

Genome Editing for Human Benefit: Ethics, Engagement and Governance

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Pecha Kucha: Governance of gene editing in Africa

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Sub-Saharan Africa will benefit from the use of CRISPR technology in various health domains including: treatment of infertility, prevention of heritable health conditions and the treatment of infectious diseases. For example, there is already a proof of concept of the potential CRISPR for the management of Mendelian genetic conditions such as sickle cell disease (SCD) and other β -thalassemia which do not currently have a cure.

Whilst, from a scientific point of view, gene editing could provide solutions to some public health problems in sub-Saharan Africa, it would also need to be adequately governed. This is especially so where changes to the human germline goes beyond somatic changes to include those that could be passed on to progeny. It is important, at an early stage, to identify possible ethical and socio-cultural concerns that are likely to arise if CRISPR technology was to be used in the African setting either for healthcare or research, and how they could possibly be addressed. There are also likely to be macro-justice and equity concerns such as access to gene editing technology by populations in Africa. We envisage that these ethical and socio-cultural issues could be best addressed through governance.

Drawing on a governance framework for genomics research that we recently developed, we will highlight key principles to be considered when developing governance (or adapting already existing governance frameworks) for human genome editing in Africa.