

# **iGEM Ethical Guideline**

## for Human Practices

Created by: iGEM Toronto

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## Promoting well-being

While our project started as a foundational advance and focused on one application, we started each of our research efforts with a clear goal in mind. In particular, when we applied our tool to gene editing, our human practices directed their efforts 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. In doing so, we identified key risks and benefits of our application. 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 stakeholders.

## Transparency

Transparency was a key consideration in our research. Firstly, we made our methods easily accessible by making our wiki searchable (through a search bar and colour coding) and organizing our notebook by experiments. We also constantly updated our protocols throughout the summer to ensure future teams could benefit from our experimental insights. Secondly, we realized the need for clear and informed dialogue with our stakeholders. While, it is not the job of researchers to promote and influence the public, resources that provide context for a meaningful discussion are invaluable. We conducted interviews directly with stakeholders and experts where we took complex subject and created digestible and accessible videos. Those concerned with different areas of the subjects can find videos that relate to that area. 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. Each video was also 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.

However, it should be mentioned that better documentation of safety protocols and equipment can be improved upon to meet the high standards mentioned in our guide. This can be achieved through developing resources that promote safety culture like fire or biological spill drills which is often missing in most biosafety programs.

## 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, recommendations from our guide 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

Firstly, we made sure to include assumptions in our ODE model were clearly identified. Moreover, we detailed confounding variables in our assays such that future researchers can accurately interpret and replicate our data. We also organized meetings with Ontario teams to provide feedback. However, we could improve our efforts by developing the committee and review board models shown in our guide.

## 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.

## Useful resources:

1. Imperial College 2016 PBL + STIR protocol
2. iGEMer' Guide to the future (Synenergene)
3. Responsible Research and Innovation Tools (RRI)
4. Human Genome Editing: Science, Ethics and Governance
5. Genetically Engineered Crops: Experiences and Prospects
6. Gene Drives on the Horizon: Advancing Science, Navigating Uncertainty, and Aligning Research with Public Values
7. Workshop on Gene Editing to Modify Animal Genomes for Research: Scientific and Ethical Considerations (Institute for Animal Laboratory Research [ILAR] Roundtable)
8. Future Biotechnology Products and Opportunities to Enhance Capabilities of the Biotechnology Regulatory System
9. Communicating Science Effectively: A Research Agenda
10. Public Participation in Environmental Assessment and Decision Making
11. Understanding Risk: Informing Decisions in a Democratic Society