory research, describe how participatory research approaches complement or overlap with community engagement practices and environmental justice, and discuss the strengths and limitations of participatory research in its use in conducting environmental health research.

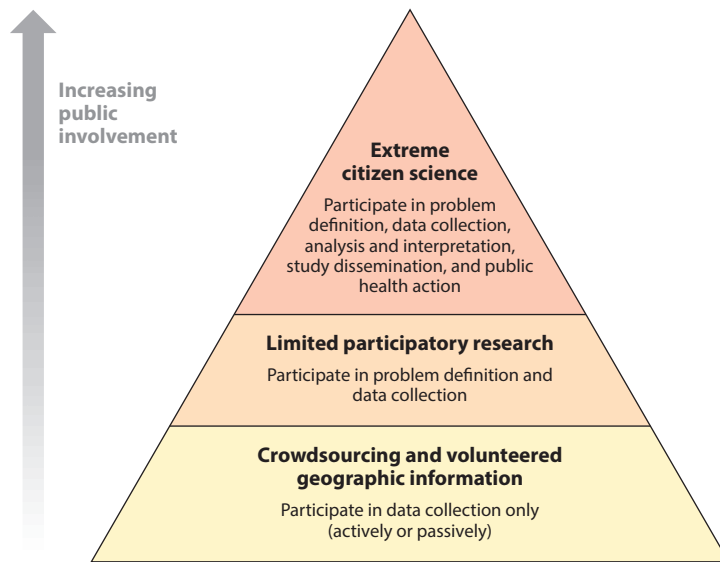
## THE BROAD SCOPE OF PARTICIPATORY RESEARCH

The emergence of participatory research approaches is best understood in the context of power dynamics in the production of scientific knowledge that has, at best, historically excluded and, at worst, exploited or violated the human rights of members of politically disadvantaged and indigenous communities in the name of science. Fals-Borda & Rahman (18) contend that research overall must be understood as a decision-making process and knowledge as a form of power that has been historically consolidated into the hands of academically trained and credentialed experts. As suggested by Latour (27) in his studies of scientists, prevailing scientific methodologies, technologies, discourses, and institutions have historically concentrated this form of power into the hands of a knowledge elite by excluding nonacademically trained people from the practice of science and categorizing them as subjects, rather than agents, in the research process. By opening up the scientific process to meaningful participation by those directly impacted by what is being studied, participatory research has the potential to challenge the "knowledge monopoly," from which this elite derive their power, by democratizing the research process (18). The impetus for this democratization, by and large, has not originated with scientists themselves, but rather from those directly impacted by egregious or exclusionary practices on the part of scientists. Communities that have been historically exploited as sites or subjects of research have played a fundamental role

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<sup>1</sup>Here we use "citizen" as denoting a member of a community, not necessarily someone with citizenship.

<sup>2</sup>"Public" is used generally in this article but does not distinguish between those who do and do not have access to mobile devices, the Internet, and other information and communications technologies.



**Figure 1**

The pyramid of participatory research approaches displays increasing levels of public involvement (adapted from concepts in Reference 13).

in advancing more ethical practices for securing informed consent for participation in scientific research and for meaningfully engaging those directly impacted in designing and carrying out this research (42).

Participatory research, in its fullest form, involves researchers and communities in all aspects of a research project, including the formation of study questions, data collection processes, data analysis, interpretation, and study dissemination. Emphasis is placed on moving from research to action; researchers and communities work together to take action on the basis of study results and in the form of changes to community behaviors, laws, and policies to improve public health outcomes, referred to here as public health action. The range of participatory research approaches is illustrated in a participatory research pyramid (**Figure 1**). Citizen participation ranges from solely data collection to full inclusion in problem definition and involvement in public health actions. Volunteered geographic information (VGI) or crowdsourcing data collection methods, where a large number of individuals may be enlisted to provide information, fall at the bottom of the pyramid, along with participants actively transmitting data or simply allowing passive data collection. VGI methods are specific to the public provision of geographic information and have included annotating on Web-based mapping platforms, uploading geographic data, and using social media to tag geographic locations with photos or videos.

Barriers in access to and literacy in the use of technologies such as computers, the Internet, and smartphones may prevent disadvantaged communities from engaging with VGI methods to collect or transmit data. The sidebar titled Low-Tech Approaches to Collecting Geographic Information elaborates on alternative ways to collect geographic information, which can be applied in communities with limited access to or familiarity with information and communications technologies or who are otherwise impacted by the digital divide.

VGI also includes spatial data uploaded by specific users for a very targeted function, such as drinking water agency managers submitting data on water service boundaries (polygons)

## LOW-TECH APPROACHES TO COLLECTING GEOGRAPHIC INFORMATION

Lower-tech approaches to collecting geographic information can be especially useful when working with communities with limited access to the Internet and mobile devices or that are otherwise impacted by the digital divide. Community members can provide geographic information by drawing or otherwise creating their own maps by physically marking the locations of places of concern on printed maps. For example, hand-drawn mapping has been used to document indigenous knowledge about local places, resources, and land uses, as well as to preserve non-Western traditions for documenting spatial or geographic information that may otherwise be missed when relying solely on geographic information systems (GIS) technologies (11). Moore & Garzón (31) describe a community mapping process using poster-sized aerial photographs of neighborhoods with streets overlaid with transparency paper to document community knowledge about freight truck traffic in West Contra Costa County, California. In a technique akin to creating and combining GIS layers, these transparencies were then placed on a poster-sized map with land use designations to enable the community to discuss potential land use conflicts, such as residential areas abutting industrial facilities that contribute to local pollution exposures from diesel pollution and other freight hazards.

(50), or the open-source provision of data intended for broader consumption, such as the locations of bus stops (points) or bike routes (lines) uploaded for the OpenStreetMap project ([https://wiki.openstreetmap.org/wiki/Main\\_Page](https://wiki.openstreetmap.org/wiki/Main_Page)). Ellwood et al. (16) have noted that VGI does not typically include traditional measures of accuracy or metadata, making it difficult to assess data quality. Furthermore, the use of VGI data does not assure that the final results will be understandable and accessible to the public nor does it assure that the public participates in any decision-making processes on the development of research questions or on how the data are used, interpreted, and disseminated.

Moving up the pyramid in **Figure 1**, limited participatory research approaches engage the public not only in data collection but also in problem definition. “Extreme” citizen science approaches go even further to involve the public in data analysis, interpretation, and, ultimately, public health actions (13). Woolley et al. see extreme citizen science as the intersection of “engagement,” “involvement,” and “participation” (50, p. 3).

## PUBLIC PARTICIPATION AND COMMUNITY-ENGAGED RESEARCH IN ENVIRONMENTAL HEALTH

Public participation and data collection are relatively new in the field of environmental health, but similar approaches have been taking place in other scientific disciplines for decades. The Christmas Bird Count conducted by the National Audubon Society started in 1900 (<http://www.audubon.org/history-christmas-bird-count>), and many geographic projects have used public data collection methods dating back to the 1930s (16). In the field of public health, a notable use of crowdsourced data sets is Google Flu Trends, a Web-based aggregation of Internet searches to provide estimates of influenza activity (35). Google Flu Trends has been highly correlated with influenza-like illness rates but has a lower correlation with surveillance for laboratory-confirmed influenza (20, 35). It has been used to forecast influenza-like illness in emergency room visits in Nebraska (2) and in an urban hospital setting (14).

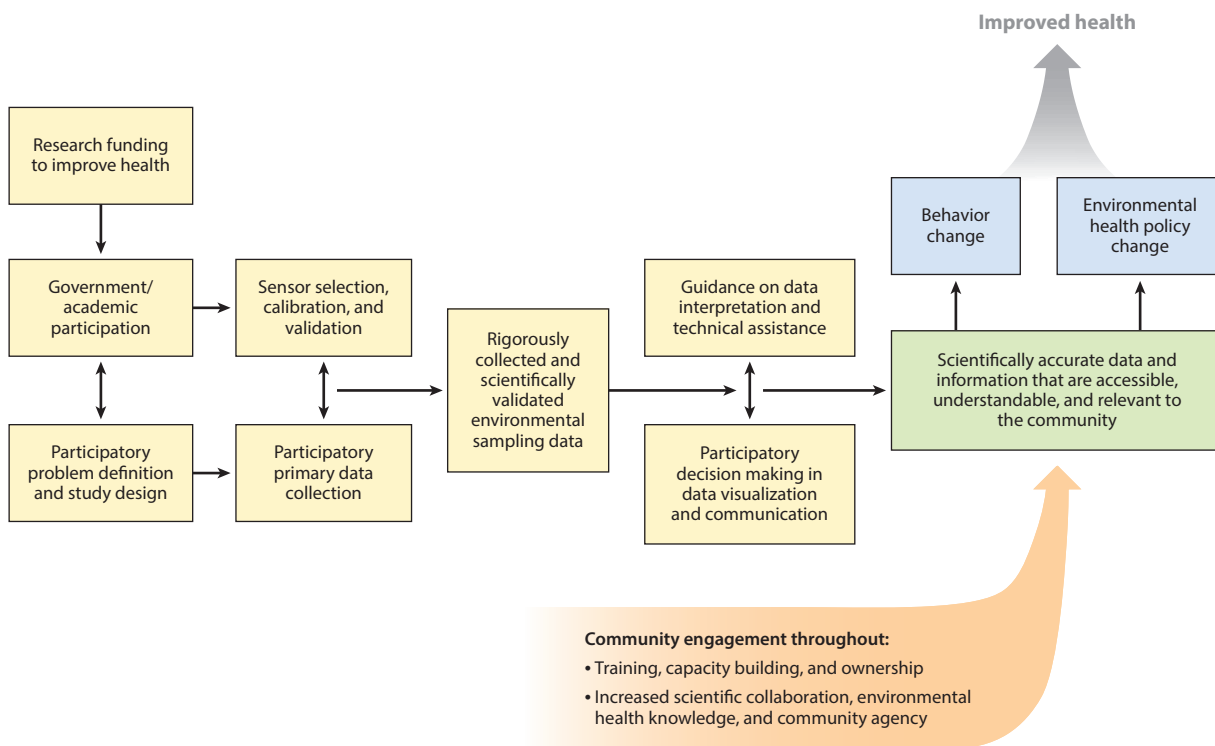
These efforts have, for the most part, involved the public only in the provision of data. Community-engaged research (CEnR) or community-based participatory research (CBPR), however, more directly involves the community impacted by the issue being studied throughout the

research process. In CEnR and CBPR, the impacted community is involved in developing the research question, implementing the study, assisting with data collection, and interpreting results to ensure that they are understandable, accessible, and actionable. O’Fallon & Finn (33) have noted that academic criteria (including an emphasis on scientific certainty) often initiate CEnR projects, whereas community concerns more frequently drive citizen science efforts. CEnR can employ citizen science data collection efforts but is uniquely characterized by direct involvement of the community in the entire research process.

In part because of its close ties to community needs and collaboration, participatory research is closely linked to efforts to democratize science, where the goal is focused not only on the outcome and use of research but also on a process that embraces transparency and accountability (23). Democratization of environmental data can enhance information found in regulatory data sets, for example, by supplementing regulatory data with temporal data on exposures and information on industrial activities at unmonitored times (19).

## CONCEPTUAL MODEL FOR PARTICIPATORY RESEARCH FOR ENVIRONMENTAL HEALTH

Community engagement is the structural foundation for participatory research in environmental health, as shown in the conceptual model in **Figure 2**. Engaging those who are directly impacted by the environmental health issue being studied at the beginning of the research process better enables community participation at multiple levels at each step of the process throughout the project and



**Figure 2**

Conceptual model for participatory research for environmental health.

generates research questions and methods that adhere to community needs. The establishment of a community advisory or steering group allows the community to provide feedback on overall study design, environmental sampling and data collection methods, communication of findings, and the development of policy actions to reduce exposures to environmental pollution.

When communities actively participate in data collection and study design, they can direct researchers to measure the environmental hazards of greatest concern. Communities are better able to provide key groundtruthed information on data collection sites and can play a role in the operation of sensors to collect primary data. Government and/or academic partners, meanwhile, can provide guidance on monitor equipment selection and testing on the basis of past experiences and the technical limitations of the data to be collected. In addition, government and academic partners may be essential in validating and calibrating study sensors with reference monitors (in the case of air quality studies), establishing data collection and data transfer protocols, and developing quality control plans to ensure the production of scientifically valid environmental sampling data. Once data are collected, communities can help make decisions about how the data will be communicated, visualized, and disseminated. Culturally relevant messaging for the data and research should include information on the environmental issue in question, its relevance to health, and lay communication products describing research methods and data interpretations. The inclusion of training throughout the process (such as on understanding basic science concepts, hosting a sensor, installing monitors, troubleshooting sensors, etc.) builds community capacity, deepens community ownership, and increases overall project sustainability.

By involving the community in the initial study design and implementation, members are more likely to remain active participants throughout the research project. The data collected can be better understood and more relevant to the community. Supporting the community's involvement through stipends and/or contracts is also critical. When the community is given ownership over the project, a deeper understanding of the environmental health issue develops, and there is greater potential to translate knowledge into public health actions capable of reducing environmental exposures or changing behaviors or policies (**Figure 2**) (40). Subsequent process and outcome evaluations of the project can generate knowledge useful for appraising community participation, project replication, and sustainability (5, 7).

## **PARTICIPATORY RESEARCH AND ENVIRONMENTAL JUSTICE**

Participatory research is increasingly being used to address environmental justice concerns and simultaneously effect policy change throughout the world. Environmental justice activists have utilized participatory research to fill gaps in government data available at a local level, to draw attention to disproportionate exposures to environmental hazards that were being denied by polluters or overlooked by decision makers, and to garner credibility for proposed policy changes and government action to reduce environmental health disparities (6, 12).

One of the earliest examples of participatory research in the environmental justice context was the “bucket brigades,” the use of inexpensive sensors by residents for air quality monitoring. Community residents in places ranging from California and Louisiana to India have taken a participatory research approach to air quality monitoring to address environmental health and justice concerns. These projects have employed primarily a method of monitoring referred to as “grab sampling” (taking a single sample within a short period of time as opposed to continuous sampling), and the data collected have been used to impact policy and regulatory change. In Norco, Louisiana, a community on the fence line of a Shell Chemical plant monitored toxic air pollutants, which led to an air quality study and resulted in an enforcement action (34, 36). In Cuddalore, Tamilnadu, India, community members living near the chemical manufacturer SIPCOT monitored ambient

toxic gases. The data collected formed the basis for an India Supreme Court Monitoring Committee decision ordering the Central Pollution Control Board to set national standards for toxic gases in ambient air (1). A community in Contra Costa County, California, used a bucket brigade to monitor releases of catacarb from a Unocal refinery in 1995. The community's data spurred the installation of a fence line monitoring system and increased industry monitoring (34). The Global Community Monitor, an international environmental justice and human rights organization based in Richmond, California, assists communities in air quality monitoring and has facilitated projects in 22 states and 19 countries ([https://www.facebook.com/pg/gcmonitor/about/?ref=page\\_internal](https://www.facebook.com/pg/gcmonitor/about/?ref=page_internal)).

Issues such as urban blight have been addressed using a participatory research approach. In Detroit, residents surveyed the entire city, cataloged property conditions, and created digitized property boundaries. These data were used in a report by Detroit's Blight Elimination Task Force to target areas of the city with high rates of vacancy and blight conditions (<https://motorcitymapping.org/about>).

Participatory research approaches have been used in California to address environmental inequities in exposure to traffic exhaust and in North Carolina to investigate health effects from hog farms. In San Diego, the Environmental Health Coalition and its academic partners trained *promotoras* (lay health workers) to be coresearchers and policy change advocates to address disproportionate exposures to toxic air contaminants (30). Their efforts helped pass legislation to limit the operation of a truck-driving school adjacent to a local elementary school (28). In West Oakland, a participatory research approach to conduct truck counts and truck idling studies in a low-income neighborhood was used to advocate in favor of a new truck route ordinance (although lack of funding for enforcement of the ordinance was viewed as a setback) (22). The community was involved in collecting data on odor, mood, blood pressure, symptoms, and immune and lung function in a study of hog farm operations in a predominately African American community in North Carolina (48).

## THE ADVENT OF NEXT-GENERATION ENVIRONMENTAL MONITORING

The availability and reduced cost of portable or personal environmental monitoring technologies have been key drivers of the increased interest in participatory research in environmental health. Snyder et al. have outlined some of the reasons for the rapid expansion in portable and lower-cost monitors, including advances in microfabrication techniques, increases in computer power, greater access to wireless networks, and more user-friendly data visualizations (43). These new environmental sensors are being deployed to support participatory research projects (see the sidebar titled Use of New Environmental Sensors in Participatory Research; see also **Figures 3** and **4**). New real-time monitoring applications have been developed for gases (37); particulate matter (32, 38); and water quality and hydrologic parameters (8, 21). Air quality monitoring technologies, in particular, have seen substantial innovation; availability of affordable and high-quality sensors able to provide continuous high-resolution monitoring in real or near-real time over a network of monitors is expanding—a significant improvement compared with grab sampling methods mentioned above. The US EPA has even developed multiple manuals and publications related to new air quality sensors, including an air sensor guidebook and toolbox for citizen science (45, 47; <https://www.epa.gov/air-sensor-toolbox>). Efforts such as developing toolboxes and manuals are essential for communities to keep up with these rapidly developing technologies. The EPA, along with the South Coast Air Pollution Control District in California, has also conducted laboratory and field evaluations of low-cost air sensors (<https://developer.epa.gov/air-quality-sensors/>).

## USE OF NEW ENVIRONMENTAL SENSORS IN PARTICIPATORY RESEARCH

In the Imperial Valley of California, Dylos DC1700 light-scattering particle counters (Dylos Corporation, Riverside, California) are being used to develop a community-based air quality monitoring system (17). This low-cost monitoring system includes the Dylos particle sensor with four bin sizes ( $>0.5\ \mu\text{m}$ ,  $>1.0\ \mu\text{m}$ ,  $>2.5\ \mu\text{m}$ , and  $>10\ \mu\text{m}$ ), temperature and relative humidity sensors, and a microcontroller to allow real-time wireless data transfer to the Internet. The monitor components are housed in a box with a cooling fan to sustain optimal sensor performance under Imperial County's harsh summer conditions (**Figure 3**). Community members were involved in identifying monitor sites and trained in monitor maintenance and troubleshooting. Monitors were validated and calibrated with government reference monitors, and, based on validation results, algorithms were developed to convert particle counts to mass (10). A website that allows the public to view the data in real time was created and is accompanied by health messaging and answers to frequently asked questions (<http://www.ivanair.org>) (**Figure 4**). Public health actions based on data from the community-based air quality monitoring system are currently being evaluated; community members have discussed how data from the monitoring network can be incorporated into existing flag programs, which display different colored flags at schools to indicate daily air quality.

Governments and regulatory agencies can assist by further defining criteria for using new technologies to help ensure that community-produced data are useable by these agencies.

Many low-cost sensors are entering the market. Citisense, a small wearable monitor that allows users to monitor air quality in real time on their cell phones, measures ozone, carbon dioxide, and nitrogen dioxide (4). The Purple Air laser particle counter has six bin sizes and a wireless connection to transfer data to the cloud and visualize it on Google Maps (<http://www.purpleair.org>). Aclima has partnered with Google and the US EPA to map real-time air quality in California

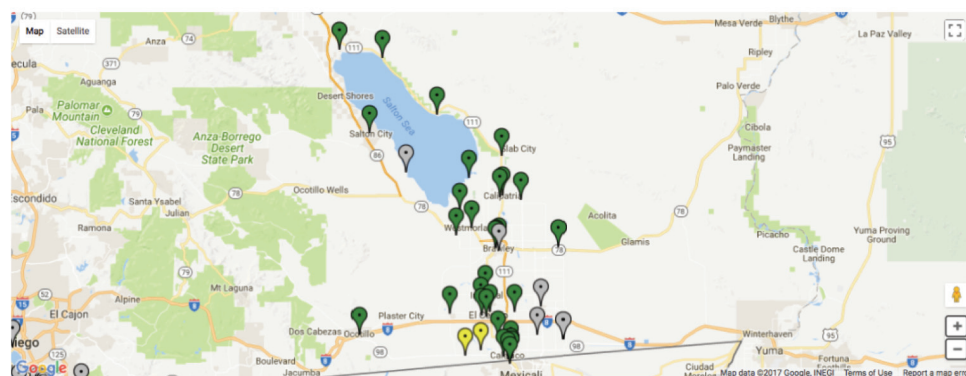


**Figure 3**

Modified Dylos 1700 particle counter.

# Map of Monitors

Tuesday, October 31, 2017 at 08:17 AM



## COMITE CIVICO DEL VALLE OFFICES

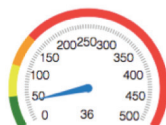
Brawley

Tuesday, October 31, 2017 at 08:23 AM

The current air quality at this monitor is

36

Health recommendations: It's a good time to be active outside



## Community Air-Quality Levels (CALs)

Number range	Category	Color	Health Recommendation
0-50	Low Risk	Green	It's a good time to be active outside
51-100	Moderate	Yellow	If you are unusually sensitive to particle pollution, reduce physical activity outdoors. Watch for symptoms like coughing or breathing problems.
101-150	Unhealthy for Sensitive Groups	Orange	Sensitive groups* should reduce physical activity outdoors. Watch out for symptoms like coughing, breathing problems, unusual heartbeat, or unusual fatigue.
Above 150	Unhealthy	Red	Avoid physical activity outdoors.

Figure 4

Visualization of Imperial Valley monitoring data and community air quality levels. Source: <https://ivan-imperial.org/air/map>.

cities via sensors mounted on Google's Street View vehicles (<http://www.businesswire.com/news/home/20150630005452/en/Aclima-Stealth-AnnouncesPartnerships-Google-EPA-Lawrence>). On the user end, mobile phone apps are being developed to display real-time air pollution data. Ambiciti, for example, provides users with real-time modeled air quality data and can show the least polluted routes to a destination (<http://ambiciti.io>). Airbeam, another wearable monitor that measures PM<sub>2.5</sub>, maps pollution levels via crowdsourcing through an Android app (<http://www.takingspace.org/aircasting/airbeam/>). Turner et al. provide further review of the latest portable monitoring devices and smartphone-based sensors that are being used for environmental exposure assessment (44).

Other online platforms, such as the US EPA's RETIGO geospatial viewer, function as intermediaries and allow a user to upload and visualize their own citizen-collected air quality data and explore the data as time-series or other data formats (<https://www.epa.gov/hesc/real-time-geospatial-data-viewer-retigo>). PublicLab (<http://publiclab.org>) posts user-submitted methods for do-it-yourself environmental sampling, such as the monitoring of stormwater runoff and particulate matter. Taken together, this growth in the availability of and accessibility to monitoring technologies offers citizen scientists more tools with which to measure, visualize, and communicate a range of environmental hazards and exposures.

## INCORPORATING LOCAL LAY KNOWLEDGE WITH ASSET AND HAZARD MAPPING

By incorporating local knowledge, participatory research can greatly enhance the quality of a needs assessment and the applicability of the research endeavor within impacted communities. In Imperial County, California, the California Environmental Health Tracking Program partnered with a community-based organization, Comite Civico del Valle, to use an asset and hazard mapping approach to facilitate the identification and ranking of environmental health priorities in a community that is disproportionately impacted by multiple environmental hazards. Asset and hazard mapping methods are often used to document and preserve residents' knowledge about the community with which they are innately familiar. Asset mapping is a strengths-based approach that identifies community resources as assets to be preserved or enhanced (15). Hazard mapping, meanwhile, is used to identify local concerns and supplement existing government and regulatory data (40). For this project, community members were trained in using a mobile phone Web-based application to collect data and information on hazards and assets in their daily lives. Hazards identified included pesticides, air pollution sources, trash/solid waste sites, toxic contaminants, polluted water, and noise. Assets identified included locations and sites that provide services or expertise, serve vulnerable populations, have political influence, or provide economic opportunities. After reviewing data from their asset and hazard mapping activities, participants prioritized the identified concerns and developed a community action plan with a vision element, goals, strategies, and activities. The community members' active participation in this process increased their capacity to identify and address local environmental issues while strengthening relationships and collaboration among residents, environmental health experts, and government agencies.

## BENEFITS IN USING PARTICIPATORY RESEARCH IN ENVIRONMENTAL HEALTH

With the increasing appeal of participatory research in environmental health, all study participants—communities, researchers, and funders—will need to leverage the benefits of participation, democratization, and transparency and be cautious of the inherent challenges of participatory research. A participatory research approach in environmental health research presents opportunities to generate research questions relevant to the impacted community, to influence environmental health policy, and ultimately to benefit the health of communities. Den Broeder et al. (13) outline three reported benefits of citizen science, namely (*a*) increased research capacity, for example, the labor-saving and increased efficiencies of crowdsourcing; (*b*) better knowledge, including the incorporation of lay local knowledge, which may lead to novel research strategies and more socially robust knowledge (see the sidebar titled Incorporating Local Lay Knowledge With Asset and Hazard Mapping); and (*c*) citizen benefits, such as improved scientific literacy, empowered communities, and engaged policy and decision making.

Balazs & Morello-Frosch have argued that participatory research increases the rigor, relevance, and reach of science by asking the right questions, improving the study's overall design, data collection methods, and interpretation, and increasing opportunities for the dissemination of the research findings to multiple diverse audiences (3). Woolley et al. acknowledge the potential benefits that participatory research can yield in terms of research capacity (50). For example, as translational biomedical research requires larger participant pools, many academic and government research programs are turning to participant-driven research, but such an approach may raise ethical concerns (see below) (50).

Wong et al. (49) used a Web-based crowdsourcing application to digitize geospatial information on thousands of public drinking water service areas in California, greatly increasing their research

capacity. Without a crowdsourcing approach, an effort of this scale would have required substantial government intervention and administrative costs. The crowdsourcing effort was made possible, in part, by the ease with which mapping technologies familiar to most computer users can be integrated into a data collection application. The resulting Water Boundary Tool gives secure access to water system engineers and state and local primacy field operations districts to create, edit, and delete service area boundaries, track boundaries as they change over time, and collaborate with other users to improve and assure accuracy of boundaries. The data have been used to support drinking water management activities, such as emergency drought planning, and have enabled or enhanced research on water affordability, nitrate pollution in agricultural communities, and cumulative environmental impacts.

Citizen benefits that accrue from participatory research include increased scientific literacy and environmental awareness (22). Research participants learn content knowledge, environmental monitoring skills, and obtain social learning, a process of self-reflection that can change assumptions and beliefs. Communally, participatory research can build social capital and leadership skills, foster collaborations between researchers and communities, and flatten the level of distinctions between experts and everyone else (26). In recognizing that communities have local content experts—as they are the ones living in the communities, dealing with the issues in question on a daily basis—inequalities between scientific and community experts are reduced.

Finally, participatory research has been demonstrated to effect positive policy change. As discussed above, bucket brigades have been successful in promoting policies to enhance environmental monitoring efforts. Other projects have focused on enforcement of existing environmental regulations in order to effect community change. IVAN (Identifying Violations Affecting Neighborhoods) is a crowdsourcing application used by communities to monitor and report on environmental hazards (<https://ivanonline.org/>). IVAN is currently available in 7 counties in California and has been used by residents to report hazards such as truck idling, hazardous material spills, and trash burning, and it allows users to monitor the status of the complaint. Residents report incidents online via a Google Earth basemap, and reports are displayed in real time. Reports are reviewed by an IVAN steering committee and then forwarded to the appropriate environmental regulatory authority, in many cases the California Department of Toxic Substances Control, for action. The IVAN system has been so popular with users that the same model was adopted by the California EPA for their Environmental Complaint System (<https://calepacomplaints.secure.force.com/complaints/>).

Cacari-Stone and colleagues cite two participatory research projects in Los Angeles and San Diego, where the majority of policy strategies developed by project partners were successful in formulating health policies (9). These policy strategies were effective by identifying the problem, bringing attention to health equity issues, constructing policy alternatives, and adopting politically feasible policy objectives (9).

## **CURRENT CHALLENGES IN PARTICIPATORY RESEARCH**

Participatory research approaches in the environmental health field also present several challenges, including potential biases in data collection; questions about the scientific rigor of research methods for data interpretation and visualization; and concerns regarding participant confidentiality and research transparency.

Bias in data collection may affect the generalizability of participatory research projects if the method of data collection—such as the use of mobile devices or Internet access—precludes certain segments of the population from participating. Bias may be particularly worrisome in low-income or marginalized communities. Solutions can include the provision of and training on mobile

devices before data collection activities commence or the development of alternative methods of data input, such as allowing for the submission of paper copies instead of mobile input. In addition, special attention is needed to provide instructions and data entry templates that are understandable and appropriate for the target population's educational level, language, and cultural norms.

In the past, a lack of resources or the inaccessibility of high-quality monitoring technologies has limited the scientific rigor of participatory research projects. For example, the use of grab sampling methods in early participatory research projects limited data interpretability. As sensors improve, costs drop, and the ease of use and maintenance increases, next-generation monitors allow researchers and residents to collect higher-quality and more representative data.

A more serious challenge to continued expansion of participatory research approaches relates to the view and acceptance of data quality by regulatory agencies and decision makers. Ottinger has proposed the use of standardized practices for air quality monitoring to address regulators' concerns about data legitimacy (36). Additionally, the US EPA has provided guidance on sensor use and data interpretation (45). In Imperial County, California, a participatory research project conducted field validation of our experimental sensors with federal equivalent method beta-attenuation monitors and federal reference method gravimetric filters at a colocation site in the study area (17). Such activities are crucial to ensure the provision of high-quality data to government and regulatory agencies and to illustrate the importance of robust community/government partnerships.

After data are collected, validated, and analyzed, proper attention needs to be paid to how the data and results are interpreted and visualized so that the information is communicated to the community in an understandable and scientifically accurate manner. Community participants should provide guidance on the most effective ways of presenting the data (such as text, charts, or infographics) and disseminating this information (such as via a website, fact sheets, or social media). Focus group testing of materials and messaging with target audiences can help ensure that information is understandable and culturally relevant. Efforts should be made to resolve any conflicting scientific (e.g., accuracy) and community needs (e.g., understandability) in presenting the data so that both parties' goals can be achieved.

Finally, researchers need to be able to ensure the confidentiality of participants' inputs while maintaining transparency throughout all study processes. Participants should be included from the beginning in discussions on how the data will be used (e.g., Who owns the data? Who can access the data? How and in what format will the data be communicated back to participants? Will the data be commercialized?) and how data and study participants will be protected from privacy breaches.

Study project leaders also need to be acutely aware of how citizen science approaches can potentially harm the community or others whom they intend their research to serve. This concern is particularly important in low-income communities and communities of color who have strong reasons to mistrust outside entities who may benefit from the research (41, 48).

The act of identifying hazards has historically led to their reduction in wealthy and white communities and to hazard transfers to disempowered communities of color. Although citizen science may presume the best interests of the community partners, partaking in traditional epidemiologic studies of hazard identification without explicit consideration of social justice may contribute to inequitable hazards in poor, disempowered, and nonwhite communities (48).

In addition, researchers may seek to profit from the data, information, and culturally embedded knowledge provided by community collaborators. Exploitation of the community can occur when researchers violate the community's or an individual's privacy, seek to monetize or benefit from

the long-held traditions against the will of the community, or fail to equitably share the benefits received (39).

Lastly, some elements of citizen science and participant-led research may fall through the cracks of standard ethics review processes and expose participants to unnecessary risks. Research efforts that form outside of traditional institutional models and funding structures, or studies that partake in self-experimentation, may not fit into existing ethics review procedures (46). Researchers who fail to seek informed participant consent and proper study oversight may expose their community collaborators to personal harm.

## **FUTURE RESEARCH DIRECTIONS**

Participatory research has shown great promise in environmental health, and several issues should be prioritized in the future to realize its full potential. First, government and academia should examine how they can best facilitate successful partnerships with communities in order to ask the right research questions and facilitate study design development, while maximizing the scientific rigor and data quality of research projects. Government and academia can play an important role by providing expertise in calibrating and validating sensors, and in ongoing quality control, but they must also ensure that the data are relevant for the impacted community.

Research should be conducted to determine which factors predict successful collaboration among government, academic, and community partners. The mutual sharing of decision-making authority, the incorporation of local community expertise, and the sharing of financial resources are three strategies to enhance collaboration and research relevance. When research projects are constructed from the ground up with resources to build capacity in community groups, the mutual collaboration and trust are more likely to take root, and the long-term sustainability of a project will be enhanced (24, 29). This process should include training on how to assemble, troubleshoot, and validate sensors as well as explicit requirements by funders for grant recipients to dedicate resources for training.

Additional research, evaluation, and strategies are needed to ensure that results from participatory research projects are communicated and disseminated in ways that are understandable and actionable by the community. The use of focus groups, material testing, and needs assessment can greatly improve the usability and quality of the final product. Researchers should understand how various mediums (such as mobile devices, social networks, and photovoice activities) can most effectively communicate project findings and propel communities to action. The methods best suited for any one community may depend on cultural norms, technological access and capacity, and social capital. In some instances, researchers may need to consider taking a multipronged approach to meet the needs of diverse constituencies.

Translating the findings from participatory research into policy outcomes is still an emerging area of research. Successful case studies should be analyzed for common themes to develop a framework for researchers and communities who are especially interested in impacting health and environmental policies (see, for example, 29).

Finally, the potential for more expansive benefits of participatory approaches in environmental health research should be investigated. To tap into this knowledge, environmental health researchers may need to partner with other content experts, such as those with expertise in health education and communication, to best realize the full potential of their work. In-depth measures of environmental health literacy should be examined, as should data on social capital, leadership skills, and social learning. Nuanced approaches may be needed to best understand the specific cultural and sociodemographic characteristics of various communities and how these factors impact ultimate research goals and project sustainability.

In summary, as environmental health challenges become more complex and technologies improve, novel research approaches will be needed to maximize the relevancy and rigor of environmental health research. Participatory research approaches, which are becoming more accessible with technological advances in sensor technologies, hold the promise of delivering more efficient and higher-quality studies by building closer collaborations among government and academic researchers and the communities they serve when compared with traditional research models. Research and solutions grounded in local questions, knowledge, and skills may provide sustainable solutions to environmental threats that continue to affect communities.

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