

Citizen science for biomedical research and contributive justice

Cristian Timmermann

Angaben zur Veröffentlichung / Publication details:

Timmermann, Cristian. 2019. "Citizen science for biomedical research and contributive justice." *The American Journal of Bioethics* 19 (8): 60–62.
<https://doi.org/10.1080/15265161.2019.1619875>.

Citizen Science for Biomedical Research and Contributive Justice

Cristian Timmermann

Centro Interdisciplinario de Estudios en Bioética, Universidad de Chile

cristian.timmermann@gmail.com

This is a “post-print” accepted manuscript, which has been published in:

The American Journal of Bioethics

Please cite this publication as follows:

Timmermann, Cristian. 2019. "Citizen science for biomedical research and contributive justice." *The American Journal of Bioethics* 19, no. 8 (2019): 60-62.

The final publication is available at Taylor & Francis via:

<https://doi.org/10.1080/15265161.2019.1619875>

Citizen Science for biomedical research and contributive justice

Cristian Timmermann

Engaging citizens in science projects has a number of epistemic benefits in terms of improving scientific outcomes and adjusting research to develop innovative solutions that are likelier to be used. Yet the emphasis on the epistemic benefits of Citizen Science projects and its risks, such as exploitation and a lack of benefit-sharing, a failure to sufficiently inform participants of possible hazards and privacy issues, and unacknowledged authorship, which we can find in Wiggins and Wilbanks (2019), should not shift to the background important justice-related interests regarding increasing participation, in particular as a prerequisite to providing the human right to participate in science (Timmermann 2014, Vayena and Tasioulas 2015). Beside the social interest in benefiting from scientific advancement—due to its major role in improving welfare—and keeping scientific practice within ethical boundaries, we need to acknowledge scientific participation to be very much in the interests of society.

To systematically assess the multiple advantages of increased participation in Citizen Science projects we can draw upon the concept of contributive justice. The concept has received renewed interest in demanding equality of opportunity in accessing meaningful work and in being in a position to make a contribution to society according to one's abilities (Gomberg 2007, Timmermann 2018). Under such a framework, we can identify multiple advantages of participatory research environments for individuals and society, such as: (1) the intrinsic benefits of participation, (2) the opportunity to learn skills, (3) empowerment, allowing people to contribute to social welfare, (4) shifting positions of dependency to mutual influence, and (5) social recognition.

Facilitating participation allows people to become part of a community, to interact with peers, acquire knowledge, develop new skills and make use of these skills for a socially important endeavor. The acquisition and further development of skills and knowledge is often perceived as self-rewarding, especially when a certain level of mastery is reached. The development of skills also opens up new possibilities for interaction. For instance, as Wiggins and Wilbanks (2019) point out, data science skills allow people to participate in many of the current biomedical science projects. Participation allows people to be involved in shaping their future by assisting in the development of innovative solutions. It gives people an active role, instead of being a mere spectator in this highly influential sphere of society.

People have a fundamental interest in improving their own circumstances and those of their community. Empowering citizens by developing skills, removing hurdles, fighting discrimination and opening up research projects is crucial in order to allow them to contribute towards social welfare. This is particularly important to biomedical research, due both to its immense capacity to improve welfare and the sympathetic urge to take action to aid a sick relative or friend. It may allow one to constructively channel tension and anxiety about the health of a loved one by becoming actively involved in speeding up research, something that can be particularly effective when citizens organize themselves to advance research on rare diseases (Woolley et al. 2016).

Significant participation in Citizen Science projects allows people to become more than mere recipients of innovative solutions, as participants acquire the ability to influence courses of action by making their own contributions and by encouraging others to join the effort. Citizens can exert even more influence when there are multiple open Citizen Science projects from which to choose, as they can thereby give greater weight to selected projects. If the correct steps are taken, we can expect an increase in citizens' influence in science, as more sophisticated participation platforms are developed and people grow better-acquainted with such models (Fiske et al. 2019).

The element of social recognition is also of significant value. Recognizing citizens as potential collaborators and service-providers brings them closer to being treated as peers of equal standing. Improving recognition builds social cohesion as it facilitates knowledge exchange and cooperation. Participating on site or online may also provide a sense of belongingness to people who have difficulty in integrating into their social environment or have lost bonds with their community. It also provides a venue for the recognition of skills and knowledge otherwise not appropriately received in the local community.

Importantly, contributive justice does not only perceive Citizen Science as a vehicle to fulfil its demands, but also sets further demands on how such projects should be designed. Particularly it demands a fair distribution of tedious tasks and meaningful work, in addition to addressing issues of discrimination and equality of opportunity. This means that participation in Citizen Science projects should not only be allowed, but also encouraged, by making it attractive and removing hurdles. This demands some redistributive measures to facilitate the material means for people to participate. Delegating citizens to be mere data collectors without allowing them to give additional feedback and raise questions diminishes the overall experience and demotivates further involvement. In other words, Citizen Science requires that citizens become engaged in *science*, that is, they also have to have a role in formulating questions and interpreting results, instead of merely monitoring events (Eitzel et al. 2017). All of the participants would have to actively confront issues of discrimination, as both a matter of justice and for its negative effect on cognitive diversity. Moreover, scientists in particular should pay attention to whether they are hoarding for themselves all the meaningful work which could be shared. Another difficult issue involves payment, as in our society money is also a token of recognition. When some contributors to a common project get paid and others not, it may raise conflicts and even deteriorate the overall work experience. Citizen Science should also not cause work that was being done for wages by early-career researchers to end up being outsourced to a general public for free (Riesch and Potter 2014).

An added benefit of facilitating citizens' participation in science is that it may allow the scientists involved to gain a better knowledge of real-world problems and worries, empowering them to contribute to social well-being by designing products and solutions that are better-suited to the circumstances and expectations of the general public, thereby serving more effectively a central demand of contributive justice.

Biomedical Citizen Science has both ethical and legal limits, as much of the research needs to be embedded in formal science and is subject to regulations. These legal protections and ethical standards need to be balanced with the demands of contributive justice. Some are easier to meet, as is the case with informing participants of potential risks. Others set strict limitations, for instance, when regulations impede the sharing of protected personal data

hindering full participation. It needs to be noted that curiosity-driven participation does not lead automatically to better governance or more effective solutions. Participants in Citizen Science also need to periodically review their research trajectories, methods and goals in view of their social role. Indeed, the stricter interpretations of contributive justice ask us to use our skills to address social problems (Gomberg 2016), which may become quite demanding.

Wiggins and Wilbanks offer a broad overview of the worries regarding the public participation in Citizen Science; I hope to have shown that more work, specifically in ethics, is needed to prevent citizens, regardless of their potential, being downgraded to the function of human sensors.

Acknowledgement: This work is supported by a postdoctoral fellowship (FONDECYT/CONICYT No. 3170068)

References

- Eitzel, Melissa, Jessica Cappadonna, Chris Santos-Lang, Ruth Duerr, Sarah West, Arika Virapongse, Christopher Kyba, Anne Bowser, Caren Cooper, Andrea Sforzi, Anya Metcalfe, Edward Harris, Martin Thiel, Mordechai Haklay, Lesandro Ponciano, Joseph Roche, Luigi Ceccaroni, Fraser Shilling, Daniel Dörler, Florian Heigl, Tim Kiessling, Brittany Davis, and Qijun Jiang. 2017. "Citizen science terminology matters: Exploring key terms." *Citizen Science: Theory and Practice* 2 (1):1-20. doi: 10.5334/cstp.96.
- Fiske, Amelia, Lorenzo Del Savio, Barbara Prainsack, and Alena Buyx. 2019. "Conceptual and Ethical Considerations for Citizen Science in Biomedicine." In *Personal Health Science*, edited by Nils B. Heyen, Sascha Dickel and Anne Brüninghaus, 195-217. Wiesbaden: Springer.
- Gomberg, Paul. 2007. *How to make opportunity equal*. New York: Wiley Blackwell.
- Gomberg, Paul. 2016. "Why Distributive Justice Is Impossible but Contributive Justice Would Work." *Science & Society* 80 (1):31-55.
- Riesch, Hauke, and Clive Potter. 2014. "Citizen science as seen by scientists: Methodological, epistemological and ethical dimensions." *Public understanding of science* 23 (1):107-120.
- Timmermann, Cristian. 2014. "Sharing in or benefiting from scientific advancement?" *Science and Engineering Ethics* 20 (1):111-133.
- Timmermann, Cristian. 2018. "Contributive Justice: An Exploration of a Wider Provision of Meaningful Work." *Social Justice Research* 31 (1):85-111.
- Vayena, Effy, and John Tasioulas. 2015. "'We the Scientists': A human right to citizen science." *Philosophy & Technology* 28 (3):479-485.
- Wiggins, Andrea, and John Wilbanks. 2019. "The Rise of Citizen Science in Health and Biomedical Research." *The American Journal of Bioethics*.
- Woolley, J Patrick, Michelle L McGowan, Harriet JA Teare, Victoria Coathup, Jennifer R Fishman, Richard A Settersten, Sigrid Sterckx, Jane Kaye, and Eric T Juengst. 2016. "Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives." *BMC medical ethics* 17:33.