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Perspective

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Citizen science to further precision medicine: from vision to implementation

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ABSTRACT

The active involvement of citizen scientists in setting research agendas, partnering with academic investigators to conduct research, analyzing and disseminating results, and implementing learnings from research can improve both processes and outcomes. Adopting a citizen science approach to the practice of precision medicine in clinical care and research will require healthcare providers, researchers, and institutions to address a number of technical, organizational, and citizen scientist collaboration issues. Some changes can be made with relative ease, while others will necessitate cultural shifts, redistribution of power, recommitment to shared goals, and improved communication. This perspective, based on a workshop held at the 2018 AMIA Annual Symposium, identifies current barriers and needed changes to facilitate broad adoption of a citizen science-based approach in healthcare.

Key words: research methodology, healthcare systems, community participation, consumer involvement, patient acceptance of healthcare, citizen science

INTRODUCTION

Precision medicine has been defined as the development of prevention and treatment strategies that take individual variability into account.[1] To date, precision medicine research efforts (eg, All of Us Research Program[2]) have emphasized largely expert-driven efforts for better identifying different interventions that work for different people at different times. A central promise of precision medicine is prevention and treatment approaches that move beyond "on

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average" patient responses[3] to create more personalized, targeted interventions.[4–6] As evidenced by the extended discussion about various "precision" efforts,[4–16] *how* to realize the vision of precision medicine remains an open question. A key consideration is how to include patients, citizens, patient innovators, patient informaticians, citizen scientists, and scientific citizens in the process and how informatics infrastructure can incorporate these contributions meaningfully.

Citizen science has been defined as "the general public engagement in scientific research activities when citizens actively contribute to science either with their intellectual effort or surrounding knowledge or their tools and resources."[17] Citizen science initiatives have contributed to academic science and continue to broaden its scope and depth.[18] Although much of the work is conducted outside the walls of academia or other organizational settings via novel methods, some patients who take on the role of citizen scientists do use traditional research and/or informatics approaches to answer their questions.[19]

Citizen science can empower individuals to generate scientific questions and share their data. Citizens can generate answers to population health questions of interest to both patients and the healthcare system,[20,21] making citizen science a feasible approach to healthcare research.[22–25] Citizen science offers an opportunity to empower marginalized groups, such as sexual and gender minorities, to shape scientific inquiry through participation.[26,27] Engagement of citizen scientists enables studies that aren't accessible without them. Technological advances, changing reimbursement models, innovative informed consent approaches, and other factors are driving a shift in power dynamics within healthcare, affording greater integration of citizen scientists' work into research and clinical care.[28–32]

Citizen science has the potential to extend and enhance the practice of precision medicine if healthcare practitioners and citizen scientists work together to develop scientifically sound approaches.[33,34] For example, the Personal Genome Project UK uses a citizen science approach in which participants have consented to open access release of personal genome, methylome, and transcriptome data and analyses thought to influence gene function.[35] However, the general movement toward citizen science is more mature in fields other than medicine, and this situation creates an opportunity for informaticians to think through what citizen science means—and could mean—in the informatics context. Within fields such as biology, conservation, ecology, and astronomy, previously unimaginable insights into topics such as migration patterns, scope of biodiversity, and asteroid surveillance have been realized through citizen science-based approaches.[36] In comparison, citizen science-based efforts within the field of population health, clinical medicine, and consumer health are relatively nascent.[21,37–40] This viewpoint delineates the minimum technical, organizational, and citizen engagement requirements needed to facilitate meaningful integration of citizen science into existing healthcare systems. The following implementation recommendations were identified during an expert workshop held at the 2018 AMIA Annual Symposium.

TECHNICAL ISSUES

To support a diverse, open, integrated citizen science ecosystem, several technical issues must be addressed. Though some considerations are specific to citizen science, others relate more broadly to the healthcare environment's increasingly person-centric approach.[41]

Platforms that facilitate collaboration among patients and researchers

To accelerate participation, it is critical to have easily accessible, usable technology platforms that facilitate idea generation, prioritization of research questions, community-building between citizens and researchers, and results dissemination. Research networks have demonstrated effective approaches to this challenge although these projects relied on one-off technical tools.[42–44] Crowdfunding platforms have emerged as examples of how individuals, scientists, and advocates can reach out to the public for donations and investments.[45] Although participants have primarily used these platforms for outreach purposes, these platforms have not enabled collaborative generation of science. Hence, an open-source approach that citizen-scientist communities could leverage and build upon could accelerate patient and researcher matching.

A distributed network

Citizen science at scale requires a network facilitating movement of heterogeneous data sources into a large-scale system in real time. Such a centralized system, however, further necessitates creating a governing body which is still able to preserve and promote citizen scientists' autonomy within such a framework. In addition, such a network must facilitate compliance with local and national privacy regulations, among others. The growth in infrastructure that facilitates data sharing will support greater implementation of citizen science,[46] so resolution of governance and related infrastructure issues is paramount. Platforms designed specifically for citizen science projects support this objective.[47] Advancing ethical structures to achieve safety, as used in some patient-led efforts such as the Connected and Open Research Exchange,[48] is critical.[49,50]

Functionality for tracing provenance of data contributions from individual data sources

The ability to potentially track the provenance of common types of data from individuals and organizations is recommended so investigators can explain underlying assumptions and potential sources of bias in studies. These metadata should be collected only when individuals wish to have identifiable data elements shared. Ideally, such functionality would support the remuneration of individuals in exchange for sharing their data. Of course, when participants desire to make personal data open access, as in PGP-UK,[35] system functionality should support this approach as well, provided that the shared personal data fall under regulation.

Functionality supporting citizen scientist access to their own health information

Tools that give citizen scientists access to their complete health information (eg, clinical notes, lab results, and radiology reports) are central to advancement of the field. This requirement is important because people who read medical notes report having a better understanding of their conditions, are more likely to take medications as prescribed, and report greater satisfaction and trust of their doctors.[51,52] Similarly, access to diverse types of data from electronic health records will allow people to provision access and sharing of their personal data. It is important to acknowledge that individuals may have a range of motivations that lead to their participation as citizen scientists. It will be essential for those engaged in supporting and promoting citizen science efforts in precision medicine to understand and be responsive to this range of motivations, which may span from an interest in improving individual health to contributing

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to a larger social movement. Technology that provides citizen scientists some control over the management and sharing of data they contributed will also incentivize research engagement.[53]

A standardized, comprehensive approach to identification and resolution of barriers to data access

Citizen scientists need a standardized process for identifying and addressing local, state, and federal policies that hinder or obstruct access to personal health data. This article was formulated in the context of the US-based healthcare system. Within this context, patients are increasingly expected to assume responsibilities related to managing their own health. Proactive management of personal health benefits from access to data from health providers is currently difficult to obtain due to restrictive policies. Although we expect citizen scientists to play a key role in advocating for revised policies, it will be essential to create structures for sharing the burden of change, particularly in under-resourced settings. With such a process in place, they could then identify ways to facilitate patients' access to their health data. For example, they could negotiate an understanding among competing health systems to adopt a data access policy providing equivalent access for all patients, thereby reducing the impact of differences in how health systems manage and share data. Such understandings will be critical in the future as greater quantities of genomic data become available and both traditional researchers and citizen scientists seek to use multiple datasets to answer questions of interest.

ORGANIZATIONAL ISSUES

Traditional research institutions must address a number of organizational issues to work effectively with citizen scientists.

Need to honor agency in individuals, families, and communities

For citizen science work to thrive, organizations should avoid treating engaged patients as the exception or as token participants in a provider-centric system. Acknowledging the contributions of the individual, family, and community implies respect and an understanding that everyone comes to the table with different abilities and perspectives. The ideal of honoring agency strives to reduce the authoritative assumption that individuals, families, or communities need to become "engaged," when in reality they already are, though perhaps outside the priorities of healthcare institutions. It includes recognition of the many forms of expertise that each person (including patients) possesses that facilitate progress toward healthier living, the need to honor the validity of different perspectives,[54] and the need to build empathy and acknowledgement of power differentials as a potentially hidden barrier to equitable participation, contribution, and benefit.[55]

Commitment to ethical behavior

Organizations must develop an ethical framework rooted in community values on which to base citizen science efforts.[56] This framework should inform a broad spectrum of issues, including but not limited to privacy, security, data ownership, informed consent, consideration of potential unintended consequences of data sharing, and patient and researcher access. Such a framework would inform how a local citizen science community might create a collaborative, less hierarchical culture based on mutual respect (rather than power) and ethical behavior by all that rewards curiosity and fosters trustworthiness. Substantive work has already been undertaken in this area, as evidenced by the European Citizen Science Association's "Ten Principles of Citizen Science," which (among other things) emphasize mutual benefit to professional and citizen scientists, availability of project data and metadata to the public, and acknowledgement of citizen scientists in results and publications.[57] Research questions that arise from citizen scientists, rather than researchers, in a community-based participatory research environment, offer another way to honor the commitment to ethical behavior.

New and expanded funding models

Because citizen science is participant-driven, it often lacks access to the traditional sources of funding (eg, government research awards, foundation grants) that support research in universities and academic medical centers. Within the United States, funding institutions (eg, the Robert Wood Johnson Foundation, the National Institutes of Health) have demonstrated growing interests in models of citizen science and those that are closely related, such as community-based participatory research. These funding opportunities, however, follow conventional models of time constraints. As such, while there are growing opportunities to initiate citizen-science-based research efforts, questions of sustainability remain unanswered. Funding structures for citizen science, including financial models that explore contribution of data where participants have substantial involvement, are needed. Patient-powered research networks may be such a model, although their sustainability too remains unproven.

New research models

Partnering institutions must embrace a variety of research models. Health- and self-related citizen science does not necessarily imply a shared experience, but technology can support both scientific endeavors and varied forms of sharing and network-building. Many technology adaptations have been developed as part of the Quantified Self movement (eg, information retrieval skills for evidence gathering, measurement device development, provider alliances based on shared decision-making),[58] and these and other approaches need to be developed and implemented more broadly.[59] The use of self-monitoring technologies to create persuasive performance feedback that motivates technology users to continue practicing healthy behaviors for further health improvement is one such new model.[60] Crowdfunding and crowdsourcing approaches have proven successful in microbiome and metagenomics research,[61] and may offer opportunities for researcher-citizen scientist partnerships. Actively engaging patients and caregivers to prevent medical errors has resulted in new technology designs and improved communication between clinicians and hospitalized patients.[62,63] Advancing an "agile scientific" model[64] that focuses first on helping individuals rather than on producing generalizable knowledge aligns with organizational structures such as learning healthcare systems, but with clearer integration of citizen scientists.[65]

Authoritative research and engagement guidelines

Patient-researcher partnerships in citizen science range from easily identifiable relationship models (eg, mentorships, co-mentorships, and patients as co-investigators) to nontraditional/creative solutions (eg, patients as principal investigator, patients working independently). Citizen science efforts follow a continuum from researcher-initiated to citizen scientist-initiated, with truly collaborative models residing in the middle of this spectrum. Each participation model

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leads to different requirements, roles, and expectations for the individuals involved in the effort. All parties must seek to understand how these new models fit within existing academic hierarchies and promote successful collaboration. The growing community of researchers with academic affiliations and research-minded patients and patients doing citizen science requires mutually accepted guidelines for engagement and practice.

Broad outreach to allied groups for shared learning and advancement

The current practice of citizen science, whether consciously described as "citizen science," as patient-clinician engagement,[66] or otherwise, has evolved in many areas without reference to each other. Although groups and programs have shared goals, needs, and challenges, they often lack awareness of and access to each other, and so miss opportunities for shared learning and development. Citizen scientists who receive healthcare in the United States have a very different experience than their counterparts in other regions where universal healthcare, minimal copayment requirements, and relatively smaller health disparities are the norm, and as such, their practice of citizen science naturally has evolved differently. US-based citizen scientists in healthcare may learn from colleagues practicing citizen science elsewhere, wholesale adoption of and alignment with other national models is neither likely nor necessarily beneficial. Citizen science practiced in the United States, in particular, needs infrastructure that facilitates communication and information sharing among organizations, programs, citizen scientists working in other regions, and potential partners (e.g., funders, government agencies).

COLLABORATION ISSUES

In addition to technical and organizational issues, several collaboration barriers must be broken down.

Failure to see patients as collaborators

Many healthcare institutions lack a culture of working with citizen scientists and may require deconstruction of a top-down culture that locates authority in medical professionals. A foundation for culture change arises through recognition of the value of patient-clinician partnerships;[67] healthcare organizations must consciously work toward this goal. The historical failure to recognize citizen scientists as qualified interpreters of human genomes and related material must be addressed going forward.[68]

Targeted approaches for bringing patients into research efforts

Because patients may have little background in science, they may need training in research methodology, ethics, and regulation. Training has already been proven feasible and productive.[69,70] When participants can contribute and prioritize research questions, and then see the progression from idea to research study to results, their interest and participation are reinforced.[71] Planning research efforts of limited duration may facilitate recruitment of patient-researchers in that minimally ambitious efforts require less time of patients who may already be juggling health needs, job and family responsibilities, and other commitments.[72] Similarly, to ensure a truly reciprocal effort, researchers and clinicians should undertake training to develop skills in engaging and collaborating with patients. Movement toward an effective model of citizen science will require adopting principles of mutual respect and learning, in which both patients and researchers are trained in ways to engage constructively with one another. In addition to efforts initiated by researchers to engage citizen scientists, it will be essential to create mechanisms that facilitate citizen scientist's ability to find and reach out to research partners.

Improved ability to find and include patient partners

Even when researchers wish to co-manage citizen science projects, they may experience difficulty finding individuals with the necessary background, interest, and time. Employing a participatory design process led by a citizen governance council and the research team has proven successful for generating participation and engagement guidelines and for ways to encourage participation throughout the entire research lifecycle in a patient-powered research network.[69] For example, Citizen Endo project participants self-track endometriosis symptoms, an activity that researchers are studying as a way to phenotype the condition,[73,74] and the "Make the Breast Pump Not Suck" project recruited nursing mothers to help redesign breast pumps.[75,76] Other approaches that operate outside traditional foundation and academic structures also are needed, in particular because although citizen scientists may actively seek clinical partners, they typically experience difficulty finding them.

Openness to meeting citizen scientists at varying skill levels

Not all participants come to citizen science with the same set of skills or background. Each situation presents a unique set of challenges that motivate individuals to explore new solutions. Academics learn their trades through a prescribed curriculum, but citizen scientists in healthcare learn out of the need to survive or improve quality of life, sheer curiosity, or a combination of the two. Healthcare organizations and researchers need to build capacity for engaging citizen scientists with variable skill sets and to help them to grow into increasing responsibility within teams as the partnership matures. Large-scale efforts that engage citizen scientists with minimal formal training, such as the American Gut Project, in which self-selected citizen scientists mailed samples through the mail at room temperature, have proven feasible and efficacious.[77,78]

Trust-building as an essential target and skillset

Although citizen scientists in health are keen to contribute meaningfully to research, they often have had negative and/or unhelpful experiences in healthcare and research environments, which may be particularly acute among marginalized populations.[79–87] These experiences may have left them mistrustful of providers, researchers, and others working within health systems and academia. Citizen science will be advanced more quickly and effectively when those in healthcare focus on gauging readiness to participate at various points of the research pipeline and establishing trust with and among patients doing citizen science.[88,89] Progress will advance more quickly when researchers use tools and strategies designed to build trust, such as more comprehensive approaches to informed consent that both inform and engage citizen scientists.[35,90]

CONCLUSION

Collaboration of citizen scientists and professional scientists supports the goals of knowledge generation and support for action. Citizens not only assist scientists, but also work across the spectrum

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of informatics: data (fact/observation collection), information (data analysis), knowledge (information refinement), and wisdom (knowledge generation for the greater good). Such collaboration in precision medicine is necessary to fully capture the meaningful differences that indicate which intervention to use, for whom, and in what context. Healthcare organizations can, and should, integrate citizen scientists into infrastructures that support evidence generation both for and with citizens. Citizen science has extraordinary potential to extend and enhance the practice of precision medicine if certain technical, organizational, and citizen engagement issues are addressed appropriately.

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AUTHOR CONTRIBUTIONS

CP, RA, UB, HC, AEC, EBH, P-YSH, KKK, AP, LS, AS, and RSV developed the ideas in this manuscript, wrote and edited the text, and revised the manuscript.

ETHICS STATEMENT

No humans or human materials were used in the production of this work, and no Institutional Review Board approvals were required.

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CONFLICT OF INTEREST

The authors have no competing interests.

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