

EDITORIAL CONTENT

Citizen Science Ethics

Lisa M. Rasmussen* and Caren Cooper†

We are very pleased to present this special issue of *Citizen Science: Theory and Practice* dedicated to ethical issues in citizen science. Readers may wonder why an entire issue devoted to ethics in citizen science is warranted. After all, ethical issues in social media research have garnered more national media attention than issues in citizen science; the overwhelming majority of citizen science volunteers are not crying out for discussion about ethics; and federal regulators have not targeted the field for new or intensified scrutiny regarding ethical issues. Moreover, citizen scientists, practitioners, and participants seem well-intentioned and motivated to do good work in service of good aims. What's the problem?

The fact that we can ask that question without a self-evident answer means both that we are engaging in healthy assessment of the field and that we may be lucky. Regulations on research in the United States, for example, resulted from a history of research abuses (particularly of human subjects) that demonstrated the inability of some researchers to pursue their work in morally appropriate ways. In other words, regulations began as a response to a problem. Because scientists and citizen science practitioners are humans, and because humans err (or worse), we should expect that problems in the field will arise. We should not wait for a problem to bring ethics to the door of citizen science and react to it then; instead, we should find and prospectively address potential problems. This will not be easy given the widely distributed nature of citizen science across many disciplines with varying norms. Another challenge is that the regulations about citizen science that do exist usually apply only to grant funding and institutions – particularly, but not solely, academic institutions – whereas many citizen science projects take place without grant funding and away from academic institutions. Moreover, no central authority or governing body oversees the field, and even agreeing about who counts as a citizen scientist is challenging.

Our experience in the field of citizen science, and in the planning for and preparation of this issue, shows that citizen scientists and citizen science practitioners do have the foresight to see a wide range of ethical issues needing discussion. Several papers in this issue address collaborations with human beings: What to call them when they are not

mere passive subjects of research; what ethical issues arise when citizen scientists are also patients reporting their own data; how to acknowledge the significant contributions of volunteers to research; how to foster inclusion, diversity, and trust; and how to establish accurate expectations for collaboration. Other papers consider potential challenges of citizen science that was not conducted ethically, including the possibility of research misconduct, disagreements between collaborators, or poor scientific methodology.

We are also mindful of all the potential ethical issues *not* represented in these pages. For example, there are significant ethical questions about labor, equity, and compensation for citizen scientists. Should citizen science practitioners pay their collaborators for their contributions? Can the field be sustained with volunteer labor, and should it be? What is the role of artificial intelligence systems in collaboration with citizen scientists? There are also questions in citizen science that may arise even more profoundly than they do in conventional science: Should this work aim merely at discovery, or should it also aim at remediation or accountability for problems discovered in research? The very fact that this conversation is being conducted in a journal aimed at citizen science practitioners and conventional scientists is also worth analysis: How can we progress in our ethical analysis of citizen science without better representation of the voices of volunteers and collaborators? All of these concerns and more must be discussed. We are under no misconception that this special journal issue has done anything other than begin a conversation, and we look forward to future work that explores the breadth of citizen science ethics even more widely (**Figure 1**).

Background

This issue resulted from a confluence of factors. One of us (Lisa Rasmussen) is a philosopher who focuses on research ethics, particularly research that falls outside of regulatory categories. The other (Caren Cooper) is a scientist who is interested in citizen science and ethical issues in the field. In the summer of 2014, Cooper co-taught a course on citizen science at the Vespucci Institute, and as students developed their projects, they persistently raised questions about a suite of ethical issues. Her experience prompted her to convene a panel on ethics at the first Citizen Science Association (CSA) conference in 2015. A year later Rasmussen, who was beginning to study unregulated human subject research, came across the panel in the online

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Figure 1: How will future work in citizen science choose to address research ethics? Image by Ed Gregory via Stokpic.

CSA program and began corresponding with Cooper. Subsequently, Rasmussen proposed and was awarded a workshop grant from the National Science Foundation to convene a group of people to begin a conversation about citizen science ethics and to think about next steps. The workshop took place in Raleigh, North Carolina, in the summer of 2017, and resulted in some of the papers in this issue. Other material from the workshop can be found on the webpage of the Ethics Working Group of the CSA (https://drive.google.com/drive/folders/0ByqFbxbay_ckNGRnXzRCeU1Hek0), which Cooper initiated after the 2015 CSA conference. The working group meets regularly via conference call, and you can learn more about it and its work at <https://www.citizenscience.org/association/about/working-groups/ethics-working-group/resources/>. We hope that some readers will join us on this working group!

In this Issue

This thematic issue begins with six essays. In **Data Donation as a Model for Citizen Science Health Research**, Matthew Bietz, Kevin Patrick, and Cinnamon Bloss present “data donation” as a model for citizen science focused on health. They discuss ethical issues identified in this kind of research—including protections for participants, representativeness, incentives and governance—and suggest ways to address these challenges. Caren Beth Cooper, Lea Shanley, Teresa Scassa, and Effy Vayena, in **Project Categories to Guide Institutional Oversight of Responsible Conduct of Scientists Leading Citizen Science in the United States**, point out that current US regulations have resulted in oversight that offers a one-size-fits-all set of paternalistic norms of human subjects research that does not always serve all types of citizen science research.

They offer a typology of citizen science projects based on criteria from US regulations; provide preliminary evidence that one category of projects almost never offers informed consent, despite collecting personally identifiable information; and urge the community of practitioners and volunteers to collectively determine the oversight needed to ensure that citizen science projects are conducted ethically. In **The Promise of Participation and Decision-Making Power in Citizen Science**, Irene Eleta, Gemma Galdon Clavell, Valeria Righi, and Mara Balestrini explore guidelines for working with the public on citizen science projects. Their recommendations include setting accurate expectations for participation, proactively considering and addressing privacy concerns, and facilitating citizen governance of research data.

This issue also brings together several philosophical considerations of ethical issues in citizen science. Kevin C. Elliott and Jon Rosenberg consider possible **Philosophical Foundations for Citizen Science**. As they point out, good scientific inquiry practices are necessary for research to be ethical, because otherwise resources are squandered and opportunities for better research are lost. Through the lens of the philosophy of science, they defend citizen science against three general objections to its overall quality. In **Confronting Research Misconduct in Citizen Science**, Lisa M. Rasmussen considers the options for addressing hypothetical cases of research misconduct in citizen science that falls outside of typical U.S. federal regulatory reach. She suggests that in keeping with the citizen science ethos, the field must establish its own novel mechanisms for fostering research integrity and confronting misconduct if it occurs. In **Citizen Scientists as Human Subjects: Ethical Issues**, David B. Resnik considers the unique ethical challenges involved in new

research approaches where patients also serve as collaborators. In viewing such individuals solely as “human subjects,” he points out, current U.S. regulatory approaches ignore other important ethical issues involved in that dual role. He outlines several categories of novel ethical issues and offers recommendations for investigators and ethical oversight bodies.

This issue also presents three rich case studies in citizen science. In **Citizen Science During the Flint, Michigan Federal Water Emergency: Ethical Dilemmas and Lessons Learned**, Siddhartha Roy and Marc Edwards offer a detailed account of the water emergency in Flint, Michigan and their role in it. They use it as a case study to explore potential ethical challenges in future emergency projects conducted by or with citizen scientists. Additionally, **Reflecting on Efforts to Design an Inclusive Citizen Science Project in West Baltimore**, by Amanda E. Sorensen, Rebecca C. Jordan, Shannon L. LaDeau, Dawn Biehler, Sacoby Wilson, John-Henry Pitas, and Paul T. Leisnham presents a case study aimed at ensuring inclusion in a citizen science project. Though they succeeded in many aspects of this aim, they frankly acknowledge and discuss their challenges, and offer a series of recommendations for more inclusive citizen science research projects. Finally, in **Designing a Platform for Ethical Citizen Science: A Case Study of CitSci.org**, Stacy J. Lynn, Greg Newman, Nicole Kaplan, Sarah Newman, and Russell Scarpino describe the kinds of ethical issues they encountered in setting up the CitSci.org platform and its options. They also discuss the values that guided their choices about platform functionality, offer a typology for citizen science openness choices, and make recommendations for platform developers and citizen science project managers.

The issue is rounded out by a Research paper by Elise Smith, Jean-Christophe Bélisle-Pipon, and David Resnik. In **Patients as Research Partners; How to Value their Perceptions, Contribution and Labor?**, they consider the subset of citizen scientists known as “patient partners.” Arguing that the contributions of patient partners are vitally important, the authors offer suggestions about ways to acknowledge these contributions scientifically, financially, and personally.

Final Notes

A journal’s most important responsibility is to provide a forum for civil discussion and careful analysis. Without such an exchange of ideas, a field cannot progress. Though editors (and guest editors) will inevitably use their own judgment in building an issue, the perspectives expressed in the issue neither necessarily represent their views nor are endorsed by them. We recognize that some of the topics discussed in this issue will be controversial, and we welcome future submissions challenging and contesting what has been said in this issue or exploring new ethical issues in the field.

As the field develops, we think that the CSA can aid in the development of an ethical research environment in several ways. First, with help from members of the Ethics Working Group, Cooper and Rasmussen received a research grant from the National Science Foundation in 2018 to engage members of the CSA in co-creating ethical norms while building the capacity of the CSA to cultivate and sustain the emerging community norms and best practices. We hope that many of you will join these efforts. Second, we would like to see the CSA work deliberately to imbue ethics throughout its activities, for example by asking conference presenters to mention any ethical challenges they faced in their work; establishing awards to recognize research following rigorous ethical practices; or building training tools for citizen science collaborators. Finally, we hope that the CSA will serve as a locus of discussion and will aspire to represent the very best of what citizen science can be.

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Competing Interests

The authors have no competing interests to declare.

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