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Policy for citizen science

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Citizen science initiatives that support collaborations between researchers and the public are flourishing. As a result of this enhanced role of the public, citizen science demonstrates more diversity and flexibility than traditional science and can encompass efforts that have no institutional affiliation, are funded entirely by participants, or continuously or suddenly change their scientific aims. But these structural differences have regulatory implications that could undermine the integrity, safety, or participatory goals of particular citizen science projects. Thus far, citizen science appears to be addressing regulatory gaps and mismatches through the voluntary actions of thoughtful and well-intentioned practitioners. But as citizen science continues to surge in popularity and increasingly engage divergent interests, vulnerable populations, and sensitive data, it is important to consider the long-term effectiveness of these private actions and whether public policies should be adjusted to complement or improve on them. Here, we focus on three policy domains that are relevant to most citizen science projects: intellectual property (IP), scientific integrity, and participant protections.

While the definitional bounds of citizen science are debated, there is general consensus that citizen science encompasses scientific endeavors in which individuals without specific scientific training participate as volunteers in one or more activities relevant to the research process other than (or in addition to) allowing personal data or specimens to be collected from them. These activities might take place at any point during the research process and include participation in study design, data collection and analysis, and dissemination of results (1). They might even encompass the entirety of the research process where, as in coordinated self-experimentation, the role of professional scientists is minimal.

Recognizing the potential for citizen science to advance scientific knowledge and promote public support of scientific activities, professional associations have emerged in the United States, Europe, and Australia to support citizen science efforts, including consideration of policy interactions. Meanwhile, the U.S. government recently passed legislation that supports agency use of citizen science and crowdsourcing to conduct projects that advance their missions (2).

INTELLECTUAL PROPERTY

Citizen scientists are usually not paid for their contributions, although they might benefit from participation in other ways. When citizen scientist volunteers are not compensated, their work is not subject to most employment-related laws and practices that govern their scientific collaborators. Some employment-related laws and practices have implications for ownership of IP, including copyrights and patents. Although domestic IP laws generally do not reach beyond national borders, international treaties have harmonized basic IP protections. Thus, application of many U.S. protections to citizen science contexts is generalizable to other countries, though some important differences persist.

U.S. copyright protection extends to authors of every original work fixed in a tangible medium. An exception exists for any “work made for hire” that is prepared by an employee within the scope of employment or by agreement as a specially ordered or commissioned contribution to a collective work (3). Because citizen scientists are volunteers, any copyrightable works they develop in the course of a project—for example, photographs, writings, and creative selections or arrangements of scientific data—likely do not constitute works for hire absent valid agreements otherwise. Rather, from a legal perspective, the volunteer who created the works is the copyright “author” and owner. Other countries do not recognize an automatic transfer of ownership to employers or commissioning parties (3).

Where projects do not require copyright assignment as a condition of volunteering, a citizen scientist who retains ownership of her works under governing domestic law can refuse to grant permission to publish them, which could disrupt the scientific process or prevent the dissemination of findings. However, projects can and often do avoid potential disputes using Creative Commons licenses, which allow creators to retain their copyrights while permitting others to copy and use their works.

A similar tool is not widely available for patents. In most countries, the legal inventor of a patentable discovery is one who contributes to its conception, and in the U.S., only inventors may apply for patents. Employers typically require their scientist employees to assign any rights to future inventions as a condition of employment, including decisions to apply for patents and license inventions. By contrast, patent assignments do not appear to be a typical condition of volunteering in citizen science projects. Yet, given the potentially robust involvement of citizen scientists in scientific discovery, it is possible that some citizen scientists will make contributions that support claims of sole inventorship or co-inventorship under domestic patent laws (4). For example, Sharon Terry, a self-described citizen scientist who helped discover the gene responsible for her children’s rare disease, pseudoxanthoma elasticum, is a named co-inventor on U.S. patents related to that discovery (5). Challenges may arise if the citizen science inventor who has retained IP rights exercises them to exclude projects from using the patented inventions or disagrees with co-inventors on whether to pursue patents or license inventions to others.

Contracts can be used to clarify rights and establish expectations related to patent and other IP rights. Projects might take a page from employment practices and require participants to assign future patent rights to project leaders as a condition of participation. However, such a

practice seems incompatible with models that view citizen scientists as respected partners in the research process. The online citizen science game FoldIt, for example, does not require patent assignments. Instead, FoldIt's IP policy provides that "players who contributed to the discovery will be considered co-inventors for any discovery produced through play" and issues of ownership will be handled at a later date by the University of Washington, where the game was developed and is managed (6). It remains to be seen how well this approach will work in practice (7).

Alternatively, contracts can incorporate advance commitments by citizen scientists and professional scientists to cede stewardship of patents to nonprofit organizations that support research. Ms. Terry's advocacy organization, for example, is the assignee of the patented inventions she helped discover (5). However, it is unclear whether this model would be readily accepted in contexts where citizen scientists do not have funding or other leverage to negotiate IP control.

According to a third approach, citizen scientists and professional scientists might forego patenting discoveries resulting from their collaborations or grant each other non-exclusive, royalty-free cross-licenses to any discoveries. While the development of standardized agreements for each of these scenarios seems achievable, support for such agreements may be limited where interest in commercialization is high (7). One-way material transfer agreements, which are a common vehicle for transferring research materials between institutions, might be adapted to promote sharing by and with citizen scientists. But in some cases, they may add unnecessary complexity to what might otherwise be straightforward transactions, and they are notoriously difficult to monitor and enforce.

In sum, although contractual approaches have limits, the ability to tailor contracts to circumstances makes them more practical than legislative approaches that would change the legal rules to produce different default outcomes—assuming that consensus on optimal outcomes even could be reached. As a policy matter, resources are probably better spent encouraging transparency and negotiation of IP terms at the outset of citizen science collaborations.

RESEARCH INTEGRITY

Concerns about the quality of data contributed by citizen scientists and the soundness of their collection, reporting, and analytical techniques have long been raised (8, 9). Although professional scientists are not immune from quality transgressions, methodological rigor is central to their training and professional advancement, and formal mechanisms exist for holding professional scientists accountable for the quality of their work. Volunteers, on the other hand, may not experience similar external pressures to ensure research integrity (10) and may prioritize other aspects of their participation. Furthermore, there may be fewer opportunities for professional scientists to address knowledge gaps and otherwise act as a check on quality if their involvement in projects is minimal.

Conflicts of interest can also undermine research integrity. Individuals who engage in citizen science can have biases stemming from their alliances with private, non-profit, and political

organizations, as well as their involvement in lawsuits (9, 10). They may also have biases based on their perceptions of how they or their community might be harmed or benefited by particular findings. Further, and especially with respect to research on politically charged topics, it is not beyond the realm of possibility that citizen scientists might be recruited to provide bad data to “improve” results or even sabotage research, although careful monitoring will help ferret out such attacks. Of course, research conducted exclusively by professional scientists can also be undermined by personal biases and conflicts of interest, but institutional rules, funding stipulations, regulatory procedures, and professional norms work to compel their identification and disclosure whether the research is conducted in for-profit, non-profit, or governmental settings. Citizen science projects that are not embedded within institutions, are self-funded, or are otherwise outside of regulatory control may operate without these traditional safeguards.

Citizen science projects have adopted a number of strategies to promote research integrity, and many guides, tools, and templates are available to support projects from the planning stages through evaluation (11, 12). Studies indicate that citizen scientists can produce reliable data on par with those produced by professionals (12). But it is not yet clear how well the best practices that have been developed address the many flavors of citizen science or are being followed by its practitioners. These questions should be studied, but in the meantime, there may be opportunities to promote integrity through policy.

As one example, recently enacted U.S. legislation aimed at promoting citizen science and crowdsourcing projects by federal agencies provides that all data collected through such efforts should be made publicly available where appropriate and to the extent possible (2). Such data accessibility creates opportunities to investigate questionable or poor-quality data and assess fitness for use through independent examination (10). The law also requires agencies to “make all practicable efforts” to ensure that participants adhere to federal research misconduct policies, which include sanctions for fabricating and falsifying data (2). For studies conducted with federal funds, the penalties for research misconduct—the most severe being a funding ban—will not apply to most citizen scientists since they do not seek such funding. However, their interests will be affected if professional collaborators lose the federal support that makes possible their work.

These regulations will not reach citizen science projects that are not conducted with U.S. federal employees or not federally funded. Journals that publish citizen science research help fill this gap through the peer review process and by placing pressure on authors to make their study data publicly available. While these policies do not affect citizen science projects that are uninterested in traditional publication, some projects may have commitments to openness that match or even exceed journal requirements. For example, DIYgenomics.org publishes protocols and data on project wikis.

A related problem is presented when citizen scientists have conflicts of interest that are not disclosed. Many national regulations and journals have adopted requirements of conflicts reporting but they may not reach citizen scientists who do not qualify as investigators or authors, although they facilitate research in meaningful ways. To promote accountability, such requirements should extend to the disclosure of relevant conflicts held by citizen

scientists. Problems will arise, however, when disclosure is incompatible with volunteer terms that allow anonymous participation. We support project discretion to offer anonymity, especially where sensitive information is involved or citizen scientists could be subjected to intimidation or harm if identified. In such cases, consideration should be given to permitting disclosure at the aggregate level (10).

PARTICIPANT PROTECTIONS

As uncompensated volunteers, citizen scientists are unable to rely on traditional labor laws to prevent and redress harm since they do not qualify as protected workers. The Common Rule, which applies to all research involving human subjects that is conducted or supported by the U.S. government, is directed at protecting research participants. For studies governed by the Common Rule and not within an exemption, Institutional Review Boards (IRBs) must ensure that any risks to subjects are minimized and reasonable in relation to anticipated benefits. Studies that take place in other countries may still be subject to the Common Rule or similar national requirements, so consideration of the Common Rule's provisions may be broadly instructive.

Importantly, Common Rule protections are directed toward "subjects" of research from whom identifiable data or biospecimens are collected. They do not explicitly authorize IRBs to consider risks or benefits to citizen scientists who facilitate research in other ways. Depending on the setting and study design, examples of specific risks to citizen scientists could include expectations of over-work, requirements to assume financial burdens, or vulnerability to harassment by others. Examples of specific benefits, on the other hand, could include training in scientific techniques, access to tools and data for personal use, or opportunities for co-authorship. Where citizen scientists are both subjects and facilitators of research, IRBs may interpret their jurisdiction to include risks and benefits associated with both roles. However, in some contexts, citizen scientists are only research facilitators and not also subjects, or their roles may be ambiguous (13). Federal protections also do not explicitly contemplate risks and benefits to communities, although community-based research review processes, including community IRBs and advisory committees, have emerged to complement traditional IRB review to ensure that involved communities are engaged in and directly benefit from proposed research and that study designs are culturally appropriate.

Many U.S.-led citizen science initiatives are not covered by the Common Rule because they are not federally conducted or supported (14). A small number may nevertheless be covered by research subject protections adopted by the Food and Drug Administration (FDA), which apply to clinical investigations that support applications for products regulated by FDA, regardless of funding source. Like the Common Rule, however, FDA research subject protections do not explicitly account for risks and benefits associated with supporting scientific initiatives in ways other than serving as research subjects.

For those citizen science initiatives outside the scope of these federal regulations and not conducted in the few states that extend these kinds of protections to all research regardless of funding source, there may be no legal requirement to evaluate or disclose potential risks to

citizen scientists. Individuals owe a duty of ordinary care to avoid foreseeable injury to others, including general volunteers, but application of this common law doctrine is highly context-specific and may be unavailable to volunteers for any number of reasons. Moreover, some projects may require waivers of liability as a condition of volunteering, which are not allowed in the context of federally regulated research.

Some unregulated projects, like Sage Bionetwork's mPower study of Parkinson's disease, which collects data through participants' mobile phones, voluntarily close this gap by securing independent IRB review of their protocols, although this can be cost-prohibitive for many projects. Others have proposed ethics evaluations by "citizen ethicists" who critique experiments and post their opinions online for potential participants to review, as well as downloadable ethics toolkits geared toward citizen scientists (15). Meanwhile, DIY biology projects may voluntarily adhere to a community code of ethics, which includes directives to pursue peaceful purposes and adopt safe practices. Until recently, the community also supported an online forum through which professional biosafety experts answered questions posed by citizen scientists. However, some projects may fail to engage in any kind of risk assessment or management.

Of the three policy domains discussed, participant protections require the most immediate attention given that they implicate direct physical harms, yet collective action focused on assessing those harms relative to other risks and benefits specific to citizen science has thus far been limited. How citizen science projects are making these risk-benefit calculations, and according to what processes, should be empirically investigated. Then, whether these data justify extending current legal protections to unregulated citizen science, or creating new policy frameworks altogether, merits study by policymakers in partnership with the citizen science community. If it is determined that additional regulation is warranted, it is unlikely to occur at the federal level given that a proposal to extend the Common Rule to additional kinds of research was recently considered and rejected. At a minimum, however, guidance should be developed by citizen science practitioners and participants in collaboration with ethicists to aid unregulated projects that cannot afford independent IRB review in conducting risk-benefit assessments. Such guidance also may be useful to traditional IRBs evaluating regulated projects in which the role of citizen scientists is multi-faceted or ambiguous. Finally, modes of risk assessment and management that are complementary or alternative to those required by the Common Rule and FDA regulations, including but not limited to ethics reviews conducted by non-traditional IRBs and citizen ethicists, should be evaluated to understand the citizen science contexts in which they could be useful.

As citizen science becomes more prevalent, it is increasingly important that policy opportunities to support participants and practitioners are identified and responsibly pursued. In the end, some policy adjustments may be in the best interests of society, but to be successful, they must appreciate the distinct ethos of citizen science and be guided by its diverse stakeholders.

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