

Genetic Kinship and the Future of Human Genome Editing

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Abstract

This text offers a feminist inside view of the Third International Summit on Human Genome Editing. It reports on the narratives and voices that were prioritized, and the excitement and tensions that followed some of the arguments presented over the future, limitations, and potentiality of human genome editing. The text offers a snapshot of how ideas of reproduction and kinship shape some of the arguments in favor of and against the advancement of technological breakthroughs. It looks critically at the place of women in science and some of the blind spots of mainstream academia in the pursuit of a genuine global dialogue over the future of human evolution.

Keywords

human genome editing, women in science, reproduction, global governance of science

In March 2023 the Francis Crick Institute hosted the Third International Summit on Human Genome Editing. An array of life and social scientists, bioethicists, transnational organizations, and patients' advocates gathered to discuss the stakes, promises, and risks of changing the course of human evolution by intentionally maneuvering our hereditary traits. At the very start of the summit, we learned from David Baltimore—1975 Nobel laureate in physiology and medicine and host of previous summits—that it was unfeasible to expect some form of international law to regulate human genome editing. Only nation-states, Baltimore said, had the capacity to design, implement, and monitor laws to

Saldaña-Tejeda, Abril. 2024. "Genetic Kinship and the Future of Human Genome Editing." *Catalyst: Feminism, Theory, Technoscience* 10 (2): 1–6.

<http://www.catalystjournal.org> | ISSN: 2380-3312

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govern citizens over the use of these technologies of life. Baltimore's speech made me think about the tension between the expectation of nation-states to regulate the future of human genome editing and an increasing global circuit where physicians, tools, knowledge, human subjects, and biological material move across borders in search of places where new reproductive technologies can be applied. Placing the focus of responsibility exclusively on the nation-state means leaving many actors (i.e., the private sector) unaccounted for and absolved of any wrongdoing (Saldaña-Tejeda et al. 2022).

Baltimore described the 2015 and 2018 summits and their focus on somatic genome editing, bioethics, issues of access and safety. He recalled how the general agreement of the past two summits was that scientists were simply not ready to proceed with germline human editing. Recounting the history of the previous events seemed to have two temporal effects. The first was to demarcate the state of scientific readiness from past to present. The mention of previous agreements served to prove scientists' capacity for self-governance and to provide the moral grounds for scientists to claim readiness in the future. But invoking the past had another important function: to leave the scandal of the first CRISPR babies behind by addressing China's measures to move forward.

Back in 2018, during the previous summit, He Jiankui announced the first CRISPR-edited babies to a deeply disturbed audience.¹ The fallout was the elephant in the room in 2023 and the organizers knew this well. Yaojin Peng from the Chinese Academy of Science presented on China's regulatory changes since 2018. Professor Joy Zhang, from the University of Kent, exposed some of the contradictions of these changes. She suggested how new restrictions over the flow of resources and data might end up isolating scientists from the rest of the world and lead to data bias in global medicine. Zhang discussed how securitization, or the view of genetic resources as matters of national sovereignty and national security, has led to the introduction of gatekeeping policies that might not mean safer science. Although Zhang welcomed a new focus on ethics in state-sponsored research, she warned against missing the ethical oversight in entrepreneurship in science. She challenged the view of China's scientists as submissive by describing open processes of bottom-up participation of scientists and non-scientists alike. The issue of language in relation to China was mentioned twice during the first morning of the Summit. Yaojin Peng mentioned that China had continuously committed to ethical and effective regulation *and* its translation. Later, Ping Yan, from Dalian University of Technology, called to move beyond debates over the CRISPR babies scandal in an American and European context to investigate China's own reaction to the event. She argued that careful attention to Chinese language debates on human genome editing shows a broader and more open involvement of stakeholders (scientists and non-scientists) than is commonly appreciated by many English-language reports. Invoking Gayatri Chakravorty Spivak's concerns, translation is politics, and any real global dialogue over the future governance of science requires taking seriously linguistic power

imbalances. There are regulations, guidelines, and practices around the world that get easily lost in translation. Debates and conversations in the Global South, found in media outlets, legislative chambers, or classrooms are not the missing voices of a much-needed dialogue. These voices are not “missing” in the sense of being lost. Instead, the unilingual limitations of mainstream, English-speaking, academia misses the contribution of some voices that are both heard and central within a local context with global implications.

Over the course of three long and fruitful days, the summit featured an impressive array of presentations on the ethics, governance, and science of human genome editing. In a section titled “Hopes and Fears for Human Genome Editing,” hope was mainly encapsulated by impressive advancements on somatic genome editing for sickle cell disease. Fear was found in the shared indignation at the difficulties of accessibility related to the current price of gene therapies, especially since sickle cell disease affects the most disadvantaged populations around the world. Today, access to basic medical (pain) treatment for sickle cell disease patients is already marked by health disparities that are often the result of race and racism. One can only imagine the challenges ahead for gene cell therapies with a price that ranges from US\$1 to \$3.5 million per patient. The summit included representation from patient advocates and patients themselves. We heard Victoria Gray, the first patient to receive a CRISPR-based therapy for sickle cell disease in the United States. She talked about her personal and life-changing experience with gene editing treatments. The feeling of convergence and camaraderie that Victoria’s moving account scattered among the attendees contrasted deeply with the tension of the third and last day of the summit.

The glee was over as we entered the unavoidable discussion of the future of heritable human genome editing. As if the strain of the subject wasn’t enough, the first panel on civil society and public engagement was repeatedly interrupted by the testing of the fire alarm at the institute. We all had to cope with measures taken to prevent the risk of fire. The disruption reminded us that some risks don’t have an end date and that preventing harm is, sometimes, not negotiable. The alarm disturbed the speeches of all participants in the panel, even those within the most selective groups in academia. Unfortunately, it is not often the case that technology behaves so indiscriminately. While the benefits of science and technology tend to reach the privileged few, the risks and harmful effects of their trial, application, or misuse are often felt by the most disadvantaged places and bodies.

The first section of the last day of the summit was unforgettable—both for the irreverent fire alarm and for a presentation that triggered some attendees’ passions like no other. Tina Rulli, from the University of California Davis, stated that heritable human genome editing has not been nor ever will be considered therapeutic as, before implantation, there was not a person, a baby, or a child to be cured or saved. She questioned the social value of heritable human genome editing, arguing that couples with heritable diseases could form a family through

other means such as adoption or egg donation. That moment became the tipping point of disagreement in the summit. Her arguments fueled some of the most emotionally charged comments at the Q & A session. Attendees shared their reproductive experiences; we heard moving stories about patients' individual cases. These comments were put forward to suggest that Rulli's argument entailed having no empathy for those suffering from rare diseases. There was no other presentation that prompted so many scientists in the room to join the line of questions and comments to express what one of them called "deep concerns" about her claims. Why? Because Rulli offered the most compelling argument against moving forward with heritable human genome editing. That is, that there are ethical limits to our desire to have genetically linked children.

During the summit, bioethicists César Palacios criticized Rulli's argument as she considered "a metaphysical and moral stretch to call a not-yet-created or unimplanted embryo a patient, since its existence is not a given." Palacios suggested that genome editing could be considered therapeutic in cases when an embryo has been created through IVF and, following the procedure, the mother is found to be homozygous for a dominant monogenic disease. Palacios's suggestion that a human embryo could be considered a patient before implantation—and therefore genome editing as therapeutic—could have serious implications for abortion politics. Another summit panelist invited attendees to consider that proceeding with human genome editing was viewed by some as morally better than discarding human embryos ruled out for reproduction after a pre-implantation diagnosis test. These are blatantly obvious pro-life suggestions that must be treated with caution in the context of the overturning of *Roe v. Wade*, the increasing number of unsafe abortions around the world, and the continuous prosecution of women who seek abortion. The fragile moral status of embryos seems to accommodate easily to changing scientific agendas along with political and neoliberal ones, a process often facilitated by a global reproductive market.

There is one claim in favor of new reproductive breakthroughs that seems to be gaining traction: the view that pursuing genetically linked offspring is a human right derived from the right to autonomy and reproductive freedom. There we were, enduring the tautness of what kinship means to us, and here I mean "us attendees," as there are other forms of kinship and parenthood outside our exclusive academic environment. Understanding our biocapacity to have genetically linked children as a human right, using whatever means we have available, is one of the most pressing ethical and societal challenges we face today. When I say "means," I refer not only to the scientific and technological breakthroughs in reproduction. I mean also the knowledge; biological material; the tools; the dubious markets and for-profit ethical review boards; the bodies (human and nonhuman) subjected to clinical trials for the advancement of science; the egg "donors" for reproduction or research; the "borrowed" uterus for transplants undertaken so that people can experience pregnancy; the surrogate mothers from countries such as India and Mexico whose wombs are living

remnants of the violence of extraction that colonization entailed. Ironically, the summit's final day, March 8, coincided with International Women's Day, while the voices of so many women, whose bodies are and will be needed for scientific research to flourish, remain in the dark due to anonymity and confidentiality agreements. A major limit of bioethics is that, in most cases, the very protection of human subjects limits their capacity to speak on their own behalf.

The summit was hosted by an institute that honors the achievements of Francis Crick. He was a scientist known for his work on the discovery of the structure of DNA but also for the controversy around the unacknowledged contribution of Rosalind Franklin to the double helix breakthrough. Just a month after the summit, *Nature* published an article that revisits the story. In the article, historians Matthew Cobb and Nathaniel Comfort (2023) reveal how another woman's work, that of Joan Bruce, could have prevented Franklin's work from going unnoticed. Bruce was a journalist working for *Time* magazine, who, in 1953, wrote an article about the double helix story where she rightly portrays Franklin as an equal player of the team behind the breakthrough. Bruce's take was never published and the story of Franklin as marginal to the milestone discovery took traction. Women are involved in science in many ways, as scientists but also as subjects of research whose reproductive bodies are taken in the name of scientific progress. Women have also written, historicized, questioned, and expressed—through literature, academia, and various forms of art—the complexities and dilemmas of scientific advancements. The harsh reaction to Tina Rullis's presentation reveals the anxiety that strong women in science still provoke not only when they do science but especially when they question some of its premises and assumptions.

In his final remarks, the summit's host, Robin Lovell-Badge, was moved to tears as he thanked the team behind the scenes. As he apologetically explained the incident by lack of rest and food, I thought of the countless times that women in academia must justify or erase emotions from view in the name of rationality and self-control. Lovell-Badge's acknowledgment of those who made the summit possible was one of the most honest and genuine moments of the event. His broken voice reminded us of something that feminists have been arguing for decades: science (scientists) is not neutral, apolitical, or objective. If we are looking for social consensus as the holy grail that would shed some light on the mis/uses of technological breakthroughs—whether that is AI, geoengineering, or human genome editing—we must come to terms with the fact that there is no such thing as a purely rational subject. Whatever is decided over the future of human genome editing will be the result of individual and collective subjectivities. The question is, then, whose subjectivities would be accounted for when deciding over the future of human evolution? It is only by finally rejecting the notion of rational and autonomous subjects that we will be able to find some clues as to how to best sculpt the shared future of our human and nonhuman Anthropocene.

Note

¹ In 2018 scientist He Jiankui announced the first twin babies born with edited genes. The procedure consisted of disabling a gene with the purpose of immunizing the babies against the HIV virus. There is substantial concern that the genetic mutations might not only prove weak to resist HIV but could also have deleterious effects on the immune system and brain function of the twins. Because the gametes' germline was edited, any benefits and damages done to their genetic makeup will be heritable to future generations.

Acknowledgements

This text was written thanks to a visiting fellowship awarded by the Department of Global Health and Social Medicine at King's College London in 2023.

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