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Authors

Valdez, Rupa S
Detmer, Don E
Bourne, Philip
et al.

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Perspective

Informatics-enabled citizen science to advance health equity

Rupa S. Valdez,^{1,2,3} Don E. Detmer,¹ Philip Bourne,⁴ Katherine K. Kim ,⁵ Robin Austin,⁶ Anna McCollister,⁷ Courtney C. Rogers,² and Karen C. Waters-Wicks^{3,8,9}

¹Department of Public Health Sciences, University of Virginia, Charlottesville, Virginia, USA, ²Department of Engineering Systems and Environment, University of Virginia, Charlottesville, Virginia, USA, ³Advisory Board, Residents for Respectful Research, Public Housing Association of Residents, Charlottesville, Virginia, USA, ⁴School of Data Science and Department of Biomedical Engineering, University of Virginia, Charlottesville, Virginia, USA, ⁵Betty Irene Moore School of Nursing, University of California-Davis, Sacramento, California, USA, ⁶School of Nursing, University of Minnesota, Minneapolis, Minnesota, USA, ⁷Four Lights Consulting LLC, Washington, District of Columbia, USA, ⁸Department of Community Engagement, Albemarle County Public Schools, Charlottesville, Virginia, USA and ⁹Department of Humanities, Piedmont Virginia Community College, Charlottesville, Virginia, USA

Corresponding Author: Rupa S. Valdez, PhD, Department of Public Health Sciences, University of Virginia, P.O. Box 800717, Charlottesville, VA 22908, USA (rsv9d@virginia.edu)

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ABSTRACT

The COVID-19 pandemic has once again highlighted the ubiquity and persistence of health inequities along with our inability to respond to them in a timely and effective manner. There is an opportunity to address the limitations of our current approaches through new models of informatics-enabled research and clinical practice that shift the norm from small- to large-scale patient engagement. We propose augmenting our approach to address health inequities through informatics-enabled citizen science, challenging the types of questions being asked, prioritized, and acted upon. We envision this democratization of informatics that builds upon the inclusive tradition of community-based participatory research (CBPR) as a logical and transformative step toward improving individual, community, and population health in a way that deeply reflects the needs of historically marginalized populations.

Key words: health equity, citizen science, health informatics, precision health, patient engagement

INTRODUCTION

The COVID-19 pandemic has emphasized the ubiquity and persistence of health inequities¹ and our inability to account for the health needs of disparate populations in times of crisis. Many reasons have been given for this poor response, including social determinants of health, mistrust of the health system, and entrenched structural 'isms' (eg, racism, ableism, sexism, sexualism, and classism, among others). Our inability to address these inequities, therefore, stems from the fact that while the preponderance of causes exists at the community and population level, the majority of our efforts focus

on the needs of individuals. A focus on the latter likely stems from medicine's longstanding emphasis on diagnosing and treating the individual.² Even precision medicine, an initiative that seeks to account for contextual realities, attempts to do so primarily in the context of an individual patient.³ We need to continue moving beyond questions that are patient-specific (eg, how does reliance on public transportation impact a treatment decision?) to ones that are community- or population-specific (eg, how can public transportation be designed for adequate access to all treatment options?). As such, addressing inequities will require that we expand the paradigm

of precision medicine⁴ to fully include one of precision health in which the concept of personalization moves beyond the person to also focus on these larger units of analysis. Committing to a paradigm of precision health will therefore not only require treating the individual in ways that account for broader social and structural realities, but also focusing on them as subjects of intervention. While essential to advancing health equity, this broader view of personalization necessitates new models of research and clinical practice.

EXISTING AND EMERGING MODELS OF PATIENT ENGAGEMENT

Community-Based Participatory Research

These new models require moving from small-scale to large-scale patient engagement efforts. Most researcher- and clinician-led initiatives to engage patients occur at smaller levels of scale (eg, advisory boards and engagement studios⁵). At a higher scale, community-based participatory research⁶ (CBPR) is considered the best practice for addressing health inequities in ways that are appropriate for and responsive to communities' needs. Community-based Research Review Boards similarly empower marginalized and previously exploited communities to influence research questions, access data, and build trust allowing for greater democratization of research across underrepresented populations.⁷ The implementation and governance of the National Patient-Centered Clinical Research Network (PCORnet) represents another evolution of deep and broad patient engagement spanning patient and community levels. PCORnet creates a community of multiple stakeholders including clinicians, patients, caregivers, payors, researchers, and health system leaders by building a network of networks with the ultimate goal of advancing patient-centered research.^{8,9} Such a model leverages patient-generated data to meet multiple objectives spanning the development and testing of new tools, support of individual behavior change, and articulation of a shared vision of future research.¹⁰ At different orders of magnitude, these paradigms allow researchers to begin explicitly addressing the impacts of larger social and structural realities at levels beyond the individual by challenging the types of questions we ask, types and amount of data we collect, and how we create, implement, and analyze interventions. The pandemic has demonstrated the need for patient engagement at an even broader scale to facilitate a rapid, coordinated, and community-driven response to emerging health equity crises. Such an inclusive model of patient engagement must expand representation and facilitate learning across stakeholders and settings¹¹ as well as catalyze the speed of transformation.

Citizen Science

Citizen science represents this next leap in patient engagement and consequently has the potential to not only further a vision of precision medicine¹² but also one of precision health. Citizen science has been defined as voluntary public participation in "the scientific process, addressing real-world problems in ways that may include formulating research questions, conducting scientific experiments, collecting and analyzing data, interpreting results, making new discoveries, developing technologies and applications, and solving complex problems."¹³ In this article, we use this term to refer to individual community members and organizations that primarily reflect community members' interests rather than corporate interests. Over the last decade, citizen science has experienced exponential growth, improving research capacity, quality of knowledge, and

public understanding of science in fields such as biology, environmental science, agriculture, and computing. Many motivations are cited for individual engagement in citizen science across these fields, such as a desire to share information, build connections with like-minded individuals, impact a real-world problem and, more broadly, contribute to scientific knowledge.¹⁴⁻¹⁶ As demonstrated by the history of CBPR, Community-based Research Review Boards, and PCORnet, such motivations are also likely to apply to participation in citizen science as oriented toward health and well-being. With the exception of environmental health, however, only recently has citizen science been actively pursued within this domain (eg,¹⁷). The pandemic showed how those without scientific or medical training could use citizen science to connect, share stories, record and pool data, making their COVID-related experiences and concerns known to the broader scientific and medical communities.¹⁸ Such an open and inclusive model of science must be further harnessed toward improving health equity by engaging thousands if not millions of people to shift the types of questions being asked, prioritized, and acted upon. Citizen science, therefore, may be seen as the next logical step in the effort to improve individual-, community-, and population-level health.

A VISION OF INFORMATICS-ENABLED CITIZEN SCIENCE TO ADVANCE HEALTH EQUITY

Informatics

Informatics should play a key role in supporting health equity across population health, clinical medicine, and consumer health.¹⁹ At present, the power of informatics is mitigated by its confinement to a small cadre of professionals and a reliance on health systems and governmental agencies to collect, share, and analyze patient data. Fragmented interoperability,²⁰ limited time with each patient,²¹ and limited domain knowledge related to broader social, behavioral, and environmental realities shaping patient experiences^{22,23} are ongoing challenges. Informatics, democratized to a broader citizenry, could overcome these challenges by creating synergies between the power of citizen science and the power of informatics to obtain and translate relevant and timely data into action deemed meaningful, not only to health professionals and researchers, but also to communities and populations that have been historically marginalized. Moreover, citizen science builds naturally upon existing trends within informatics to improve patient engagement through the collection and application of patient-generated data. Thus, there is an opportunity to harness the latent potential of patients' individual experiences, including those often invisible to researchers and clinicians,^{24,25} empower them to transform these experiences into information, and work with them to translate such information into policy guidance at the institutional, local, state, and federal levels. Initial efforts^{26,27} show feasibility and potential of leveraging the synergy between informatics and citizen science for health equity efforts. For example, Kim et al,²⁶ conducted a community health and food security study in which Karuk Tribe youth developed leadership and research skills and used a mobile app for data collection. The authors found that the youth-led findings resulted in permanent changes in local school lunch, educational curricula, community gardens, and tribal services.

Vision

Achieving health equity through informatics-enabled citizen science requires a broader vision of patient engagement at all stages of research and treatment processes. Patients currently participate mini-

mally in informatics-enabled efforts. This role is often confined to providing prespecified data elements and reviewing the outcomes of predetermined analyses. The remainder—which includes everything from determining ethical standards (eg, considerations related to privacy, ownership, and access including data collected by the private sector) and selecting which data elements should be collected to how such data should be analyzed, presented, and translated into action—remain largely off limits to patients. This likely contributes to mistrust, as well as reinforcement of the notion that science does not reflect the priorities of marginalized populations. The informatics community must facilitate the creation of tools that are widely usable, accessible, and promote community building. The educational material and technological tools must be freely available and modular in nature, allowing anyone to be certified as a citizen informatician with support for varying levels of education, health and technological literacy, as well as cultural practices, among other factors. A burgeoning partnership between the University of Virginia's IRB and the Public Housing Association of Residents/Residents for Respectful Research in Charlottesville Virginia is indicative of this approach.²⁸ A coalition of residents, students, researchers, and community members is working to create a culturally competent resident-friendly companion guide to aid in achieving CITI certification, which will enable low-wealth residents to qualify to review research as members of the IRB, in addition to creating a venue for community access to data and expanded influence on areas of inquiry. To be broadly relevant and appropriate, an initiative to catalyze informatics-enabled citizen science must, therefore, be created in partnership with multiple health-disparity populations, including racial and ethnic minorities, gender minorities, people with low wealth, people with disabilities, and people living in underresourced geographic areas. As the number of citizen-informaticians increases, the power embedded in paradigms such as CBPR and Community-Based Research Review Boards will grow by enabling members of these communities to connect with one another outside a confined geographic region, to pool their collective data, and to drive the types of questions asked and interventions implemented. In doing so, it will enable the research and clinical communities to more fully engage with patients as equal partners in both the research and treatment processes.

Health equity that is synergistic with precision health and informatics-enabled citizen science is one component of achieving this vision. Essential first steps include creating a more comprehensive model of patient engagement, relevant and robust informatics training, and an open network of citizen scientists, researchers, health professionals, and policy makers. This vision of informatics-enabled citizen science will honor and scale the equity-oriented traditions of patient engagement and CBPR, accelerating our ability to respond both to existing inequities as well as those that are newly emergent.

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AUTHOR CONTRIBUTIONS

All authors substantially contributed to the conceptualization of this article. RSV drafted the manuscript, and all other authors revised it critically for important intellectual content and approved the final version for publication.

DATA AVAILABILITY

No new data were generated or analyzed in support of this research.

CONFLICT OF INTEREST STATEMENT

None declared.

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