

Genome Editing for Human Benefit: Ethics, Engagement and Governance

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Guidance and policy paper: Prudence in germline gene editing: The urgent need for collaborative partnerships in Africa

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Brief description of the context

There is an urgent need for collaborative partnerships¹ within Africa, and between Africa and expert organisations outside Africa, to foster Africa's authentic engagement in the critical debate on the ethics of germline gene editing (GGE). Such collaborative partnerships would need to focus on, among others, prudent research-based advocacy, public education and sensitisation, to ensure truly informed policy decision-making in Africa. In particular, this guidance and policy proposal highlights the possibility of international collaborative partnerships between Africa Institute for Human Dignity (AIHD) and expert organisations, such as the Global Forum on Bioethics in Research (GFBR).

Commentary

The advent of the CRISPR (Clustered Regularly Interspaced Short Palindromic Repeats)-Cas9 system in human gene editing is a monumental milestone in the current biotechnology revolution. The beneficial use of CRISPR-Cas9 in somatic cell gene editing is generally uncontroversial and has been widely endorsed. Its use for GGE, however, is beset with serious ethical concerns, mainly because of issues of trans-generational heritability.² Understandably, various Western and other expert organisations have called for due prudence in the pursuit of heritable gene editing.³

Conspicuously, despite its significant burden of genetic diseases, Africa appears to have no articulated position yet on GGE. Although Africa is not a homogeneous entity, the common strands of its postcolonial sociocultural and geopolitical realities, as well as the commonality of its disease burden, warrant a unified outlook on the unprecedented beneficial promises and serious ethical concerns arising from GGE. A good example of a genetic disorder commonly prevalent in Africa is sickle cell disease (SCD). Being a single-gene disorder, SCD would be a particularly suitable indication for therapeutic GGE - because of the possibility of radical trans-generational benefit with relatively minimal risk of off-target mutations. Similarly, therapeutic GGE for the autosomal recessive oculocutaneous albinism (OCA) would not only alleviate (and hopefully eliminate) the disease burden but also possibly put an end to the deplorable superstitious killing of the innocent people with OCA in many parts of Africa. Evidently, GGE heralds potential exponential benefits (including physical and emotional healing; stigma reduction; and prevention of social harms) to many in Africa, and Africa presents a unique opportunity for the research and therapeutic application of GGE. It is imperative, therefore, that Africa proactively engages in the current debate on the ethics of GGE.

Meanwhile, the animated debate on GGE is notable for its lack of consensus on the key foundational concepts that inform human values and human flourishing, namely, the concepts of human personhood, human nature, human dignity, human rights and the human good, among others. Notably, traditional African thought enshrines these key foundational concepts in a cosmological worldview. According to this characteristically traditional African perspective, the metaphysical vital force of being^{4,5} exists in a communitarian and environmental harmony that is centred on the invaluableness of human life.⁶ Critically, human life here refers not only to the living but also to the 'living dead'⁷ and, by extension, to the 'future living'. Hence, African acculturation⁸ notwithstanding, any acceptable GGE intervention in Africa would have to authentically engage with the delicate harmonious African communitarian values (such as 'humaneness', or *ubuntu/botho/obuntubulamu/utu*) and the African reverence for human life. For instance, with the welfare

of current and future human life in GGE being paramount, the possibility of deliberate embryo destruction and abortion in cases of off-target mutations² raises highly contentious ethical concerns. Indisputably, therefore, a precautionary approach to the new GGE biotechnology is indispensable - as highlighted in the various declarations of expert organisations worldwide.³

Conclusion

Prudence^{9,10} in GGE is a global imperative and demands creative recourse to the precautionary principle.¹¹ Although Africa would greatly benefit from ethical therapeutic GGE, it lags far behind in articulating its prudent outlook on heritable gene editing. The urgent need for authentic African engagement in the debate on the ethics of GGE calls for comprehensive articulation of the key concepts and values involved, and for effective public education and sensitisation. As Gyngell et al point out, “[m]aking truly informed decisions about complex scientific matters requires people to understand science ... [and] for people to make truly informed decision on *ethical* matters, ethical education is required.”³ It is vital, therefore, that Africa prioritises the relevant science and ethics education with regard to GGE. To this end, there is need to build authentic collaborative partnerships within Africa, and between Africa and expert organisations worldwide.

Recommendation

In order to foster research-based advocacy for the prudent application of GGE in clinical research and treatment in Africa, it is imperative to develop effective collaborative partnerships between expert organisations, such as GFBR, and committed African organisations, such as AIHD. AIHD is a pan-African Trust domiciled in Gaborone, Botswana. It “is a merit-based not-for-profit non-governmental organisation, which does not discriminate on basis of race, colour, nationality, gender, age, social status, religion or political affiliation.”¹² AIHD aims to articulate contemporary African thought on the dignity of the human person, human values and human flourishing, through a synergistic network of committed scholars and researchers. Indeed, one of its main objectives is to effectively “advise and influence policy and practice in academic and research institutions; governments; non-governmental organisations; business organisations; indigenous leadership settings; youth organisations; communities; and individuals on contemporary African thought on the dignity of the human person, human values and human flourishing.”¹² In particular, therefore, AIHD could be supported in developing and delivering (through its emerging pan-African network) appropriate workshops, meetings and short courses on the ethics of GGE.

References

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