

Committee: Environment

Topic: The question of genetic modification of humans during foetal development

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Summary

Human genetic modification can be applied in two ways: “somatic genetic medication” and “germline genetic modification.” Somatic genetic modification includes adding, cutting or changing genes in some cells of an existing person, a procedure that is generally accepted. However, germline genetic modification which includes the modification of embryos is broadly agreed as wrong in the eyes of many ethicists, policy makers and scientists. However, previous attempts to edit embryos has sparked debate around the issue between people who desire technology to move forward for the benefit of future generations and those who believe it will disrupt society in a negative way.

Definition of Key Terms

Genetic modification - The process of altering the genetic makeup of an organism

Foetus - A developing mammal after the embryonic stage and before birth OR An unborn or unhatched offspring of a mammal in particular an unborn human more than eight weeks after conception

Designer baby - A baby whose genetic make-up has been selected in order to eradicate a particular defect or to ensure that a particular gene is present

CRISPR – A technology that makes it easy to alter DNA sequences and modify gene function.

Background Information

The introduction of CRISPR technology has brought about many new possibilities in terms of genetic modification. China being one of the leading countries in pushing forward research and the Chinese government are even said to have set aside funds to support research particularly linked to the issue. However, there is little information in terms of the legal, cultural and scientific conditions under which the research is conducted. However, many other countries appose genetic modification during foetal development for a variety of ethical, legal and cultural concerns. Most genetic testing to date has undergone to identify or cure serious disorders that will affect the growing foetus. Although, there is concern in the fact that the testing can be used to identify and manipulate much broader characteristics such as the foetus potential sex and height which in the eyes of some is taking it too far. The process also spikes controversy in terms of the foetus not being able to have a say as to whether they have the treatment as it has the potential to cause long term

side effects for the child that have yet to be identified. The U.S government for example being hesitant to fund genetic modification research in humans for these ethical issues.

Major Countries and Organizations Involved

Japan – Holds loose regulations in terms of gene editing and with its status as the “superpower of fertility treatment” it’s likely that research into modification of humans during foetal development could be a key issue for Japan

USA – The USA does not prohibit genome editing as such and the FDA allows germ-line research if it doesn’t fall under “research in which a human embryo is intentionally created or modified to include a heritable genetic modification”. However, they impose limits on funding for research involving embryos and genome editing of embryos in particular.

France – The French Civil Code prohibits the violation of the integrity of the human specie and any eugenic practice aimed at the selection of persons as well as prohibiting modification of genetic traits with the purpose of modifying the germ line.

Germany – Restricts research involving human embryos, enforcing the rules with the threat of criminal charges

China - They are widely recognised as being one of the leading countries in terms of research and experimentation regarding genetic modification during foetal development despite loose regulations against the issue.

United Kingdom – The UK became the first country to license genetic modification human embryos for research

Other important countries include:

- Mexico
- Australia
- Russia
- Israel
- India
- Sweden
- South Korea
- Singapore

Timeline of Events

Date: April 2015

Description: Chinese scientists genetically modified a human embryo for the very first time. It was reported that they attempted to modify the gene responsible for a potentially fatal blood disorder, using a gene editing technique known as CRISPR.

Date: December 2015

Description: The national scientific academies of the U.S, UK and China help the first-ever International Summit on Human Gene Editing where it was acknowledged that research should proceed with subsequent meetings in the following years reaffirmed the significance of technologies such as CRISPR as well preaching extreme caution

Date: February 2016

Description: UK regulators granted approval for a team from the Francis Crick Institute to genetically modify human embryos.

Date: Late 2016

Description: A Swedish researcher manipulated the fabric of a dozen embryos, investigating new ways to treat infertility and prevent miscarriages

Date: July 2017

Description: The US allowed researchers to use CRISPR to edit the DNA of dozens of human embryos [MD1]

Date: November 2018

Description: He Jiankui (Chinese biophysics researcher) [MD2] announced that he successfully used CRISPR to alter the genes of twin girls when they were embryos in hopes for them to be resistant to the AIDS virus

Date: March 2019

Description: A group of 18 scientists from seven countries [MD3] called for a global “moratorium” on introducing heritable changes into human sperm, eggs, or embryos to make genetically altered children

Relevant UN Treaties and Events

- ICGEB The International Centre for Genetic Engineering and Biotechnology [MD4]
- UNESCO Universal Declaration on the Human Genome and Human Rights 1997
- The 1994 Pre-conception and Pre-natal Diagnostic Techniques Act (as amended in 2002)
- The 2006 convention on the rights of persons with disabilities
- Human Rights Treaties:
 - The 1997 European Convention on Human Rights and Biomedicine
 - The EU charter of fundamental rights

- Legal Frameworks:
 - The common heritage regime
 - Environmental law
 - The protection of human rights and fundamental freedoms
- The 2015 International Summit on Human Gene Editing

Previous Attempts to solve the Issue

- The 2015 International Summit on Human Gene Editing
- The group of 18 scientists calling for a global moratorium in March 2019 regarding introducing heritable changes into human sperm, eggs, or embryos to make genetically altered children
- Countries such as China setting aside funding for research regarding the issue

Possible Solutions

- Suggest that gene editing of human embryos should be considered on a case-by-case basis
- Urge the government to set up a new body to ensure that as many voices as possible are involved in public discussions about what should and should not be permissible
- Legislation to ban all genetic modification during foetal development
- Funding for research
- Databases to ensure there is no malpractice
- Creation of a UN sub-committee to oversee issues and monitor progress
- Annual conference to discuss developments in research

Advantages

- It could prevent children from inheriting serious diseases caused by faulty genes
- “Making changes to common gene variants in sperm and eggs could save roughly 5% of babies from painful diseases” - Geneticist at Harvard University
- It could reduce the need for abortions in some cases where one is requested due to serious illnesses recognised in the foetus
- Reduce dangerous black-market genetic modification if it was legalised and regulated
- It could be cost saving in the long term as healthy people require less medical attention in later life and less welfare overall

Disadvantages

- It may worsen inequality and social division
- 'Designer babies' could have a bad effect on society [MD5]
- It could be very costly to regularly provide people with the treatment as well as the start-up costs of getting the required equipment and facilities
- It may infringe on people's religious beliefs
- It could cause illnesses and disabilities that we are not yet aware of

Bibliography

<https://www.ncbi.nlm.nih.gov/books/NBK343651/>

http://www3.weforum.org/docs/IP/2017/HE/HumanGenomeEditing_ScienceEthicsGovernance_NAS_NAM.pdf

<http://nuffieldbioethics.org/wp-content/uploads/Report-regulation-GEHR-for-web.pdf>

<https://www.google.co.uk/amp/s/amp.theguardian.com/science/2018/jul/17/gEnetically-modified-babies-given-go-ahead-by-uk-ethics-body>

<https://www.laboratoryequipment.com/news/2018/10/japan-joins-list-countries-allow-gene-editing-human-embryos>

<https://www.google.co.uk/amp/s/www.inverse.com/amp/article/49725-governments-regulate-human-embryo-gene-editing>

<https://www.google.co.uk/amp/s/qz.com/607032/the-uk-has-become-the-first-country-to-license-genetic-modification-of-human-embryos/amp/>

<https://www.sciencemag.org/news/2019/03/new-call-ban-gene-edited-babies-divides-biologists>