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Citizen Science in News Media: Boundary Mediation of Public Participation in Health Expertise

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Abstract

In this article, I examine how scientific boundary work describes or represents citizen science as credible forms of expertise. Citizen science is an ambiguous concept, and I leverage that ambiguity to examine citizen science as a proxy for nonprofessional or noninstitutional scientific practices more generally. I argue that media representations of citizen science perform boundary work through different articulations of institutional “buy-in” to the legitimacy or credibility of citizen science. Using a discourse analysis of mainstream news media, I trace three framings of citizen science’s relationship to institutional networks, which I describe as subservient to, corrective to, and exceeding the norms of institutional expertise. I find that the perspectives of professional, credentialed scientists dominate public discourse concerning citizen science and perform different adjudications of how citizen science contributes to networks of expertise. By focusing on citizen science concerning human health and medicine, I additionally show how mainstream

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framings of citizen science engage with overlapping media representations of personal health responsibility and patient empowerment. I suggest that representations of citizen science as a form of “missing expertise” can conflict with portrayals of citizen science as “going too far” in the pursuit of treatments or interventions.

Keywords

citizen science, expertise, public participation, boundary work, biomedicine

In 2019, the *American Journal of Bioethics* released a Special Issue on a rising form of research in health and medical contexts: citizen science. The accompanying editorial describes citizen science as a collection of research models “through which nonprofessionals collaborate in the generation of health and biomedical knowledge” (Patrick-Lake and Goldsack 2019). As other contributions to the Special Issue demonstrate, this open-ended and ambiguous definition of nonprofessional involvement in science is a matter of substantial disagreement. Noninstitutional research is celebrated for its creativity, thrift, open-access commitments, and anti-elitist ethos, characteristics that are sometimes described as antidotes to bureaucratic sluggishness in institutional science (Rasmussen et al. 2020; Talbot 2020). However, deviations from established institutional structures and regulatory processes are also condemned as undermining the authority of institutional science (Caplan and Bateman-House 2020). The ongoing COVID-19 pandemic has produced a microcosm of both perspectives, as public responses to informational or resource gaps are recurrently praised and criticized for highlighting the shortcomings of scientific institutions (Erikainen and Stewart 2020). Emerging diagnostic profiles like “Long COVID” are presented as case studies of how individual experiences can inform institutional knowledge (Callard and Perego 2021; Mahr and Strasser 2021), but do-it-yourself (DIY) efforts to develop vaccines are described as “rogue” initiatives endangering their participants and public trust in regulatory institutions (Caplan and Bateman-House 2020).

The conversations that have emerged out of the pandemic are not new concerns, but continuations of the dialogue contained in the *American Journal of Bioethics*’ Special Issue: how should institutional structures contend with noninstitutional actors and practices participating in the construction of scientific knowledge? In this article, I pursue this question beyond the paywalled environment of academic discourse to ask how

noninstitutional practices captured by the umbrella term “citizen science” are represented in mainstream news media. I argue that media representations of citizen science demonstrate different forms of institutional boundary work and that professional, credentialed scientists participate in these representations as adjudicators of citizen science credibility. Specifically, I identify and describe three framings of citizen science’s relationship to professional or institutional science: first, as forms of participatory labor subservient to expert institutions; second, as expansionary practices correcting flaws within institutional structures; and finally, as potentially independent and unregulated practices divorced from institutional standards and norms. These framings both reveal how citizen science and other allegories of noninstitutional or nonprofessional science are publicly portrayed as sources of expertise and also demonstrate that their expert status is not predetermined or fixed.

Citizen Science and Networks of Expertise

Boundary work analyses have typically addressed how experts negotiate and demarcate “real” or legitimate science from illegitimate forms of knowledge or practice (Gieryn 1999). The very concept of “citizen science” is itself a product of boundary work, demarcating citizen science as distinct from “science” proper. Crucially, however, whether citizen science is disconnected from, or part of, institutional scientific networks is both context-dependent and contested. There is no agreed upon definition of citizen science or what forms of public participation it consists of; the label is commonly associated with top-down, institutionally led research programs (Kelty and Panofsky 2014; Strasser et al. 2019; Mahr and Dickel 2019; Mahr and Strasser 2021) as well as anti-institutional, “outlaw” (Kelty 2010) practices like biohacking (McGowan et al 2017; Giordano 2018). Some participants in citizen science initiatives explicitly call out the boundary work contained in the label “citizen science” and regard the term as conveying a lesser status than institutional science (Trejo et al. 2021). Complicating matters further, citizen science also does not exclusively refer to practices undertaken by amateur or noninstitutional actors. As Giordano (2018) has argued, some DIY bio initiatives identify themselves as “proper publics” for deinstitutionalized practices precisely because they possess institutional affiliations and professional skills. While Giordano suggests that perhaps democratic science movements present a false choice between institutional and deinstitutionalized science, the institutional affiliations of some citizen science practitioners can also become grounds for

interprofessional criticism. The DIY vaccine project mentioned above, RaDVaC, received significant attention in part because its organizers were biomedical professionals deliberately skirting regulatory review in favor of self-experimentation (Regalado 2020).

Because the label “citizen science” does not have consistent meaning and in fact may even obscure highly dichotomous epistemic practices and changes in institutional knowledge structures (Strasser et al. 2019), representations of citizen science simultaneously mediate different affordances of credibility and legitimacy. Representations are also sites of active boundary negotiation (Erikainen and Stewart 2020), where different stakeholders in citizen science—including professional scientists—can claim authority and jurisdiction over what citizen science is or should be, whether or when it is credible, and how it should be understood in terms of expertise. I argue that media representations of citizen science demonstrate institutional boundary work and that different forms of institutional buy-in to the legitimacy or credibility of citizen science perform different ideas of how citizen science contributes to networks of expertise (Eyal 2013).

Within STS scholarship, absolute distinctions between experts and non-experts have been repeatedly deconstructed. Different forms of expertise, such as lay expertise (Epstein 1995), lay or local knowledge (Wynne 1992; Callon 1999), and contributory versus interactional expertise (Collins and Evans 2002), demonstrate that expertise and expert credentials are not reducible. Eyal (2013) particularly argues that expertise and experts must be analytically separated in order to account for how expertise is actually coproduced within the context of a knowledge network. Eyal argues that expertise is not a property of individuals with expert status but of the network itself; actors who lack credentialed or professional status may nonetheless perform crucial roles within the network. Networks that incorporate amateur or noninstitutional actors can reinforce their authority because the overall jurisdiction of expertise gains rather than refuses collaborators. Credentialed experts may therefore lose professional autonomy or monopolies on knowledge, as with the medical profession today (Timmermans and Oh 2010), but expertise itself retains or transforms authority through the network’s extensiveness.

However, Eyal’s conceptualization understates the extent to which buy-in from credentialed experts enables the expansion of institutional knowledge networks to include nonprofessional or noninstitutional practices and sources. In Eyal’s (2010) discussion, although key figures among the autism parents were themselves professionals in psychology and psychiatry, they remained fairly isolated until coming into contact with Ivar Lovaas, an

institutionally affiliated behavioral psychologist. The exchange of information that took place following this contact involved the network of parents morphing into an “army of paraprofessionals” trained in and employing “behaviorist tools” (Eyal 2013, 886). Similarly, in Epstein’s (1995) analysis of AIDS activism, activists came to pursue scientific credibility explicitly, learning biomedical language and demonstrating their familiarity with biomedical explanations as a means of “getting in the door” of scientific institutions. Their success in transforming the norms and standards of clinical trials makes clear their acquiescence to others; namely, the “methodological common ground” that could combine heterogeneous and “impure” research subjects with strict trial protocols (Epstein, 1995, 424). Networks of expertise are built and negotiated through the interactions of different actors and their unequally recognized knowledge backgrounds (Buchanan 2017), where the authority of institutional science still holds considerable power to accept, modify, or reject other contributions. This is not to say that expertise only exists in the context of institutionally grounded or affiliated networks, but that mainstream representations of expertise will often employ credentialed and institutional perspectives to make credibility claims. Therefore, I examine how ascertainment of non-professional or noninstitutional credibility reflects different formations of buy-in from credentialed professionals and institutional structures or expansionary boundary work (Gieryn 1999).

Popular news media presents a space for exploring how this buy-in produces different conceptualizations of nonprofessional or noninstitutional status within a knowledge network via boundary work negotiations. There is no inherent role or status that citizen science practices must take, and like the AIDS activism studied by Epstein, practices that emerge as “rogue” or as direct challenges to institutional structures can become incorporated within those same structures through network expansion. Rather than tracing the pathways of a particular network that has incorporated citizen science, then, I use media discourse to assess how citizen science broadly is represented as different forms of and in different relationships to expertise, demonstrating alternative modes of institutional buy-in and how distance is created between practices characterized as illegitimate. While media discourse is not exclusively the domain of credentialed perspectives, it is an empirical and contextual question how stakeholders assert voice and authority in popular forums, particularly on matters of scientific disagreement. Science journalism participates in constructing and disseminating norms about science (Nelkin 1995; Lee 2015; Briggs and Hallin 2016) and often mobilizes input from recognized or credentialed experts

(Bucchi 1996; Gieryn 1999; Erikainen and Stewart 2020). As this study helps demonstrate, media coverage can both initiate credibility contests by drawing attention to an issue and directly construct representations of credibility by extending voice to specific commentators and not others.

Science journalism is also not unidirectional flow of information, and although media representations may privilege the perspective of some actors and sources over others, they also participate in “calling up” their audience as subjects within the discourse (Horst 2007; Briggs and Hallin 2007). In the case of citizen science, and specifically health and medical citizen science, media discourse both performs boundary work concerning noninstitutional contributions to knowledge networks and suggests roles, responsibilities, and expectations regarding individual engagement with research and individual management of personal health. In the current era of digital health technologies and mobile or “mhealth” research programs, which includes a number of self-described citizen science projects, participation in research is becoming associated with patient responsibilities (Erikainen et al. 2019). Popular representations of health behaviors, notably “informed” or “engaged” patient roles, encourage individuals to surveil their bodies and act on new information (Lupton 2012) and to advocate for their own experiences and perspectives (Timmermans 2020). Rhetoric of individual empowerment sits in contrast, however, to skepticism that non-professional actors truly possess the expertise to engage in independent health management (Ward et al. 2010). A critique of the RaDVaC project, for example, suggests that professionals engaging in nontraditional research programs “can sometimes suffer from a curse of knowledge” and fail to consider that nonprofessionals may lack the “technical know-how” to safely pursue interventions on their own (Guerrini et al. 2020, 1572).

By following discourse concerning specifically health and medical citizen science research, then, I pursue how representations of citizen science credibility circulate alongside and contend with representations of personal health responsibility and expertise. The three framings I describe indicate different ways that boundary work distributes citizen science into networks of expertise, which I argue provides evidence of how institutional networks afford credibility to noninstitutional actors and practices. First, in the subservient framing, citizen science contributions are portrayed as akin to a source of bonus labor power for scientists, which also constrains the expertise of participants to a form of information processing. Second, in the corrective framing, citizen science is represented as remedying broken or malfunctioning structures within institutional science. Here, noninstitutional collaboration is sometimes directly described as revitalizing

expertise, and expert status is extended, at least nominally, to nonprofessional collaborators. However, third and finally, citizen science that is characterized as independent or deviating from the standards of norms of institutional science is questioned as legitimate or credible. Citizen science becomes capable of going too far in its differentiation from institutional science, such that practices may be qualified or defended, depicted as inappropriate, or rejected as scientifically invalid. These framings are not mutually exclusive and occasionally do overlap within articles and should not be taken as depictions of static formations. Rather, they reflect the dynamic and contextual nature of boundary work, and by extension, the multiple possible mediations of citizen science within a network of expertise.

Methods and Data

This study takes a discourse analysis approach to the framings of citizen science projects in public media using a corpus of fifty-one news and magazine articles from US-based publications. The articles were downloaded from the database NexusUni in June of 2019, using a key word search to find articles containing the exact phrase “citizen science” and the prefixes “medic*” and “bio*.” These key words were chosen to identify articles that specifically described a research project as citizen science while restricting the search to articles that referenced medical or biological research or applications. Initial filtering was done using NexusUni’s own filtering tools for publication location, language, and publication source. Press releases and trade publications were excluded from the sampling frame in order to restrict the sample to sources that represented a broad and generally public audience. No restrictions on date of publication was employed and the final sample included articles published between 2010 and 2019.¹

The key word search produced an initial result of 854 articles, which were subsequently manually read and filtered to determine whether the subject matter discussed or referenced a citizen science project or projects primarily concerned with producing medical or biological knowledge about human health. This filtering yielded the final count of fifty-one articles. Inclusion was determined by the specifics of the project as described in each article: a water-monitoring project described exclusively in terms of habitat conservation would be excluded, while a water-monitoring project that addressed human consumption would be retained. The final fifty-one articles were spread across thirty-seven total publications, some with a national

audience (e.g., *The New York Times*), some with a local audience (e.g., *The San Diego Union Tribune*), and some with a national reach but more subject-focused scope (e.g., *Business Insider*).

The fifty-one articles were coded and analyzed using Atlas.ti software. Ten articles were not substantively concerned with either citizen science or specific projects and only made relatively brief mentions of a project or an aspect of citizen science research. In these cases, the entire article was not coded, and the discourse analysis was restricted to the contexts that discussed citizen science. Following Timmermans and Tavory's argument for abductive analysis and their suggestion to be an "informed theoretical agnostic," a codebook was not prepared prior to analysis nor was the data approached from an inductively pure clean slate (Timmermans and Tavory 2012). Instead, I generated codes by pursuing an initial coding structure oriented to how the nature or substance of citizen science was described and then building out a more specific secondary codebook to track particular forms and subjects of critique or positive description. By iteratively returning to the data, I revised my initial coding structure into three broad framings of the relationship of citizen science to institutional science, discussed below.

Additionally, I developed codes to identify whose voices were present in each article, how often an individual was quoted, and how each article identified quoted speakers according to their involvement in a citizen science project and any noted academic or other professional background. These speakers were categorized according to their described backgrounds and condensed into the broad framework of professional scientists (including industry and/or academic-affiliations), other professionals who were described as having a degree or occupation outside of science, technology, or medicine adult participants in a citizen science project who did not have a noted background in a scientific field, and students of any field (Table 1). I was thereby able to keep track of who was enabled to speak on the subject of citizen science and compare the frequency of explicitly professional scientific voices to those of other individuals with different and unclear professional statuses. Although the representation of speakers in these articles cannot conclusively demonstrate how citizen science is conceptualized in news media, it does indicate how citizen science is positioned in relation to institutional, professional science. As Table 1 shows, I find that professional scientific voices dominate the news media discourse about citizen science. Lay or nonprofessional actors are quoted much more rarely, and in this data set, never exclusively; nonprofessional voices were never the sole perspective referenced in an article.

Table 1. Quoted Speakers.

Speaker	Total Number of Articles	Number of Articles Only Speaker	Total Number of Quotes
Professional scientist	34	15	107
Other professional	13	3	24
Adult participant	9	0	22
Student	7	1	15

Discursive Boundary Work in Citizen Science News Media

Citizen Subservience

I describe this first frame as “subservience” to capture both the roles allocated to nonprofessionals and the broader relationship of citizen science projects to scientific institutions. In this framing, citizen science is subsumed within the jurisdiction of professional science, and the participatory relationship is structured like a resource for scientists to tap into, with the agency of participants dictated by the specific needs of scientists in charge of the research. The unique features of citizen science in this regard are predominantly professional access to an expanded, and typically volunteer, labor force. For example, citizen scientists might employ their critical reading skills in the task of identifying what findings in recent biomedical publications might be useful to professional researchers:

Four scientists at The Scripps Research Institute in La Jolla are seeking the public’s help to find cures for rare diseases. They’re not looking for money, but something even more precious to scientists backlogged with work—your time. A team led by Andrew Su is recruiting volunteers to serve as “citizen scientists” who would spot useful information in the ever-growing mountain of biomedical research. His team can’t keep up on its own. (Fikes 2015)

The subservient framing is therefore not dismissive of the capacity of citizen science to contribute to knowledge processes. Instead, it is highly constrained. Citizen science is more like a means to an end, where the decisions about the ends and the means were previously determined and implemented by professional actors. Unlike classical models of public participation in science, which have defined a spectrum of interaction

spanning separation, debate, and coproduction (Callon 1999), the subservient framing invites collaboration but not necessarily conversation. Nonprofessionals are not excluded from the world of scientific practice but nor are they advising research programs or participating as equal contributors at the table. Rather, citizen science in this frame is incorporated into institutional science almost like a labor-saving device, making it possible for professionals to gather data or conduct analyses at a scale that is otherwise impossible to replicate.

The subservient frame therefore also poses an interesting contrast to the network of expertise model proposed by Eyal. Like the networks of autism parents, citizen science projects often make use of outsourced labor, including in some cases personal health data self-reported by participants and participants' contributions are recognized as expanding the knowledge base in a materially significant way. What I describe as subservient citizen science is not indicative of professional devaluation of nonprofessional contributions, but of a relationship grounded in the premise that citizen science offers institutional science something that it does not already have. This relationship was at times made explicit in the texts, such as in this comment describing a water-monitoring project:

This is not window dressing. Folks are collecting real scientific data, and doing something that would be pretty impossible otherwise, Skelly said. A handful of scientists cannot do it on their own. You need an army. (Ruth 2011)

This framing does, however, situate citizen science within a quantitative rather than qualitative shift to the practice of science. While citizen scientists may contribute new data to a knowledge network, in the subservient framing, those contributions do not necessarily extend to new ideas. Citizen science contributions are additive rather than dynamic and interactive; they are fitted to predetermined purposes that noninstitutional participants are then invited to complete. These contributions follow invited pathways that reaffirm, rather than reconceptualize, a hierarchy of knowledge and authority between institutional experts and the public (Mahr and Dickel 2019).

Many previous analyses of citizen science projects have criticized initiatives that recruit members of the public for their time and labor power, without offering opportunities to contribute more meaningfully to research design or analysis (Del Salvio et al. 2016; Fiske et al. 2019; Keune 2019). In the subservient framing of citizen science, however, these critiques were

inverted, and citizen science was denied the status of expertise *because* it was limited to labor:

As disciplines become increasingly complex and require ever more specific knowledge, citizen scientists will be contributing mostly labor to the fight—but not necessarily insight. You can call yourself a scientist and spend your weekend tagging chromosome data, but someone else’s name will go on the final paper. (Tucker 2013)

Here, the work completed by citizen scientists is juxtaposed to “insight,” with the increasing specialization of scientific fields portrayed as a key intervening factor separating the labor of public participants from the knowledge outcomes of research. This contrast between labor and knowledge devolves specifically on the implied substance of expertise, which noninstitutional collaborators are presumed to not have—scientific knowledge is imagined to be so increasingly esoteric as to exclude nonprofessionals from “insightful” opportunities.

A particularly interesting example of how the knowledge/labor separation manifests in the subservient framing came from multiple discussions of the online protein folding game Foldit within the data set. Foldit has been heralded in the citizen science literature for its combined use of crowdsourcing and gamification (Curtis 2015), a combination that allowed thousands of “players” to create collaborative protein structure models and in at least one instance produces a protein crystal structure solution (Khatib et al. 2011). In the discussions of Foldit that I encountered in the data set, the contributions of its participants were by no means downplayed, but they were characterized in computational terms. The labor contributed by Foldit’s players was presented as an extension of computer processing power and algorithmic capabilities, described in one piece as “supplemental human brain power” (Wright 2010). Foldit’s participatory model was in fact celebrated for incorporating human cognitive capacity to fulfill functions that algorithms could not perform well, such as in this opinion piece concerning crowdsourced citizen science:

There are many tasks that are beyond the grasp of even today’s computers, particularly those which involve interpreting complex images The Internet, it turns out, is a brilliant way to feed those problems into an array of the planet’s true supercomputers—human brains. (Cook 2011)

The characterizations of labor in these descriptions, I argue, position the contributions of nonprofessionals within an implicitly subjugated role.

Subservient framings of citizen science recognize the power of an extended knowledge network and encourage its creation, but in a manner that enrolls nonprofessional contributors into research structures dictated by an existing institutional network. Even though lay participants here are often directly acknowledged as providing something that enclosed, institutional processes of research cannot fulfill on their own, they are also portrayed as performing limited and institutionally dependent tasks. The subservient framing appropriates public participation as a service, conceptualizing it within an institutionally oriented structure that the contributions of nonprofessionals do not normatively challenge.

Corrective Citizen Science

The framing I am characterizing as “corrective” is in many ways a descendent of the participatory turn in scientific governance (Jasanoff 2003) and criticisms of the deficit model in public understandings of science (McNeil 2013). Here, public participation is given value because it incorporates the ideas and perspectives of nonprofessionals, enabling research to be less exclusionary and detached from its context. I describe this framing as corrective because unlike the subservient framing, public participation was not portrayed as yielding additive effects to an existing process, such as increased time, cognitive energy, or labor. Instead, nonprofessional perspectives and ideas were emphasized as bringing needed changes to institutional science, expanding not just the number of actors contributing to a knowledge network but potentially the substance of the network itself.

Corrective framings of citizen science problematized the knowledge network of science as being too limited, shortchanging both the products of research and the society that would ostensibly benefit from them. In other words, corrective discourse criticized exclusively professional networks for constraining the quality and utility of the knowledge they produced or for gatekeeping the tools that would allow nonprofessionals to conduct research themselves. In one article discussing the DIY biology movement, for example, “democratized” biology being conducted in the “real world” posed a contrast to the “out of reach” world of university science and biotechnology (Krieger 2010). Several similar articles referenced the prohibitive cost of biotech equipment in particular and presented community biology labs, open-source technology, and home laboratories made of scavenged material as ways to free research from the confines of expensive and exclusive institutions. An editorial by Ellen Jorgensen, founder of the community biology lab Genspace, appealed directly to the capacity of public-

driven research to empower lay understandings and repair harms perpetuated by unjust research in the past:

Empowerment through hands-on knowledge is particularly important for those—such as women and African-Americans—who have not been served well by genetics discussions in the past. Public forums where scientists attempt to educate from a position of more knowledge can sometimes create hostility and an us versus them dynamic, whereas participatory science does not. (Jorgensen 2016)

But corrective citizen science framings also called out institutional scientific structures for actually overlooking expertise by not engaging with the public. A major distinction between the corrective frame and the subservient frame concerned the content of the research projects: initiatives that did not make use of personal health information tended to segregate nonprofessional contributions into labor without insight. Initiatives that did utilize participants' health information, however, or encouraged participation on the grounds of personal or community health concerns, often explicitly cited nonprofessional perspectives as missing, essential components of health and biomedical knowledge. For example, one article described a researcher's shift in perspective about patient engagement, from something that would primarily benefit an individual's personal health to something that could actually expand medical knowledge:

Until a few years ago, he said, he saw efforts to share patient data as mainly a step to get people more engaged in their own health, but not something that could improve medical research. Today, Dr. Friend said, his perspective is very different. "The patient, doctor and researcher—each is a different kind of expert," he said. The promise, Dr. Friend said, is to "democratize medical discovery." (Lohr 2015)

Like the DIY biology movement and community biology labs discussed above, here a reference is made to the "democratization" of research by extending the environment of knowledge production to include nonprofessionals. Distinctively, democratization is also linked to an expanded sphere of expertise; nonprofessionals are needed components of a knowledge network not only to repair or reinforce lay understandings of science but also to contribute information that professionals cannot obtain on their own. Situating the patient as another kind of expert implicitly draws upon the idea that patients are the most knowledgeable

actors concerning their own health; they are “informed” because they have the capacity and the responsibility to generate personal health expertise. Whereas in the subservient frame, public participation quantitatively expanded the capacity for knowledge generation, in the corrective framing, public participation qualitatively changed the knowledge inputs themselves. Nonprofessionals were characterized even as “missing experts” (Carlson 2016).

As I discuss in greater detail below, however, patient expertise may not always be recognized as legitimate, or only considered valuable and acceptable under certain conditions. In one article, for example, patient expertise was linked to wearable devices and other forms of biometric data generation, indicating that the patient-as-expert may trend closer to patient reporting of biomedically standardized information (Fox et al. 2005; Mahr and Strasser 2021). Moreover, the broader context of these discussions in the framework of corrective citizen science additionally positions the patient expert as a role that patients *should* perform and that institutional research structures should actively encourage. The corrective framing may therefore resemble an inversion of citizen science into civic duty, wherein public participation in research becomes akin to a public and personal health imperative (Wooley et al. 2016).

The corrective framing of citizen science thus performs boundary work differently, by situating institutional science less as a structure that public participation can supplement than as a flawed system of knowledge production that it can revitalize or transform. Specific aspects of traditional research processes, such as cost, profit motives, insularity, and expert detachment from “real world” problems, were presented as impairments to knowledge that public participation could help alleviate. In situating citizen science as corrective to institutional science, public participation is presented simultaneously as a normative challenge and a solution; participatory frameworks highlight the specific flaws of closed-off, elitist and “broken” science, while also situating public participation as a remedy. Citizen science is represented as a desirable, even necessary, expansion to institutional networks, enhancing the network’s expert authority because it diversifies the sources of expertise. The corrective framing of citizen science does not, however, imbue citizen science or nonprofessional contributors with the authority to fundamentally redefine what “counts” as scientific expertise. In other words, and as I show below, noninstitutional practices were recurrently evaluated against institutional norms.

Normativity and Autonomy: Crossing Boundaries

While the previous framings of citizen science performed primarily expansionary boundary work, adding nonprofessional actors and nonprofessional knowledge to the network of science, in this section, I turn to how these discussions also negotiated limits to the legitimacy of public participation. I found the central factor demarcating acceptable from unacceptable forms of nonprofessional involvement to be perceived “epistemic deviations” (Mahr and Dickel 2019) from institutional science. Moments of potential deviation were particularly heightened when nonprofessionals possessed, or were perceived to possess, autonomy over their activities without professional checks. For example, in the same article that included the declaration that patients were the “missing experts” in biomedicine, described above, citizen science was also portrayed as inviting potential perils if lay individuals strayed from institutional paradigms:

It is truly inspiring to see what patients can do for themselves, and for others. That is the promise of citizen science. But there are also perils,” said Kingshuk Sinha, a professor at the U’s Carlson School of Management. Sinha cited the example of Japan’s “patent king” Yoshiro Nakamatsu, known as Dr. NakaMats in the press, who has raised concerns among researchers worldwide with the announcement that Nakamatsu plans to self-treat his cancer without radiation, using foods and teas said to boost cancer immunity, among other nontraditional remedies. But Sinha noted that citizen-driven science doesn’t have to be seen as an alternative to traditional science. “It’s not an either/or,” he said. (Carlson 2016)

The contrast within this article presents two different faces of citizen science: one in which lay contributors are a necessary component to the future of biomedicine and another in which patients who pursue their own research or treatment programs pose a danger to themselves. Here, the possibility that nonscientists will conduct research independently from institutional norms may disqualify this work from being recognized by scientific professionals as research and positions these activities as both suspect and categorically separated from traditional science. Even though Yoshiro Nakamatsu has a form of professional status in the form of a doctorate, he is very distinctively treated here as outside of, if not outright disobeying, professional scientific norms. Indeed, his own professional status seems to increase the suspect nature of his work, in the insinuation that his relatively high profile could propel citizen science as a serious alternative to traditional expertise.

The example of Dr. Nakamatsu, whose cancer self-treatment program has included a blend of his own inventions and herbal remedies (Jozuka 2016), further links the risks of citizen science to a broader thread of anxiety concerning self-experimentation. The fear that lay participants may take research into their own hands and bodies recurrently emerged in discussions of personal health research, but particularly when the research structure allowed some degree of autonomy in participant activities or an absence of oversight. One strand of this form of boundary work was directed at the DIY biology movement specifically, through repeated juxtapositions of DIY activities to dangerous, unregulated, or even intentionally harmful forms of research, such as bioterrorism. In one discussion of the community biology lab Genspace and other DIY communities, this pushback was presented as almost an inherent threat of deinstitutionalizing science, requiring the founders of these spaces to institute preventive measures:

The idea of amateurs doing their own biology has raised fears about both deliberate bioterrorism and the unintentional creation of a deadly disease. But making a new and virulent pathogen is far from easy, and the DIYbio community has adopted a set of safety standards to minimize such risks. “Within a very narrow scope, it’s possible that somebody could cause harm,” Mr. Garvey said. “But they could only cause a disease to emerge if they were working with disease.” Genspace has a strict policy against working with anything that can infect humans, and it has established a safety review board of experts from the Massachusetts Institute of Technology, the United States Department of Health and Human Services and other institutions to approve proposals for new experiments. (King 2012)

Articles concerning DIY biology programs and community biology labs were particularly heightened spaces of boundary work concerning participant or nonprofessional autonomy. In the example above, the language of amateurs calls attention to the lack of specialized training that participants in these programs are assumed to have, while also alluding to the possibility that nonprofessionals may have ulterior or harmful motives in pursuing scientific research. The community lab referenced, Genspace, had therefore adopted precautionary measures that foreclosed any opportunity of nonprofessional malfeasance by simply ensuring that “amateurs” were only given access to tools that the professionals leading Genspace had precleared.

Boundary work pertaining to DIY biology and similar movements also reflects how negotiations about nonprofessional contributions to science take place at the interprofessional level. DIY biology initiatives including

Genspace are often, if not typically, led or organized by individuals with professional scientific training or institutional affiliations, and their claims to represent a participatory ethos are carefully constructed (Kelty 2010; McGowan et al. 2017; Giordano 2018). How such professionals design or conceptualize participatory science indicates how they themselves adjudicate the validity of specific forms of nonprofessional research activity, but their articulations of participatory science also reveal boundary work concerning their own relationship to institutional norms. In other words, this boundary work can demonstrate the circumstances in which different forms or sources of knowledge are or are not recognized as expertise, including when professionals receive pushback on their own attempts to extend the scientific network. Thus, in the example above, DIY citizen science is constrained by an assertion that certain forms of research are too dangerous to be made open to nonprofessional interventions, and in the same editorial described in the previous section, the founder of Genspace responds to and defends the decision to allow participants in the lab to experiment with the DNA-editing technology CRISPR:

I take heart in the fact that, while conventional gene therapy is growing as a medical practice, people do not attempt it in the comfort of their own homes. I don't think the availability of CRISPR will change this Just because it could potentially be put to work for "edgier" purposes does not mean that citizen-scientists should be prevented from using it. (Jorgensen 2016)

Like in the discussion of Yoshiro Nakamatsu, the issue of self-experimentation is raised as a potential consequence of allowing nonprofessionals too much autonomy in their engagement with science. But while Dr. Nakamatsu was singled out as an example of a nonscientist operating outside the norms of traditional science, here, a scientific professional is responding to perceived deviation from their own professional community. Although the Genspace editorial did include corrective elements, as described above, these elements are part of a larger context of responding to critiques of the tools Genspace allows its participants to access. In other words, the appeal to participant empowerment through hands-on experience of science is embedded in an environment of skepticism about what technologies participants will be enabled to get their hands on, and specifically, whether this access by nonprofessionals is safe.

The implication here is that a degree of gatekeeping is not always problematic, and when the opportunity to perform or undertake a health intervention emerges, it is in fact warranted. Anxieties concerning self-

intervention allude to the possibility that nonprofessionals will “go too far” and potentially appropriate biotechnologies for personal interventions that may cause harm to themselves or others. These sorts of fears did not only concern biotechnologies like CRISPR but also extended to crowdsourcing projects that return personal information to participants in exchange for samples and financial support. In these instances of boundary work, non-institutional involvement was envisioned as a balancing act between anticipation of the products of research (Adams et al. 2009) and managed expectations about the current state of research development (Gardner et al 2015). Such refusals to grant participants autonomy over the products of their research participation counter, and sometimes directly acknowledge, the invitation to informed, engaged patients to actively appropriate health knowledge.

In an interview with one of the research leads of the microbiome project American Gut, for example, readers were cautioned to not get carried away:

Individual bug maps are not (yet) medically critical information. The science that might someday tell an individual what microbes to take, and which ones to avoid, is in its infancy. Still, American Gut researchers aren't the only people thinking about microbes. In fact, many people increasingly are interested in what's inside them, and some are venturing into risky, do-it-yourself techniques to get answers . . . “As much as I'm excited about this field, and I love it when others are excited too, I find it important to continue to urge caution,” McDonald said. “I encourage people to be careful. This is a new area of research (and) there are a lot of questions we're working on answering. . . . I don't want to see people get harmed. (Williams 2018)

While the corrective framing situated patients as “missing experts” in research processes, here a project that intentionally returned personal information to participants nonetheless discouraged them from deploying that information to intervene on or manage their health. The research itself was downplayed as too new to be medically utilized, “in its infancy,” and therefore, off limits as a form of health information that participants could translate into health changes. Simultaneously, however, the *eventual* significance of this research for personal health was still maintained, indicating that participation in microbiome studies is still warranted and worthwhile for health-conscious individuals to pursue. In one sense, this contradiction reveals the overlapping, “hybrid” nature of biomedicine (Keating and Cambrosio 2006), wherein the boundaries between research and clinical interventions become fluid. But these forms of boundary work also suggest

professional discomfort with nonprofessional autonomy over the process and products of science, and an unwillingness to recognize knowledge or activities as legitimate that do not conform to the norms of institutional scientific networks.

This contradiction was perhaps most vividly apparent in a first-person account also covering *American Gut*. Here, the author featured multiple quotes from researchers who hesitated or refused to suggest steps that individuals could take to intervene in their microbial health, yet who nonetheless acknowledged undertaking interventions themselves:

When I asked Gordon about do-it-yourself microbiome management, he said he looked forward to a day “when people can cultivate this wonderful garden that is so influential in our health and well-being”—but that day awaits a lot more science. So he declined to offer any gardening tips or dietary advice. “We have to manage expectations,” he said. Alas, I am impatient. So I gave up asking scientists for recommendations and began asking them instead how, in light of what they’ve learned about the microbiome, they have changed their own diets and lifestyles. Most of them have made changes. (Pollan 2013)

The paradoxical narrative of this piece, that of a lay participant in a citizen science project who desired to partake in personal interventions yet was confronted by professional gatekeeping of such activities, emphasizes the demarcation between professional expertise and public enthusiasm. Like the example of *Genspace*, this boundary work reflects intraprofessional scrutiny, such that professionals who are extending access to tools with interventional capacities may feel obliged to defend the extension or demonstrate that precautionary gatekeeping is in place. The author’s direct interest in interventional activities is met by clear acknowledgment of the public audience and space of communication; professionals must “manage expectations” lest potential participants express similar desires to self-experiment. Strikingly, although the applications of microbiome research are stated to require “more science,” the limitations of this knowledge are circumscribed for the audience, but not the researchers. Boundary work concerning self-interventions and self-experimentation demonstrates anxieties that nonprofessionals may jeopardize their health if they are not constrained in their activities and additionally suggests doubts among professionals that members of the public can be trusted with certain information or technologies without professional direction. By situating self-interventions as risky behaviors that might go “too far,” professionals

are negotiating boundaries between encouraged participation in research and discouraged appropriation of research that are nonetheless differently applied to themselves. Nonprofessionals are invited to participate on the grounds that they have something new and unique to offer science, including expertise of their own, but their autonomy is circumscribed by professional adjudications of what activities are “safe” for nonprofessionals.

Conclusion

News media discourse concerning citizen science demonstrates different professional assessments of how public participation fits within, alongside, or against institutional science. Boundary work by professionals identifies different forms of noninstitutional practices as legitimate, but it also suggests when and why the particular status of “expertise” is used to describe these practices. This boundary work is not constitutive of what is or is not “really” expertise, but it does show how professionals actively appraise and negotiate the contributions of nonprofessionals as potential nodes in knowledge networks. By naming patients as “missing experts” in health and medical research, institutional actors signal their recognition of limitations to an institutionally exclusive knowledge network and suggest that the sources of expertise should expand. However, as the subservient and normative framings indicate, citizen science may also be articulated through the boundaries of institutional science as a quantitative extension of the network’s labor or an overextension of the network’s norms.

Importantly, the discourse analyzed here takes place in a sphere of communication that is both deployed by professionals seeking to present their point of view and employed by mediating actors to mobilize credibility questions. The fact that noninstitutional voices were extremely underrepresented in this data set is itself a demonstration of how mainstream science communication mediates credibility through institutional perspectives. A large number of citizen science projects are indeed led by institutionally affiliated and credentialed professionals, which is not to say that their perspectives on citizen science are necessarily deferential to institutional norms. But the apparent overrepresentation of professional perspectives is also a reflection of the underlying tension between citizen and institutional science, which is fundamentally about how the authority of expertise is preserved. In the context of popular media, we are able to see how citizen science-as-expertise comes in and out of view when it is portrayed as lending authority to a network versus when it is problematized as dangerous to that authority. Thus, even perspectives that are broadly in favor of

increased noninstitutional access to scientific tools and material, such as those from the creators of Genspace, are directed to respond to hypotheticals about risk and misuse if noninstitutional actions are not checked.

The stakes of nontraditional or noninstitutional research now exist in a landscape radically refigured by the ongoing pandemic. “Subversive” (McGowan et al. 2017) and “outlaw” (Kelty 2010) research programs are now colored as much by concerns over disintegrating public trust in science as by ideals of individual empowerment or entrepreneurial disruption. Individuals can be at once at risk of doing too much, at risk of not doing enough, or caught between admonitions to abide by the recommendations of scientific institutions even when those same institutions are perceived as not meeting public needs (Erikainen and Stewart 2020). At the same time, institutions facing a “credibility gap” (Epstein 1995, 411) may fear that the wrong kinds of expansion could destabilize the whole network; if self-experimentation for vaccines is acceptable, how might collective standards of knowledge validation be impacted? I emphasize these tensions not to suggest that research should not follow some degree of norms but to call attention to how the real complexity of knowledge networks requires ongoing negotiation between institutional and noninstitutional practices. Acknowledging boundary work can make the stakeholders and the stakes involved in constructing expertise more visible and potentially enable more generous communication across networks.

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Note

1. Although I found no temporal patterns to the three framings, there were more articles published in 2016 (11) than any other year. Many of these articles responded to or referenced events of 2016; namely, the Flint, Michigan water crisis, which was declared a state of emergency in January of that year (Associated Press 2021) and the 2016 presidential election.

References

- Adams, Vincanne, Michelle Murphy, and Adele E Clarke. 2009. "Anticipation: Technoscience, Life, Affect, Temporality." *Subjectivity* 28 (1): 246-65.
- Associated Press. 2021. "Key Moments in Flint, Michigan's Lead-tainted Water Crisis." *The Associated Press*. Accessed July 20, 2021. <https://apnews.com/article/us-news-health-michigan-rick-snyder-flint-7295d05da09d7d5b1184b0e349545897>.
- Briggs, Charles L, and Daniel C Hallin. 2007. "Biocommunicability: The Neoliberal Subject and Its Contradictions in News Coverage of Health Issues." *Social Text* 25 (4): 43-66.
- Briggs, Charles L, and Daniel C Hallin. 2016. *Making Health Public: How News Coverage Is Remaking Media, Medicine, and Contemporary Life*. Routledge.
- Bucchi, Massimiano. 1996. "When Scientists Turn to the Public: Alternative Routes in Science Communication." *Public Understanding of Science* 5 (4): 375-94.
- Buchanan, Nicholas. 2017. "Which Fish? Knowledge, Articulation, and Legitimization in Claims about Endangered and Culturally Significant Animals." *Science, Technology & Human Values* 42 (3): 520-42.
- Callard, Felicity, and Elisa Perego. 2021. "How and Why Patients Made Long Covid." *Social Science and Medicine* 268 (October 2020): 113426.
- Callon, Michel. 1999. "The Role of Lay People in the Production and Dissemination of Scientific Knowledge." *Science Technology & Society* 4 (1): 81-94.
- Caplan, Arthur L., and Alison Bateman-House. 2020. "The Danger of DIY Vaccines." *Science* 369 (6507): 1035.
- Carlson, Joe. 2016. "Panel: Patient-led Movement Is Transforming Medical Research." *Star Tribune*. Accessed June 3, 2019. <https://www.startribune.com/panel-patient-led-movement-is-transforming-medical-research/405118076/>.
- Collins, H M, and Robert Evans. 2002. "The Third Wave of Science Studies: Studies of Expertise and Experience." *Social Studies of Science* 32 (2): 235-96.

- Cook, Gareth. 2011. "Crowd Science—Tapping the Brilliance of a Dispersed and Motley Team." *St. Paul Pioneer Press*. Accessed June 3, 2019. <https://www.twincities.com/2011/11/18/gareth-cook-crowd-science-tapping-the-brilliance-of-a-dispersed-and-motley-team/>.
- Curtis, Vickie. 2015. "Motivation to Participate in an Online Citizen Science Game: A Study of Foldit." *Science Communication* 37 (6): 723-46.
- Epstein, Steven. 1995. "The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials." *Science, Technology & Human Values* 20 (4): 408-37.
- Erikainen, Sonja, Martyn Pickersgill, Sarah Cunningham-Burley, and Sarah Chan. 2019. "Patienthood and Participation in the Digital Era." *Digital Health* 5: 1-10.
- Erikainen, Sonja, and Ellen Stewart. 2020. "Credibility Contests: Media Debates on Do-it-yourself Coronavirus Responses and the Role of Citizens in Health Crises." *Frontiers in Sociology* 5 (November): 1-13.
- Eyal, Gil. 2010. *The Autism Matrix*. Cambridge, England: Polity.
- Eyal, Gil. 2013. "For a Sociology of Expertise: The Social Origins of the Autism Epidemic." *American Journal of Sociology* 118 (4): 863-907.
- Fikes, Bradley J. 2015. "Medical Researchers Seek Public's Help." *The San Diego Union-Tribune*. Accessed June 3, 2019. <https://www.sandiegouniontribune.com/business/biotech/sdut-citizen-science-andrew-su-rare-diseases-2015jan31-story.html>.
- Fiske, Amelia, Lorenzo Del Savio, Barbara Prainsack, and Alena Buyx. 2019. "Conceptual and Ethical Considerations for Citizen Science in Biomedicine." In *Personal Health Science*, edited by Nils B Heyen, Sascha Dickel, and Anne Bruninghaus, 195-217. Wiesbaden, Germany: Springer VS.
- Fox, Nicholas J, Katie J. Ward, and Alan J. O'Rourke. 2005. "The 'Expert Patient': Empowerment or Medical Dominance? The Case of Weight Loss, Pharmaceutical Drugs and the Internet." *Social Science and Medicine* 60 (6): 1299-1309.
- Gardner, John, Gabrielle Samuel, and Clare Williams. 2015. "Sociology of Low Expectations: Recalibration as Innovation Work in Biomedicine." *Science Technology and Human Values* 40 (6): 998-1021.
- Gieryn, Thomas F. 1999. *Cultural Boundaries of Science: Credibility on the Line*. Chicago: University of Chicago Press.
- Giordano, Sara. 2018. "New Democratic Sciences, Ethics, and Proper Publics." *Science, Technology & Human Values* 43 (3): 401-30.
- Guerrini, Christi J, Jacob S Sherkow, Michelle N Meyer, Patricia J Zettler, Health Care Policy, The James, Comprehensive Cancer, and Drug Enforcement. 2020. "Self-experimentations, Ethics, and Regulation of Vaccines." *Science* 369 (6511): 1570-72.

- Horst, Maja. 2007. "Public Expectations of Gene Therapy: Scientific Futures and Their Performative Effects on Scientific Citizenship." *Science, Technology & Human Values* 32 (2): 150-71.
- Jasanoff, Sheila. 2003. "Technologies of Humility: Citizen Participation in Governing Science." *Minerva* 41: 223-44.
- Jorgensen, Ellen. 2016. "Opinion: How DIY Bio-hackers Are Changing the Conversation around Genetic Engineering." *Washington Post*. Accessed June 3, 2019. <https://www.washingtonpost.com/news/in-theory/wp/2016/05/20/how-diy-bio-hackers-are-changing-the-conversation-around-genetic-engineering/>.
- Jozuka, Emily. 2016. "Japan's 87-year-old Patent King Is Trying to Invent Treatment for His Own Cancer." *Vice*. Accessed July 20, 2021. <https://www.vice.com/en/article/bmvz48/japans-87-year-old-patent-king-is-trying-to-invent-treatment-for-his-own-cancer>.
- Keating, Peter, and Alberto Cambrosio. 2006. *Biomedical Platforms: Realigning the Normal and the Pathological in Late-twentieth-century Medicine*. Cambridge, MA: MIT Press.
- Kelty, Christopher M. 2010. "Outlaw, Hackers, Victorian Amateurs: Diagnosing Public Participation in the Life Sciences Today." *Journal of Science Communication* 9 (1): 1-8.
- Kelty, Christopher M., and Aaron Panofsky. 2014. "Disentangling Public Participation in Science and Biomedicine." *Genome Medicine* 6 (1): 1-14.
- Keune, Jason David. 2019. "Considering Power Relations in Citizen Science." *American Journal of Bioethics* 19 (8): 48-49.
- Khatib, Firas, Frank DiMaio, Seth Cooper, Maciej Kazmierczyk, Mirosław Gilski, et al. Foldit Contenders Group, Foldit Void Crushers Group. 2011. "Crystal Structure of a Monomeric Retroviral Protease Solved by Protein Folding Game Players." *Nature Structural Molecular Biology* 18 (10): 1175-77.
- King, Ritchie S. 2012. "When Breakthroughs Begin at Home." *The New York Times*. Accessed June 3, 2019. <https://www.nytimes.com/2012/01/17/science/for-bio-hackers-lab-work-often-begins-at-home.html>.
- Krieger, Lisa M. 2010. "Biohackers Aim to Open Silicon Valley Lab for Group Research and Lessons." *San Jose Mercury News*. Accessed June 3, 2019. <https://www.mercurynews.com/2010/09/23/biohackers-aim-to-open-silicon-valley-lab-for-group-research-and-lessons/>.
- Lee, Nancy S. 2015. "Framing Choice: The Origins and Impact of Consumer Rhetoric in US Health Care Debates." *Social Science and Medicine* 138: 136-43.
- Lohr, Steve. 2015. "Using Patient Data to Democratize Medical Discovery." *The New York Times Blogs*. April 2, 2015. Accessed June 3, 2019. <https://bits.blogs.nytimes.com/2015/04/02/using-patient-data-to-democratize-medical-discovery/>.

- Lupton, Deborah. 2012. "M-Health and Health Promotion: The Digital Cyborg and Surveillance Society." *Social Theory and Health* 10 (3): 229-44.
- Mahr, Dana, and Sascha Dickel. 2019. "Citizen Science beyond Invited Participation: Nineteenth Century Amateur Naturalists, Epistemic Autonomy, and Big Data Approaches Avant La Lettre." *History and Philosophy of the Life Sciences* 41 (4): 1-19.
- Mahr, Dana, and Bruno J Strasser. 2021. "Citizen Science and Biomedical Research." *The Lancet Child & Adolescent Health* 5 (10): 682-83.
- McGowan, Michelle L, Suparna Choudhury, Eric T Juengst, Marcie Lambrix, Richard A Settersten, and Jennifer R Fishman. 2017. "'Let's Pull These Technologies out of the Ivory Tower': The Politics, Ethos, and Ironies of Participant-driven Genomic Research." *BioSocieties* 12 (4): 494-519.
- McNeil, Maureen. 2013. "Between a Rock and a Hard Place: The Deficit Model, the Diffusion Model and Publics in STS." *Science as Culture* 22 (4): 589-608.
- Nelkin, Dorothy. 1995. *Selling Science: How the Press Covers Science and Technology*. New York, NY: W. H. Freeman and Company.
- Patrick-Lake, Bray, and Jennifer C. Goldsack. 2019. "Mind the Gap: The Ethics Void Created by the Rise of Citizen Science in Health and Biomedical Research." *American Journal of Bioethics* 19 (8): 1-2. doi: 10.1080/15265161.2019.1639389.
- Pollan, Michael. 2013. "Some of My Best Friends Are Bacteria." *The New York Times*. Accessed June 3, 2019. <https://www.nytimes.com/2013/05/19/magazine/say-hello-to-the-100-trillion-bacteria-that-make-up-your-microbiome.html>.
- Rasmussen, Lisa M., Christi J. Guerrini, Todd Kuiken, Camille Nebeker, Alex Pearlman, Sarah B. Ware, Anna Wexler, and Patricia J. Zettler. 2020. "Realizing Present and Future Promise of DIY Biology and Medicine through a Trust Architecture." *The Hastings Center Report* 50 (6): 10-14.
- Regalado, Antonio. 2020. "Some Scientists Are Taking a DIY Coronavirus Vaccine, and Nobody Knows If It's Legal or If It Works." *MIT Technology Review*. Accessed June 8, 2021. <https://www.technologyreview.com/2020/07/29/1005720/george-church-diy-coronavirus-vaccine/>.
- Ruth, Julie. 2011. "Greenwich Native Calls on Volunteers to Study Toxin." *The Stamford Advocate*. Accessed June 3, 2019. <https://www.ctpost.com/local/article/Greenwich-native-calls-on-volunteers-to-study-1349308.php>.
- Savio, Lorenzo Del, Barbara Prainsack, and Alena Buyx. 2016. "Crowdsourcing the Human Gut. Is Crowdsourcing Also 'Citizen Science'?" *Journal of Science Communication* 15 (3): 1-16.
- Strasser, Bruno J., Jérôme Baudry, Dana Mahr, Gabriela Sanchez, and Elise Tancoigne. 2019. "'Citizen Science'? Rethinking Science and Public Participation." *Science & Technology Studies* 32 (2): 52-76.

- Talbot, Margaret. 2020. "The Rogue Experimenters." *New Yorker*. Accessed July 20, 2021. <https://www.newyorker.com/magazine/2020/05/25/the-rogue-experimenters>.
- Timmermans, Stefan. 2020. "The Engaged Patient: The Relevance of Patient–Physician Communication for Twenty-first-century Health." *Journal of Health and Social Behavior* 61 (3): 259-73.
- Timmermans, Stefan, and Oh Hyeyoung. 2010. "The Continued Social Transformation of the Medical Profession." *Journal of Health and Social Behavior* 51 (1_ suppl): S94-106.
- Timmermans, Stefan, and Iddo Tavory. 2012. "Theory Construction in Qualitative Research: From Grounded Theory to Abductive Analysis." *Sociological Theory* 30 (3): 167-86.
- Trejo, Meredith, Isabel Canfield, Jill O Robinson, and Christi J Guerrini. 2021. "How Biomedical Citizen Scientists Define What They Do: It's All in the Name." *AJOB Empirical Bioethics* 12 (1): 63-70.
- Tucker, Patrick. 2013. "The Future Is Not a Destination: The Futurist Magazine's Top 10 Forecasts for 2014 and Beyond." *Slate Magazine*. Accessed June 3, 2019. <https://slate.com/technology/2013/10/futurist-magazines-predictions-on-quantum-computing-big-data-and-more.html>.
- Ward, Paul R., Jill Thompson, Rosemary Barber, Christopher J. Armitage, Jonathan D. Boote, Cindy L. Cooper, and Georgina L. Jones. 2010. "Critical Perspectives on 'Consumer Involvement' in Health Research: Epistemological Dissonance and the Know-do Gap." *Journal of Sociology* 46 (1): 63-82.
- Williams, Lauren. 2018. "Searching for What Is in a Surfer's Gut; A Scientist, One of Many Studying Bacteria on Humans, Believes Long-term Exposure to the Sea Can Change People." *Orange County Register*. Accessed June 3, 2019. <https://www.ocregister.com/2018/01/10/gut-bugs-citizen-science-showing-how-the-ocean-changes-surfers/>.
- Woolley, J. Patrick, Michelle L. McGowan, Harriet J. A. Teare, Victoria Coathup, Jennifer R. Fishman, Richard A. Settersten, Sigrid Sterckx, Jane Kaye, and Eric T. Juengst. 2016. "Citizen Science or Scientific Citizenship? Disentangling the Uses of Public Engagement Rhetoric in National Research Initiatives." *BMC Medical Ethics* 17 (1): 33.
- Wright, Alex. 2010. "Managing Scientific Inquiry in a Laboratory the Size of the Web." *The New York Times*. Accessed June 3, 2019. <https://www.nytimes.com/2010/12/28/science/28citizen.html>.
- Wynne, Brian. 1992. "Misunderstood Misunderstanding: Social Identities and Public Uptake of Science." *Public Understanding of Science* 1 (3): 281-304.

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