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POLICY MEMO
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8TH GRADE LEARNING EXPEDITION PROBLEM STATEMENT

GENETICS AND ETHICS

Gene editing is a powerful biological tool with potential to both improve the world and endanger it. Currently, there is no significant legislation on this issue due to a lack of understanding of potential impacts of gene editing.

How can we inform the public on the ethical implications of gene editing, and make recommendations to Congress regarding its regulation?

MEMO SUMMARY

Ever since 1987 when it was first discovered the natural genome editor known as CRISPR/cas 9 A natural bacterial immune system has given scientists the opportunity to both learn about and edit the genome of organisms in a way scientists never thought previously possible. CRISPR/cas9 is a tool that can be used to change an organism's features or traits in their genome by essentially cutting a strand of an organism's DNA and then binding itself to it. With this constantly evolving tool humans now have the ability to potentially cure or wipe out all genetically born diseases. This brings up the question of how far we as a society will be able to both ethically and safely utilise this tool. One of the biggest problems facing the gene editing community is the inevitability of biohackers taking gene editing too far. Because of CRISPR/cas9's low cost and high accessibility a unregulated community of people known as biohackers have been doing tests on themselves and other organisms without proper forsite of the consequences of their actions.

By doing this they are both endangering themselves and others. This experimentation is dangerous because without proper oversight they could unknowingly change our environment or themselves in unintended ways. This is relevant to today because the high cost of formal treatments using CRISPR/cas9 and gene editing tools is encouraging people with genetic disease and disorders to buy low cost experimental unregulated treatments created by biohackers and other unregulated sources. This policy memo will look into the chaotic world of gene editing and how we as A society can better regulate the use of substances such as CRISPR/cas9.

BACKGROUND INFORMATION

Of the unethical and unregulated world of gene editing here are four explainers on the background of what this policy memo is about to help you fully understand the topic at hand.

CRISPR/CAS9 AND GENE MUTATIONS

As stated in the summary CRISPR or clustered regularly interspaced short palindromic repeats is a natural genome editor discovered in 1987. But it wasn't until 2012 when two biochemist's named Jennifer Doudna and Emmanuelle Charpentier introduced the idea of using CRISPR/cas9 for editing genes. By doing this they created one of the biggest discoveries in the field of biochemistry.With this new technology humans now have the ability to both test and cure genetically born diseases and mutations. This brings us to the next point : mutations, mutations in the words of The American Cancer Society medical and editorial content team, are abnormal changes in the DNA (deoxyribonucleic acid) of genes. The two major types of gene mutations are acquired and inherited mutations. Acquired mutations also known as sporadic, or somatic are mutations acquired later in life and cannot be inherited. On the other hand inherited mutations also called germline or hereditary are as mentioned by the The American Cancer Society medical and editorial content team are when after the egg is fertilised it creates a zygote which divides to become the fetus.

Since all the cells are replicated based on the cell containing the mutation or zygote all of the subjects cells will contain the mutation allowing it to be passed down to the subjects future generations. Mutations connect to gene editing because certain genetically born diseases such as cancer which are usually caused by acquired mutations such as can be cured by gene editing.

CONSEQUENTIALIST THEORIES OF ETHICS

Ethics are the moral principle that guides someone's decisions in life. For example the choice to help a stranger you don't know. A common flaw in people's perception of ethics is confusing other topics such as morals for ethics. Though both ethics and morals are closely related, that doesn't mean they are the same. This is because morals are the ideas that are governed by the principles of ethics. According to the article "A Framework for Making Ethical Decisions" in Ethics there are three broad types of ethical theory. These theories are consequentialist theories, Non-consequentialist theories, and Agent-centered theories. In class, we learned about the three main approaches of consequentialist theories: the Utilitarian approach, the Egotistical approach, and the Common Good approach.

The Utilitarian approach or utilitarianism is a theory that understands that there will always be good and bad results from whatever choice someone makes In a situation. Instead, it focuses on how to get the best result for the largest number of people. The utilitarian approach is the most common of the three main approaches. The most common ethical scenario that uses utilitarianism is the trolley problem. The trolley problem is an ethical dilemma that forces you to make the decision to kill one person to save five or let the five die to save the one. About 80%-90% of the participants choose to kill one person to save the five giving the best outcome to the largest number of people in the situation. Many participants choose this because by killing the one to save the five they are giving themselves the result that leads to the most amount of pleasure and the least amount of pain. The trolley problem presents a simple way of demonstrating the Utilitarian approach without the real-life implications of the aftermath of the situation.

The egotistical approach or ethical egoism is the second of the three main consequentialist theories. Ethical egoism is a variation of the utilitarian approach where the subject in question uses utilitarianism to get the best outcome for themselves regardless of how it affects others. Ethical egoism is sometimes confused with or compared to laissez-faire economic theories. Laissez-faire economic theories like ethical egoism focus on self-interest but unlike ethical egoism, laissez-faire economic theories focus on how self-interest leads to benefiting society, unlike ethical egoism which only treats the benefits to society as an after effect of the subject's decision.

The common good approach is the third of the three main consequentialist theories. The common good approach focuses on the outcome that gives everyone most commonly in a community or society the best results for everyone. With that said the common good approach focuses on respect and compassion to others with special emphasis on the elderly or the disabled, the people who are most vulnerable.

These are the three main approaches to consequentialist theories and even though there are many more ethical theories with many more approaches to each one. I hope you have gained a more solid understanding of the three main ethical approaches to consequentialist theories.

DNA TESTING AND HOW IT WORKS

DNA or deoxyribonucleic acid is a spiral-shaped molecule inside cells of all living organisms that carry genetic information. With DNA tests you can learn about your ancestors or if you or your family may be at high risk for a disease or genetic disorder For example in the article “DNA Tests Allow Doctors to See Into the Future" the text talks about a woman who had gallbladder cancer and through genetic testing her doctors discovered that drugs used on leukemia patients might work for her. That being said Not all DNA tests tell you about your ancestors and not all DNA tests tell you of your risk of disease in this way DNA testing kits are not all equal. In class, we learned about the three main types of testing kits.

The first main type of testing kit is whole-genome sequencing. Whole-genome sequencing according to the text “Explainer: How DNA Testing Works” looks at an organism's full genome and tries to read all of it but sadly while doing this the test usually accidentally misses some of the information. Testing kits that use whole-genome tests will miss big chunks of DNA or DNA that have been rearranged furthermore it may miss a section if the said section was repeated frequently. Some of the companies that use these tests are Veritas Genetics and Darwin’s Ark.

The second main type of testing kits is Exome sequencing. Exome sequencing according to the article “Explainer: How DNA testing works” looks at the proteins and only reads a very small percentage of it. Furthermore, exome sequencing excludes all the genes that don't make said proteins. Some of the companies that use this type of test are Genos and Helix.

The third and final main type of testing kits is nucleotides testing. The nucleotides testing according to the text Explainer: How DNA testing works looks at SNP's and looks for the misspellings in the genome. In DNA there are four letters, these being adenine (A), cytosine (C), thymine (T), and guanine (G). These letters give the instructions that tell cells what molecules they should make furthermore these letters all go in a precise order. With nucleotide or SNP testing, the test looks at these letters to find the misspellings. The companies that use this type of testing are Ancestry, 23andMe, Wisdom Panel, home DNA, and emBark.

With testing kits regardless of which one you use, DNA testing kits can give you valuable information from your ancestry to what genetic traits are prominent in your family and even in some cases save someone's life.

THE ETHICAL IMPLICATIONS OF GENE EDITING AND CRISPR/CAS9

The ethics of DNA testing have been a grey area in gene testing companies for many years. This is because Using home DNA testing kits is both ethical and unethical (even if companies tend to be unethical.). DNA kits can be used ethically by companies if the companies use their kits to help their customers learn about themselves while also keeping all of their customers' information private.

But on the contrary DNA testing kits can be used unethically by companies as a means to sell their customer's genetics and other information to outside sources without their knowing consent.

According to the first main approach of consequentialist theories, DNA testing could be used ethically if testing companies just kept their customers' information private because in the text “Ethical Use of Home DNA Testing” the text states “its privacy policy 23andMe states that “This class action lawsuit claims that personal information was released to outside parties without customer consent. Further contentions include that the waiver of consumer rights through consent forms is often vague, general in scope, and ever-changing. The fine print may not accurately spell out what the company, its third-party associates, and collaborators can or will do with customer information. ” This use of shared information allows testing services and third parties to build a comprehensive personal profile on you, which may include your genetic information. ” What this shows is that a big problem these companies have is not keeping their customers' information to themselves and selling their information to other sources. If companies just kept their customers' information to themselves the companies would be using utilitarianism because then both the customer would only lose money and gain information getting the most pleasure for the least amount of pain. Rather than getting information about their DNA at the price of their personal information and of course money showing the egotistical approche.

Overall, DNA testing has the potential to be both ethical and unethical. The real problem is that there are no real guidelines on how this information that the testing companies have must be handled and shared. Most companies know this if they didn't they wouldn't put stuff about your information being sold or used if they didn't plan on selling or using it in the disclosure agreement.

With that, I hope you understand that DNA testing companies can be ethical. They just choose not to and some companies are ethical and do amazing things but even then from what I've seen through the articles in class they are one in a million.

POLICY RECOMMENDATION

Now that you the reader have at least a base level of understanding of the topic at hand this is an example of what A policy recommendation at least at base level should be on how CRISPR/cas9 and other sources of gene editing should be regulated to ensure the safety of both patents and the environment.

1) All gene editing practices public or private and acts of legeslation must not break or make exceptions to any of the rules explicitly written in the Nuremberg code of ethical conduct. Along with said proposal all gene editing practices will be required to read the full form of consent to their patient before they may sign the consent form. Failure to comply by these rules make the guilty practice's owner viable to lawsuits and in more serious cases jail time or complete shutdown of the practice.

2) All gene editing cures and treatments shall not go over the monthly income of the average middle class family. Along with that there must be only one upfront cost for the whole payment that the company or practice may add to.

3) Any and all breakthroughs in the gene editing community no matter the country will be made public and transparent on the international scale. Any and all world changing experiments must first be looked over and approved by approved medical professionals. Each proposal may only be looked over when deemed needed in a state of international or state crisis.

4) All gene editing and CRISPR/cas9 must only be used for medicinal purposes except in the presence of international crises. Any and all gene editing experiments must be done in A contained lab with professionals ready to dispose of said edited genes if deemed necessary. Any and all attempts at commercialization of gene editing and testing will be met with serious consiquences.

CONCLUSION

This recommendation may be strict but in the presence of a significant problem strict regulation must be instituted to insure we as a society don't cross the ethical lines we have instated. Because of the morally grey area that the gene editing and testing community has become we need strict clear guidelines. With these regulations we can safely control the way CRISPR/cas9 and other sources of the gene editing community as it becomes more researched and better understood.