

Medical Committee Briefing Paper

The issue of international regulation regarding gene editing in human embryos

Gene editing is a scientific advancement which enables specific changes to the genetic code of an organism. The rapid progression within this field is raising concerns on the ethical implications on how far this technology will go. Already boundaries and restrictions have been broken to produce individuals with HIV resistance, so what next? Parents picking and choosing what traits, hobbies and skills they want their future child to possess, or medical solutions and treatments to cancers.

The opportunities predicted for these technologies is revolutionary, from eradicating genetic diseases, to aiding in diagnostics and prevention of infectious diseases. A promising technology for gene editing is CRISPR, Clustered Regularly Interspaced Short Palindromic Repeats. This has emerged as a powerful tool scientist and researchers are utilising in many areas of biomedical research and clinical medicine. Scientists have repurposed CRISPR associated proteins to act as molecular scissors, cutting specific sections of DNA to enable deletion and replacement of areas of the genetic code. The FDA has approved the first use of CRISPR therapy to treat sickle cell anaemia after clinical trials showed that participants experienced significant and sustained increases in fetal haemoglobin production. Furthermore, a novel dual gene editing strategy using CRISPR has been shown to provide long term phenotypic correction in mouse model of haemophilia B, providing a promising new approach to the treatment of this disease which affects an estimated 1 in 10,000 people. However, challenges arise in the ethical implications of such advanced technologies, especially at the rate at which it is advancing internationally.

Currently scientists cannot ensure that unwanted modifications within the genome aren't created. This becomes immensely problematic if it occurs during a germ cell editing procedure, as it could lead to hereditary modifications of the genome with unknown, intergenerational side effects. With further progression in scientific development, the technology available will likely become more accurate and hence reduce the probability of imprecise cuts within genetic sequencing. However, this may lead to the technologies becoming more widely available, those motivated by profit may use the new equipment available to their advantage. Genome editing used for non-therapeutic, enhancement procedures may be abused by those who can afford it. It could establish 'classes of people defined by the quality of their engineered genome' (NNHGRI, 2017) creating further disparities in healthcare access and possibly even

encouraging and enabling eugenics. The potential implications of producing further, socio-economic divides on a genomic level through the opportunity to develop “designer babies” many consider not to be worth the medical advancements which could arrive from this technology.

There are varying guidelines in different nations, however there are no comprehensive, international policies regulating genome editing. Distinguishing between somatic (in non-reproductive cells) and germline (reproductive cells) editing is a key step in this process. For example, the United States of America prohibits germline editing, however many countries are still debating the best way to tackle regulation.

Questions you may consider

Should there be different regulations between somatic and germline gene editing?

Should germline editing research continue?

What regulations are required to ensure that ethical obligations are prioritised?

Useful links

<https://medlineplus.gov/genetics/understanding/genomicresearch/genomeediting/>

<https://www.ncbi.nlm.nih.gov>

<https://www.genome.gov>

<https://pmc.ncbi.nlm.nih.gov>