



## A Reckless Experiment: on Gene-edited Babies

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(The editorial is based on the article “A reckless experiment: on gene-edited babies” which appears in The Hindu for 24th January 2019. In this editorial we will see the various aspects of the governance of human genome editing, especially important now, since it has been used for altering the genes of human embryos.)

[Read the earlier editorial here.](#)

**“Editing the ‘human germline’ is an exercise fraught with unknown risks”** - this sentence sums up the truth about the state of genetic science today. Apparently, it is no longer only about ethics (perhaps it always had been like that) as scientists discover that suppressing one gene may cause ‘unknown’ (unknown as of yet) reactions or results elsewhere in the human body.

**For example**, in the case of the Chinese Dr. He, who deactivated the CCR5 gene in a newborn to protect it against HIV resulted in making the baby ‘more susceptible to West-Nile Fever’. Therefore the working word here is - ‘unknown’ - unknown as in what will happen if we manipulate the human germline, what sort of risks will we face when existing diseases react to gene-edited human beings, or will the genetic inheritance of babies born to gene-edited parents be good or bad for them, etc. These type of questions, whose answers may take decades to unravel, are being debated and experimented with across the world of genetic science.

Now, let us take a look at some of the acting and proposed principles for Human Genome Editing.

### The proposed principles for Human Genome Editing:

- **Promoting well-being:** The principle of promoting well-being supports providing benefit and preventing harm to those affected, often referred to in the bioethics literature as the principles of **‘beneficence and nonmaleficence’\***. **Responsibilities that flow from adherence to this principle include - (A)** pursuing applications of

human genome editing that promote the health and well-being of individuals, such as treating or preventing disease, while minimizing risk to individuals in early applications with a high degree of uncertainty; and **(B)** ensuring a **reasonable balance of risk and benefit** for any application of human genome editing.

- **Transparency:** The principle of transparency requires openness and sharing of information in ways that are accessible and understandable to stakeholders. Responsibilities that flow from adherence to this principle include **(A)** a commitment to **disclosure of information to the fullest extent possible** and in a timely manner, and **(B) meaningful public input** into the policy-making process related to human genome editing, as well as other novel and **disruptive technologies\***.
- **Due care:** The principle of due care for patients enrolled in research studies or receiving clinical care requires proceeding carefully and deliberately, and only when supported by sufficient and robust evidence. Responsibilities that flow from adherence to this principle include **proceeding cautiously and incrementally, under appropriate supervision** and in ways that **allow for frequent reassessment in light of future advances and cultural opinions**.
- **Responsible science:** The principle of responsible science underpins **adherence to the highest standards of research**, from bench to bedside, in accordance with international and professional norms. Responsibilities that flow from adherence to this principle include a commitment to **(A)** high-quality experimental design and analysis, **(B)** appropriate review and evaluation of protocols and resulting data, **(C)** transparency, and **(D)** correction of false or misleading data or analysis.
- **Respect for persons:** The principle of respect for persons requires **recognition of the personal dignity of all individuals**, acknowledgment of the centrality of personal choice, and respect for individual decisions. ***All people have equal moral value, regardless of their genetic qualities.*** Responsibilities that flow from adherence to this principle include **(A)** a commitment to the equal value of all individuals, **(B)** respect for and promotion of individual decision making, **(C) a commitment to preventing recurrence of the abusive forms of eugenics\* practiced in the past**, and **(D)** a commitment to destigmatizing disability.
- **Fairness:** The principle of **fairness requires that like cases be treated alike**, and that risks and benefits be equitably distributed (distributive justice). Responsibilities that flow from adherence to this principle include **(A)** equitable distribution of the burdens and benefits of research and **(B) broad and equitable access to the benefits of resulting clinical applications of human genome editing**.
- **Transnational cooperation:** The principle of transnational cooperation supports a commitment to collaborative approaches to **research and governance while respecting different cultural contexts**. Responsibilities that flow from adherence to this principle include **(A)** respect for differing national policies, **(B) coordination of regulatory standards** and procedures whenever possible, and **(C)** transnational collaboration and **data sharing** among different scientific communities and

responsible regulatory authorities.

**\*Beneficence:** The quality of being kind, helpful or generous; **Nonmaleficence:** Non-harming or inflicting the least harm possible to reach a beneficial outcome; **Disruptive technologies:** A disruptive technology is one that displaces an established technology and shakes up the industry or a ground-breaking product that creates a completely new industry. Harvard Business School professor Clayton M. Christensen coined the term disruptive technology; **Eugenics:** The study of methods of improving genetic qualities by selective breeding (especially as applied to human mating); **Huntington's disease:** An inherited condition in which nerve cells in the brain break down over time.

**Starting from December 2018, the WHO is establishing an expert panel to develop global standards for governance and oversight of human gene editing.**

- It will be a global multidisciplinary expert panel which **will examine the scientific, ethical, social and legal challenges** associated with human gene editing (**both somatic and germ cell\***).
- The panel will **review the current literature** on the state of the research and its applications, and **societal attitudes** towards the different uses of this technology.
- WHO will then receive advice from the panel on **appropriate oversight and governance mechanisms, both at the national and global level.**
- Core to this work will be understanding **how to promote transparency and trustworthy practices and how to ensure appropriate risk/benefit assessments are performed** prior to any decision on authorization.
- **The recent application of tools such as CRISPR-Cas9 to edit the human genome have highlighted the need for the development of standards in this area.**

**\*Somatic and germ cell difference:**

- **Somatic** cell gene therapy changes/fixes/replaces genes in just one person. The targeted cells are the only ones affected, the changes are not passed on to that person's offspring.
- **Germ line** gene therapy makes changes in the sperm or egg of an individual. The changes that are made, adding or subtracting genes from the person's DNA, will be passed on to their offspring. This type of gene therapy raises a lot of ethical questions because it impacts the inheritance patterns of humans.

## Way Forward

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- **Like most other issues, the answer to the question of whether or not to manipulate the human genome lies somewhere in a grey area.** We can clearly see the advantages of it while being able to recognise at the same time that there could be great dangers to the entire human race if 'the experiment' goes wrong.

- Ethically speaking, the argument that genetic modification is unnatural will perhaps not play out right in the long run as it is based on the assumption that all things 'natural' is good. It doesn't take much to consider otherwise because the modern world is nothing but unnatural (as in man-made; imagine houses, cars, phones etc).
- That 'ethical issues presented by altering the germline in a way that affects the next generation without their consent', also won't work because every new generation inherits its traits (be technologies like computers, or various laws etc) without the consent of their own. The current (and living) generations are always and will always be, responsible for the next (yet unborn) generations.
- **In any case, 'the error-rates of Crispr (CRISPR-Cas9) are falling with each passing year' and the future is for genetic editing but with oversight and regulations.**
- Therefore, we should first certainly find out as much as possible about the risks of gene-editing human embryos before any and such research can proceed. **But when the suffering and death caused by such terrible single-gene disorders as cystic fibrosis and Huntington's disease might be averted, the decision to delay such research should not be made lightly.**

To conclude, one may say - *'Just as justice delayed is justice denied, so, too, therapy delayed is therapy denied'*. That denial costs human lives, day after day. Considering that protecting and saving human lives is the cornerstone of all human-ethics, as such, research into human gene editing should continue but with appropriate safeguards and regulations in place. There is simply no way to wish this away.