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Altruism, recklessness, or something else? A summary of the forum on self-experimentation in the time of COVID-19

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In December of 2020, the Forum for Global Health Ethics and *Swiss Medical Weekly* jointly organised the first of a series of online events targeting a community of practitioners, researchers, students and policymakers interested in topics that pose ethical challenges in the field of global health. The Forum for Global Health Ethics is an initiative hosted by the Institute of Biomedical Ethics and History of Medicine at the University of Zurich (a World Health Organization collaborating centre). This first event addressed ethical questions related to the topic of self-experimentation in the time of COVID-19. Self-experimentation has a long history in science and refers to cases in which a researcher conducts experiments on himself or herself. This practice is newly sparking controversy as some of those looking to respond to the COVID-19 pandemic are interested in accelerating vaccine development by being their own test subjects, and sidestepping ethics board reviews and regulations. Hosted by Nikola Biller-Andorno and moderated by Tania Manríquez Roa, this event included the following experts, who presented arguments for and against self-experimentation: Preston Estep, the founder of the Rapid Deployment Vaccine Collaborative; Rebecca Dresser, a Professor of Washington University in St. Louis; Peter Kleist, the Director of Zurich Cantonal Ethics Committee; and Samia Hurst-Majno, the Director of the Institute for Ethics, History, and Humanities at the University of Geneva. These presenters' expertise led the way for a rich, interactive discussion with impressions, insights and questions from those attending. Here we summarise some key points from the discussion.

What are some factors that make self-experimentation compelling?

There are some advantages of self-experimentation that are especially highlighted by those exploring vaccine development during this pandemic. Notably, there is freedom and agility that can accelerate advances. For example, a self-experimenter not bound by an early approved study protocol may easily incorporate emerging information to improve upon his or her design. This also has benefits related to easy collaboration and exchange. Self-experimentation is attractive to those with altruistic motives, given the potential easy sharing of insights to benefit others. In the case of COVID-19 vaccine development, for example, self-experimenters can freely post production information and protocols for any to access. Scientists who self-experiment may be especially committed to open-source information sharing.

Another appeal of self-experimentation is the opportunity it affords researchers to participate in studies as an educational experience. Researchers might become a subject in their own study in order to learn about participants' experiences and thereby refine their own methods and positions. Some argue that those who participate in their own studies are the best informed about risks and advantages, so deceptive exploitation and other ethical concerns around engaging participants are avoided.

Historically, self-experimentation has led to valuable scientific contribution, as illustrated by the number of self-experimenting scientists whose work has been recognised through Nobel prize awards (table 1).

How might self-experimentation influence public opinion of science?

There is some concern that because self-experimentation is not held to the same high standards as other regulated studies, it weakens confidence in scientific findings generally. Self-experimentation, therefore, might harm public opinion of science. Formal vaccine development, for example, requires great oversight, and emphasis is placed on rigorous clinical trials to prove both efficacy and safety. Because of the current debate over vaccine safety and public scepticism, one might argue that it is especially relevant to do everything possible to reassure people of the validity of findings, which means avoiding less-sound methods such as self-experimentation.

From another perspective, self-experimentation can offer transparency and insight into the scientific process. In the case of COVID-19 vaccine development, there has been remarkable speed in development, both in terms of the

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Table 1: Self-experimenters who were awarded a Noble prize.

Recipient	Year	Prize	Self-experiment
Neils Finsen	*1903*	*Phototherapy*	*Tested effects of sunlight and fractions of sunlight*
William Ramsey	1904	Discovery of inert elements	Tested anaesthetic effect of gases to find new ones
Elie Mechnikoff	1908	Phagocytes	Injected himself with Borellia to help find cause of relapsing fever
Frederick Banting	1923	Insulin	Gave himself mustard gas burns to test treatment
Charles Nicolle	*1928*	*Cause of typhus*	*Exposed himself to typhus to prove Koch's postulates*
Karl Landsteiner	*1930*	*Blood types*	*Tested his own blood for blood type research*
Gerhard Domagk	1939	Sulfa drugs	Injected himself with sterilised human cancers
Ernest Lawrence	1939	Cyclotron	Drank water with radioactive sodium to examine sodium circulation
George de Hevesy	1943	Polarography	Drank heavy water to determine half-life of H_20 in the body
Max Theiler	*1951*	*Yellow fever*	*Tested yellow fever vaccine*
Albert Schweitzer	1952	Humanitarianism	Tested yellow fever vaccine
Werner Forßmann	*1956*	*Cardiac catheterisation*	*Catheterised his own heart to show it could be done safely*
Rosalyn Yalow	*1977*	*ACTH*	*Tested her own blood in her ACTH research*
Barry Marshall	*2004*	Helicobacter pylori *and ulcers*	*Drank a culture of* H. pylori
Ralph Steinman	2011	Immune system	Tried unproven cancer therapy treatments
Tu Youyou	*2015*	*Malaria treatment*	*Took Qinghao extract*

Those in italics experimented in the area for which they won a Nobel prize. This is an updated table from: Hanley BP, Bains W, Church G. Review of scientific self-experimentation: ethics history, regulation, scenarios, and views among ethics committees and prominent scientists. Rejuvenation Res. 2019;22(1):31–42.

innovations from self-experimenters such as those at the Rapid Deployment Vaccine Collaborative and from companies such as Pfizer, Moderna and Johnson and Johnson. These factors may positively shape public opinion as testaments to the power of science and collaboration. Because self-experimentation is often motivated by altruism, it might positively shape the public's opinion of the virtue of science and scientists.

One concern, though, is that serious harm is possible when individuals take upon themselves scientific and medical activities that are regulated for a reason. Laypeople may overestimate the safety of self-experiment procedures and have confidence in the findings that is disproportionate to the actual significance or reliability of the findings. Using the example of vaccine development, laypeople who prepare or administer vaccine doses according to self-experiment guidelines might suffer serious consequences, especially if they do so without the input of a doctor and outside a context that could offer emergency care. Self-experimentation might encourage such actions, which is concerning since experts and laypeople have differing competencies. This could compromise both the public's health and the public's trust in science.

How should self-experimentation be regulated, if at all?

Some believe self-experimentation should be allowed but with regulatory safeguards, and that self-experimentation would benefit from being subject to review by research ethics committees. Others argue self-experimentation should not be subject to oversight since individuals have the right to self-determination, even if actions taken cause self-harm. The freedom to act according to the principle of self-determination may not hold, though, when more than one person is involved in the experiment, since this is no longer a case of strictly dealing with self-imposed risks.

It is unclear whether people, in the case hypothetical self-experimenters, have a duty to themselves. Outside of the scope of self-experimentation, it is evident that people do often self-sacrifice for a cause. Considering the moral philosophy of whether we have a responsibility to act in our own best self-interest might inform how individuals should relate to self-experimentation.

Some other concerns

One important concern is the possibility for pressure in situations of unequal power; there may be situations ripe for exploitation and coercion. A junior researcher might feel obliged to please a supervisor or an investigator might feel compelled if his best means for prestige and future opportunity comes from subjecting himself to self-experimentation. There is also concern that a researcher might be blind to the risks of his or her own study. Moreover, there is an important question about whether experiments with one subject offer valid data. Some argue that these experiments rarely produce scientifically useful data since important elements, such as having a control subject, are not possible, and self-assessment is heavily prone to bias. If self-experimentation has limited impact value in so much as it may not meet the necessary criteria to produce useable data, then some argue that self-experimentation should be restricted because if a study does not offer a benefit, harm should not be tolerated.

You can watch the forum on ethics and self-experimentation in times of COVID-19 here.

Questions for future research

1. Are there features of self-experimentation, such as greater agility and open information sharing, that can have a place in more traditional research methods?
2. What would be lost if we restrict self-experimentation?
3. How is self-experimentation perceived by different stakeholders and how much should this perception influence the permissibility of self-experimentation?
4. What duty do we have to ourselves and how might an understanding of that shape our conception of what is and is not permissible when it comes to self-experimentation?
5. What lessons does vaccine development in the time of COVID-19 offer to better understand possible future harms and benefits of self-experimentation?

Key concepts

Open source: Decentralised and universal sharing of a product's design or blueprint so that all may see, modify, and distribute the information

Research ethics review: An independent evaluation of proposed research studies to ensure that the research does not proceed unless standards and regulations, largely designed to protect the safety and welfare of human research participants, are met

Self-experiment: An experiment in which the researcher is the subject of her own study

Self-determination: The process by which a person controls his or her own life

Study protocol: A document that describes the study objectives, design, methods, assessment types, and other information

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Suggestions for further reading

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