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A "Tyranny of Structurelessness"? The Benefits and Burdens of Power Sharing and Governance Models in Citizen Science

RESEARCH PAPER

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ABSTRACT

In 1970, Jo Freeman wrote the essay "The Tyranny of Structurelessness," drawing attention to the ways power dynamics pervaded so-called "structureless" groups during the women's liberation movement. Similarly, biomedical citizen science groups are looking to new ways to organize themselves, and are grappling with questions of structure, governance, and leadership (or lack thereof), particularly given the problematic hierarchies found in corporate and academic biomedicine. Based on three years of observations, in-depth interviews, and document analysis of a community biology initiative to make insulin, this paper follows the group's collective decision-making practices and the shift from horizontal, self-directed governance approaches to the implementation of a formal organizational structure. This paper identifies three mutually constitutive themes that acted as sites of change and shaped how internal governance was enacted, including membership and mechanisms of exclusion and inclusion; leadership and decision-making structures; and the mission as a social process in which objectives and implicit values were regularly negotiated. Findings underscore both the benefits of an open structure, such as facilitating participation in science, as well as challenges, including questions of when, how, and by whom decisions are made. I argue that thoughtful governance to actualize values such as power sharing can be difficult to construct and put into practice; yet, failing to do so risks reproducing problematic structures and norms many biomedical citizen scientists seek to avoid.

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INTRODUCTION

> *"Any group of people of whatever nature coming together for any length of time, for any purpose, will inevitably structure itself in some fashion... We cannot decide whether to have a structured or structureless group; only whether or not to have a formally structured one."* (Freeman 1972)

Many citizen scientist groups recognize how mainstream scientific institutions – academic, corporate, and government – have structured the scientific enterprise in ways that are harmful to both scientists and society. The publish or perish system, for example, induces immense stress among academic scientists, while the increasing entwinement between science and capital exacerbates inequities through unequal access to the products and benefits of science (Sunder Rajan 2006; Clarke et al. 2010). Many scientists are burdened by bureaucratic responsibilities required by institutional structures, often at the expense of advancing their research. Weber (1930) famously wrote about the perils of structure in the form of technocratic decision-making, depicting bureaucracy's inevitability as an "iron cage." Overly structured ways of operating can also feel antagonistic to small, community projects positioned as "fun," as many citizen science projects are self-described.

Yet, there are limits to eschewing formalized structures altogether. Jo Freeman (1972), in her essay "The Tyranny of Structurelessness," exposed hidden power dynamics that pervade so-called "leaderless" groups. Examining the women's liberation movement, she argued that the widespread and uncritiqued use of structureless groups as the primary organizational form weakened the movement. Freeman noted that structurelessness may work for certain goals, for example, consciousness-raising groups to increase women's understanding of gendered oppression. However, when groups sought more specific actions, such as change beyond the local and toward national and regional levels, the limits of structurelessness became apparent.

In this paper, I adapt Freeman's argument to the case of citizen science groups who have specific goals of developing practices and infrastructure that resist and reimagine dominant ways of doing biomedical science. Drawing on three years of ethnographic research with the Open Insulin Foundation, I argue biomedical citizen science projects that seek more emancipatory practices (e.g., shifting from neoliberal biomedicine to collectivist goals) must develop and implement governance thoughtfully. Biomedicine is entrenched in multiple overlapping structures of power, or as Murray (2020) aptly describes in his case study of Open Insulin, "trickiness all around." To reimagine this system, or aspects of this system, requires specific actions and intentionality that may benefit from structured decision-making. That is, governance offers mechanisms of accountability to align fundamental values, such as power sharing, to the mission and decision-making authority. Without this, projects risk reproducing problematic structures and norms many biomedical citizen scientists seek to avoid.

Open Insulin offers an ideal case study for examining organizational governance as it seeks specific actions for social change: to intervene on multiple points within the pharmaceutical industrial complex – including patents, profit, complex supply chains, and power sharing – by putting people with diabetes in control over the production and distribution of insulin (Open Insulin, n.d.; see also Foti 2020). Open Insulin began as a project under the nonprofit community biology lab Counter Cultures Labs in Oakland, California. The project is largely volunteer based and is led by members of the public with and without scientific training, as opposed to "establishment" (i.e., institution-based) scientists (Rasmussen et al. 2020). Importantly, the project was founded in 2015 during a period when the price of insulin rose dramatically in the United States (US). Insulin tripled in price between 2002 and 2013 (and has since increased further), leading an estimated 7.4 million individuals who depend on insulin to ration and underuse their medication (Hua et al. 2016; Herkert et al. 2019). Three pharmaceutical manufacturers control the US insulin market and raised their prices concurrently (Robbins 2016; Cefalu et al. 2018). This resulted in numerous deaths and drew substantial attention from the media and legislators (Sable-Smith 2018; Pear 2019).

This paper examines internal governance practices of Open Insulin between 2018 to 2021. I describe their initial informal structure based on horizontal frameworks and trace their shift to a formal organization with membership and board structures. I then describe mutually constitutive themes that acted as sites of tension and change for how internal governance was enacted. These include membership and mechanisms of inclusion and exclusion; leadership and decision-making authority; and the mission as a social process that was regularly debated and constructed. Findings describe benefits of an open and non-bureaucratic structure, such as appealing to new participants to easily join and drive aspects of the project, as well as challenges participants grappled with, including hidden power dynamics that emerged. The final section discusses and underscores the importance of governance decisions in biomedical citizen science projects that seek to reconstitute biomedicine's relationship with society.

BACKGROUND

There has been a rise in health and biomedical citizen science projects in recent years (Wiggins and Wilbanks 2019). These initiatives vary from people in their individual homes or kitchens, to groups in home- or garage-based labs, to projects seeded in community biology labs (Talbot 2020). Projects have included, for instance, hacked medical devices, self-experimentation, and patient-led health data collection for often rare medical conditions (Pauwels and Denton 2018). Some praise these efforts as promoting more inclusive approaches to healthcare and biomedical innovation (Fragnito 2020). Others have raised questions about the ethical contours and ambivalences of these projects (Fiske et al. 2019; Trejo et al. 2021). As biomedical citizen science expands, questions about internal and external governance are pertinent. First, this section covers mechanisms of external governance for these groups. Then, I move to scholarship on internal governance and its implications for social change, which many biomedical citizen science projects formed to carry out.

Scholarship on governance, both within and beyond citizen science, suggests a wide breadth of practices and organizational forms to structure relations and collective social action. Scholars have defined governance as "various institutionalized modes of social coordination to produce and implement collectively binding rules, or to provide collective goods" (Börzel and Risse 2010, p. 114; see also Levi-Faur 2012). Research on governance among citizen science communities similarly reflects a wide range of relational structures and varied degrees of participation and authority (Göbel et al. 2019). Shirk and colleagues (2012) account for power relations among citizen science projects and suggest that all public participation in scientific research is influenced by the degree and quality of participation.

Within do-it-yourself biology (DIYbio),[1] there have been a variety of efforts to address governance concerns across the budding community. In 2011, a code of ethics was drafted by both the North American and European DIYbio Congresses that includes principles of open access, transparency, and the creation of biotechnology for "peaceful purposes" (DIYbio, 2011). The Global Community Biosummit – an annual conference for DIYbio enthusiasts – expanded these principles in 2019 to include accountability, autonomy, and diversity and inclusion (GCBS, 2019). There has also been considerable attention to safety oversight, including the implementation of an "Ask a Biosafety Officer" program, collaboration with the US Federal Bureau of Investigation, and the development of a biosafety handbook for community labs (Rasmussen et al. 2020). Similar to Open Insulin, many of these initiatives were spurred to balance desires for inclusivity and openness that are central to the DIYbio movement with concerns about safety and mal intent.

Most biomedical citizen science initiatives are directed informally by individuals or groups, while a handful operate in community biology labs, or public laboratory spaces, with formalized governance structures. For example, The Baltimore Underground Science Space established a board of directors for long-term planning and an executive board for day-to-day operations, citing a common issue in all-volunteer groups concerning stability through shifts in leadership (Scheifele and Burkett 2016). Others have also cited risks community labs face by relying on volunteers, where access is limited to those with the financial means to contribute time (de Lange et al. 2021), a known problem in other fields such as conservation biology that leads to issues of representation and inequalities (Vercammen et al. 2020). Counter Culture Labs also has a board of directors, offering a mechanism for fiscal oversight and a body in which serious issues – for example, safety and bullying – could be addressed for projects within the lab and, additionally, requires a membership agreement for new members (CCL, n.d.). However, the mission of community biology labs is largely educational – to increase access to biotechnology – and does not necessarily comport to project missions borne in these labs. Thus, groups like Open Insulin are driven to formulate their own organizational structure and mission.

This article focuses on internal governance (while acknowledging broader forms of governance inevitably shape internal processes) and examines power dynamics, both explicit and inadvertent, within a biomedical community science project. To this end, scholars have illuminated the ways in which internal power relations and organizational forms carry implications for organizing for social change. The organizational approach "do-ocracy" that champions self-motivated participation – to "do" something rather than wait to be directed – is found in hacker circles (including Open Insulin) and has been described by Worden (2012, p.219) as a "practical anarchy that works well for getting things done. However, it doesn't work well for resolving conflicts between people who want different things to happen; it doesn't protect people who have less ability to do things because of unequal access to time, or to resources, or unequal physical ability; and it is no help to people who believe that certain things just shouldn't be done at all."

Pleyers (2010) specifically identifies frictions between "more informal and horizontal logic" and that of "efficiency and delegation" (p. 212), while Teivainen (2012) argues that unstructured governance can generate ambiguity in political aims and values, leading to undemocratic

leadership. Relatedly, della Porta (2013) distinguishes between democratic leadership selection and participatory deliberative models, contending that the former relies on pre-existing identities of members, while the latter results in a process of identity formation through shared decision-making. There are associated debates about tensions between spontaneity versus bureaucratization and the impacts of this for social change (Rigon 2015). The push-and-pull between institutionalization and structurelessness is particularly germane in biomedical citizen science as biomedical regulations demand standardized practices for quality and safety, thus creating strain against anti-structure tendencies.

Many biomedical citizen science projects organize against bureaucratic and neoliberal norms in biomedicine, without always having a clear and detailed picture of what they are for. Importantly, such ambiguity can generate tension between "aspirations and practices (vision and methods)" (Caruso 2013, p. 81). For example, Rigon's (2015) assessment of the World Social Forum as being defined by what they stood against – neoliberalism – left it vulnerable to ambiguity and "issues of power implicit and unclearly defined" (p. 76). Similarly, Open Insulin formed in reaction to corporatization that deprioritizes affordable medicines, without always having clear consensus on what it was for and how to get there.

Tensions between broad consensus building and representation in decision-making become more acute as initiatives for social change grow in scale (Caruso and Teivainen 2014). As Bacon (2012) suggests, smaller groups (e.g., ten people) may not require governance, whereas it becomes more pressing in larger groups. Despite growing interest in biomedical citizen science, there is little understanding of internal governance and how this impacts participation, objectives, and values. This paper seeks to fill this gap by examining a bottom-up project between open, horizontal logics and more traditional hierarchical forms of representation.

METHODS

Data reported are drawn from a multi-year ethnographic study exploring open source and organizational practices of the community project Open Insulin. This paper draws on 18 in-depth interviews with Open Insulin participants and more than 300 hours of fieldwork in the laboratory and online from August 2018 to October 2021. Observations focused on working group meetings, with emphasis on Safety and Regulations, Business, and Legal working groups, as well as general and ad hoc meetings; a three-day strategy session in 2019 and nine "vision" meetings in 2021; and two conferences, Biohack the Planet in 2018 and Global Community Bio Summit in 2020. Detailed fieldnotes were taken during observations.

In-depth interviews, lasting 60 to 120 minutes, were conducted with Open Insulin volunteers, paid members, and board members. Interviews were conducted via Zoom or in person, and followed a semi-structured, open-ended format. Interview topics explored included participant motivations, on-the-ground practices, group structure and goals, and comparisons of institutions versus community labs, in addition to how members navigated intellectual property and operationalized open source principles. Community lab demographics tend to reflect the broader scientific world, with white, educated men, typically middle to upper class, largely participating in and leading decisions (Walajahi 2019; Erikainen 2022). This is similarly reflected in Open Insulin (although to greater and lesser extents at different points in the project) and in the interview sample. The data set also comprises documents such as newsletters and media articles about Open Insulin and documents shared in meetings such as grant proposals and governance documents.

Grounded theory (Charmaz 2014) was employed to analyze all data, using initial line-by-line coding and analytic memos to identify relationships between codes and emergent findings. Qualitative software MAXQDA was used to analyze all data. Institutional review board approval was obtained from University of California San Francisco. I use pseudonyms to allow for anonymity except when consent was obtained to allow the use of real names.

AUTHOR POSITIONALITY

I followed a particular form of ethnography that draws on concepts of politically engaged ethnography found in social movement research (Juris and Khasnabish 2013). This methodology promotes active participation in ethnographic observations and pushes researchers to be accountable to both the academic world and the group of movement actors under study. Following this method, I actively participated in governance discussions. My role in these activities was primarily supportive; I helped review and organize governance documents (including bylaws, organizational structure, and membership criteria), and provided limited feedback in meetings. I also joined informational talks with two outside organizations influential in the drafting of the formal documents. Although I, along with all participants, was invited to provide written comments on the final set of governance documents, I did not, nor did I vote on their adoption.

The participant-observer role comes with challenges that include navigating a precarious position of providing feedback, and potentially dissent, that puts the researcher

at risk of losing access to their research site and participants. Of course, there are additional risks to the research itself, including shaping the social situation in a way that makes the research not "objective," and thus less legitimate. Many scholars have dismissed this objectivist view of ethnographic research as an illusion, yet there remain real concerns about researcher involvement, especially as it relates to power and positionality. I navigated these tensions by limiting my scope of involvement to gentle suggestions that governance be prioritized and that a formal structure be considered that attends to power. Because of this, I believe my participation played a limited role in influencing the outcomes of governance decisions.

FINDINGS

Below, I identify and describe three mutually constructed issues Open Insulin grappled with while negotiating structurelessness versus structured approaches to internal governance: membership and the demarcation of inclusion and exclusion; leadership and decision-making authority; and social processes that shaped the mission, including objectives and underlying values. Sometimes these questions were articulated explicitly during discussions about governance and were visible to members who wrestled with when, why, and how to invoke frameworks for decision-making and power sharing. Other times, these issues surfaced unintentionally while confronting seemingly unrelated challenges. For example, day-to-day operations discussions frequently led to, as one member put it, "heavy meetings," where ostensibly technical conversations morphed into tense discussions about the project's scope, strategies, and purpose.

THE OPEN INSULIN FOUNDATION AND ORGANIZATIONAL (RE)STRUCTURING

First, I provide an overview of Open Insulin's structure chronologically, beginning with their informal organizational approach and then tracing the formation of a formal structure. From their inception in 2015 until 2021, Open Insulin organized themselves informally under horizonal governance frameworks, relinquishing titles and formal hierarchy to delineate tasks and decisions. A horizontal structure was adopted largely in opposition to bureaucratic forms found in corporate and academic science, characterized by centralized and hierarchical decision-making, with an emphasis on qualifications and rules, and a disregard of non-expert knowledge. In the absence of a formal hierarchy, Open Insulin took a "do-ocratic" approach to manage and execute tasks and cited the P2P Foundation in onboarding materials: "'Do-ocracy' is a notion that encourages open participation. It is based on the self-allocation of tasks, and it allows those who carry out these tasks to be recognised and become more influential in order to make decisions" (P2PF n.d.). In practice, this frequently led to ad hoc decision-making. Sometimes participants weighed in to obtain "rough consensus" (Russell 2006); other times participants were silent, effectively making decisions through presumed consensus or lack of dissent. This approach also resulted in eight organically formed working groups in Open Insulin, in which participants engaged in work that most appealed to them.

Many interviewees flagged the lack of organizational structure and management as one of the biggest issues Open Insulin faced. As one participant put it, "It's just kind of like chaotic… I think we'd get more done if everybody knew what they were going to do, like 'this is your task.'" He points to a tradeoff between self-directedness on the one hand, versus efficiency and clarity of tasks on the other. Relatedly, another member reflected on a time when numerous sub-groups were working on different things that were difficult to balance simultaneously: "People are going in a bunch of different directions… hundreds of people showing up to the onboarding meetings over the course of a few months… At the same time that there was this internship project going on." He identified a challenge of do-ocratic governance as leading members in too many directions and resulting in people feeling "stretched too thin."

There was a push to formalize the organization in 2021 that was catalyzed by multiple events. The informal structure posed more challenges as participation grew from a small, local group of people to dozens networked around the world. For instance, following a high-profile media article about Open Insulin (Berning 2021), nearly a hundred interested volunteers attended the next onboarding meeting. This prompted practical challenges for organizing volunteers and integrating diverse skills and interests. The push to formalize was furthered after a volunteer used fake credentials to provide legal advice, including an attempt to illegally file fiscal paperwork. This incident brought to the fore a tension that participants regularly grappled with: how to keep a project open and inclusive, while also effectively vetting bad actors. In these instances, Open Insulin confronted similar issues that have pervaded the wider DIYbio movement, including questions about inclusion and exclusion and how to execute decisions (e.g., Just One Giant Lab's developed a "community review" process for distributed projects with hundreds of participants).

In 2021, Open Insulin moved to implement a new, formal organizational structure. They filed for their own

nonprofit status with a board of directors, bylaws, and new membership structure. The structure blended cooperative and open source governance models. It created two forms of participation: an "individual capacity," drawing on concepts from a worker self-directed nonprofit model (or, cooperative) from the Sustainable Economies Law Center, and an "organizational capacity," drawing on Wikimedia Foundation's affiliate framework. The former functions to maintain power among workers and people with diabetes in the organization; the latter attends to intellectual property concerns for open source technology.

While there were numerous levels and sub-levels of participation that created the overall organizational framework, two features stood out: definitions of work that structured membership and, relatedly, qualifications for becoming a "Member"[2] with voting power. Definitions of work included four priority areas identified as "mission-centric" activities: (1) "backend research and development," which included bioengineering insulin and open hardware activities; (2) "production and distribution," focusing on "how medicines get made and into people's hands" (e.g., manufacturing, regulation, and distribution); (3) "work coordination and infrastructure" that sought to harmonize different aspects of the project; and (4) "recruiting, onboarding, and staffing" (Fieldnotes, September 2021).

Importantly, mission-centric activities helped to structure and define membership. To become a Member, the only status with voting power, an individual had to contribute in one of these areas. All previous informal working groups were reflected in these defined work areas except one, "Open Insulin in Society," a mixed group of academic social scientists (the author included) and community members who met "to contextualize, theorize, and analyze Open Insulin's place in contemporary society" (Fieldnotes, November 2019). This group was categorized without voting power. Additional requirements to apply as a Member included five volunteer hours per week (or 20 hours paid), a peer to vouch for you, and approval by the board. The board of directors' seats were split among people with diabetes and workers, defined as "active contributors to the project" in the four priority areas (i.e., Members) (Fieldnotes, September 2021).

Throughout my observations, participants grappled broadly with three areas of governance concerns, including membership, leadership, and the mission. The sections below illustrate both the three sets of concerns, as well as their substantial overlap and the ways in which they mutually intertwined.

MEMBERSHIP

Questions about membership, including inclusion and exclusion, emerged as a central element informing discussions of governance. In order to make and vet decisions for the project, there needed to be shared understanding about who was part of the group, and thus party to those decisions, and who was not. As participants grappled with where to draw the line, they emphasized benefits and challenges of both open and restricted forms of membership.

A few participants noted the appeal of an organization in which anyone could participate in and shape decisions, potentially benefitting the project by attracting volunteers: "One of the things that's super attractive to me is I can join the organization and within a few months have a pretty good understanding of who everyone is and what everyone is doing… Having worked in biotech… you quickly lose [sight of] the business decision drivers." This participant juxtaposes her experience in industry where she felt removed from organizational decisions to that of Open Insulin, where being able to see and understand everyone's roles acted as an incentive to join the project. Another member recognized the appeal of joining a "very open" group but suggests a disadvantage:

> "When you want to have a structure that is very open, [where] people are independent, they can choose what they want to work on and not just assign stuff to people… the problem is that you will tend to attract people who are very confident in themselves, and with skills already recognized as experience by society in general."

The participant draws a connection between the open and self-directed nature of the project to the types of people this tends to attract – those with recognized skills and expertise. In other words, she suggests the structure is less conducive to individuals without socially legitimized forms of expertise. She goes onto say "I don't think this is a problem," but she does believe that the group composition needs to be "monitored" by project members to ensure inclusion and "collaboration." Another member echoed a similar cautionary sentiment: "I don't want a bunch of Elon Musk dudes around… That is not a type of lab that I would want to be in." She cited the "proto-libertarian" mentality as characteristically being at odds with centering social inequality, which she placed a high value on and wanted to see reflected in the project.

The open nature of membership also created tension when a subset of members began pushing the project toward contract manufacturing. As one participant shared about this activity: "That spread us thin and kind of resulted in a whole different side of the organization, with a whole different set of backgrounds and interests, popping up." He goes onto note a shift in organizational activities and

priorities that reflected the "status quo" and that this was a result of who was 'in the room': "A lot of people coming from commercial pharma economy who were just kind of like in the mindset of, 'well, this is just how it works.' … So all kinds of gaps just started getting filled in with presumptions around how things work in the status quo." The concomitant open and do-ocratic approach both allowed for industry experts to join and also drive activities, including in controversial directions, by prioritizing views of those most active.

The new formalized governance was designed to address many of these concerns. While the long-term effects are yet to be recognized, there were immediate implications. One participant shared her hesitation to apply through the new membership process because it required a peer to attest to her contributions to the project. As much of her time had been spent working with a member who left, she felt she would not qualify, despite clearly meeting the required hours. Multiple women who previously held influential roles in the project did not apply for membership and lost their informal leadership status in the new structure. It is unclear why exactly. Yet, it begs examination of hidden mechanisms of inclusion and exclusion.

LEADERSHIP AND DECISION-MAKING AUTHORITY

The horizontal structure was formed in reaction to mainstream biomedical institutions that prioritize top-down decision-making and incentivize patents and profits over affordable medicines. Numerous interviewees articulated this problem as something that community-based science addresses by offering different organizational forms and incentives. As one participant stated:

> "Bureaucratic organizations that operate on a large scale and [that] are very closed in who they let in to work on things and what they let people work on, both of those things are very much determined in a top-down fashion… Here, if someone thinks something is worth doing, they can just try to do it. So the lack of access to insulin has been a huge problem for a long time… but within those institutional structures, nothing could be done about it, because it's not really that profitable to address."

He connects characteristics of large bureaucratic institutions, including restrictions around membership and objectives (e.g., prioritization of profits), to the problem of insulin access. This is juxtaposed to the open and self-directed structure of Open Insulin, which he suggests fosters potentially different outcomes.

Participants were attentive to both pros and cons of the open, horizontal structure. Some conveyed enthusiasm toward a "bottom-up" approach to decision-making, including multiple participants who praised it as facilitating goals of "democratizing science" by allowing volunteers to participate in and drive scientific decisions. Others, however, grappled with deeper issues that surfaced in the horizontal structure, where some members had their voices heard over others, potentially reproducing power dynamics the group sought to avoid:

> "Claiming to be a collaborative, cooperative space without really thinking through how to make that happen and just defaulting to more or less the problematic things, with men just saying 'I'm going to do this. I'm going to do this; you're going to do this.' That kind of thing… It's the same structural similarity but just hidden or unarticulated."

This participant described a key problem emanating from lack of intentionality around power sharing: similar structures of hierarchical decision-making and authority arise regardless but are "hidden or unarticulated" and thus unable to be reconciled. This happens when people, often men he notes, make decisions for themselves and others with no mechanism for accountability to ensure organizational values of horizontal decision-making are put into practice.

Another participant reflected on the stated goals of shared decision-making versus on-the-ground practices:

> "The idea of collective decision [making]… this idea that it is not just experts deciding, that we all decide together [and] we all are experts, not because you have a degree or whatever … I think we are not feeling like a nonprofit… [since] we don't have the board and all of this [organizational hierarchy] in place."

But as she noted, "this isn't really true. It's always like a few people deciding," and that some members "have more power … decision power over other people." She emphasizes the disconnect between the reality in-practice of a handful of people making decisions versus the objective of "collective" decision-making, and suggests this discrepancy or illusion can be sustained because of the absence of a formal organizational structure.

Project members recognized that individuals did indeed hold more influence in shaping organizational priorities and practices. This small handful of people were referred to by different titles, including "core members" or "key people," and were sought out for all consequential decisions.

The scientist directing much of the laboratory work was referred to as the "scientific lead," and other "project leads" emerged to help organize and direct working groups. The founder also recognized himself as the "de facto leader," often serving as an obligatory point in which many decisions passed.

Those in authoritative roles likewise recognized themselves in this hidden structure, sometimes critiquing it: "I don't want to be the only one making decisions," one participant voiced in a meeting while discussing project long-term plans. The scientific leader shared similar cautionary observations:

> "The whole power dynamic, how people interact- The thing sometimes I think about is how it could be that somebody took over too much on a project… when they are speaking with authority for everybody. *And this kind of stuff can happen even if you don't necessarily understand it's happening*… When I speak, because I have this title of PhD and it seems that I know what I'm talking about, people say you should know what he's talking about. But then, the issue with that for me, the fact that *there is no balance, and I am the only one doing stuff and I am not challenged*." (emphasis added)

Here he reflects on both his own position of influence in the project and points out an important driver of this: the fact that he holds a PhD and people imbue this credential with social and scientific legitimacy. While group members began to unveil the not-so-hidden structure and critique it, they also wrestled with how to organize differently and the complexity of doing so. He goes on to note "I have no idea how I can fix that and if it can be fixed… It's complicated."

The formation of a formal governance structure, including parameters around which decisions could be made by whom, offered potential to alleviate these issues; however, new challenges also surfaced. First, the new board composition reflected much of the hidden structure of those in positions of authority and even exacerbated inequalities in leadership: The new board reflected wider scientific and societal hierarchies with all white, highly educated men filling positions of power; none of the women who previously held informal leadership roles were on the new board. A special meeting was planned to select additional board members, but no qualified candidates applied.

Second, there was limited engagement to do the arduous work of thinking through power sharing mechanisms and ways to structure decision-making authority, leaving it almost exclusively to the founder. Participants attended focused meetings on and supported the idea of governance, especially to enact the goal for diabetic and worker control. However, there was little action to translate complex ideas to bylaws and collaborative agreements. As the founder expressed to me: "I've actually gotten very little feedback… I posted these documents in the group and they're all there, but I don't think a lot of people have really read them carefully." Additionally, there was a dearth of governance precedents to bring together traditionally distinct aims – co-operative owned, open source, and biomedical nonprofit – resulting in an especially time-intensive process to create documents. Finally, a key goal of the new structure allotted a proportion of board seats for people who use insulin, offering a mechanism to confer control by constituents most impacted. To my knowledge, there has been no recruitment to fulfill this objective, and only one person with diabetes, the founder and board president, is represented.

MISSION

My analysis identified the mission as a social process that was regularly debated and constructed. Participants grappled with the project's objectives and strategies for how to reach their stated goals. Embedded in these negotiations about what the mission was, and was not, were values (e.g., individualism versus collectivism). The organizational approaches structured who was 'in the room' and who was 'at the table,' granting those in decision-making positions influence over tasks and the direction of the organization, effectively allowing them to express their values.

A key concern among project members was that of mission creep, when objectives change or expand beyond the organization's original scope. Several participants voiced concern that Open Insulin would fall back into practices of corporatization (e.g., proprietary- and profit-driven) or be coopted by corporate interests. As one interviewee stated bluntly: "The biggest problem will be to become too corporate. And we have seen a lot of diabetic organizations starting as very grassroots and just moving towards a lot of centralized structure, or just being bought out… So for me that's the main preoccupation, to keep the mission straight." She goes on to identify "open source" and "keeping the patient at the center" as key elements of the mission. Another participant expressed frustration that venture capitalist (VC) funding continued to be suggested during meetings: "We don't say to somebody who is new, this is the value we carry, and we don't really challenge, necessarily, what people are suggesting… [Like] when people say, 'should we take money from VCs,' [it's like] let's just put it under a rug and not talk about it." For him, VC money did not align with the values of Open Insulin, yet he found the informal decision-making approach led to indecisiveness and was inadequate to enforce this view.

The ambiguity in objectives manifested tensions as the project confronted how to move from the laboratory to manufacturing. In 2020, a working group dedicated to regulations and safety arose, primarily driven by professionals with biotech and pharmaceutical industry backgrounds. The group identified contract manufacturing organizations (CMOs) as "the most feasible" way to interact with federal regulations and to safely produce insulin (Fieldnotes 2020 and 2021). Open Insulin successfully secured an initial partnership with a CMO, and volunteers spent countless hours wading through challenging technical details to move forward. Many participants viewed this work as falling within the mission, citing this as a "promising option;" however, one interviewee questioned this logic:

> "We weren't really ready to pursue anything like manufacturing... without the organization in place and without the consistent labor and resources and all that behind it, it's just difficult to do. And so we were able to make a connection with a CMO and start to think about manufacturing, but *manufacturing itself, at that time, informally at least, was outside of the scope of the organization.*" (emphasis added)

This statement highlights both incongruent understandings of what was in and out of the project's scope, and also elastic interpretations based on formal and informal articulations.

Another longtime member commented during a meeting on the sudden shift toward CMOs, saying "we've only been talking about this [CMOs], really, for about six months." This, along with the rapidly expanding volunteer-base, prompted her to suggest they consider whether to be "mission-driven," and prioritize making and distributing insulin by focusing resources toward this end, or "remain educational." In other words, she surfaced two objectives that she viewed in conflict: making insulin, which prioritized expertise and efficacy, and open science, which prioritized time for training and collaboration. Participants pushed back suggesting they could do both; however, limited resources were recognized as a major barrier. Another interviewee and biotech professional suggested such a mission shift was imperative if they were to become more than "a group of disrupters." While others viewed pharma experts in leadership roles more critically, fearing they would (re)shape the mission in compromising ways, she saw this as essential to achieve the aim of making safe insulin. Embedded in these negotiations were issues about the mission but also implications for membership and decision-making authority (e.g., through the prioritization of industry experts over other groups).

DISCUSSION

This paper examines the internal governance practices of the biomedical citizen science project Open Insulin between 2018 to 2021. It describes their initial informal structure derived from horizontal frameworks and traces the shift to a formal organization with a board of directors. I identify mutually constitutive themes that emerged, which acted as sites of change and shaped how internal governance was enacted. These include membership and mechanisms of inclusion and exclusion; leadership and decision-making structures; and the mission as a social process, where objectives and strategies were regularly negotiated. Findings illustrate benefits of an informal and open structure, such as facilitating participation in science through low barriers to entry, as well as present challenges participants grappled with, including questions of when, how, and by whom decisions were made and the resulting implications.

Participants perceived advantages and disadvantages to different forms of internal governance. On the one hand, horizontal, self-directed approaches facilitated goals of attracting volunteers and expanding membership, thus broadening access to science. On the other hand, a hidden structure of members with more authority and influence emerged that threatened the goals of power sharing inherent in the horizontal model. Those that held scientific degrees (e.g., PhD) tended to have more power, much like broader society, as participants imported logics of legitimacy and deferred scientific and other decisions to these members. Results also revealed that as pharmaceutical and biotech industry experts assumed a larger role, they ultimately directed the project toward prevailing ways of producing medicines through contract manufacturers, which some viewed as misaligned with earlier interpretations of the mission. Nearly all consequential decisions were, in practice, made by a small group of people. This was veiled under the pretense of horizontal decision-making and thus unable to be reconciled. In other words, there was no mechanism through which to ensure this form of power sharing was enacted. Additionally, lack of clarity around when and how a decision was made, and when it was binding, led to floundered attempts to implement changes in the informal structure.

It was hoped that the formation of a formal governance structure would alleviate many issues. There are promising elements such as designated board seats for people with diabetes to ensure constituent-based power by those who use insulin. Still, new challenges surfaced. First, during the process of developing a new approach, a dearth of governance precedents to carry out simultaneous aims for a co-operative owned, open source, biomedical nonprofit

resulted in a time-intensive process for formulating governance that balanced these. Attempts by the founder to establish more egalitarian processes were stymied by lack of involvement and feedback from others on how to translate complex mechanisms for power sharing into documented procedures. The process for developing governance thus lacked deep collaboration, potentially undermining its impact through lack of buy-in. Second, following the implementation of the new structure, women who previously occupied informal authoritative roles were not retained in leadership positions. It is unclear why, although one female member shared that the shift away from meetings and toward online communication played a role.

Finally, the new structure runs the risk of prioritizing scientific and expert authority over other forms of knowledge expertise through definitional constructions of "mission-centric" activities that are tied to membership and power. Technical scientific work offers a clear path to membership with decision-making authority. Certain other forms of contribution, however, were conceived as less legitimate (important, maybe, but not so important to confer decision-making power) – for example, the careful and challenging work to attend to the social, moral, economic, and political ecosystem surrounding technology and innovation. Thus, the way decision-making authority was delineated did not inherently support a mechanism that centers critical values, for example, critiques of neoliberalism and re-evaluation of practices to counter harmful norms in biomedicine. In reacting to the issue of mission creep and corporate capture, the project stands vulnerable to another trap: prioritization of expert authority.

Ikemoto (2017) contends that DIYbio reflects norms of institutional science, in part because they have not clarified their position on values and norms, and thus fall back into a similar ethos and practices. I argue one mechanism to address this is through increased attention to internal governance, including interrelated aspects of membership, decision-making authority, and mission. Not being intentional about creating a different way of doing science, including the organizational infrastructure to structure decisions and relations, poses a threat to the mission to reimagine the process of scientific knowledge production. Invoking a horizontal structure suggests the project values power sharing. Yet, as findings underscore, unequal power and decision-making inadvertently happened but were obfuscated and concealed.

Additionally, I suggest that biomedical citizen science projects are more at risk of falling back into similar problematic practices found in scientific institutions because they inherently rely on expertise. Expertise is needed not only to bioengineer insulin but also to navigate complex regulatory systems and patent regimes. Expert knowledge potentially undermines the creation of new norms and practices by importing particular logics from biomedical intuitions that reflect the status quo. There is also the risk of reflecting the larger scientific order through this prioritization – all white men leading and making decisions, as is the case currently – and consequently importing logics that emanate from positions of privilege in society.

Biomedical citizen projects that seek to challenge and reconstitute the biopolitical economy through more emancipatory practices must attend to and construct infrastructure that will allow them to do this. This extends beyond the physical space and laboratory equipment to carry out the scientific aspects and into organizational infrastructure, including explicating values and how to operationalize those values. Thoughtful governance to actualize values such as power sharing can be tricky to construct, negotiate, and put into practice. Yet, failing to do so risks reproducing problematic structures and norms many biomedical citizen scientists strive to avoid.

LIMITATIONS

There are many citizen science projects seeded in community labs that do not define themselves outside typical scientific organizational structures (Erikainen 2022). In fact, many position themselves as champions of and places for start-ups to get their start. The extent to which Open Insulin reflects other groups in the biomedical citizen science space is unclear, and thus may affect governance approaches.

NOTES

1 I follow Keulartz and van den Belt's (2016) description of the do-it-yourself biology (DIYbio) movement that underscores its development as influenced by four related movements and applying threads of each to genes, cells, etc.: do-it-yourself (also, do-it-together), citizen science, free software and computer hacking, and the maker movements. Community biology labs also tend to be characterized under the DIYbio umbrella movement.

2 Uppercase "Member" is used to indicate a participant's membership in this specific defined role in the formal nonprofit structure. Lowercase "member" is used elsewhere as a participant, volunteer, or paid contributor in the informal structure.

ETHICS AND CONSENT

The study protocol was reviewed and approved by University of California San Francisco.

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COMPETING INTERESTS

The author has no competing interests to declare.

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