



Gene editing: Does it have a place in Africa?

Is gene editing 'blue sky' research in the current African context, or does it have practical applications for use on the continent? And if so, what would the ethical, legal and social complexities be that need to be addressed proactively so as to prevent problems into the future? Globally, laboratory-based basic science research in gene editing is well underway, and clinical applications involving somatic gene editing are already in the early stages. There is no question about the potential for the use of this technology in germline cells. Currently, South Africa (SA) does not have an ethicolegal framework in place around the governance of gene editing, and while we contemplate catch-up, the first CRISPR-edited babies have already arrived.^[1] The 1st SA Gene Editing Conference, an initiative of the SA Medical Research Council (SAMRC) and the Faculty of Health Sciences, University of the Witwatersrand (Wits), at the end of November, brought together local and international experts to discuss and debate these issues, and to consider appropriate and relevant recommendations. The conference organising committee was made up of Profs Glenda Gray (SAMRC), Martin Veller (Wits), Daynia Ballot (Wits) and Ames Dhai (Wits).

Manipulating the genome is not new. What has changed is the pace of this innovation, with CRISPR-Cas9 now making precise, simple and cheap editing of the genome a reality that has the potential to eradicate diseases of poverty, including infectious diseases. Somatic editing affects the individual only. Germline editing, however, is heritable, and will be transmitted to generations that follow, resulting in questions of responsibility to and protection of these future generations. While germline gene editing introduces heritable changes with the potential to stamp out rare and devastating genetic diseases, scientists have expressed enormous concern about off-target effects, and safety.

^[2] Some have called for a global moratorium on heritable genome editing. Lander *et al.*^[2] explain that such a moratorium would not mean a permanent ban. They have made a call for the establishment of an international framework under which countries retain the right to make their own decisions, but at the same time voluntarily undertake not to approve any use of clinical germline editing unless certain conditions are met. These include a fixed period during which no clinical uses of germline editing are allowed, and committing to comprehensive discussions on the technical, scientific, medical, societal, ethical and moral issues prior to permitting germline gene editing.^[2] In the meantime, the US National Academies of Medicine and the UK's Royal Society have brought together representatives from 10 countries (including Prof. Michèle Ramsay from SA) to develop a framework that identifies the scientific, medical and ethical requirements for the clinical use of germline gene editing.^[1] The World Health Organization (WHO) has convened an advisory committee towards developing global standards for germline editing governance and oversight.^[1] Its 18-member interdisciplinary panel includes Justice Edwin Cameron and Prof. Jantina de Vries from SA. These SA experts shared their global insights at the 1st SA Gene Editing Conference. Katherine Littler, senior ethics specialist at the WHO and a participant at the conference, described the governance challenges in this context globally as a patchwork of regulations and responses.

There was general agreement at the conference that not only is Africa ready for somatic gene editing, but that this technology has a major

role to play in addressing the African disease burden. Prof. Johnny Mahlangu highlighted the role of gene editing in inherited bleeding disorders, and Prof. Abdullah Ely addressed gene editing in the context of a cure for chronic hepatitis B virus infection. Prof. Joseph Mfutso-Bengo, a leading bioethicist on the continent, drew attention to two possible ethical reactions to revolutionary technological advancements – technological optimism and technological skepticism. The optimists regard advancements as beneficial for the human condition, with transhumanists believing that technological developments are morally good, and that the fact that one *can* means that one *ought* to forge ahead towards overcoming human limiting conditions. On the other hand, sceptics are reluctant to embrace radical technological advances, especially those by means of which the human condition can be enhanced, citing fears of human dignity being compromised. Their position is that the fact that one can does not necessarily mean that one ought to. He stressed that Africa is definitely a home for human gene editing, and based his arguments on scientific and human equality. All humans, including Africans, have equal dignity and potentially possess equal capabilities, despite having unequal capacity, opportunities and incentives. If Africa is deprived of gene editing research, this could result in creating further health inequalities, and perpetuate the 10/90 gap. Scientific equity should be considered as the means and process of achieving equality. If Africa is left out, there is the risk of missing the bandwagon.

Certain values, norms and standards were emphasised repeatedly at the conference, both by presenters and attending delegates. There is a need for transparency in scientific and governance processes. Vigorous communication is required at several levels, including with the public. The justice principle must be foremost, in that there should be equitable access to these technologies. Gene editing should not be allowed to result in us increasing our current disparities. Patient-centricity, autonomy and the public and common good are essential considerations. Safety is paramount, with protections extending to future generations. Research must be conducted responsibly, and integrity is pivotal. A robust and enforceable ethicoregulatory framework for gene editing that includes these norms and standards is needed as a matter of urgency. To this end, there was an undertaking by Prof. Glenda Gray, President of the SAMRC, to establish a working group of multidisciplinary experts and representatives from the relevant government departments, to develop a national framework for the governance of gene editing.

Ames Dhai

Editor

ames.dhai@wits.ac.za

S Afr J Bioethics Law 2019;12(2):49. <https://doi.org/10.7196/SAJBL.2019.v12i2.702>

1. Opar A. CRISPR-edited babies arrived, and regulators are still racing to catch up. *Nat Med* 2019;25:1634-1636. <https://doi.org/10.1038/s41591-019-0641-x>
2. Lander E, Baylis F, Zhang F, et al. Adopt a moratorium on heritable genome editing. *Nature* 2019;567(7747):165-168. <https://doi.org/10.1038/d41586-019-00726-5>