

A Neglected Ethical Issue in Citizen Science and DIY Biology

Lucie White

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Andrea Wiggins and John Wilbanks's article (2019) presents us with a welcome overview of the neglected, novel ethical issues raised by the advent of citizen science in health and biomedical contexts. This contribution takes a rather different approach, focusing on a very specific (yet also overlooked) problem in this context. This problem, however, is particularly illustrative of the "ethics gap" between traditional medical settings and new public-driven scientific practices, emphasized by Wiggins and Wilbanks in their more wide-ranging treatment.

As Wiggins and Wilbanks note, one of the most well-developed areas of nonprofessional-driven scientific activity involves individual inquiry into one's own health, "in order to satisfy one's own personal interests or needs" (2019, 3). Wiggins and Wilbanks highlight "self-tracking" of health indicators, generally undertaken with the assistance of proprietary systems, as a prominent example of this activity. Due to the reliance on third-party systems here,¹ Wiggins and Wilbanks focus their attention on the admittedly pressing issue of data protection, particularly in light of the data-sharing controversy surrounding genetic testing service 23andme.

However, these types of activities can also take place without the involvement of such third parties. New technologies such as Bento Lab and Biomeme—small, portable machines that can isolate and multiply DNA to testable quantities, and then analyze it and identify specific genes within the sample—now bring DNA analysis within reach of the unassisted individual. Such technologies clearly have a multitude of potential uses. But significant media attention has focused on the potential of these technologies to allow individuals to look into their own genome—and to identify genetic markers associated with the development of a disease (Orchard 2017; Reyes 2015; Zaleski 2016). DIY biology labs reflect this enthusiasm, offering workshops that explain how to use this technology to test for genetic predispositions for disease.²

¹ And also a focus on the production of collaborative or generalizable knowledge. I contend, however, that these individual-focused inquiries should not be overlooked as an important element of citizen science.

² See, e.g., <https://www.meetup.com/Brooklyn-Biohackers/events/241435477>; <http://www.biotop-heidelberg.de/event/lowcostpcr-workshop>.

Due to the protracted battle between 23andme and the Food and Drug Administration about the lack of clinical validation of 23andme's health-related genetic testing (Ratner 2018), Bento Lab and Biomeme are cautious about marketing their products for this purpose. Bento Lab does not provide necessary markers that allow identification of genetic variations associated with disease (Zaleski 2016), and tries to steer people away from using the technology for this purpose, although a cofounder acknowledges that it would be possible for others to develop and sell the required biomarkers (Orchard 2017). Biomeme, on the other hand, embraces the potential for self-administered genetic testing, though its founders are careful to note that this testing should be used for research purposes only, not diagnosis (Reyes 2015).

Despite these caveats, it is clear that the enthusiasm and potential for self-administered genetic testing are burgeoning. This raises the question—what if someone discovers something disturbing about their own genome? Does anyone bear responsibility here for mitigating risk or harm, and how is this best achieved? Attention has been paid to these problems in direct-to-consumer genetic testing, as displayed by the dispute between the FDA and 23andme—23andme was initially banned from providing information about genetic predisposition for disease, before receiving approval to provide information concerning predisposition for ten conditions, on the condition that they explain how the tests work and how to interpret them, and include the caveat that “they are not intended to diagnose disease nor guide medication use” (Ratner 2018). Similar provisos are included in collaborative citizen-scientist endeavors such as the Harvard Medical School's “Personal Genome Project,” in which volunteers contribute their DNA for analysis and compilation of data. Volunteers are required to submit a comprehensive consent form, which warns, among other things, of possible inaccuracies in the data, uncertainty in results, and possible psychological distress from findings, as well as maintaining that any information gleaned from the study should not be used for diagnostic purposes, and directing those with questions to their physician (Harvard University Faculty of Medicine IRB 2015).

Although there is much to debate concerning the adequacy of these measures, it is clear that a context in which there is no institutional collaboration or oversight presents a different set of challenges. It is difficult to see how, for example, an informed consent requirement might be introduced when someone is conducting testing of their own DNA, or whether it makes sense to demand such measures. At the same time, finding that you have a gene linked to predisposition for a certain disease could cause significant distress. In addition, these findings can be extremely difficult to interpret. A genetic predisposition to a disease might not provide a good prediction of how likely someone is to develop that disease. Similarly, a finding that a certain mutation is lacking does not provide a good indication that a person will not develop a disease. Even non-

geneticist physicians routinely encounter problems interpreting such results (Vassy, Korf and Green 2015). If a person reacts to her findings by changing her medication, or by falsely believing that she is not at risk for a disease, these practices could cause physical as well as psychological harm.

The intricacies of these findings and their drastic potential for harm have formed a significant ethical focus in traditional medical contexts. The rise of specialist genetic counselors, who can talk patients through the potential implications of results and whether the potential burdens of testing might outweigh the benefits, as well as assisting with interpretation and explaining the inherent uncertainties of genetic testing, is a testament to how seriously these issues are taken. In the context of DIY biology, on the other hand, these issues receive no attention, despite the wide interest in conducting one's own genetic testing and the popularity of workshops that provide assistance in doing so.

Ethical discussion of DIY biology focuses overwhelmingly on issues of biosafety and biosecurity (Jefferson, Lentzos and Marris 2014; Seyfried, Pei and Schmidt 2014). It is perhaps no surprise that there has been so much focus on the potentially catastrophic consequences of the accidental or malevolent release of some devastating biological agent, particularly given the media attention surrounding such possibilities (Kuiken 2016). However, this focus has swamped all other concerns. Part of the problem here could also stem from the difficulties of the issue—do the concerns that I have raised here actually pose a significant problem? Even if so, is there anything that can be done about it? Restriction of self-testing seems difficult, and difficult to justify. But there are possible measures that might be put in place. Workshops at DIY biology labs, which provide information about how to conduct self-administered genetic testing, sometimes involve discussion of ethics—this is a possible place in which some pertinent information about the risks and uncertainties of genetic testing might be conveyed. DIY biology groups are often suspicious of outside regulation—and some advocates of DIY biology, such as Todd Kuiken, argue that DIY biologists manifest a “proactive culture of responsibility” (2016, 168), as exhibited by their development of codes of ethics and the appointment of advisory boards. Perhaps these boards and codes might discuss what responsibilities lab coordinators might have to the people who conduct experiments in their labs, or based on information gleaned from lab-run events, or to the citizen-scientist community at large, and what measures might be taken to mitigate potential harm from self-administered genetic testing. The conduct of the companies that produce these technologies is also of interest—does Bento Lab have the right idea in nudging people away from this type of inquiry, or is this unjustified, or perhaps even an abrogation of responsibility?

Whether significant steps must be taken or not, these issues are certainly worthy of a fraction of the sustained attention they have received in traditional medical contexts, and (albeit to a lesser extent) in collaborative citizen-scientist endeavors. In addition, and more broadly, the unique challenges posed by dealing with these types of risks in citizen-run scientific inquiry, as well as the lack of attention that these otherwise much-discussed ethical issues have received in this context, lay bare the breadth of the “ethics gap” between citizen science and traditional medicine. The new and novel issues raised by the wide range of citizen-science endeavors, in all their variability and nuance, require the type of sustained and sophisticated ethical scrutiny focused for so long on problems in traditional medical settings. Wiggins and Willbanks’s contribution provides us with an excellent start.

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