CITIZEN SCIENCE:
THEORY AND PRACTICE

Diverse, Emergent, Disruptive: Perspectives on and Developments in Biomedical Citizen Science

COLLECTION: BIOMED

ESSAY

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ABSTRACT

Editorial for the special collection on biomedical citizen science.

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INTRODUCTION

Citizen science projects relevant to human health and the biosciences are on the rise. Initiated, executed, and championed by individuals from diverse disciplinary and experiential backgrounds, these projects cover a range of objectives and participatory designs. Examples of biomedical citizen science activities include public health studies that engage communities in data collection, including participatory and community epidemiology studies; initiatives led by patients and caregivers to understand and treat disease; biomedical research and biotechnology development occurring in non-traditional spaces, such as community laboratories; and self-tracking and self-experimentation to improve health and well-being (Pauwels and Denton 2018; Wiggins and Wilbanks 2019). For convenience, we refer to all of these activities as biomedical citizen science and to the individuals who participate in them outside of their professional work as biomedical citizen scientists.

Although a singular definition of biomedical citizen science has been difficult to develop beyond its focus on human biology and/or health, it is possible to identify common features. First, biomedical citizen science includes research activities conducted by members of the public who are typically not involved in knowledge production. In addition, many–although certainly not all–biomedical citizen science projects involve individuals whose participation is motivated by personal health experiences or the health experiences of loved ones. These and other projects might be associated with ethical and legal questions related to biosafety or bodily autonomy that are not usually present in other citizen science domains (Guerrini, Wexler, Zettler, and McGuire 2019; Kelty 2010). Finally, and similar to other domains, biomedical citizen science raises important and provocative questions about the risks and rewards inherent in critiquing and disrupting established scientific institutions and standards.

Our conviction that the field would benefit from a special collection dedicated to biomedical citizen science is the byproduct of our conversations over the past several years with an interdisciplinary group of scholars and practitioners who, like us, were grappling with issues, opportunities, and concerns in biomedical citizen science. Who, for example, qualifies as an expert if credentials don’t matter? What forms of ethical oversight are necessary and appropriate for specific projects? What are the safety obligations and potential liabilities of projects vis-à-vis participants and members of the public not involved in the research? And how might projects partner with industry and technical experts to achieve their objectives?

The purpose of this collection is to improve understanding of the practical, social, legal, and ethical dimensions of biomedical citizen science, at a conceptual level and in the context of specific projects, by exploring these and other questions. More generally, as editors of the special collection, we hope to increase awareness of citizen science engagement in the biomedical sciences, promote dialogue among its global stakeholders, and support productive relationships, where desired, between citizen scientists and institutionalized forms of biomedicine.

This special collection comprises 12 research articles and essays that make novel contributions to citizen science theory and practice. Three conceptual themes emerge from this scholarship: definition and breadth, credibility, and governance.

DEFINITION AND BREADTH

The first theme concerns definition and breadth. These concepts are inextricably linked given that characterizations of the field depend on its definitional boundaries. The multiplicity of terms and definitions in citizen science is a well-described phenomenon (Eitzel et al. 2017; Haklay, Dörler, Heigl, Manzoni, Hecker, and Vohland 2021), but citizen science relevant to human health and the biosciences is associated with a lexicon all its own. Although online biology games, such as FoldIt, and large-scale public health projects, like Outbreaks Near Me, might be described using standard citizen science vocabulary, other biomedical citizen science activities are associated with novel terms such as patient-led research, citizen-driven biomedical research, N-of-We, N-of-Many-1s, community biology, do-it-yourself (DIY) biology, garage biology, health hacking, embodied health movement, and popular epidemiology (Brown 1997; Brown, Zavestoski, McCormick, Mayer, Morello-Frosch, and Gasior Altman 2004; Meyer 2013; Pauwels and Denton 2018; Trejo, Canfield, Robinson, and Guerrini 2021; Wiggins and Wilbanks 2019). Depending on the practical, political, and philosophical aims of those engaged in these activities, they might be called biohackers, biopunks, bioactivists, life hackers, or grinders (Guerrini et al. 2019; Trejo et al. 2021; Wexler 2017; Wohlsen 2012).

The breadth of projects in the field is captured in **Biomedical Citizen Science at the National Institutes of Health**, Mintz and Couch’s review of biomedical citizen science supported by the U.S. National Institutes of Health (NIH). The authors describe a portfolio analysis conducted by an NIH working group dedicated to investigating the utility of citizen science methodologies in health research and working to incorporate public participation in the research enterprise. Based on this analysis, they provide examples of the diverse biomedical citizen science projects and programs that NIH has funded, from online community games to public health partnerships to genomic data projects. Finally, they note the definitional challenges inherent in identifying what exactly constitutes a "citizen science" project or initiative. Indeed, many funded projects did not self-identify using that term but rather referenced public involvement in research and bidirectional information flows between researchers and the public.

In **Mapping the Landscape of Do-It-Yourself Medicine**, Wexler traces one strand of biomedical citizen science known as DIY medicine as it has emerged across medical fields including neurology, gastroenterology, infectious disease, and endocrinology. In these areas, patients who are frustrated with their existing care have worked to replicate or advance therapeutics for their own conditions, often administering experimental, but as-yet unavailable, therapies in their own homes. In recognizing DIY medicine as a cross-cutting phenomenon, Wexler identifies several key definitional features–frustrated patients, online fora, access barriers, and the ease of creation or acquisition of the therapeutic–that lead to the creation, growth, and uptake of a DIY medical movement.

Finally, Kariotis, Borda, Winkel, and Gray examine the connectedness of human-animal-ecosystem health in their rapid review of digitally enabled citizen science studies focused on the health impacts of air quality in **Citizen Science for One Digital Health: A Rapid Qualitative Review of Studies in Air Quality with Reflections on a Conceptual Model**. Their review includes detailed description of 12 studies carried out in high-, middle-, and low-income countries with outcomes including adoption of policies to increase tree coverage in high-risk asthma areas and reconsideration of transportation decisions. The authors conclude with a proposed conceptual model describing inputs, outputs, and mechanisms of citizen-engaged, digitally enabled "One Health." More generally, their article reminds us that the biomedical citizen science domain can be coextensive with potentially many other domains when impacts on human health is a focus of concern or action.

CREDIBILITY

The second theme is credibility, which is often associated with questions of authority. As a result of the specific contexts in which citizen science takes place and external assumptions about it, some citizen science projects might have difficulty being taken seriously by those with power in the circumstances, whether institution-based scientists, policy makers, or the public (Freitag, Meyer, and Whiteman 2016; Kosmala, Wiggins, Swanson, and Simmons 2016). In recent years, scholars and practitioners have recommended thoughtful strategies to help address this problem, including training of citizen scientists, validity checks of data, documentation of data quality, and peer review and publication of data sets and results (Downs, Ramapriyan, Peng, and Wei 2021; Freitag, Meyer, and Whiteman 2016; Kosmala et al. 2016).

In **Barriers to Citizen Science and Dissemination of Knowledge in Healthcare**, Lewis focuses on one issue that can undermine efforts by citizen scientists to demonstrate credibility of their work and reinforce assumptions that it is not or cannot be credible: dissemination via journal publication. Although journal publication can be a challenge even for employed, grant-funded scientists, citizen scientists face additional dissemination barriers. For example, citizen scientists may have to learn the skill of academic writing, and even if they do, editors may still decline to review their work if projects are led by those without advanced degrees or university employment. Although many of these barriers may also apply to traditional researchers, Lewis argues that the cumulative effect can be far greater for citizen science researchers. She offers several suggestions for addressing these challenges, such as working with a larger, umbrella organization (such as PatientsLikeMe) or using a well-known condition or disease as a springboard to tie new research approaches to familiar problems.

Because of barriers such as lack of funding or equipment, one way for citizen science to engage with the standards of establishment science is by reexamining what counts as a standard. In **Standards Without Labs: Drug Development in the Psychedelic Underground**, Bailey and Kempner explore the efforts of Clusterbusters, a network of people developing a protocol for the use of psilocybin as a treatment for cluster headache. They can access psilocybin—a Schedule I drug—only via the consumption of psychedelic mushrooms, but there is no standard dosage for this route of administration. Like others in the psychedelic underground, the group makes do by using an "embodied standard" for dosage that combines both the weight of the dried mushroom and the subjective experience the dosage produced. This phenomenological understanding may offer non-establishment researchers an alternative model to the conventional, resource-intensive forms of a standardized protocol. It also demonstrates differences between citizen scientists' often more pragmatic goal of producing usable knowledge and the establishment science motive of "legitimating" findings.

Finally, in **Citizen Science and Scientific Authority: Have You Checked the Boundary Work?**, Mayes addresses the very legitimacy of the credibility crisis endemic within biomedical citizen science, arguing that this crisis has less to do with the quality of evidence produced by citizen scientists and more to do with the broader power relations in which scientific authority is allocated and standard of proof is determined and employed. Her incisive analysis draws from two case studies—scientific journalism covering non-expert participation in health research during the COVID-19 pandemic and an analysis of the Flint, Michigan water crisis conducted by two members of the Virginia Tech water testing team. In both cases, Mayes found that those with power assessed the work of citizen scientists by the norms and standards of dominant scientific cultures, even when citizen scientists engaged in "informed refusal," i.e., rejection of the structure of one tradition through the counter-knowledge of another. Mayes flags an important epistemological issue for those interested in opening scientific research to non-institutional actors: Those with power can easily dismiss novel forms of inquiry, no matter the importance of the research or the quality of evidence it produces.

GOVERNANCE

Governance, the third theme, encompasses regulation and ethics. Although regulatory and ethical matters can and do overlap (for example, when regulations are designed with the aim of promoting ethical practices or achieving ethical outcomes), we describe the relevant articles in an order that reflects their primary focus, moving from regulation to ethics.

Regulatory issues are perhaps more salient in biomedical citizen science than many other citizen science domains given the complex regulatory landscape that applies specifically to biomedical research and biotechnology development. Two papers in this special collection make useful contributions to understanding how regulations intended to prevent harms from research processes and outputs can influence the shape and trajectory of individual projects. First, complementing the rich literature on the intersection of citizen science with federal human research subject protections and medical product regulations (Cooper, Shanley, Scassa, and Vayena 2019; Evans 2020; Nebeker 2020; Resnik 2019a, b), Zettler explores relevant legal authorities of US states in **State Regulation of Biomedical Citizen Science**. These authorities include state medical practice and food and drug statutes, as well as laws and regulations that do not have an obvious relationship to citizen science activities, such as consumer protection statutes. Although limited to the United States, Zettler's survey is an important reminder that, regardless of where they take place, few biomedical citizen science activities are likely truly unregulated, i.e., beyond the reach of any law. It also provokes questions about whether, in the future, we should expect jurisdictions around the world to extend and increasingly exercise regulatory authority over these activities as they become more visible.

Second, in **Structural Challenges in Deployment of an Open Source Diagnostic by Independent Researchers During a Public Health Emergency**, Monaco and Ware describe their experience as independent scientists navigating regulations applicable to an open-source COVID-19 diagnostic test they developed at the beginning of the pandemic. They explain that the process of developing and validating a testing protocol was easy in comparison to making the test available for widespread use. The authors attempted to make the test available via two different regulatory pathways in the United States, but despite their best efforts and some early successes, they were ultimately unable to deploy the test. The authors conclude with recommendations regarding how to support independent scientists to successfully navigate these issues in the future.

Whereas Monaco and Ware describe practical and legal challenges faced by citizen scientists engaged in biomedical research and development, in **Pirate Talk: Practical, Ethical, and Legal Considerations for Conducting Interview Studies with Bottom-Up Biomedical Citizen Scientists,** Guerrini, Bash Brooks, and McCurdy describe challenges faced by qualitative researchers seeking to learn about the experiences of citizen scientists who have loose or no affiliations with traditional research institutions. Both articles provoke questions regarding who is obligated to ensure that citizen science practices and products are safe and what exactly are those obligations. Drawing on interviews conducted with other qualitative researchers, the authors explain that safety is generally promoted and monitored by community laboratories via education and self-regulation. Still, as a best practice, they advise those studying activities in non-traditional laboratory and health research settings to plan how they will manage information learned about potentially unsafe practices.

At the intersection of self-regulation and ethics, Foti's **A "Tyranny of Structurelessness"? The Benefits and Burdens of Power Sharing and Governance Models in Citizen Science** provides a rare inside look at how the Open Insulin Project grappled with its governance structure in an ongoing effort to avoid inequitable power dynamics typically seen within corporate and academic biomedicine. Their original, open governance structure provided the public more opportunities to participate in science, but it also reproduced the same hierarchical power structures that the group wished to avoid. To alleviate some of these issues, the project shifted to a more formal governance structure. However, Foti explains, this structure still runs the risks of reproducing race, class, and gender power dynamics found in broader society and institutionalized science, and of taking credentialed scientific expertise more seriously than embodied patient knowledge. Foti recommends that citizen science organizations continually reflect on their governance and infrastructure if their mission includes an emancipatory political orientation toward science and power.

Finally, two articles address questions of ethical oversight and review of biomedical citizen science. First, in **Community Bio Ethics: Provocations for Institutionalized Ethics from Community-Based Biology**, Murray and Santos join the debate about what is the proper role, if any, of traditional (or "establishment") ethics review mechanisms, such as Institutional Review Boards (IRBs), in citizen science. Drawing on their ethnographic analysis of the Open Insulin Project, the authors note the challenges that establishment research ethics poses for community biology and that community biology poses for establishment research ethics. Like Foti, they argue that community biology's work to build systems and structures to foster ethical research risks recapitulating the same problematic structures found in establishment research. For example, if IRBs are inadequate to the task of reviewing community biology projects, there is some reason to think that simply building new IRBs *within* the community will not solve the problem. Similarly, focusing overmuch on finding consensus on ethical principles risks ignoring moral pluralism. Instead, they argue that community biology should build not only a new approach to science, but also potentially a new approach to "community bioethics."

An Ethics Framework for Evaluating Ownership Practices in Biomedical Citizen Science by Guerrini and McGuire also examines the application of traditional ethics review processes to citizen science, but the authors focus specifically on evaluation of project practices related to ownership, which they define broadly to encompass access to, control of, and share in the benefits of research outputs. They observe that ownership issues can be especially salient in biomedical citizen science, but traditional research ethics, as codified in IRB regulations, is largely silent on matters of ownership. To help fill this gap, the authors describe a new conceptual framework to help project leaders evaluate practices related to ownership based on four considerations: reciprocal treatment, relative treatment, risk-benefit assessment, and reasonable expectations. The framework is intended to be in conversation with the growing body of ethics literature in citizen science.

CONCLUDING REMARKS

In this special collection, a range of conceptual topics and practical challenges are confronted; a mix of top-down, collaborative, and grassroots projects are described; and a variety of governmental, academic, and community affiliations are represented. At the same time, the articles and essays in the collection feature predominantly US-based activities and perspectives, and few describe projects involving marginalized populations. Notably, our editorial team also lacks diversity. We hope that others building on the research published here will help to address these gaps and further broaden understanding of the actors, activities, aims, and outcomes that are possible in biomedical citizen science.

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The authors have no competing interests to declare.

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