

# Human Germline gene-editing

## Introduction:

Human germline gene-editing is the process by which the genome of an individual is edited in such a way that the change is heritable. This is achieved through genetic alterations within the gametes, such as the egg and sperm. Germline gene-editing is different to somatic gene-editing in which changes made to the DNA remain in one generation. When looking at human germline gene-editing, there are many ethical considerations to take into account.

## Method:

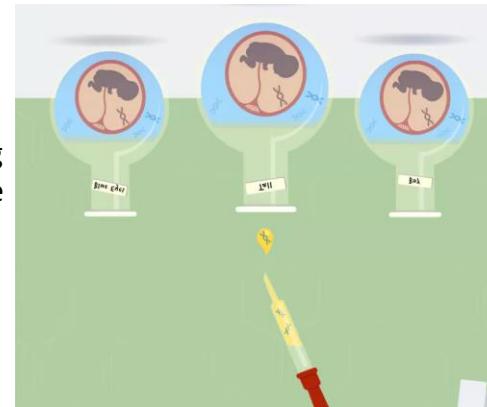
Gene editing is a group of technologies that give scientists the ability to change an organism's DNA. These technologies allow genetic material to be added, removed, or altered at particular locations in the genome. Human germline gene editing was made possible with the discovery of CRISPR-Cas9. CRISPR-Cas9 is short for clustered regularly interspaced short palindromic repeats and CRISPR-associated protein 9. CRISPR-Cas9 was adapted from a naturally occurring genome editing system in bacteria and works similarly in the lab.

Researchers create a small piece of RNA with a short "guide" sequence that binds to a specific target sequence of DNA in a genome. The RNA also binds to the Cas9 enzyme. As in bacteria, the modified specific guide RNA is used to recognize the DNA sequence, and the Cas9 enzyme cuts the DNA at the targeted location. Once the DNA is cut, researchers use the cell's own DNA repair machinery to add or delete pieces of genetic material, or to make changes to the DNA by replacing an existing segment with a customized DNA sequence. It essentially acts as a cut and paste tool. In the future scientists hope to use CRISPR-Cas 9 to develop critical advances in patient care or even cure lifelong inherited diseases.

- Many people are concerned that genetic enhancement will infringe on the child's autonomy in a way that makes it more difficult to shape her own destiny. Gene therapy for the treatment of severe disease is considered ethical because it can be supported by the fundamental moral principle of beneficence: It would relieve human suffering. Gene therapy would be, therefore, a moral good.



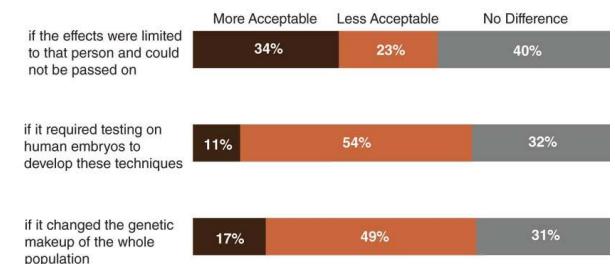
- Moreover, you are altering the genome of future generations without consent, which violates their autonomy. If parents are able to have an input in a child's genome, they are in a sense writing the genetic instructions that shape his entire life. If your parents gave you green eyes instead of brown eyes or if they make you tall instead of medium height, their choices will have a direct, lifelong effect on you. If a parent decides to genetically engineer a child with the goal of being tall, many would argue that the parents' decision is preventing the child from being fully autonomous. If the height of the child works out in her favour, do the parents deserve some (or all) of the credit? What if her height works against her in some way? Are the parents to blame? If the child was allowed to develop without any genetic enhancements ("natural lottery"), her personal autonomy would never have been violated, her decisions would have been hers alone, and her accomplishments and failures would have fallen on her shoulders.



- The transition from therapy to enhancement in medicine is significant, but it can be difficult to establish in some cases. If you were able to lower a person's cholesterol for example, where would the cut-off be? Some scholars have reasonably objected to, or at least raised difficulties with, the distinction between therapy and enhancement. For instance, how should we think about vaccinations: are they a form of therapy or are they an enhancement of our immune system? On one hand, a vaccination seems to be an enhancement in that there is no existing pathology it is attempting to cure, merely a possible or likely pathology we wish to avoid. However, it could be considered as preventative therapy.
- Furthermore, the use of germline gene-editing for enhancement is a scary prospect. It is the opening of a return to the agenda of eugenics: the positive selection of "good" versions of the human genome and the weeding out of "bad" versions, not just for the health of the individual, but for the future of the species.

- Human germline gene-editing can be used for both enhancement and therapy reasons. Enhancement is the directed use of biotechnical power to alter, by direct intervention, not disease processes but the "normal" workings of the human body and psyche, to augment or improve their native capacities and performances.
- An example of enhancement through germline gene-editing is changing the gene for eye colour of an embryo- This is not done for medical reasons but rather for aesthetic reasons.
- One the other hand, therapy is the use of biotechnical power to treat individuals with known diseases, disabilities, or impairments, in an attempt to restore them to a normal state of health and fitness. For example, sickle-cell anaemia is an inherited disorder that causes the red blood cells to develop into sickle (or crescent) shapes, instead of the normal, healthy disk shape. Those with sickle cell anaemia can have a variety of symptoms, including poor circulation, increased risk of infection, and a decreased life span. It was found that sickle cell anaemia can be treated using CRISPR Cas9 as it is caused by one mutation.
- The lines when looking at human germline gene-editing is blurred because the side opposing human germline modification believes that it will be used to create humans with "perfect", or "desirable" traits. Those in favour of human germline modification see it as a potential medical tool, or a medical cure for certain diseases that lie within the genetic code. There is a debate as to if this is morally acceptable for human germline gene-editing to go further than research and be used clinically. While typically there is a clash between religion and science, the topic of human germline engineering has shown some unity between the two fields.

**Public Beliefs about the Acceptability of Gene-Editing Research**  
Percent of U.S. adults who say gene-editing that gives healthy babies a much reduced risk of serious diseases would be more acceptable, less acceptable, or make no difference...



Respondents who did not give an answer are not shown.  
Source: Pew Research Center, N=4,726, survey conducted March 2-26, 2016.