iGEM Ethical Guideline

for Human Practices

(iGEM Toronto Example)

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Promoting well-being

Our project aimed to promote the well-being of the end users of gene therapy. The core of our Human Practices project involved interviewing professionals and those who interact with possible end users of gene editing. The reason we chose to take this approach was directly related to the concept of promoting well-being. In thinking about possible applications of our project we recognized the likelihood that such a project would increase the presence of gene-editing. While this is an exciting prospect it is also something that comes with many ethical roadblocks. In conducting our interviews one of the main goals was to parse out these concerns and have an in-depth analysis of how we may promote the well-being of end-users.

Transparency

By conducting interviews directly with stakeholders and experts we took complex subject and created digestible and accessible videos which most can understand. Those concerned with different areas of the subjects can find videos that relate to that area. In having these available those who may have little knowledge of the subject or want to learn more about an area that relates to them can easily access such material. While we do not claim this is the be all end all of available information we feel it is a good start for community members to learn more about the topic. As apart of creating easily understood content for every person we ensured that each video was subtitled to meet accessibility needs for those who may need. This was an important aspect as in discussion such an issue we understood that the content should be easily understood by everyone especially those with disabilities; of whom the videos heavily discuss.

Due care

Due to the foundational nature of our project we did not directly apply this to our design. However, our process of carefully considering all the issues allows for due care in the future. As our project advances and the uses of CRISPR-Cas9 become more advanced considerations we have made will have to be applied. As such those using the technology will need to ensure that the principle of due care is applied. Before any such advance in the application of gene editing are made we must ensure that the technology is of the highest quality. This was something expressed by nearly all of our interviewees. In order to ensure due care is met the technology must be of a level that no mistakes are foreseeable.

Responsible science

By consulting with stakeholders and end users we promoted the practice of responsible science. Something one must acknowledge is that the science does not simply stop in the lab. Our process of considering the the real-world application of CRISPR-Cas9 encouraged the extension of scientific advances beyond the lab. By doing this we put ourselves in a position to encourage the thoughtful and responsible applications of our project. To fully practice responsible science, one must think about all the possible applications of this technology and its consequences. By consulting with experts and stakeholders we were able to take their advice and thoughts and consider how we may look to restrict or extend the reach of CRISPR-Cas9 in the future.

Respect for persons

A key component of respect for persons involves acknowledging individual autonomy. When one's autonomy is recognized they can make informed decisions about their own well-being. The hope with our project was to encourage individual autonomy by giving community members the tools make informed decisions. By creating an easily understood dialogue about the possibilities of gene editing we have enabled individuals to apply their own values to its use. Whether they may choose to use this technology in the future is up to them; but by giving them the tools to explore such a possibility we have applied the principle of respect for persons.

Fairness

Fairness as applied to our project is one thing that appeared multiple times when conducting interviews. A key issue in the fair distribution of the technology was present; that is, who will have access to such technology? This is something we hope will be explored more as gene editing becomes more prevalent. In order to ensure the science is fairly distributed socio-economic status will play a huge role in this discussion. Another issue on the topic of fairness was the status of disabled people in our community. The advocates for disability rights who we spoke to expressed great concern for the place of disabled citizens in this technology. The concern that needs to be explored is how we can implement this technology without further stigmatizing disabled people. In a world where having a disability is often considered a negative by society how will we ensure the rights and considerations of the disabled are preserved?

Transnational Cooperation

The nature of this project inherently global, the creation of these technologies is not something that is easily controlled. A scientific advance such as this is something that would contain knowledge and applications available to the world on a global basis. While this is not something we could directly address it is something we acknowledge needs to be considered. Due to the power of this technology and its possible usage there should be needs to be thorough discussion between countries on the availability and uses. Such a discussion would need a large amount of co-operation between countries in order to ensure safe advancement of CRISPR-Cas9.