

## **Maximizing the Promise of Citizen Science to Advance Health and Prevent Disease**

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“Citizen science”—a field with an increasingly broad collection of definitions, terms, and standards worldwide (Eitzel et al., 2017; European Citizen Science Association, 2015; Standards Development Partnership, 2018; Woolley et al., 2016)—can be described generally as laypersons participating in the research process for purposes of scientific advancement (Kelty and Panofsky, 2014). The field has gained increasing interest in medical and broader health fields both in the U.S. and internationally (Den Broeder et al., 2016; Eitzel et al., 2017; Standards Development Partnership, 2018). In the current climate of confusion and mistrust of scientific inquiry among some, efforts to engage community members in the scientific process can demystify science and make it more accessible and inclusive (Kelty and Panofsky, 2014). At the same time, citizen science can aid in advancing biomedical and other health-related discoveries and impacts (Jasanoff, 2006; Kelty and Panofsky, 2014; Nowotny, 2014). As important, in light of the aging U.S. population, escalating health costs, and widespread health disparities, leveraging the power of the public as change agents in promoting health-enhancing conditions can complement the work of health professionals. This can potentially produce additional benefits for population health. However, maximizing the advantages that citizen science offers the health sciences requires expansion of thought and action beyond the more limited definitions currently being emphasized in the U.S. health arena (Rowbotham et al., 2017; Woolley et al., 2016).

### **Citizen Science “For the People”**

To date, a major focus of federal citizen science health initiatives (e.g., NIH’s Citizen Science Common Fund Initiative; the U.S. government’s Precision Medicine Initiative) is what can be termed citizen science “for the people” (King et al., 2016) (see **Table 1**). Sharing similarities with

“contributory” citizen science approaches described by other researchers (Rowbotham et al., 2017), this type of citizen science includes donation of biological samples and other person-level health information gathered from individuals, where research planning and data collection, analysis, interpretation, and use are generally driven by scientists. In this approach, participant involvement typically ends at the clinic or laboratory door. Another example of “for the people” citizen science involves utilizing available online social media and other “big” data for free-living, population-level surveillance of health behaviors or disease outcomes (Unger et al., 2018; Young et al., 2014). While the promise of medical breakthroughs through these activities has been well described (Kelty and Panofsky, 2014), translation of such scientific discoveries to tangible public health benefits can take years (Balas and Boren, 2000; Mold and Peterson, 2005). In addition, such “for the people” initiatives arguably tap only a small portion of the vast potential offered by citizen science in advancing scientific knowledge along with individual and population health (Woolley et al., 2016). This is particularly the case in relation to applications in the preventive medicine and population health fields, where thoughtfully conceptualized and planned citizen science initiatives can potentially create a number of useful benefits, including improved public awareness of population health, increased trust in the scientific methods and approaches used in the field, and new insights and perspectives that can accelerate population health advances (Rowbotham et al., 2017).

### **Citizen Science “With the People”**

A second form of citizen science, characterized as citizen science “with the people,” involves residents as active data collectors in the advancement of science (King et al., 2016) (**Table 1**). Sharing some similarities with “collaborative” citizen science approaches described

previously (Rowbotham et al., 2017), this citizen science type has been popular in ecology (e.g., annual bird counts) and meteorology (e.g., weather observation), where changes in patterns of observed phenomena can be revealed over time. Of particular relevance to biomedicine, wearable devices and sensors have ushered in a new era of citizen science opportunities to collect continuous individual behavioral and physiological data at both unprecedented scales (e.g., millions of people) and time-frames (e.g., minute-by-minute data capture across years) (Althoff et al., 2017). While some characteristics of mobile device data collection align with “for the people” citizen science (e.g., passive collection of smartphone accelerometry data that are automatically “pushed” to researchers (McConnell et al., 2017) or the general use of social media surveillance data (Unger et al., 2018) that are currently available), others involve users as active collectors of behavioral, social, and/or physiological data relevant to health that can be shared with scientists and practitioners (e.g., Patients Like Me) (Kelty and Panofsky, 2014). Another increasingly popular “with the people” activity is crowdsourcing of information to benefit science and/or the larger community. Examples include biomedical crowd-sourcing activities, such as the online games offered by Eterna where “players” can engage in online puzzle-solving related to folding of RNA molecules, and online citizen reporting of local conditions that can negatively impact health (e.g., hazardous intersections). While citizen science “with the people” opens up unique opportunities to unlock new ideas from the public, the scientific community typically retains control over research planning, question development, types of data collected, and uses of group-level data (Kelty and Panofsky, 2014).

### **Citizen Science “By the People”: An Additional Tool for Advancing Preventive Medicine and Population Health**

A third type of citizen science has the potential for contributing to national and international health through actively involving residents to catalyze changes in local environmental and social drivers of health that account for a significant proportion of disease (National Academies of Sciences et al., 2017). Characterized as citizen science “by the people,” this perspective blends the active resident engagement of community-based participatory research with the standardized resident-based data collection methods that are a hallmark of citizen science (King et al., 2016) (**Table 1**). Rowbotham and colleagues (Rowbotham et al., 2017) refer to this as “co-creation” of new knowledge that enhances its immediate relevance locally and, at the same time, can be scaled up beyond a particular locale or issue. As in “with the people” citizen science, mobile health tools can provide a starting point for engaging community members more fully in the scientific process. Here, however, citizen scientists also are invited to engage in question identification and project planning in ways that help to ensure the relevance of the scientific endeavor to the health of their communities. They then learn how to collect, analyze, and interpret data pertaining to those questions, and actively participate with local stakeholders in developing realistic, community-relevant solutions (Woolley et al., 2016). An example of this approach is the *Our Voice* Citizen Science Research Initiative, which includes U.S. and international research partners and civic organizations that are members of an 18-country, and growing, global network (Hinckson et al., 2017; King et al., 2016). The fundamental aim of *Our Voice* is to unleash the latent power of residents, irrespective of age, education, language spoken, or economic or social circumstances, as catalyzers of health-enhancing changes in their local communities. Armed with a simple mobile app—called the Discovery Tool (Buman et al., 2013)—residents from ages 9 to 90 have learned

how to quickly capture and catalogue those aspects of their neighborhoods that help or hinder healthy living (e.g., access to healthy foods or safe places to walk). In as few as two facilitated community meetings, participants learn how to make sense of their own data, build consensus around high-priority issues, and then positively engage local decision makers in developing and enacting realistic solutions. In this way, citizen science projects can function as a regular conduit for connecting residents to decision makers with the power to enact change (Rowbotham et al., 2017). Local facilitators can be remotely trained to assist with the citizen science process. Such facilitators may come from any sector, including local public health departments, health care organizations, non-governmental organizations (e.g., The Food Trust) (Chrisinger et al., 2018), research teams, philanthropic or grassroots organizations (e.g., GirlTrek), or residents themselves (King et al., 2016). Additionally, through this type of community-engaged process, the local facilitators themselves may become increasingly receptive to alternative perspectives and ideas (King et al., 2016). Among the local environmental and policy solutions that have been enacted across diverse under-resourced communities are safer citywide walking environments resulting from documentation of inadequate streetscapes and sidewalks that needed repair (Winter et al., 2014); development of strategies to contain roaming dogs to promote neighborhood safety and walkability (Rosas et al., 2016); a new senior community garden to increase healthy food access (Winter et al., 2014); and resident contributions to transportation solutions for healthier local food environments (Sheats et al., 2017).

Empowering residents as data gatherers, interpreters, and activators of healthful changes in their communities also has led to positive “ripple effects,” as some residents have continued to employ their newfound civic engagement skills in addressing other local problems impacting

their health (Sheats et al., 2017). Fostering citizen science at a young age also can promote civic literacy and agency in future generations. For example, *Our Voice* projects are occurring where youth are tackling local problems such as promoting safer walking and biking routes to school; making college campuses safer and more health-promoting; broadening public transit options and opportunities; and ensuring tobacco-free affordable housing.

Emerging “by the people” citizen science research methods include systems for tracking individual, community, and built and policy environment changes over time, and the use of mobile sensors to enhance the types of information that can inform local decision making around health. Examples include air quality and noise sensors as well as real-time stress monitors to capture resident experiences moving through different neighborhood and social environments (Chrisinger and King, 2018; Wong et al., 2018).

Another example of this type of community-engaged citizen science is the Community Health Improvement and Research Partnerships (CHIRPS) program that has been developed to activate rural and underserved communities around community-identified health issues (Davis et al., 2014). Through such partnerships, increased understanding, solution-building, and monitoring of how solutions are implemented around the typically complex health problems facing populations may be more fully addressed (Rowbotham et al., 2017).

As a nation we face daunting challenges in promoting individual and population health while addressing health inequities. Such challenges demand a broader cadre of “scientists” to more fully document the factors impacting health and help build pragmatic solutions. Activating all three types of citizen science through productive community member-scientist partnerships

can create pathways to more comprehensively address all of the personal and community drivers of individual and population health.

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**Table 1.** Examples of Types of Health-related Citizen Science

Citizen Science Type	Planning	Data Collection	Data Analysis, Interpretation, and Use	Primary Applications/ Uses	Primary level at which scientific inquiry is aimed	Examples
For the People	Scientists	Scientists		By scientists	<ul style="list-style-type: none"> <li>• Person-level drivers of health</li> </ul>	<ul style="list-style-type: none"> <li>• Donation of biological specimens</li> <li>• Passive data collection via mobile devices or sensors</li> </ul>
With the People	Primarily scientists	Community members	Scientists	By scientists, with some sharing occurring at times with community members	<ul style="list-style-type: none"> <li>• Person-level drivers of health</li> </ul>	<ul style="list-style-type: none"> <li>• Active data collection of physical, behavioral, other data</li> <li>• Online crowdsourced ideas related to molecular structures</li> </ul>
By the People	Typically, a group of scientists, community members, and practitioners/ community organizations	Community members, in partnership with scientists and/or practitioners		Community members in partnership with practitioners/ community organizations, scientists	<ul style="list-style-type: none"> <li>• Social- and environment-level drivers of health</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Our Voice</i> community-engaged citizen science approach (King et al., 2016)</li> <li>• Community Health Improvement &amp; Research Partnerships (Davis et al., 2014)</li> </ul>