



2016 Environmental Health Summit

Community Engaged Research and Citizen Science: Advancing Environmental Public Health to Meet the Needs of Our Communities

Research Triangle Environmental Health Collaborative 9th Summit
December 8-9, 2016
Research Triangle Park, North Carolina

Abstract

With the rapid development of technologies for exposure monitoring and data analysis, opportunities for utilizing citizen science and community-engaged research approaches in advancing environmental health research are ever increasing. On December 8-9, 2016, the Research Triangle Environmental Health Collaborative (Collaborative) held its 9th Summit, Community Engaged Research and Citizen Science Summit: Advancing Environmental Public Health to Meet the Needs of Our Communities in Research Triangle Park, NC. The timing of this particular Summit was fortuitous as it dovetailed with the *Environmental Health Sciences FEST* held in celebration of the National Institute of Environmental Health Sciences's (NIEHS) 50th anniversary in Durham, NC. NIEHS has been a leader in advancing community-engaged research. The Summit also immediately preceded

publication of a report by the National Advisory Council for Environmental Policy and Technology recommending citizen science to the Environmental Protection Agency (EPA). Over the course of the Summit, academic researchers, public health officials, non-profit and private industry representatives, along with members of government agencies from around the nation, discussed key questions and challenges facing the field of citizen science today. Attendees were divided into three workgroups to explore and develop recommendations regarding the conduct of citizen science research, new data and technology challenges and opportunities, and ethical, legal, and social issues that arise when using these paradigms. This report summarizes the discussions, key questions, and recommendations of the Summit.

WORKGROUP	KEY QUESTIONS	CHALLENGES	RECOMMENDATIONS
CONDUCT OF CITIZEN SCIENCE (PG. 8-11)	1. How do we build acceptance of community data, particularly of qualitative data? How do we link health data to location data while protecting the privacy of vulnerable populations?	1. Data collected by community is not used in regulatory decisions (pg. 9)	<ul style="list-style-type: none"> Define clear purposes and audiences Create a compendium of success stories Increase awareness of citizen science Make data more accessible to the public
	2. How do we get community questions into the crowd-sourced space? How do we diversify participation in this area to include under-represented groups? How do we reach impacted communities, especially in those affected by disasters?	2. Perceived inability to take action on environmental health issues (pg. 9)	<ul style="list-style-type: none"> Establish collaborations Establish ownership of data Identify steps for addressing hierarchies
	3. How can we activate existing infrastructure? Can we connect independent investigations using crowd-sourcing? How do we connect citizen science methods to the social justice movement?	3. Citizen science approach is not valued by traditional research or policy-making institutions (pg. 10)	<ul style="list-style-type: none"> Promote acceptance for publications of citizen science Integrate citizen science into traditional research training
		4. Lack of funding (pg. 10)	<ul style="list-style-type: none"> Provide technical assistance for funding applications Evaluate and tailor language to be more persuasive and competitive
		5. Identifying research questions in a multi-community collaboration (pg. 10)	<ul style="list-style-type: none"> Introduce local actors to global network/movement Encourage bi-directional communication
		6. Lack of baseline data (pg. 10-11)	<ul style="list-style-type: none"> Standardize data collection protocols Compile existing data sources so they are publicly available

WORKGROUP	KEY QUESTIONS	CHALLENGES	RECOMMENDATIONS
DATA AND TECHNOLOGY (PG. 11-13)	1. How can we leverage low-cost sensors and monitoring methods with professional scientific methods to develop health-relevant and actionable information for communities?	1. Identifying the right tool (pg. 12)	<ul style="list-style-type: none"> ● Define what types of tools can be used for what purpose ● Improve location and access to tools ● Distribute the burden of data validation ● Establish compliance standards
	2. How can we increase the use of data from non-accredited, open sources while addressing privacy and covert research?	2. Multiple data sources and needs to serve many purposes (pg. 12)	<ul style="list-style-type: none"> ● Build a flexible framework for data utilization, incorporation, and matching data quality with potential uses
	3. How do we address the need for validating quality of data collected by current technologies? 4. How do we ensure that the tools, data collection procedures, research purpose and findings, are effectively translated and communicated to lay audiences?	3. Community-collected data needs to be translated to different uses and purposes (pg. 12-13)	<ul style="list-style-type: none"> ● Place data into context from the beginning ● Determine effective communication strategies for data, significance, risk, and action potential ● Involve communities early in the research process ● Make data accessible to the user/community

WORKGROUP	KEY QUESTIONS	CHALLENGES	RECOMMENDATIONS
<p>ETHICAL, SOCIAL, AND LEGAL ISSUES (PG. 13-14)</p>	<p>1. How can we ensure that scientific institutions and/or regulatory standards do not exclude citizen science work? Are existing guidelines available but not being used (e.g., Title VI remedies)?</p>	<p>1. Producing citizen-driven data without harming well-being or privacy of participants (pg. 14)</p>	<ul style="list-style-type: none"> ● Build on existing toolkits ● Partner with law clinics already working on these issues (e.g. privacy/ethical domain)
	<p>2. How can we ensure that citizen science and community-based research is culturally appropriate? (Institutional Review Boards [IRBs] are not sufficient or designed to do so).</p>	<p>2. Ensure citizen science is culturally appropriate (pg. 14)</p>	<ul style="list-style-type: none"> ● Ensure clear communication between researchers and the community ● Implement a community advisory board/review board
	<p>3. How can citizen science better utilize IRBs for the benefit of the human subjects (participants) in citizen science studies?</p> <p>4. Under what circumstances can sensitive and confidential community data and information be shared? What tools can be used to protect privacy?</p>	<p>3. Improve inclusion of citizen science into academia, regulatory standards, and policy decisions (pg. 14)</p>	<ul style="list-style-type: none"> ● Find appropriate partners ● Customize the citizen science approach to the data/information needs based on the agencies involved ● Involve citizen scientists in research planning process

Introduction

To begin the Summit, a number of popular definitions of the concepts of citizen science were offered for the attendees' consideration. For example:

“Citizen science is the involvement of the public in scientific research—whether community-driven research or global investigations.” — Citizen Science Association

*“Citizen science can mean anything from citizens observing natural events and characteristics to a genuine revolution in ‘science’ that democratizes the important social role of learning about the world around us.”
— 2007 Citizen Science Toolkit Conference*

The past two years have seen a significant increase in the number of citizen science projects initiated through private or government-funded entities. While much of the national conversation has focused primarily on its use in natural and environmental sciences, the Collaborative feels there is much more room for robust discussion on citizen science in the context of environmental health research and environmental public health.

In 2014, the Collaborative convened a workshop entitled *Exposure Science in the 21st Century: Role of Citizen and Communities* in response to a National Academies of Science report on exposure science. This meeting began a conversation among

Collaborative members and the environmental health community around the conduct of citizen science, developing technologies to accommodate citizen science data collection, and effective community engagement. The Collaborative's 2016 Summit sought to extend and expand this conversation. The goals of the workshop were to highlight and reflect on successful citizen science projects and approaches, identify key challenges in implementing environmental health and public health research through citizen science, and offer actionable next steps that meet the needs of communities and the field of environmental health science.

Plenaries and Panel Discussions

Plenary

Key leaders in the field of citizen science presented plenaries during the Summit, followed by expert panel discussions. **Jay Benforado**, Chief Innovation Officer at the U.S. EPA, discussed the broad scope and untapped potential of citizen and crowd-sourced science, what he termed “looking at problems through a citizen science lens,” and cited examples of crowd-sourced solutions including for validation of satellite imagery at NASA and citizen documentation of climate change through observation of the timing of flowering in plants. The EPA is embracing citizen science, spurred by its National Advisory Council on Environmental Policy and Technology that recently released recommendations on incorporating citizen

science into the work of the Agency. Benforado's suggestions for improving the field centered on increasing community collaboration and interactions on the local level, building trust and working with and through local organizations as intermediaries, and providing financial support through small grants to individuals and communities.

Symma Finn, Ph.D., an anthropologist and Program Officer in the Population Health Branch at NIEHS, began her presentation by discussing the concomitant emergence of environmental health sciences, the NIEHS, the environmental justice movement, and citizen science, beginning as early as the 1960s. She presented a graphic

framework for understanding the difference between community engaged research (more academic-based motivations) and citizen science research (grassroots effort to address community concerns). She emphasized the importance of cultural sensitivity on the part of scientific researchers by highlighting issues that can arise due to a lack of respect, understanding, or listening to the communities with which they work. Finally, she asserted that the future of citizen science lies in finding ways to address both scientific needs as well as community concerns.

Omega R. Wilson, President and Co-founder of the West End Revitalization Association (WERA) in Mebane, NC, gave a joint plenary presentation with **Sacoby M. Wilson, Ph.D.**, (no relation), Assistant Professor and Director for Community Engagement, Environmental Justice, and Health at the University of Maryland-College Park. The two discussed the development and use of the WERA Community-Owned and Managed Research (COMR) model, one framework for conducting community-engaged research. They outlined key principles that guide the use of the COMR model by community-based organizations (CBOs) when partnering with university and other federally-funded researchers. These principles include funding equity, management parity, and science for compliance. Unlike university-managed research models, COMR places community members in the role of principal investigator, and requires that CBOs be funded directly (rather than through universities), manage the research process, and retain ownership of any resulting or collected scientific data. With support from the Z. Smith Reynolds Foundation (1997-2017), and environmental justice grants (2000-2001; 2004-2007) from the EPA, WERA developed a collaborative problem-solving model to demonstrate the COMR approach.

A major difference between COMR and traditional community-based participatory research (CBPR)-type models is the emphasis of COMR on the use of collected data in leveraging legal actions to address violations of public health or civil rights statutes. WERA used COMR to

facilitate the collection of scientific data needed to encourage legal compliance and the enforcement of public health and civil rights statutes by local, state, and federal agencies. As part of efforts by WERA and the EPA to address the denial of basic amenities such as safe drinking water and sewer connections in three African American and Native American communities in Mebane, a partnership was formed with students (including Sacoby Wilson at the time) and faculty at the UNC-Chapel Hill Gillings School of Global Public Health to collect and analyze drinking water and community stream water samples. Later, as a professor, Sacoby Wilson used COMR principles to facilitate several NIEHS research studies with grassroots environmental justice organizations in North Charleston, SC, and Washington, DC. The Wilson-Wilson plenary team highlighted challenges that come with attaining funding for these kinds of community-based projects, and called for increased transparency in grant review and funding processes. They called for directed federal funding for the WERA “Right to Basic Amenities Training Institute,” which they deemed an innovative approach that will empower citizen scientists and build community capacity to address environmental health issues.

Expert panel members included the following:

Moderator:

- **Brian Southwell, Ph.D.**, Program Director, RTI International, Center for Communication Science

Panelists:

- **Jay Benforado**, Chief Innovation Officer, EPA's Office of Research and Development
- **Bryan Brice**, Attorney, Law Offices of Bryan Brice, Raleigh, NC
- **Monica Ramirez-Andreotta, Ph.D.**, Assistant Professor, University of Arizona, College of Agriculture and Life Science
- **Omega Wilson**, President, West End Revitalization Association
- **Sacoby Wilson, Ph.D.**, Assistant Professor and Director for Community Engagement, Environmental Justice, and Health at the University of Maryland-College Park

Moderator Brian Southwell began the discussion by asking panelists to comment on the relevancy of Merton's Norms of Science [see box insert] to citizen science, as well as to describe their experiences of failure and success in this area.

From the beginning of the panel, the general consensus was that citizen science is a "science" and thus should conform to the norms of science. Discussion centered on ways that citizen science manifests Merton's norms and areas that need improvement. The knowledge gained by citizen science is often of interest to the entire community, satisfying the universalism and disinterestedness norms. On the other hand, Benforado noted that citizen science can be prone to biases brought by people who care about the issues doing the science. Bryan Brice noted that, similar to scientific evidence brought up in a courtroom, citizen science needs to be accountable by some standard of reliability and to be explained in an accessible way (communism). Finally, panelists and audience members repeatedly highlighted that citizen science has met challenges

Merton's 1942 Norms of Science

- **Universalism:** science should be accessible to all and address broader claims about the world
- **Communism:** knowledge should be shared
- **Disinterestedness:** knowledge gains should not benefit the scientist solely or specifically
- **Organized Skepticism:** scientific claims should be critically evaluated before acceptance

with the acceptance of the data (organized skepticism), possibly due to unclear standards and biases towards "academic research" and against citizen-collected data.

Examples of "citizen science failures" cited by the panel included instances of data generated by citizen science not being incorporated into regulatory decisions due to a perceived lack of credibility; dismissal of concerns raised by communities in courtrooms, academia, and by researchers because of the source of the concern and doubts about data quality in citizen science that result in the persistent undervaluing of citizen science by more traditional research and policy organizations.

1 Over the course of the discussion, a clear theme emerged concerning the existence among many of bias toward traditional research paradigms and a reluctance to accept the credibility of citizen-generated data and analysis.

2 The underlying causes of such bias included a concern for lack of rigorous scientific training among non-scientists, the potential for the corruption of data collected in non-controlled situations (or

at least not by traditional means), and factors in such settings that might cause inconsistencies in the quality of the data or research conducted. As a means of addressing these concerns, panelists and audience members discussed that the concept of success for academic research may be publication of the research in a top-tier journal, but that success

also could be defined in other ways by the community impacted and in the realm of environmental justice. One measure of success emphasized was that the citizen science is actionable, meaning that it is used by the community for solving environmental health problems and disparities.

Work Group Discussions and Recommendations

Over the course of the Summit, attendees, including academic researchers and students, public health officials, non-profit and private industry representatives, and representatives of government agencies from around the nation, discussed key questions and challenges facing the field of citizen science face today. Attendees were

divided into three workgroups to explore and develop recommendations regarding the Conduct of Citizen Science and Community-Engaged Research; new Data and Technology Challenges and Opportunities; and Ethical, Legal, and Social issues that arise when using these paradigms.

CONDUCT OF CITIZEN SCIENCE AND COMMUNITY-ENGAGED RESEARCH

Charge: To explore issues related to the definition, design, and conduct of citizen science and community-engaged research including research design, collection and handling of samples, integration of traditional researchers with citizen scientists, education and training, and funding sources, among others.

Discussion: **Chip Hughes** is the director of the Worker Training Program at the NIEHS, a program that trains people in handling hazardous material, waste removal, and emergency response. Hughes discussed the benefits and challenges, in implementation and ethical issues, of including citizen science in environmental health, environmental emergencies, and emerging threats. Additionally, he emphasized the importance of bringing the voice of the community and emergency responders, who often times are the ones affected in an emergency situation, into the conversation on conduct of citizen science projects. **Amanda Kaufman, MSPH**, from the U.S. EPA, shared lessons learned from projects on community air monitoring using low-cost sensors and the online-based, Air Sensor Toolbox developed by the EPA. These air quality

monitoring studies have been done in multiple US locations and in Puerto Rico. A key theme from all these studies was the importance of collaboration with community groups to build trust and foster scientific literacy. **Caren Cooper** from NC State University and the NC Museum of Natural Sciences highlighted the growing acceptance of crowd-based approaches in scientific discovery (e.g. monarch migrations, plant development, bird-watching). However, there is a lack of inclusion of these techniques in community-based, environmental health/justice science (e.g. research targeted for policy change, addresses legal issues/compliance). Integrating crowd-based approaches could help in developing proactive collection of data, functioning as a scaffold and foundation that can support community-based issues as they arise.

Key questions identified:

1 Data Acceptance and Quality: How do we build acceptance of community data, particularly of qualitative data? How do we link health data to location data while protecting the privacy of vulnerable populations?

2 Community Participation: How do we get community questions into the crowd-sourced space? How do we diversify participation in this area to include under-represented groups? How do we reach impacted communities, especially in those affected by disasters?

3 Infrastructure: How can we activate existing infrastructure? Can we connect independent investigations using crowd-sourcing? How do we connect citizen science methods to the social justice movement?

The workgroup summarized these key questions into six challenges, and proposed recommendations for addressing each of them:

Challenge 1: Data collected by the community are often excluded from use in regulatory decisions. Citizen science data, including qualitative data are not valued as much as they could be.

Recommendations:

- **Define clear purposes and audiences for citizen science data.** Establishing these make it easier to identify the appropriate data standards needed to meet to achieve the desired goal. Transparency about where to find such standards and guidance and how to meet them effectively is needed for community-engaged researchers and citizen scientists. Collaboration with key persons in research agencies and with appropriate policy makers would help to facilitate incorporation and standardization of community-collected data into the scientific knowledge base and policy decisions.

- **Create a compendium of success stories.** Documentation of research questions, study designs, and findings that were instrumental in meeting a research and/or community goal would help to demonstrate the validity of data collection

methods and improve future study designs.

- **Increase awareness of citizen science.** Efforts to identify and develop relationships with “influencers” in science, as well as engaging scientific publishers, professional organizations, and journalists who can shine a spotlight on citizen science would help to improve its acceptance and validity. Use of “citizen science” in the keywords of scientific publications can also increase awareness among readers.

- **Make data more accessible.** Citizen scientists need access to data (baseline and otherwise) to make informed decisions to protect their communities. Work with publishers to make data more transparent and /or provide access to proprietary literature. There are new models of data publication that are more transparent such as open source, “self-correcting”, and crowd-sourced data.

Challenge 2: There can be a perceived inability on the part of communities and citizens to take action on environmental health issues. Power hierarchies (or the perceptions of them) in community-engaged research, wherein the opinions of academics and researchers are valued more (considered “more expert”) than those of community partners, can result in disinterest and distrust among the community and a lack of expertise diversity in the study. This effect is often to exclude the communities most impacted from the leadership and decision-making roles in the research project.

Recommendations:

- **Establish collaborations.** Researchers and policy makers should work to engage community members in decision-making and solution-seeking processes. It is important to clearly communicate the limitations of organizations and manage expectations from the beginning of a joint project.

- **Establish ownership of data.** Before a study begins, the question of who owns community-collected data and to what purpose such data can be applied should be clearly resolved among all parties and participants.

- **Identify steps for addressing hierarchies.** If such imbalances (or perceptions of imbalance) occur, there should be clear paths to resolving such issues. A repository of appropriate neutral parties who can intervene, as well as case-studies and other relevant resources to inform citizens of what can or cannot be done in certain situations would be highly useful.

Challenge 3: The citizen science approach is not valued by traditional research or policy-making institutions. This can be especially true in cases of social injustice, where data generated by citizens can be dismissed as a service, outreach, or extracurricular activity to the main goals of the research.

Recommendations:

- **Promote acceptance for publication and understanding of the contributions of citizen science.**

- Cross-talk of public/environmental health journals and professionals with citizen science journals will help to increase recognition and acceptance of the value of community-collected data and enable publication.

- **Integrate citizen science into traditional research training.** Explicit incorporation of the proper conduct of citizen science into formal academic training will help to provide long-term sustainability.

Challenge 4: Lack of funding sources for citizen science hampers its conduct and inclusion of its findings in decision making. Funding is needed to create and sustain projects citizen science projects where a traditional funding infrastructure is lacking. Expenses can include identifying partners, providing monitoring technologies and equipment, costs of data infrastructure, compensation for participants, and costs of publication.

Recommendations:

- **Provide technical assistance to citizen science groups for applications to potential funding sources such as:**

- Grant-making institutions such as federal, state, and local governments, hospital systems and public health departments

- Foundations and non-profits for bridge funding

- Crowd-funding methods such as GoFundMe

- Faith-based communities, particularly in rural communities

- **Evaluate and tailor language in grant applications to be more persuasive and competitive.** Language that focuses on worker wellness, returns on investment, resilience, infrastructure, community empowerment, and decreasing government involvement may increase the political suitability of applications.

Challenge 5: Identifying joint research questions in a multi-community collaboration can be difficult. Processes need to be clear for determining who has input and how research questions are identified. Are there questions not considered due to imbalances of power?

Recommendations:

- **Introduce local actors to global network/movement.** Potential connections include the National Environmental Justice Advisory Council, Citizen Science Association, NIH, state public health agencies, NIH CARE grantees, EPA Environmental Education grantees

- **Encourage bi-directional communication.** Clear communication between communities and researchers can help identify research questions of concern to the community and best next steps to solving the problem.

Challenge 6: The lack of baseline data to provide an appropriate reference for the research is a problem.

Recommendations:

- **Standardize data collection protocols to allow data to be comparable across time points and populations.**

- **Compile existing data sources so that they are publicly available.** One suggestion

was to establish a consortium of stakeholder institutions to sponsor the collection of such data with transparency of funding sources. Careful consideration of privacy and potential consequences of data collection and use are needed to prevent misuse of information.

- ***Establish appropriate measures of environmental quality (air, water, soil, etc.) that are essential to monitor in communities as a foundation for baseline measurements.***

DATA AND TECHNOLOGY CHALLENGES AND OPPORTUNITIES

Charge: To identify issues related to the rapid development of technology and tools (social media, open source data platforms, wearable sensors and other data collection devices, GIS and mapping tools, etc.) that can facilitate citizen science and community engaged research, as well as some of the problems that may be associated with their development and use.

Discussion: Ron Williams, Research Chemist at the EPA's National Exposure Research Laboratory who develops and tests air quality sensors, emphasized in his presentation that data collection should be purposeful, meaning that "the why, for whom, and what will it be used for" kinds of questions need to be considered in the development of technology. Purposes can range from educating the general public on environmental topics, to increasing environmental health awareness, to data collection, to influence decision making on local issues. **Gretchen Gehrke** is the Data Quality and Advocacy Manager at the Public Laboratory for Open Technology & Science. The Public Lab is an open community and internet platform facilitating research questions investigating environmental concerns through the development and distribution of low-cost, easy-to-use, open-sourced tools for data collection. Gehrke discussed lessons learned when designing citizen science studies, such as using appropriate technologies for the research goal, proper data collection and open distribution, and the importance of data literacy among citizen science participants. She also identified three opportunities that arise with the availability of low-cost technologies, enabling the expansion of scope and scale and the challenging of standard methods of data collection. **Damian Shea, Ph.D.**,

Professor of Environmental Toxicology at NC State University and University Director of the DOI Southeast Climate Science Center, discussed how different data collection methods (low-tech such as surveys, exposure diaries) versus high-tech (such as passive environmental samplers attached to clothing) can be used in combination to both collect data and inform people of their chemical exposures in a cost-effective way. In some cases, low-tech (and typically lower-cost) methods can be more accurate monitors of exposure than high-tech samplers.

Key questions identified:

1 How can we leverage aspects of low-cost, widely-available sensors and monitoring methods (real-time measurements, high spatial resolution, sampling repetition) with aspects of standard professional scientific methods (chemical specificity, low detection limits, high accuracy and precision) to develop the most health-relevant and actionable information for communities?

2 How can we increase the use of data from non-accredited sources open data, and open data processing, which are critical but non-standard practices in most arenas, while addressing community concerns about privacy and covert research engendered by such practices?

3 How do we address the need for validating the quality of data collected by current citizen science technologies, especially when validation testing is not feasible for communities and government agencies facing funding reductions? Can we incentivize or require certain testing of such instruments before they go to market?

4 How do we ensure that the tools, data collection procedures, research purpose and findings, including actionable findings, are effectively translated and communicated to lay audiences?

Challenge 1: There is a diversity of monitoring equipment available for citizen science, but it can be hard to determine which tool provides sufficient and appropriate data for the desired purpose at the desired cost level. Information and access to citizen science tools and technologies can be limited. Furthermore, these data need to be validated for different purposes, but who has the time, skill, and financial capacity to do so may be unclear. Appropriate compliance standards and the kind of data needed at the regulatory level can be difficult to identify.

Recommendations:

- **Define what types of tools can be used for what purposes.** There are a variety of qualitative and quantitative tool types that can generate data for defined purposes (universal v. specific, high sensitivity v. low sensitivity, calibrated v. uncalibrated). The purpose of the monitoring needs to be very clear so that data quality objectives (DQOs) can be developed, and appropriate tools are selected that can meet those DQOs.
- **Improve location and access to tools.** Because citizen science can be applied to a broad range of scientific problems, a national repository of tools from a collaboration of government agencies would be beneficial to have. Best practices and purpose development also must be established for each monitor/category of data collection to establish consistency and validity. Funding initiatives should be created to expand citizen science tools and practices networks.
- **Distribute the burden of data validation based on use by individuals, community, regional agencies, or policy makers for both data collection tools and the collected data.** Citizen scientists need to gain a greater understanding of data validation procedures and apply them. Resources like the EPA's Community

Air Monitoring Training videos and the Air Sensor Toolbox can help to train and inform on this issue.

- **Establish compliance standards.** Create protocols and mixed methods of data collection that create a growth model of data collection and actionable translation of data. Activity logs need to be a part of monitoring data. Create motivation for extended participation.

Challenge 2: Data comes from many sources and needs to serve many purposes. People involved in citizen science have a range of data literacy, which may impede accurate data collection or community buy-in to the research purpose, and leading to wasted time, money, and effort.

Recommendations:

- **Build a flexible framework for data utilization, incorporating multiple types of data and metadata, and matching data quality indices with potential use.** This could be written as a guidance document.
- **Develop school and community curricula to integrate data literacy into communities.** These could manifest as specific in-person, hands-on trainings or web and video trainings with an interactive interface. To facilitate user technical capacity and understanding of the data collected, transparency is needed in data processing, including in sensor-user interfaces. Often, this includes addressing how the data fit into the larger picture and what actions should be taken given this particular data.

Challenge 3: Community-collected data needs to be translated for different uses and purposes such as educating and informing the public, motivating community action, presenting to policy makers, and driving behaviors to protect health.

Recommendations:

- **Place data into context from the beginning.** The type and quality of the data must match the intended purpose. There is no “one-size-fits-all” approach for citizen science.

- **Determine effective communication strategies for data, significance, risk, and action potential.** Translation of data involves numerous factors, such as what is the nature of its purpose or use, who is the end user of the data, who will present such information, and who is the audience.
- **Involve communities early in the research process.** Communities should have input into

defining the purpose of data and research questions, recognizing uses and limitations, collecting data, and translating data in order to meet their needs and purposes.

- **Make data accessible to the user/community.** Ensure appropriate language, consider literacy levels, utilize graphical presentations, and create user-friendly interfaces to increase accessibility.

ETHICAL, LEGAL, AND SOCIAL ISSUES

Charge: To raise and explore various ethical, legal, and social issues surrounding citizen science research. These include acceptance of citizen science research results by decision makers, communication of results to participants/affected communities, privacy concerns, data ownership, and community inclusion in decision-making processes.

Discussion: **Lea Shanley, Ph.D.**, co-executive director of South Big Data Hubs based at UNC Chapel Hill, highlighted key ethical issues that arise when participants are engaged in citizen science: classifying and transcribing data, solving problems, gathering data, data analysis, data sharing, and interacting with researchers and fellow citizen scientists. Defining codes of ethical practice, when to apply them, and who to conduct them is essential and many established resources are available to build off of (e.g. European Citizen Science Association’s 10 principles, framework developed with the Wilson Center, Association for Volunteer Administration). **Sally Darney, Ph.D.**, Editor-in-Chief of *Environmental Health Perspectives*, provided insight from the publishing perspective on rigor and reproducibility and the concept of “fit for purpose” and how these should be applied in citizen science studies. Her presentation initiated a discussion of how to make citizen science more acceptable for publication in scientific journals, as well as more accessible to the public, thinking beyond scientific articles. The EHP has made advances to increase scientific literacy and accessibility through publishing

summary articles of technical reports in layman language, active communications on social media, and creating “landing pages” that compile news and links to reliable sources of information. **Christine Goforth**, Director of Citizen Science at NC Museum of Natural Science, raised questions on privacy issues based on results of an informal survey she conducted and from her experiences working with citizen science projects. There is a broad range of concern among participants about privacy and about what kinds of information they want to protect or are willing to share publicly. Many people enjoy having their real names connected with their contribution and are more concerned with being inconvenienced (e.g. receiving junk email) than protecting their privacy. She concludes that there needs to be increased education of privacy risks associated with participation in citizen science and that the burden of privacy protection falls on researchers leading these projects.

Key questions identified:

1 How can we ensure that scientific institutions and/or regulatory standards do not exclude citizen science work? Are existing guidelines available but not being used (e.g., Title VI remedies)?

2 How can we ensure that citizen science and community-based research is culturally appropriate? (Institutional Review Boards [IRBs] are not sufficient or designed to do so).

3 How can citizen science better utilize IRBs for the benefit of the human subjects (participants) in citizen science studies?

4 Under what circumstances can sensitive and confidential community data and information be shared? What tools can be used to protect privacy?

Challenge 1: Producing citizen-driven data without harming the well-being or privacy of participants. A balance must be struck between protecting data and not limiting the ability of citizen scientists to make change.

Recommendations:

- **Build on existing toolkits.** Many resources are available already for liability, privacy, and intellectual property. There needs to be further development of legal issues, consent, improved technology for data masking and encryption specifically for citizen science. Further clarification of Freedom of Information Act-specific considerations will define what is vs. is not discoverable in citizen science work (e.g. parcel, soil, and well data). Additional protection measures need to be developed for citizen scientists that are subpoenaed or threatened.
- **Partner with law clinics already working on these issues (e.g. privacy/ethical domain).** To glean expertise from lawyers already working on similar issues, forums and training sessions could be organized to address harassment/intimidation of communities and citizen scientists.

Challenge 2: Ensuring that citizen science is culturally appropriate—in some cases of citizen science, the needs of the community are not being met. Being culturally appropriate is ethically warranted and improves data reliability due to increased community cooperation.

Recommendations:

- **Ensure clear communication between researchers and the community.** By working closely with local community organizations and non-profits, researchers can ensure that

community needs are being met. Communities should help to shape the research. They also have the right to know all potential risks, benefits, and limitations of the research results.

- **Implement a community advisory board/review board.** Ensuring that a project is culturally appropriate is not the job of the university IRB. Instituting a similar review board with community members for citizen science research projects will help ensure the research or project meets the needs of both the community and researchers.

Challenge 3: Including citizen science work in scientific institution projects, and its consideration in development of regulatory standards and policy decisions needs to be improved. Also, application of citizen science to compliance actions can be contentious.

Recommendations:

- **Find appropriate partners.** It is important for community members and citizen scientists to know who can guide them through complicated processes in government, as well as identify the right agency to which to present the data/problem and findings. Such contacts can help citizen scientists to identify the appropriate guidelines their data must meet in order to be included in the regulatory process.
- **Customize the citizen science approach to the data/information needs based on the agencies involved.** Citizen science should be designed for the desired purpose, such as for regulatory and compliance actions. Information about data quality, collection, and type of data needs to be communicated to citizen scientists in order for their data to be used effectively.
- **Involve citizen scientists in research planning process.** Inclusion of the community voice in all aspects of the research (from design and problem definition to data analysis and conclusion) will ensure that the study reflects the full range of citizen concerns.

A subtheme that emerged during the Summit was the potential for leveraging citizen science in emergency and disaster response situations. Citizen science opportunities are present in pre, during, and post-disaster research scenarios. Often times, a lack of pre-disaster data in a community can hinder public health response. Local groups could be tapped to help collect baseline surveillance data in topics and areas that might be highly relevant to disasters.

The development and spread of exposure monitors, both personal and at the community/regional level, increases the amount of available data. One question is how responders and communities can use the data and information generated by existing exposure monitors in disaster situations. One example discussed was the ongoing detection of particulate matter by

monitors in Charlotte and how it might have been used to provide baseline health data prior to the onset of the East Tennessee and West North Carolina wildfires this past year. Such data might also be used to predict similar disasters. Issues to be explored include how to capture data during a disaster event, how to connect community members and workers with researchers and public health officials interested in improving existing emergency response structures, what types of training of community members would be required to best integrate citizen science into emergency response (such as using sensors to collect data during/following an event, purchasing of data collection equipment, and generating plans for what information should and can be collected in certain disaster situations), and how to approach groups that already collect relevant data on applying it to disaster research.

Citizen science is a growing, powerful, and valuable tool for advancing environmental health research. With the rise of personal monitoring systems, big data analytical tools, and interactive and user-friendly applications (made even more accessible due to smartphones and the internet), collecting data quickly and broadly is easier than ever before. This rise in data collection capacity requires that researchers and stakeholders make careful and thoughtful considerations about best practices when conducting citizen science and community-engaged research.

Throughout the course of the Summit, three cross-cutting themes pervaded discussions across all three workgroups: how to include citizen science in regulatory actions/standards, a need for frameworks and best practices to guide citizen science research, and respect for and engagement of the community in research efforts.

While the field of citizen science is progressing towards a more active role in environmental health research and environmental justice efforts, the current regulatory and funding infrastructure is not equipped to facilitate citizen science. The lack of transparency about the process and data quality requirements can leave citizen scientists with a perceived inability to take action. These problems can be remedied by establishing resources (databases, tool networks, contact personnel, funding opportunities) that can assist in the design, implementation, and translation of citizen science research.

All workgroups called for development of frameworks, toolkits, resource databases, and best practices guidelines for data collection, data quality standards, privacy, ownership, and legal protections; communication of success stories, and community engagement.

Engaging community in the research effort from start to finish was identified as most essential

to the success of citizen science research. Clear communication with community leaders will ensure that the purpose of the research meets the desires of the community and that the data collected will meet their desired purpose. Inclusion and training of the community in data collection, interpretation, and translation will empower them to act on their own behalf, as well as improve science and data literacy in communities. Building communal trust and respect between communities and researchers will allow for the inclusion of unique and critical data in research projects, and in turn, enable citizen science to become a more effective, recognized, and utilized method of scientific inquiry.

References and Resources

All presentations and abstracts of speakers can be accessed at the Environmental Health Collaborative 2016 Summit Meeting website:
<http://environmentalhealthcollaborative.org/?/summit/2016-presentations>

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Conduct of Research

National Environmental Justice Advisory Council.
<https://www.epa.gov/environmentaljustice/national-environmental-justice-advisory-council>

Citizen Science Association.
<http://citizenscience.org>

EPA Environmental Education Grants.
<https://www.epa.gov/education/environmental-education-ee-grants>

Data and Technology

Environmental Protection Agency Air Sensor Toolbox for Citizen Scientists, Researchers, and Developers. <https://www.epa.gov/air-sensor-toolbox>

Citizenscience.gov: Helping federal agencies accelerate innovation through public participation.
<https://www.citizenscience.gov>

Clean Air Carolina website.
<http://cleanaircarolina.org>

The Public Laboratory for Open Technology & Science.
<https://publiclab.org>

North Carolina Museum of Natural Sciences website.
<http://naturalsciences.org/research-collections/citizen-science>

Social, Legal, Ethical Issues

Title VI and Environmental Justice.

<https://www.epa.gov/environmentaljustice/title-vi-and-environmental-justice>

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www.EnvironmentalHealthCollaborative.org

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