

***Participant-Driven Research:
What (and Who) Is Driving “Citizen
Scientist” Projects in Genomics?***

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**Workshop to Explore the Ethical, Legal, and Social
Implications (ELSI) of Citizen Science Related to the
NIH Mission**

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Participant-Driven Genomic Research

- Characterize the types of participant-driven genomic organizations
- Understand the objectives of their work and the ways in which their practices embody their moral and political goals (and how these do and do not align with traditional genomic research goals)
- How participant-driven science challenges and complicates traditional approaches to genomic research *and* traditional research ethics

Citizen Science

Actively interrogate and disrupt the traditional relationships between research, the university, and the market.

Their goals include:

- to engage the public in (the conduct of) science
- to promote the use of open source software and open access to data
- to transpose 'hacking' practices onto the realm of genomics and synthetic biology
- to deinstitutionalize research
- to develop innovative solutions to scientific problems or simply as matters of curiosity

Working outside traditional venues

“I think it’s the regulatory environment, and I think it’s continuing to look at this new information through an old lens that no longer serves and no longer fits. It’s like trying to look at the sun with a microscope.”

“I still today get frustrated with the strains of paternalism that I see sometimes in scientific and medical research where there are still studies that are structured in a way . . .that would shield individuals and shield participants from knowing certain things, from being able to access certain information.”

Citizen Science Ethos

“I don’t really want or need somebody else to tell me how to 1) do my research or 2) live my life, or whatever it is. Like . . . whatever the belief is or whatever your personal reason is, there are some shared aspects of these cultures. Like a dedication to transparency, to open source, to lowering the cost of access, freedom of data.”

“There’s part of that that’s sort of you know ‘Let’s pull these technologies out of the ivory tower,’ and I would say it’s not even so much a reaction against authority as it is a belief in grassroots, a belief in ‘I’m the best monitor of my own health. I’m the best judge of what I should do about it, and I don’t necessarily want to go to someone who sits in a big chair with a fancy degree to tell me what to do. I want to know and understand and take that action myself.’”

Societal Obligations

“We ought to be doing more for ourselves and the world in just publishing things in journals that only other scientists read. You know there has to be some translational mechanism ...There has to be some way so that we can discuss and make available to at least those who are interested to non-scientists, as well as scientists,....Well it seems that if you put billions of dollars into sequencing and trying to understand the point of the genome, then there ought to be numerous ways (SNPedia is one of them) to make it matter to people.”

Conclusions

- The goals and motives for the organizations shape how research is conducted and future participants' relationship to research
- PDGR positioned as *a challenge* to traditional research and with a different set of values and ethics
- These ethics sometimes run counter to conventional research ethics (which was developed in conjunction with traditional academic research) and engage larger principles about the purpose and orientation of contemporary scientific research.