The ethics, equity, and governance of human genome editing need greater consideration

Adopting a purely scientific view of human genome editing risks ignoring ethical, societal, and equity considerations, writes Sarojini Nadimpally

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Challenges exist around heritable gene editing, its potential medical applications, ethical implications, and the need for regulatory mechanisms in the field. In March this year I spoke at the Third International Summit on Human Genome Editing, held in London, about “The Role of Civil Society and Culture in Fostering Public Engagement on the Ethics of Human Genome Editing.” In my presentation on public engagement in somatic, germline, and heritable human genome editing, I questioned who the “public or publics” were that we hoped to “engage” with.

The category of “the public” is intersectional, not homogenous, with differences and overlapping identities including race, caste, class, religion, gender identity, disability status, ethnicity, refugee or migratory status, and more. These identities, which are often ignored in the process of developing genome editing, take centre stage when we consider the implications of these technologies. Marginalisation is relevant in the domain of technological advancement, as marginalised communities are largely at the fringes of “public” engagement with genome editing.

This was evident during the summit. A session on genome editing strategies for sickle cell disease (SCD) highlighted a success story of the experimental gene editing technique CRISPR for the treatment of SCD. One patient shared her positive experience of being treated for SCD with CRISPR in the US, where she volunteered to undergo clinical trials. She shared how this helped her cope with severe, debilitating pain as she struggled to care for her four children.

In contrast, I shared the story of a 5 year old boy from a poor tribal family living in a rural district in India, who had to travel 250 km (155 miles) from his village to undergo haemoglobin electrophoresis to confirm or rule out SCD at an institute. I pointed out that people such as this boy must travel long distances to access diagnostic tests. Without adequate healthcare systems, access to medicine such as hydroxyurea, and regular blood transfusions, the treatment trajectory involves travelling long distances and catastrophic out-of-pocket costs, among other obstacles. CRISPR gene editing for SCD may offer solutions for the people who can afford it, but concerns remain around access and equity apart from ethical concerns, as genome editing may not be widely available or affordable for marginalised individuals.

Context and relevance

Conversations about science, technology, medicine, and health must be centred around an economic, political, cultural, and national context lest they lose their relevance to the public they hope to help. The focus of the “Heritable Editing of Embryos” presentations was primarily scientific and rendered the technology separate from the sociocultural context. This did not resonate with my experience of working with reproductive technologies in India, especially in terms of the sociopolitical implications of categorisations such as “disability,” “disease,” and “normalcy.”

In the past 15 years I have witnessed how in India the purely scientific approach to IVF technology has failed to tackle the social construct of infertility, which is still stigmatised. Additionally, many advertisements by fertility clinics have preferred egg donors and surrogates from the upper caste and those with fair skin, for example. Many couples opting for IVF showed preferences for male children with fair skin, particular hair and eye colours, and the misuse of preimplantation genetic diagnostics (PGD) and prenatal testing (PNT) for disability. This raises serious concerns about the development, marketing, and application of advanced technologies such as genome editing, as well as the potential for abuse in the context of existing caste based discrimination, racism, ableism, eugenics, inequities, and a lack of regulation.

The discussions at the summit brought up the challenges of heritable gene editing and its different areas of application and called for ethical and social dimensions to be considered. Like many emerging technological advancements, genome editing must also be subject to public engagement and debate on its ramifications. To increase public engagement there must be an ongoing process of discussion, deliberation, and debate involving a diverse spectrum of people with definitive knowledge, perspective, communication, and power.

It is also important to consider the intersectional identities of the public, especially people who are marginalised and often left out of conversations. These discussions should be premised on the core principles of equity, justice, human rights, autonomy, and accountability.

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1 Stein R. Sickle cell patient’s success with gene editing raises hopes and questions. NPR 2023 Mar 16 https://www.npr.org/sections/health-shots/2023/03/16/116310422/crispr-gene-editing-sickle-cell-success-cost-ethics