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Core values of genomic citizen science: results from a qualitative interview study

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Abstract

Genomic citizen science initiatives that promote public involvement in the study or manipulation of genetic information are flourishing. These initiatives are diverse and range from data donation studies, to biological experimentation conducted in home and community laboratories, to self-experimentation. Understanding the values that citizen scientists associate with their activities and communities can be useful to policy development for citizen science. Here, we report values-relevant data from qualitative interviews with 38 stakeholders in genomic citizen science. Applying a theoretical framework that describes values as transcendent beliefs about desirable end states or behaviors that can be categorized according to the motivational goals that they express and the interests they serve, we identified nine core values of genomic citizen science: altruism, autonomy, fun, inclusivity, openness, reciprocity, respect, safety, and solidarity.

Keywords

citizen science; community science; biohacking; ELSI; genetic privacy

1.0 Background

Citizen science initiatives that promote public involvement in research are on the rise (Hecker et al., 2018). There is no universally agreed upon definition of citizen science (Ceccaroni et al., 2017; Eitzel et al., 2017; Kullenberg and Kasperowski, 2016), but a common formulation describes citizen science as an approach to scientific inquiry in which members of the public make meaningful contributions to the research process. Such contributions can include identifying research questions, shaping study design, collecting and analyzing data, and reporting results (Shirk et al., 2012).

Historically, ecology, environmental science studies, and astronomy have dominated the citizen science landscape (Bonetta, 2009; Wiggins and Wilbanks, 2019). Over the years,

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however, citizen science has spread to other disciplines, including the biomedical sciences (Bonetta, 2009). Biomedical citizen science projects involving genetic information in particular are flourishing in part as a result of easier access to personal genetic data from direct-to-consumer (DTC) genetic testing services and clinical testing laboratories and an expanding landscape of online tools and platforms that help individuals interpret and share those data for research purposes (Guerrini et al., 2020; Nelson and Fullerton, 2018; Thorogood et al., 2018). Decreasing costs and other barriers associated with obtaining scientific equipment and information (Meyer, 2013; Guerrini et al., 2019b), as well as the accelerating speed at which biotechnologies are transitioning from being accessible to only well-resourced specialists to individuals with relatively low levels of technical skill (Jackson et al., 2019), have also promoted genomic citizen science efforts.

These efforts take many different forms, involve varying degrees of engagement, and have diverse objectives (Aungst et al., 2017). A common flavor of genomic citizen science is described as *data donation* initiatives that solicit the public to provide access to their genetic information and other health-related information (Bietz et al., 2019). Examples of data donation initiatives include research conducted with information donated by individuals to professional scientists, such as studies associated with the National Genographic Project (NGP, no date), or to public databases, such as openSNP, for investigation by professional and citizen scientists. *Co-research* initiatives are collaborations between professional and citizen scientists in scientific studies. For example, at the Genetics of Taste Lab at the Denver Museum of Nature and Science, citizen scientists are trained to collect and analyze biospecimens in experiments designed to identify genetic bases for taste preferences and sensitivities (Garneau et al., 2014). There are also many examples of co-research involving institution-based researchers and patient advocacy groups as these groups become increasingly engaged in (and assert control over) identification of research questions, development of research infrastructures, and collection and maintenance of data (Aungst et al., 2017).

On the far end of this continuum of engagement are *self-experimentation* activities designed and executed exclusively by citizen scientists, sometimes in collaboration with one another. In one such study, a group of citizen scientists tested the effect of different vitamin regimens on their homocysteine levels according to a research protocol designed and executed entirely by themselves (Swan et al., 2010). Finally, genomic citizen science encompasses investigation of and experimentation with bacteria, plants, and animals in *home and community laboratories*. For example, in the Cuttlefish Project at BioCurious, a California community laboratory, citizen scientists are working to sequence the genome of the Dwarf Cuttlefish and create the first immortal cell line for a mollusc species (TCP, no date). Although terminology in biomedical citizen science is contested and evolving (Guerrini et al., 2019c), some of these activities have been described as ‘biohacking.’

U.S. policymakers have demonstrated a strong commitment to citizen science approaches to research. The federal government has launched a website that publishes citizen science resources (CitizenScience.gov, no date), and a ‘community of practice’ of over 350 federal employees who implement or fund these projects has organized to share lessons learned and develop best practices (Gustetic, 2018). Specific to the biomedical sciences, the National

Institutes of Health (NIH) has formed a Citizen Science Working Group consisting of NIH program officers, scientific review officers, and other employees interested in investigating the utility of incorporating citizen science methodologies into biomedical studies (NIH CSWG, 2016).

While largely supportive of biomedical citizen science, policymakers are also aware of the ethical challenges posed by some of these projects—and perhaps especially genomic citizen science projects. Initiatives that are not federally funded or affiliated with universities and do not constitute regulated clinical trials are outside the scope of protections that apply to traditional studies involving human subjects (CFR 2019) and most also are not governed by federal privacy regulations that apply to health care providers and their business associates (HIPAA, 1996). Safety, privacy, and other concerns about independent genomic and other biomedical citizen science projects are at the center of an expanding literature (Bietz et al., 2019; Fiske et al., 2019; Guerrini et al., 2018; Resnik, 2019; Rothstein et al., 2015; Vayena and Tasioulas, 2013; Wiggins and Wilbanks, 2019), and in the past few years, national workshops have been held for the purpose of elucidating and prioritizing them (Kuiken et al., 2018; NHGRI, 2015). Meanwhile, policymakers have begun responding to these challenges. For example, focusing on safety concerns, in December 2017, the U.S. Food and Drug Administration issued a public warning that the sale of gene therapy kits for self-administration is illegal (FDA, 2017).

Elsewhere, some of us have urged regulators to engage with genomic and other biomedical citizen science communities to ensure that any policies that are adopted to minimize the risks of their activities are based on an accurate understanding of those activities, rather than hype or conjecture (Guerrini et al., 2019b; Zettler et al., 2019). To help ensure that such policies are appropriately tailored, we also recommend that those proposing them work to understand the values of the regulated communities. Here, we adopt Schwartz and Bilsky's definition of a value as a belief about a desirable end state or behavior that transcends specific situations and guides selection or evaluation of behavior and events (Schwartz and Bilsky, 1987). Values can be categorized by motivational domain, meaning the motivational goals that they express, and whether they serve individual, collective, or mixed (both individual and collective) interests (Schwartz and Bilsky, 1987).

Understanding the values of communities can help predict their attitudes and behaviors (Schwartz and Bilsky, 1987), which can be useful in conducting risk assessments that might help inform policy development. For example, if values relevant to autonomy are important to genomic citizen scientists, the adoption of overbroad policies that significantly limit the ability to 'do science' outside of traditional scientific institutions could prompt some to move their activities into the shadows where it is harder for society to address potential harms (Kellogg, 2012). Understanding community values can also provide insight into the potential social benefits of regulated activities. For example, if values relevant to curiosity and creativity are important in genomic citizen science, policies that stifle investigation of questions that professional scientists tend to neglect or overlook might hinder valuable innovation.

Other scholars have identified virtues and philosophical foundations of citizen science (Elliott and Rosenberg, 2019; Kimura and Kinchy, 2016) and reported data from survey, interview, and ethnographic studies involving citizen scientists regarding their motivations, goals, identities, practices, and experiences (Davies, 2018; Eveleigh et al., 2014; Frensley et al., 2017; Raddick et al., 2010; Rotman et al., 2012; Toombs et al., 2014; Tyson, 2019). Many of these studies focus on the experiences of citizen scientists in ecology, environmental, weather, or space science projects or as members of maker spaces. Relatively few have involved biomedical citizen scientists, and of those, we are aware of only two that report data relevant to the values they associated with their activities or communities. In the first study, 18 key informants from 12 organizations associated with participant-driven genomic research (PDGR) were asked to identify the goals, values, and research priorities of the PDGR organizations they represented (McGowan et al., 2017). Results are presented as five goals or commitments of these organizations, and although it is clear that trans-situational values underlie these goals, they are not the focus of analysis. In another study, three values of biohacking were identified from interviews with seven biohackers and various media reports of biohacking (Sanchez Barba, 2014). However, none of the interviewees were located in the United States.

We aim to fill gaps in the citizen science literature specific to values associated with biomedical citizen science activities and communities by reporting the results of an interview study. This study involved the systematic collection and analysis of values-relevant qualitative data from a primarily U.S.-based population of 38 individuals whose biomedical citizen science interests encompassed genomic citizen science activities. As explained in a companion landscape study (Guerrini et al., 2019a), these interviews were conducted as part of a broader effort to identify gaps in practices, principles, preferences, and policies relevant to ownership interests in genomic citizen science. Here, we present nine values that interviewees identified with their citizen science activities and communities, which we have organized according to a theoretical framework of universal human values.

2.0 Methods

2.1 Interviews

From August to December 2018, we conducted qualitative interviews with individuals who led, facilitated, participated in, or studied genomic citizen science initiatives. Each interviewee was asked to identify the values they associated with their citizen science activities or communities and ownership of citizen science research outputs. Qualitative methods were used to collect these data because such methods are well suited to exploring the meaning of things and obtaining ‘insider’ perspectives on shared phenomena with attention to context (Patton, 2015).

A purposive sample of interview candidates was developed in connection with the companion landscape analysis (Guerrini et al., 2019a) and related research activities. To be considered for inclusion in the study, each candidate was required to be at least 18 years old; speak fluent English; and have led, facilitated, participated in, or studied genomic citizen science initiatives, as evidenced by publications, presentations, news reports, or websites describing the candidate’s relevant activities. Candidates were preference-ranked based on their activities and demographic considerations intended to enhance the diversity of opinions and were then contacted in order of preference. Additional candidates were identified through snowball sampling until saturation was reached and additional interviews did not generate data that yielded new insights.

Each candidate was contacted via email with an invitation to participate that described the purpose of the study. If the candidate did not respond to the initial invitation within two weeks, a follow-up email was sent. If the candidate did not reply to the first follow-up email, a second follow-up email was sent. No additional emails were sent after the second follow-up email.

Interviews were conducted by two authors (CG, MT) using a semi-structured interview guide. Interviews were conducted in-person or by telephone, audio recorded with permission, and professionally transcribed. Each interviewee provided verbal consent to participate and was offered $75 compensation at the conclusion of the interview. The mean interview length was 49 minutes.

This study was designed, analyzed, and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007). The study protocol was reviewed and approved by the Institutional Review Board of Baylor College of Medicine (H-40925).

2.2 Coding

Two authors (CG, MT) reviewed all transcripts for fidelity to the audio recordings. Transcripts were then entered into NVivo 12 (Melbourne, Australia: QSR International) for storage and management. Data were analyzed according to thematic analysis as described by Braun and Clarke (2006). Two authors (CG, MT) developed a preliminary codebook on the basis of their review of three transcripts. This preliminary codebook was then pilot tested with three other transcripts and subsequently refined, resulting in a final codebook. The final codebook consisted of ten nodes directed to values.

Each transcript, including those used in the development of the codebook, was independently coded according to the final codebook by two of three authors (CG, MT, IC). Any disagreements were resolved by consensus of the two coders, and if no consensus could be reached, the third coder was included to facilitate resolution. Three authors (CG, MT, IC) reviewed the coded transcripts to identify salient themes and organize the data.

3.0 Results

Results are presented as interviewee characteristics and values that interviewees associated with their citizen science activities and communities. Although some interviewees participated on a non-confidential basis, for consistency and to avoid introducing bias in readers' perceptions of reported data, all quoted information is attributed to interviewees using their assigned interview numbers.

All interviewees were interviewed as individuals. None purported to speak on behalf of their employers, affiliated institutions, or colleagues.

3.1 Interviewee Characteristics

3.1.1 Demographics—

Sixty-four individuals were invited to participate in an interview. A total of 38 individuals completed an interview, for an overall response rate of 59%. Of the 26 individuals who did not participate in an interview, half did not respond to any of the invitations sent to them; the other half expressly declined to schedule an interview.

To understand the breadth of interviewees' experiences, each interviewee was categorized according to their genomic citizen science activities as a scholar, biohacker, project organizer, community builder, or entrepreneur (Table 1). We further subcategorized biohackers as data, laboratory, or self-experimentation biohackers, which loosely maps onto, respectively, data donation, home and community laboratory investigation, and self-experimentation activities described in the above typology of genomic citizen science. These categories (and, for biohackers, subcategories) were not mutually exclusive, and in fact, most interviewees (n=22, 58%) fell into multiple categories or biohacking subcategories.

Nineteen interviewees (50%) met the definition of community builder, while eighteen (47%) met the definition of biohacker. The largest percentage of biohackers (n=9, 24%) were subcategorized as laboratory biohackers who study or manipulate genetic information in non-traditional laboratory settings.

Interviewees categorized specifically as biohackers, project organizers, and/or community builders described many kinds of genomic citizen science projects that they had led, facilitated, or participated in over time. Some projects involved citizen scientists acting alone to analyze their personal health data or conduct self-interventions. Others involved dozens, hundreds, or even thousands of citizen scientists participating in online or in-person projects, sometimes in collaboration with or at the direction of institution-based scientists.

The majority of interviewees (n=27, 71%) were male (Table 2). Interviewees ranged in age from 18–69 years old. Most interviewees (n=27, 71%) had been awarded at least one graduate degree, and almost half (n=17, 45%) had been awarded a PhD in particular. However, the highest level of education for four interviewees (11%), three of whom were over age 25, was a high school diploma or GED. Nine interviewees (24%) were employed by academic institutions.

Interviewees were clustered in three U.S. geographical regions (US Census Bureau, 2010). At the time of their interview, eighteen (47%) resided in the West, ten (26%) in the South, and seven (18%) in the Northeast (Table 2). Three interviewees (8%) resided outside the United States.

3.1.2 Experiences—

All interviewees were asked how they came to be involved in citizen science to understand experiences that might have informed the values they identified. While interviewees' experiences were highly individualized, several themes emerged. The first theme was substandard or unfulfilling science instruction in high school or college, which had the effect of encouraging some to seek out alternative educational opportunities. These interviewees described participation in science programs that were under-resourced or directed by overworked or disengaged instructors. For example, one interviewee, who described his high school as “grossly underfunded,” built a laboratory in his home in order to “answer questions that my teachers never really had the time to [answer]” (15). The interviewee elaborated:

> I was told so many times that, “I don’t have time for that. I don’t have the answer to it.” One of the hardest hits for me was [when] I was told by my academic advisor, “You’re not here to learn. You’re here to get your degree.” That killed me (15).

Another interviewee described a disillusionment with the scientific establishment that stemmed in part from the culture of her high school, where “it almost felt belittling if you didn’t have the right answer to something rather than really encouraging someone to be questioning or to be curious” (27).

For those who studied science in universities, another theme was a disappointing realization that they were unlikely to achieve long-term professional success in academia. One interviewee expressed cynicism stemming from the small percentage of individuals with PhDs who obtain tenure:

> [W]hen you look at those numbers, you start to realize that basically it’s a lot of manual labor for people that are in a position that you’re probably never going to have because they just don’t die fast enough to fill up more professorships. . . . So convincing people that that’s the way to go is kind of a con (4).

Others described a growing awareness that they would not be personally fulfilled working as scientists in traditional settings. Explained one interviewee who had worked at a scientific institution after obtaining a PhD: “I probably started moving away from traditional science when I realized it’s not what it pretends to be” (1). In particular, he explained, traditional science “pretends” to encourage exploration when in reality, scientists in traditional settings are often compelled “to focus very narrowly on things that nobody really cares about” (1).

Not all interviewees eschewed traditional scientific careers, however. Some were employed as scientists by traditional institutions and participated in citizen science activities in their personal capacities or incorporated citizen science approaches into their grant-funded research to, among other things, promote educational objectives or broaden access to or use of data. Others used citizen science approaches to support trainees. For example, one scientist who had been employed in academia and industry observed that graduate students —including herself some years ago—are often left to “wander around begging for a lab, internships” (17). By supporting a community laboratory, she saw an opportunity to help trainees and not just be “a brick in the wall” (17).

Finally, interviewees described a common experience with health problems that prompted some to pursue solutions outside of traditional medical and research settings. For example, one interviewee described becoming a citizen scientist through researching a health condition that afflicts her relatives. A second interviewee stepped into the role of citizen scientist in the process of developing new ways to manage his health condition. Some explained that these and other self-help activities can be an appropriate—and perhaps is becoming a common—response to failures of the medical system. For example, in the course of conducting independent research that helped correctly diagnose a relative who had been misdiagnosed by medical professionals, an interviewee learned that “there are all these amazing individuals that collectively are helping one another, that are conducting their own sorts of studies. . . . [a]nd this is going largely unnoticed but they [are] changing people’s lives” (27). As a result of this experience, the interviewee made “a silent commitment to help elevate” her fellow citizen scientists, who she called “heroes” (27).

3.2 Values Identified by Interviewees

Interviewees described nine values they associated with their citizen science activities or communities (Fig. 1). Consistent with the theoretical framework developed by Schwartz and Bilsky (Schwartz 1992, 1994; Schwartz and Bilsky 1987; 1990), we categorized each value according to seven motivational domains: (1) achievement, or personal success through the demonstration of competence; (2) benevolence, or concern for the welfare of those with whom one is in frequent contact; (3) conformity, or personal restraint from hurting the interests of others in everyday interactions; (4) hedonism, or personal pleasure or gratification; (5) security, or societal and individual stability; (6) self-direction, or reliance on and gratification from independent thoughts and actions; and (7) universalism, or concern for the welfare of all people. Also consistent with the theoretical framework, we then categorized each value based on the interests it serves: individual interests, collective interests, or mixed (both individual and collective) interests. The values are presented below alphabetically according to interests served.

Some values are so closely related to or aligned with one another that their boundaries blur in certain contexts. Nevertheless, the values are presented as distinct because none captures fully and precisely the meaning of any other. In addition, although some values were more salient with respect to specific activities and communities, most interviewees participated in multiple citizen activities and communities and tended to identify values through the lens of their overall experiences. However, we describe below the close alignment of conceptualizations with specific activities and communities when those relationships were observed.

3.2.1 Individual interests served

Autonomy.: Many interviewees—and especially those who were not affiliated with traditional scientific institutions—emphasized the value of autonomy, which was generally conceptualized as “liberty” (11), an “ethic of self-determination” (9), and an attitude of, “I’m empowered to do myself and you’re empowered to do yourself” (22). The freedom of citizen scientists to have “full control to decide what they would like to do and what they would like to study” (6) was sometimes described as an individual right, although not one without limits. As one interviewee explained, “at a basic level,” individuals have a “right . . . to be able to experiment,” but not to harm others in the process (12).

Some interviewees conceptualized autonomy more specifically as a freedom to conduct scientific investigations unencumbered by the expectations and concerns that dominate traditional research, such as publishing in peer-reviewed journals and securing grant funding. It was noted that being autonomous in this way not only promotes personal empowerment; it also supports innovation. As one interviewee explained, “the benefit of citizen science is that it's people who . . . have no obligations to a particular university necessarily. . . . In that regard it's tremendously powerful because it opens up areas of research" that might otherwise be ignored (26). Autonomy to conduct research in these overlooked areas can be especially important when they are relevant to the personal health of citizen scientists or their family members.

Some biohackers—and especially those who had engaged in self-experimentation—discussed autonomy specifically in terms of the freedom to do with their bodies as they wished. Described as "bodily autonomy" (1) and "morphological freedom" (5), this value has long been recognized as salient in communities of "grinders" who implant their bodies with magnets and RFID chips (Popper, 2012). But one biohacker explained that this value also extends to altering one's own genome: "[I]t seems to me as basic a right to control your genome and your gene expression as it is to control tattoos and piercings . . . . [I]n terms of things like 'I should be able to alter my genes,' nobody in the [biohacking] community argues against it" (5). This biohacker described any attempts by the government to limit self-modification at the molecular level as not justifiable—or "insane" (5).

Fun.: Almost every interviewee identified fun as an important value in their citizen science activities and communities. Also called a right to "tinker" (17, 28) and do "cool" things (1, 22, 26), fun was described as the experience of pleasure from the pursuit of knowledge or discovery. One interviewee summarized the point of citizen science as follows: "You just do it because it's something you love doing" (26).

Fun was also often associated specifically with exploration and curiosity, which according to some interviewees, can be discouraged or at least not prioritized in traditional scientific educational and research settings. For example, when asked about the values he associated with citizen science, one interviewee explained that "the first term that comes to mind for me is explore," or "[p]eople wanting to understand more about themselves or their world" (10). Another agreed: "I don't know if exploration is a value. But I think that's what's driving people. Curiosity is what's driving people here" (12).

Interviewees described many projects that they or others had pursued for fun and their communities' celebration of their "funny and interesting" projects (6). Some also noted that it was unlikely that such projects would be pursued by researchers in traditional scientific institutions because they were not the type that would attract grant funding or result in commercial products. Thus, the value of fun—like the value of autonomy—can result in innovation in areas that would otherwise be neglected. By supporting "really small, beautiful little projects that nobody would care about" in academia (5), citizen science can lead to new ideas and discoveries. However, interviewees emphasized that these projects are worthwhile regardless of whether they lead to scientific advances simply because they "tickle the brain" (27). Thus, for some genomic citizen scientists, the process of investigation is just as (and perhaps even more) important than the outcomes.

Respect.: Interviewees discussed the value of respect in several contexts. First, they described the "tremendous respect" for each other that characterized the citizen science communities in which they participated (22). Citizen scientists demonstrated respect by sharing resources to support each other's projects and providing encouragement. One interviewee explained that respect was especially salient in the Quantified Self communities in which he had participated: "Everyone got excited by the things that other people were doing. It was super positive. It was one of the most positive groups I've ever been in" (22).

Interviewees also discussed respect as approval of or admiration for the quality of research conducted by citizen scientists and their actual and potential contributions to scientific understanding and discovery. Characterizing respect in this context as the "right to be taken seriously," one interviewee stressed that citizen scientists earn this respect by holding themselves to the same rigorous standards as traditional science: "[W]e don't want standards [for citizen science] to drop, because if that happens, it will be dismissed as 'this cute sandbox of people learning' or the training wheels for what one day will be 'real' science" (15). On the other hand, when collaborating with citizen scientists, traditional scientific communities demonstrate respect by recognizing citizen scientists' efforts:

> It should be on both parts that the person involved in amateur science should apply rigor as much as possible and the person organizing the project should recognize the person's efforts. And not in a condescending way, but genuinely. Whatever effort was deemed of quality should be heralded just like everyone else's (15).

Focusing on projects that crowdsource participants' genetic and other health data, interviewees emphasized the importance of demonstrating respect for those contributions by, for example, ensuring that citizen scientists are not exploited but rather are treated as partners in the research process. As one project leader explained, "We felt the responsibility that if we were going to work with people throughout the world . . . then we had to find a way to work with them and not work through them in a sense" (14). However, another interviewee emphasized that demonstrating respect for participants by keeping them "central" should be the "guiding star" of all research projects, whether or not they identify as citizen science (34).

Also relevant to projects that crowdsource participants' data, interviewees explained the importance of demonstrating respect for personal privacy preferences around the use and disclosure of individual genetic and other health data, although many did not have privacy concerns with respect to their own data. Indeed, some shared their genotypes and medical histories with initiatives that they knew did not prioritize—or even were explicit that they would or could not protect—participants' privacy. "I think in citizen science and person-empowered research, people tend to be more likely to share openly without restriction," a community organizer explained (33). At the same time, there was general agreement that initiatives might have some obligation to explain the implications of sharing individual-level data for contributors' family members given that "[a] genome is one expression of a network of people who share traits and who share ancestry and who will share the offspring or legacy" (16). More generally, interviewees appreciated that their views on privacy might be atypical and agreed that individual privacy preferences, whatever they are, should be respected.

3.2.2 Collective interests served

Altruism.: Whether the projects they supported were studies conducted in home or community laboratories, or online data projects involving thousands of anonymous contributors, interviewees viewed those projects as altruistic vehicles "for the betterment of humanity" (29). Summarized one interviewee, citizen science is about "making the world a better place" (36). Citizen science's potential benefits to others were often framed as discoveries that might lead to health gains. For example, an interviewee who was involved in several initiatives involving large datasets described "feeling like I'm helping other people that may have similar genetics. Or in one case, I have an extremely rare [] mutation that I feel like I can represent in a dataset just by contributing my data" (19). One interviewee characterized his involvement in these projects specifically as "medical altruism," explaining that "I have made my DNA, my stem cells, my microbiome, my medical record, and every aspect of me available to the public" for the benefit of the public (35). However, academics stressed that traditional studies, and participation in those studies as human subjects, are also animated by the desire to help others.

As explained by some interviewees, citizen science might depart from traditional science in the conceptualization of altruism as encompassing strong commitments to making scientific education and experimental opportunities widely available. Interviewees who led or were active members of community laboratories in particular emphasized that education, including generally "broadening people's awareness of" science, was "a very important service that we do" (28). Some interviewees further described their mentorship of individuals interested in citizen science as an important facet of educational outreach. The aim of these relationships, explained one interviewee, was "to cathartically be the mentor that we never had and be able to support the folks who have their questions to just pursue it on their own time" (15).

Inclusivity.: Altruism conceptualized as education is closely aligned with the value of inclusivity, which was framed as access to opportunities to participate in science regardless of one's credentials, socioeconomic status, or place of residence. As one interviewee explained, citizen science is "inherently a very egalitarian way of seeing the work of science because it means that people should be able to participate in science regardless of their standing in some kind of an institution or some kind of a social structure that might otherwise prevent them from doing that" (24). Whereas traditional science is "very closed off to who can participate," citizen science is open to anyone (37). In this way, it provides what was described as a "level playing field" (30).

Interviewees involved in U.S.-based community laboratories where genetic investigation took place were especially concerned about limited opportunities outside the United States to participate in science. Responding to these concerns, some laboratories are working to promote inclusivity on a global scale:

> [T]here is a bit of a disconnect right now that there are some great community labs in the developed world, in the first world. But in the developing world, they're still trying to get their community labs up and running and they have more difficulties with regulat[ions] and access to equipment and suppl[ies]. And so the ability to

> participate equally in science and discovery, I think, is going to start to become more of a fundamental, ethical right. And so where we come in is helping advise and help out labs in different countries.. . . So, seeing that there is inequality and trying to figure out how can we help that as an advocate, as trying to source supplies, give advice, et cetera . . . (37).

Other interviewees emphasized that an essential feature of these and other programs to address inequalities in participation in knowledge production is access to scientific information. That is because “[i]f there is anything veiled in secrecy, it’s really hard to actually be equal partners with other people. There is inherently a power struggle among those who know and don’t know” (23).

Openness.: So conceptualized, inclusivity is achieved in part through the value of openness. Interviewees described openness as availability of, or access to, research ideas, protocols, technologies, data, and results. Also described as “transparency” and a “sharing culture,” openness was identified by most interviewees, regardless of their citizen science experiences, as a critical value—even the “hallmark”—of citizen science (10). The reason, it was explained, is that openness is ultimately what makes possible the efforts of citizen scientists and, more generally, promotes scientific understanding and discovery by everyone.

Interviewees contrasted openness with strategies of exclusion and secrecy, which were sometimes associated with commercialization strategies. For example, one project organizer described his work with a particular citizen scientist community as follows: “There was no ‘I’m keeping this idea because I’m going to go start something on it,’” like a business (22). Rather, “[e]veryone shared everything and it was incredibly transparent and open” (22). Some interviewees also described a culture of openness among citizen scientists as a direct response to their struggles to access information and materials held tightly by the scientific establishment. As one interviewee explained, “after you’ve worked so hard to get [a resource], it feels like you’re a [expletive] to just hold it from other people and make them struggle” (5).

While openness was endorsed by almost every interviewee, limits were recognized as appropriate when disclosure of information might put others at risk of harm. For example, if an experiment is dangerous, asserted one interviewee, it might not be appropriate to disclose the protocol, although the data should be disclosed. However, some cautioned that such risks should be balanced against possible benefits. For example, it might be appropriate to disclose the failed protocol if it is instructive as to how to avoid harms. Further, some interviewees recognized that some gatekeeping might be necessary to pursue certain commercial objectives or to protect participants’ privacy.

3.2.3 Mixed interests served

Reciprocity.: Whereas openness was described as a selfless act, interviewees conceptualized reciprocity as the provision of something of value in response to the receipt of something of value. Because the responsive action is motivated by fairness, the value of reciprocity is aligned with notions of justice.

Reciprocity was frequently raised in the context of data donation studies that solicit the public to contribute their genetic data and other health-related information. One interviewee described the return of information that might be interesting or personally useful to participants as a “moral obligation” on the part of these studies (2). Leaders of these studies explained that they took this obligation seriously by providing participants, for example, ancestry or trait information in return for their participation.

A number of interviewees went further and stated that reciprocity required giving credit to participants or inviting them to share in profits resulting from the research. Absent such a “nod” back to the community, explained an interviewee, “there’s no even exchange” (23). This creates a risk that participants are being exploited. Another interviewee explained that participants are justified in expecting this nod. If something of value “was created on my back and on the back of my fellow participants,” he asked, “why wouldn’t we have a stake in that?”:

> That’s just ridiculous to me that we wouldn’t. I think we would want a stake in it, not just or sometimes not even primarily because of economic benefit of it, but because we’re now part of that world. We’re part of what resulted in that discovery (9).

However, some interviewees recognized that sharing profits with participants is “tricky” and faces significant implementation challenges (33).

Finally, reciprocity was discussed in ‘pay-it-forward’ contexts where citizen scientists do something to benefit individuals who are different than those who provided the original benefit. For example, citizen scientists who did not have access to academic or community laboratories sometimes described sharing information or resources with others not as a philanthropic gesture, but as a general expression of gratitude to those who had earlier shared information or resources with them.

Safety.: The value of safety was endorsed not only by interviewees who conducted grant-funded citizen science research subject to institutional ethics review, but also by interviewees who did not work in traditional scientific institutions. Although safety was also discussed in terms of environmental harms, many interviewees focused on risks to humans—especially persons other than themselves. Thus, while self-experimentation biohackers in particular expressed willingness to assume what might be considered elevated risks of harm to themselves, none considered it acceptable to expose others to such risks. Summarizing this consensus, one interviewee described the “number one rule” of biohacking as “don’t hurt people” (1). Thus, before publishing videos or descriptions of their citizen science activities, some biohackers mentioned that they consider whether others might try to replicate their activities and what might be the risks to those individuals of doing so. One biohacker described a decision not to disclose information about a genetic experiment after concluding that risks of harm to others outweighed the potential benefits.

Interviewees also described deep unease with the possibility that some who suffer from serious medical conditions, or have family members who suffer from serious medical conditions, might be willing to assume more serious risks of harm. Medical self-help, observed one interviewee, “is really hard, it’s rarely successful, and it’s dangerous. But, when you’re dying, you’re willing to take a lot of risks” (5). Such risks sometimes include contacting biohackers to inquire about, among other things, gene therapy. Importantly, no interviewee reported actually working with sick individuals or caregivers, but instead only turning them away: “You have to tell these people no, and it’s heartbreaking” (5).

For interviewees who worked outside of traditional scientific institutions, safety was valued at least in part as the basis for what scholars have called a “social license to operate” (Kuiken et al., 2018). One explained that “the whole movement will be blamed if one person messes up” and someone gets seriously hurt (15). Another elaborated on this point:

> [A]ny of us who are serious about this have committed to doing it safely and securely because we know that people are looking at us and that if we screw up, as one of my friends in the FBI so eloquently put it, “If you screw up, we’re going to have to shut you down, because the public will demand it of us” (17).

A third interviewee worried that injury to a handful of self-experimenters in particular “will cast horrible shadows over both the legitimate professional field and other people who are self-experimenting and trying to do it in a really safe, careful manner” (10). Finally, several observed that adherence to safety standards was necessary (although perhaps not sufficient) to avoid personal liability. A community builder summarized this concern as follows: “I want to encourage inquiry but I also want to ensure safety. I don’t want to be held liable for anything that happens” (23).

Solidarity.: Finally, the value of solidarity was characterized as commitment to and identification as a community. Importantly, citizen science is “not a monolithic community” (21), but rather is comprised of multiple communities, each of which works to achieve the goals determined by the community’s members. As an academic who studies genomic citizen science observed, “it’s [] about collectively shaping agendas, so collectively deciding, ‘What do we want to get or how do we understand what’s valuable in terms of what type of knowledge?’” (36). According to several interviewees, citizen science’s emphasis on community is a primary reason why individuals become and stay involved in its initiatives.

One interviewee involved in various citizen science projects described his observation that those who contribute their personal genetic data to research initiatives have an especially strong sense of solidarity because they have more “skin in the game ” than those who contribute to research in other ways (20). Another interviewee comparing genomic citizen science communities with open-source software and hacker communities opined that the former are more cohesive as a result of shared commitments to, among other things, education.

However, specific communities were described as more or less cohesive. On one end of the spectrum might be Quantified Self communities, which were described by one participant as follows:

> [W]e were all on the same journey or whatever. We all saw the same future. There were different flavors of it, but directionally we were all very aligned in what was

> happening and going to happen, and we wanted to push it forward and see it go . . . (22).

Similarly, an interviewee who led grant-funded research initiatives described intentionally designing his studies around communities of active participants, where “we’re trying to do something together” (7).

On the other end of the spectrum, interviewees opined that biohackers conducting their own research do not comprise a cohesive community. Specifically, tensions were observed among individual biohackers as well as groups of biohackers that seemed driven by clashes in personality and disagreement about the appropriateness of commercial interests in their work. As one interviewee explained:

> [Biohacking is] like a lawn of plants. You’ve got all these flowers popping up in the field in various places, and over time they spread into a continuous meadow, and eventually they work out an ecosystem on their own (5).

He predicted, “I think that’s what will happen with biohacking,” but it just was not there yet (5).

4.0 Discussion

Thematic content analysis of data from interviews of 38 individuals whose biomedical citizen science activities encompassed leading, facilitating, participating in, or studying genomic citizen science initiatives revealed nine core values. Three values serve individual interests, three serve collective interests, and three serve both individual and collective interests. Represented by six of nine values, the most common primary domains were security, meaning motivated by societal and individual stability, and universalism, meaning motivated by a positive concern for the welfare of all people. By secondary domain, four values were categorized as either benevolence, meaning motivated by concern for the welfare of close associates, or conformity, meaning motivated to restrain oneself from hurting the interests of others.

As conceptualized by interviewees, some values are strongly aligned and appear to reinforce one another. For example, the values of openness and inclusivity benefit others and promote a more knowledgeable, curious, and empowered populace, consistent with the values of altruism, fun, and autonomy. The value of respect is demonstrated by efforts to promote access to tools and information and opportunities to learn about science and participate in scientific activities, consistent with the values of openness and inclusivity. Respect is also demonstrated through fair exchanges of information and resources, consistent with the value of reciprocity.

However, as predicted by the theoretical framework (Schwartz 1992, 1994; Schwartz and Bilsky 1987, 1990) and consistent with the findings of McGowan and colleagues (2017), some values appear to be in tension. Autonomy and solidarity, for example, can be difficult to reconcile when individuals prefer to act in ways that are not consistent with community standards, goals, or priorities. Moreover, for those who choose to conduct their work alone, autonomy is prioritized to the exclusion of solidarity, although in practice, instances of solo work are rare given that genomic and other biomedical citizen scientists generally must depend on each other for information and resources (Meyer, 2013; Guerrini et al., 2019b). As another example, fun and respect are in tension when citizen scientists pursue projects that traditional scientists (or others) dismiss as inconsequential. However, this tension might be more or less salient depending on the activities at issue. It has been observed, for example, that "playfulness" is uniquely valued in synthetic biology involving the standardization of genomic and other biological parts, which is perhaps not surprising given that the leaders of this interdisciplinary subfield have long been vocal supporters of "garage biology" (Bensaude-Vincent 2016).

Some values that appear to be in conflict can probably be reconciled. For example, autonomy might seem at odds with the consensus we heard that citizen scientists should not engage in unsafe practices. However, interviewees recognized that limits on autonomy are necessary to avoid harm to the environment and others. It is only when conduct poses risks of harm exclusively to oneself that some interviewees were comfortable respecting citizen scientists' decisions to assume those risks.

In addition to situating genomic citizen science values within a theoretical framework, our findings expand on and sharpen the meaning of values identified by previous interview studies involving biomedical citizen scientists. Sanchez Barba (2014) extracted three values in biohacking from various sources including interviews with seven biohackers: openness, or "[p]rovid[ing] accessible, affordable, easy-to-use resources with no entry requirements or qualifications needed"; freedom, meaning that "[e]veryone can freely pursue their own interests and curiosities"; and collaboration, which mandates "[s]har[ing] everything as free and open-source." These values align with many of those that we identified, including openness, inclusivity, autonomy, fun, solidarity, and reciprocity. Although not identified as values, Sanchez Barba also reported that interviewees "expressed a pronounced sense of making a change; to contribute something of value to society," consistent with altruism, and stressed "the importance of responsibility," consistent with safety.

Specific to genomic citizen science, McGowan and colleagues (2017) reported PDGR leaders' expressed commitments to "radical openness" of and access to scientific tools and knowledge, empowerment through education, and democratization of scientific discovery, which align with this study's identification of values of openness, autonomy, and inclusivity. Like some of our interviewees, PDGR leaders also described frustration with traditional research priorities and processes that animated their citizen science efforts.

The values we identified are also well represented in the codes and consensus statements that have thus far been developed for biomedical citizen science. Specifically, DIYbio.org, which was formed in 2008 to support individuals seeking to access and do science outside of traditional scientific institutions, drafted North American and European Codes of Ethics that emphasize "tinkering," open access, transparency, safety, and specifically in Europe, also community (DIYbio.org, 2011), consistent with our interviewees' identification of fun, openness, safety, and solidarity as important values. In 2018, participants of the Global Community Bio Summit developed a Statement of Shared Purpose that focuses on inspiring creativity, democratizing biotechnology, and cultivating knowledge and resource commons

(GCBS, no date), consistent with our interviewees' identification of fun, inclusivity, and openness as important values. In recent years, DIYbio.org has become inactive and the Bio Summit has essentially taken over efforts to coordinate and build fellowship among biomedical citizen scientists around the world. Notably, the Bio Summit explicitly frames this work in terms of growing a social "movement" and has enlisted the help of prominent community organizers to support its efforts (GCBS, no date).

Consistent with the emergence of biomedical citizen science as a social movement, six of the nine values we identified fall into motivational domains that serve collective or mixed interests. In this respect, our findings appear to diverge from interview and survey studies of citizen scientists in other disciplines that emphasize selfish motivations. In interviews with citizen scientists recruited through strategies directed at biodiversity and conversation projects, for example, Rotman and colleagues (2012) identified egoism—or the goal of increasing one's own welfare—as the primary motivation for citizen scientists' initial interest to participate in projects. Following their initial engagement, a "crucial" secondary motivation that influenced interviewees' ongoing participation was "an intense need to be recognized and appreciated for their contributions," although other secondary motivations included a desire to help and advocate for their communities. Similarly, Eveleigh and colleagues (2014) found that initial decisions to participate in an online citizen science project to transcribe historical weather data were guided by egoism.

An interview study with members of hackerspaces and makerspaces, on the other hand, found that participation was motivated not only by self-actualization and sheer enjoyment, but also deep commitments to the "gnarly, exciting, inspiring" communities that characterized these spaces (Davies, 2018). Notably, two of the twelve spaces involved in the study focused primarily on DIY biology. Similarly, 34 participants of the Personal Genome Project (PGP), which is a genome sequencing and biobanking project that publicly discloses individual-level data, described their motivations for joining PGP as both selfish—for example, gaining access to their genetic information and learning about their health—and selfless—namely, helping others by supporting the advancement of personalized medicine and de-stigmatizing certain conditions (Zarate et al., 2016). Like some of our interviewees, PGP participants also reported a strong sense of community with each other as well as with other aspects of citizen science (Zarate et al., 2016).

That interviewees who were not affiliated with traditional scientific institutions identified safety as a core value was inconsistent with some media reports suggesting that these individuals can be intentionally reckless or willfully ignorant of the safety issues associated with their activities (Baumgaertner, 2018; Brown, 2017). In one report on the potential dangers of synthetic biology biohacking, for example, a prominent genomic scientist warned that anyone who participates in these activities "should be under surveillance, and anyone who does it without a license should be suspect" (Baumgaertner, 2018). Consistent with the observations of other scholars (Seyfried et al., 2014), however, interviewees told us that the safety of others was a priority for them and their communities. They not only felt a moral responsibility to prevent harm to others, but some also feared personal liability if they failed to do so. Of course, those who are unaware of the safety risks of their activities might still harm bystanders, even if unintentionally. But understanding that this result is unacceptable to them suggests that risk assessments of certain biomedical citizen science activities—including but perhaps not limited to genomic activities—should assume a general desire to avoid injury to others and also that those engaged in these activities will welcome educational and other initiatives directed at ensuring the safety of bystanders. Consistent with this prediction, community laboratories have long cooperated with law enforcement to identify bad actors (CGSR, 2016) and have initiated efforts to promote and standardize their biosafety practices that build on existing biosafety policies (Mulligan, 2017). A recent biosafety bootcamp held at a Baltimore community laboratory, for example, was reported to be a positive experience for the citizen scientists around the world who attended (BUGSS, no date). By contrast, a credentialing or licensing requirement to conduct biological experimentation would likely be viewed by these individuals as an overly broad, even elitist restriction on the public's ability to access information and participate in knowledge production. Policies that essentially ban self-experimentation would likely provoke an even stronger negative reaction among biohackers in particular.

Indeed, of all the values identified by interviewees, autonomy, openness, and inclusivity are perhaps most useful in distinguishing the ethos of genomic citizen science—and especially genomic biohacking—from the practices of traditional science, which have been characterized as focused on maintaining power by controlling research agendas and restricting access. As other scholars have observed (Delfanti, 2013; Meyer, 2013), this ethos has political dimensions for citizen scientists having explicit aims to dismantle social and institutional barriers to scientific resources and activities, challenge notions of scientific expertise and authority, and recruit others to do the same. Although not all of our interviewees described their activities in political terms, it was clear that at least some were reactive to prior negative experiences with traditional scientific and medical institutions in their roles as learners, researchers, patients, or caregivers. For other interviewees, their activities might have assumed a political character only after those activities were initiated as they came to appreciate the potential social benefits. Especially for those who framed their work in political contrast to traditional research, self-regulation would likely always be preferred to government regulation, suggesting that policy efforts should focus on building and sustaining self-regulatory capacities within citizen science communities when informed risk assessments do not advise more aggressive policy responses.

Finally, although there is some debate about the appropriate role of advocacy in citizen science given its potential to introduce bias (Elliott and Rosenberg, 2019), several values identified by interviewees indicate that advocacy may be intrinsic to biomedical citizen science communities, including those engaged in studying or manipulating genetic information, adding yet another political dimension to their activities. For example, altruism, inclusivity, and openness were operationalized in part as efforts to educate and support the scientific activities of others. The strong link between biomedical citizen science and formal educational systems is well-known (Grushkin et al., 2013; Meyer, 2013; Ikemoto, 2017) and was also observed in our study population. Some citizen scientists are or once held positions as high school teachers, university professors, or other professional educators; others are mentored by these individuals. That interviewees viewed education as a moral responsibility of their communities suggests that citizen scientists could be valuable partners in the development and execution of science, technology, engineering, and math (STEM) programs for learners of all ages. Further, risk assessments of specific citizen science activities might want to account for this link to the extent that citizen scientists are likely to know, and their activities will therefore likely reflect, safety and other harm-reduction practices that are prioritized in traditional scientific settings.

Our analysis is subject to several limitations. First, we did not seek to determine the relative importance of the identified values to interviewees, although that ordering is likely to have a strong influence on their attitudes and behaviors (Schwartz and Bilsky, 1987). These preference data are better suited for collection using other empirical methods, such as rating or ranking exercises or discrete choice experiments, although our qualitative data might help inform the design of such studies.

Second, the data are not generalizable but rather describe the opinions and experiences of the individuals who agreed to participate. Nevertheless, interviewees were selected in part based on the diversity of their experiences. Relatedly, third, there may be bias in that the opinions of participants may be systematically different from the opinions of individuals who were contacted but chose not to participate or those who were not contacted because we were unaware of their activities. These individuals might have more extreme opinions than the interviewees, which might be related to their non-participation, or they might prioritize different values.

Fourth, there were geographical gaps in the interview population. Specifically, the population did not include any residents of the U.S. Midwest. Our efforts to address this gap, however, were hindered in part by the seeming concentration of community laboratories and genomic citizen science projects in particular on the West and East Coasts during the interview period (DIYbiosphere, no date). Further, although some of these projects are global in scope (Bonetta, 2009), the majority of interviewees were U.S. residents; only three (8%) resided abroad. As a result, the data might not capture the full range or importance of values associated with other cultures. However, at least two interviewees were temporarily residing in the U.S. at the time of their interviews and a number of interviewees collaborated on projects with team members residing in other countries. Consequently, non-U.S. perspectives are probably better represented than the demographic data suggest.

Fifth, the interview population was dominated by men, who comprised three-quarters of interviewees, although gender imbalance is not unusual in interview studies relevant to biomedical citizen science. In the study by Sanchez Barba (2014), for example, 6 of the 7 interviewees were men. In the study of participant-driven genomic research by McGowan and colleagues (2017), 18 individuals were interviewed, and although demographic data were not reported, 10 of the 13 interviewees who were identified by name were men. As a third example, 59% of interviewees in the PGP study were men (Zarate et al., 2016).

Our efforts to address gender imbalance were hindered in part by what we observed to be a tendency of published accounts of biomedical citizen science—and especially genomic citizen science—to feature the activities of men (Baumgaertner, 2018; Brown, 2016; 2017). One potential reason for this media bias may be that there are fewer women and non-binary individuals than men who are active in this space. Consistent with this hypothesis, 75%

of 356 respondents of a 2013 survey of DIY biologists were men (DIYbio Community Survey, 2013). Similarly, a recent analysis of published articles reporting the gender of participants in 43 citizen science projects or meta-populations found that men comprised 58% of participants (NASEM, 2018). Focusing only on 11 projects conducted online, male participation increased to 73% (NASEM, 2018). Alternatively, women and non-binary individuals who are active in this space may be less interested than men in discussing their citizen science activities with outsiders. We note, however, that the response rates of our interview candidates by gender were approximately equivalent.

Finally, there was considerable variation in the background of interviewees, which could have contributed to significant differences in opinions that our analysis did not detect. For example, it might be argued that biohackers who work exclusively in home laboratories do not have enough in common with institution-based scientists executing grant-funded studies to justify their inclusion in the same study. We decided to include data from all interviewees in this analysis consistent with another interview study of genomic citizen scientists that did not exclude potential interviewees based on their specific experiences in this space (McGowan et al., 2017). Relatedly, some might disagree with our identification of particular interviewees as citizen scientists or their work as citizen science. While acknowledging issues associated with adopting broad definitions for these terms, we believe it is generally preferable to adopting narrow and exclusive definitions, for reasons discussed in the companion landscape study (Guerrini et al., 2019a). Nevertheless, we support future research with discrete populations of genomic and other biomedical citizen scientists, however they are defined, to triangulate findings.

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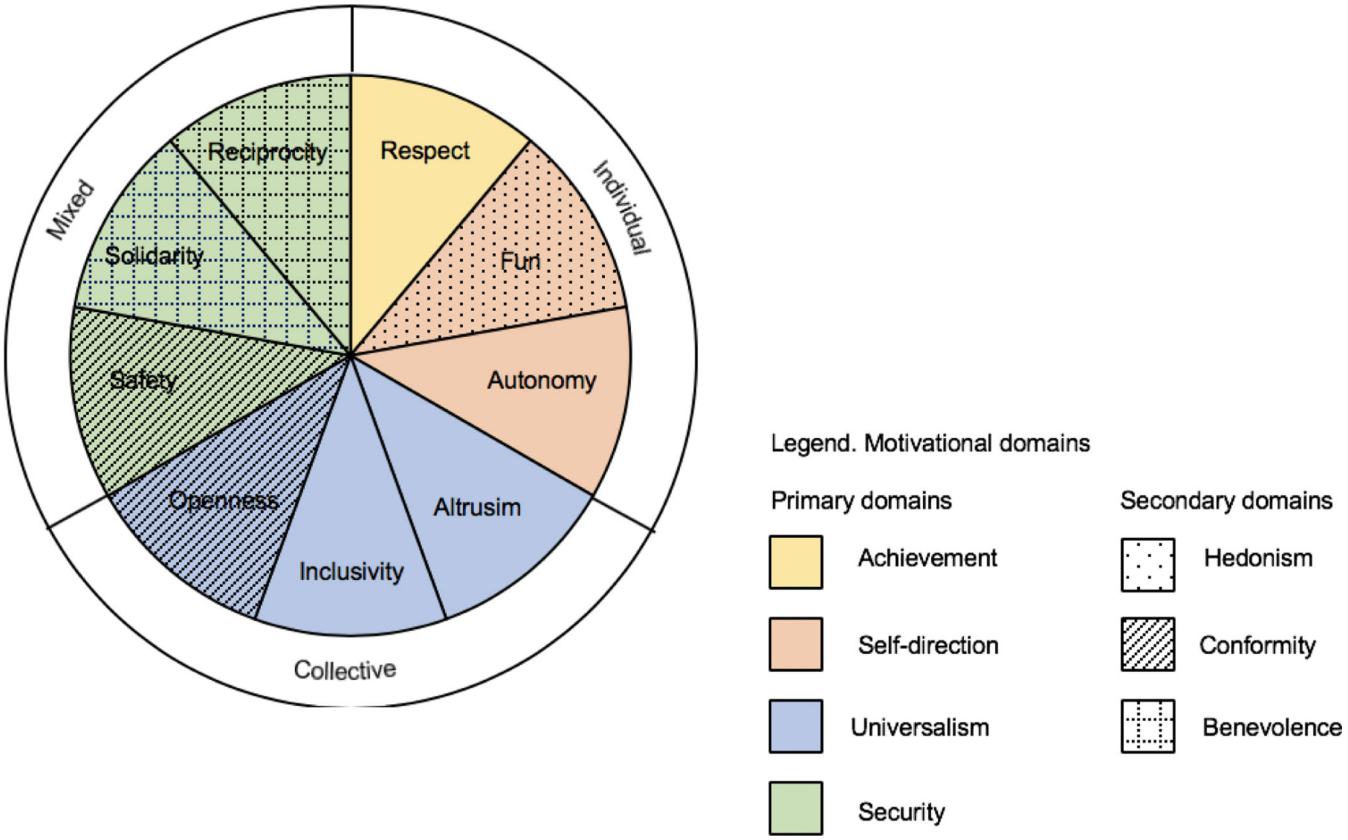

Fig. 1.

Values that interviewees associated with their citizen science activities and communities, by motivational domains and interests served

Table 1:

Involvement of interviewees in genomic citizen science activities, by category (*N*=38).

Category[*]	**n (%)**
Scholar	5 (13%)
Biohacker	18 (47%)
Data biohacker	7 (18%)
Laboratory biohacker	9 (24%)
Self-experimentation biohacker	5 (13%)
Project organizer	12 (32%)
Community builder	19 (50%)
Entrepreneur	11 (29%)

[*] Categories and subcategories not mutually exclusive. Scholars: studied citizen science. Biohackers: studied or manipulated genetic information. Data biohackers: studied or manipulated genetic information in online environments. Laboratory biohackers: studied or manipulated genetic information in non-traditional laboratory settings. Self-experimentation biohackers: conducted self-experiments based on or involving own genetic information. Project organizers: led specific genomic citizen science initiatives. Community builders: facilitated genomic citizen science activities of others. Entrepreneurs: founded or operated commercial entities related to genomic citizen science activities.

Table 2.

Characteristics of interviewees (*N*=38).

Characteristic	**n (%)**
Gender	
Male	27 (71%)
Female	10 (26%)
Gender non-conforming	1 (3%)
Age	
18–19	1 (3%)
20–29	3 (8%)
30–39	16 (42%)
40–49	8 (21%)
50–59	6 (16%)
60–69	4 (11%)
Region[+]	
U.S. Northeast	7 (18%)
U.S. Midwest	0 (0%)
U.S. South	10 (26%)
U.S. West	18 (47%)
International	3 (8%)
Employer	
Academic institution	9 (24%)
Other or none	29 (76%)
Highest level education	
High school diploma/GED	4 (11%)
College graduate	7 (18%)
Graduate[*]	27 (71%)
PhD	17 (45%)
MD	2 (5%)
MBA	2 (5%)
Other	16 (42%)

Percentages may not add up to 100% due to rounding.

[*] Not mutually exclusive.

[+] As defined by U.S. Census Region (U.S. Census Bureau, 2010)