# Designing a Smartphone App to Educate on CRISPR

## The Ethical Implications of CRISPR in Human Genetic Modification

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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#### Introduction

The scientific landscape has witnessed a plethora of leaps in innovation in recent years, reshaping our understanding of life at its most fundamental level. One of the most important of these innovations is the Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR) and its associated protein, Cas9. At its core, CRISPR-Cas9 is a naturally occurring system found within bacteria, serving as a form of acquired immunity. These bacteria utilize CRISPR to precisely target and neutralize invasive genetic material from viruses by cutting them at specific locations. Scientists, harnessing this inherent mechanism, have repurposed CRISPR-Cas9 as a customizable tool that can accurately target specific sequences of DNA in any organism (Doudna & Charpentier, 2014).

In medicine, CRISPR offers hope for treating a host of genetic disorders, from cystic fibrosis to sickle cell anemia, by directly rectifying the underlying genetic anomalies (Ledford, 2015). Beyond therapeutic interventions, CRISPR holds promise in the field of agriculture, where it can be used to engineer crops that are more nutritious, resilient to pests, or tolerant to harsh environmental conditions. Additionally, in the realm of biological research, CRISPR serves as a tool, enabling scientists to probe the functions of different genes, helping to deepen our understanding of the intricacies of life.

While CRISPR has many positive implementations, the technology comes with many concerns as well. One of the most prominent concerns surrounding CRISPR is the idea of "designer babies." The technology's potential to modify the human germline means that changes made to an individual's DNA could be passed on to subsequent generations. Such alterations, once introduced into the human population, could become irreversible, potentially reshaping the trajectory of our species in unpredictable ways (Knoppers & Kleiderman, 2019).

Beyond the human realm, the application of CRISPR in ecosystems, termed "gene drives," presents another set of challenges. While the technology could be employed to combat pests or control disease vectors, the long-term ecological consequences remain largely unknown. Introducing or removing a particular species from an ecosystem could have devastating effects on biodiversity, leading to unforeseen imbalances. Furthermore, the dual-use nature of CRISPR means that the same tools used for beneficial purposes could be misappropriated for malicious ends, raising biosecurity and bioterrorism concerns. The possibility of weaponizing gene-editing tools, either to create enhanced pathogens or to target specific genetic profiles, is a looming threat that necessitates robust international oversight (Kosal, 2020).

Amidst these complex challenges, the role of the public becomes paramount. For technologies that have such profound societal implications, it's essential that decisions about their use are made collectively, informed by diverse perspectives. However, the current landscape of CRISPR communication is lacking. Many segments of the population remain unaware or misinformed about the technology's nuances, potentials, and risks. This knowledge gap can lead to unwarranted fears, misconceptions, or an uninformed acceptance of the technology.

Therefore, there's an urgent need for comprehensive and accessible educational platforms dedicated to CRISPR. While the scientific community is well-versed in the technology's intricacies, the broader public remains largely in the dark. Bridging this gap is crucial. It is vital that society, particularly the people in wealthier nations where this research is being conducted and experimented with, namely the US, Germany, China, and Japan , is equipped to make informed decisions about how, when, and where CRISPR technology should be deployed. This is because in these regions, the people living there are the ones being affected by CRISPR the most,

whether that be the pesticides being used in the crops or CRISPR being used in the medicines consumed. While the public cannot make decisions on the use of CRISPR directly, it is still important for them to be informed as they can make decisions on what food they buy, what medical treatments they opt in for, and even what politicians they elect, who do have the power to control the use of CRISPR.

This is why I propose the solution of creating an interactive app with the sole purpose of educating the general public on the advantages, disadvantages, and nuances of CRISPR in order to create a community around the technology and garner consolidated public opinion. In addition, I will research into how CRISPR's development and application have shaped the ethical conversation around human genetic modification. My study will utilize a comprehensive literature review and qualitative research methods, engaging with various academic sources and recent events to understand the ethical landscape surrounding CRISPR. In addition, I will employ the Social Construction of Technology framework to unravel how different societal groups have influenced the discourse on CRISPR.

#### **Technical Topic**

Currently, the challenge of misinformation regarding CRISPR and the associated lack of accurate information dissemination to the public has been primarily addressed through various channels. Educational institutions and research bodies often release publications and studies to shed light on CRISPR's intricacies. However, these publications generally are not able to get to the eyes of the general public unless they explicitly search for the topic or if a news company picks up the publications. Websites and online platforms, including those managed by scientific communities, have dedicated sections or blogs that aim to bring light to genetic engineering topics. However, these sites are generally not focused and can be quite opinionated. Additionally, digital media, including podcasts and video platforms such as YouTube, have seen an influx of experts attempting to bridge the knowledge gap. Furthermore, initiatives like online courses on platforms like Coursera or edX offer structured learning paths for those keen to delve deeper. However, the scattering of these resources across the digital landscape and the absence of interactive elements can pose challenges for the general public in accessing and comprehending this information.

My proposed idea, "CRISPRUnfolded," is meant to be an immersive, digital educational mobile app tailored to highlight the intricacies of CRISPR for a global audience. The platform will intricately meld interactive modules allowing users to grasp the science behind CRISPR. Complementing this are the platform's virtual laboratories, offering users a hands-on experience as they simulate CRISPR experiments, diving deep into the meticulous world of genetic editing within a controlled, virtual realm.

The app will also host ethical debate forums. These curated spaces will foster robust discussions about the moral, societal, and philosophical implications of genetic modifications, allowing the general public to learn from each other and create a safe space to discuss difficult topics. Augmenting the learning experience, the platform will boast an array of visual explainers, ensuring users receive a comprehensive visual understanding of genes and CRISPR's transformative role in editing them.

To bridge the gap between academia and the general populace, the platform will feature in-depth, curated expert interviews, comments, and papers. This is so users can learn directly from the source and stay accurately informed. In addition, to keep users updated about the rapid

advancements in the field, a dedicated section will provide real-time research updates, spotlighting the latest findings, breakthroughs, and innovations in CRISPR from global laboratories.

While this may sound like a daunting task, I have extensive experience in app development, machine learning, and LLM integrations that will allow me to promptly develop and deploy this application. The following steps will be completed to develop the app:

As an initial foundation, the app will be developed using SwiftUI, a modern UI toolkit introduced by Apple. My proficiency in this language, stemming from the successful creation and deployment of "Spot", a niche social media platform tailored for the weightlifting community, assures that the platform will have a robust and user-friendly interface. It's worth noting that this decision will initially limit the user base to Apple users; however, starting with a specific audience allows to refine the platform's features and stability before considering broader platform expansions.

Updated information is key to the mission, so to continuously furnish the app with the most recent and accurate information related to CRISPR, I will employ the "Metaphor" web scraping Large Language Model (LLM). This relatively new API scrapes the web for the most relevant information regarding a query. This integration will automate the process of acquiring and updating data, ensuring that our users have access to the most recent advancements and findings in the realm of CRISPR. This will be done by integrating the API and writing meaningful prompts to find the information.

In addition, ensuring the information found is reliable and relevant is also of utmost importance. To enhance the reliability and relevance of the acquired data, I will integrate an advanced LLM, like GPT. This LLM will analyze the vast array of information gathered,

meticulously sifting through to spotlight valuable content. This information will then be uploaded to the platform so that users can stay updated with the newest and most relevant information possible. My hands-on experience with LLMs, both in the development of a trading algorithm and in corporate settings during internships, will ensure a smooth and efficient integration process. Key to this will be crafting precise prompts that enable the LLM to effectively filter and classify data.

Furthermore, given the sensitive nature of discussions around genetic modifications in the open forums, and the personal opinions users might share, the app will prioritize security features. We will implement end-to-end encryption for user data, ensuring their privacy remains uncompromised. Additionally, regular security audits, multi-factor authentication, and stringent data storage protocols will be adopted to safeguard user information and foster trust within the community.

These open forums will be designed to encourage and facilitate informed discussions on the ethical, societal, and philosophical facets of CRISPR. A clear and stringent set of guidelines will be established to ensure discussions remain respectful and productive. Features such as threaded comments, user moderation, upvoting, and categorization will make navigation and participation intuitive and engaging. The inclusion of moderators, either AI or human, will further ensure the quality and decorum of conversations.

Looking forward, post-launch, it's imperative to establish a user feedback loop. This will help in understanding user needs, addressing concerns, and refining the platform based on realworld usage. As CRISPR technology evolves, so should our platform. Periodic training sessions or webinars can be organized to keep users abreast of the latest techniques and tools. While the initial focus is on Apple users, future phases should look at expanding to other platforms like Android to capture a broader audience.

The "CRISPRUnfolded" platform distinguishes itself as a comprehensive answer to the current challenges in the realm of CRISPR information. Unlike the disjointed resources available today, "CRISPRUnfolded" serves as a centralized hub where users can seamlessly access a wide array of content, ranging from fundamental overviews to the latest research findings. This consolidation ensures that users have a one-stop destination for a thorough grasp of the topic. What makes it truly different is its emphasis on interactive learning. By incorporating virtual labs and engaging modules, it enables users to interact directly with CRISPR concepts, a method proven to bolster understanding and memory, especially for those unfamiliar with the intricacies of the subject. Moreover, the platform actively promotes community interaction through open forums focused on ethical discussions. These forums not only debunk misconceptions but also cultivate a learning environment enriched by diverse viewpoints and shared experiences. To sum it up, "CRISPRUnfolded" is more than just a mere informational hub. By melding interactive learning, community discourse, and expert input, it offers a solution to the issues of misinformation and the prevalent knowledge deficit about CRISPR in the wider community.

"CRISPRUnfolded" will be a comprehensive, secure, and user-centric platform, bridging the gap between the intricate world of genetic editing and the curious global populace. Leveraging cutting-edge technologies and methodologies, combined with a clear roadmap, ensures that the platform will not just inform but also engage and inspire its audience.

#### **STS Topic**

CRISPR is a tool renowned for its surgical precision in genome engineering as underscored by researchers like Doudna and Charpentier in 2014. It heralds a spectrum of transformative medical and agricultural innovations. Yet, intertwined with its promises are profound ethical issues and societal ramifications.

One of the most profound socio-technical challenges presented by CRISPR technology is the ethical considerations surrounding its use, particularly in the modification of human genes. The possibility of editing human genes holds the promise of eradicating hereditary diseases and improving human capacities, but it also raises concerns about "designer babies," the unintended consequences of genetic modifications, and the potential for widening social disparities based on genetic enhancements. Given these ethical complexities, the research question I aim to explore is: How has the development and application of CRISPR technology influenced the ethical discourse around genetic modification in humans?

To being answering this question, let's take a look at a recent event. In 2018, the global scientific community was shaken by a controversial announcement from Dr. He Jiankui, a Chinese scientist. He claimed to have successfully created the world's first CRISPR-edited babies, twin girls named Lulu and Nana. Using the CRISPR technology, Dr. He reported modifying the embryos' genes to eliminate the CCR5 gene, which theoretically would render the twins resistant to HIV infection. The purported objective of this experiment was to offer a solution for couples where one partner is HIV-positive, allowing them to give birth to children resistant to the virus (Cyranoski and Ledford, 2018).

However, the revelation was met with widespread condemnation and concern from scientists, bioethicists, and the broader public alike (Rainie, Funk, Anderson, & Tyson, 2022). Key issues raised included the bypassing of ethical standards, potential unintended consequences

of the edits, and the implications for future generations since such genetic changes would be hereditary. The media played a significant role in shaping public opinion, with many outlets emphasizing the risks and ethical challenges of such endeavors, often using terms like "Frankenstein science" to convey the potential dangers of unchecked genetic modifications (Raposo, 2019).

The aftermath of Dr. He's announcement was swift and decisive. Chinese authorities immediately halted his research activities. Later, he was sentenced to three years in prison for conducting illegal medical practices (Cyranoski and Ledford, 2018). This incident not only highlighted the technical capabilities of CRISPR but also underscored the profound ethical and sociotechnical challenges it presents. The global outcry, especially in the US and China, emphasized the urgent need for a cohesive ethical framework guiding the application of CRISPR, especially when it comes to human genetics.

The implications of CRISPR technology stretch far beyond the realm of science and into society. The potential to eliminate genetic diseases could reshape our healthcare systems and redefine our understanding of human potential. However, without careful ethical considerations, we run the risk of creating a society where genetic modifications determine one's social status or where unforeseen genetic changes result in adverse consequences for future generations. Therefore, it is imperative to understand the ethical discourse surrounding CRISPR to ensure its responsible development and application.

To truly understand the ethical landscape that has evolved around CRISPR, a multifaceted approach is crucial. Firstly, I plan on immersing myself in a comprehensive literature review. This will help to provide a baseline understanding of the ethical concerns that have emerged since CRISPR's inception and will allow me to learn more about the history with

regards to CRISPR and ethics in genetics as a whole. I will also be able to see how and why these concerns have evolved over time and how they compare to the current landscape. The literature will encompass academic journals, case studies, and expert opinions, giving a holistic view of the academic discourse on the matter.

Also, in order to ensure a well-rounded comprehension and to encompass real-world views, I'll be actively engaging with key stakeholders in the CRISPR domain. Through in-depth interviews with bioethicists, such as Hilary Bok and Anna Mastroianni from Johns Hopkins University, I aim to capture the philosophical and moral underpinnings that guide their views on genetic editing. I have a good relationship with Johns Hopkins as I have spoken with many of their research teams in the past, so I will use my connections there to set up a meeting with these bioethicists. I will also speak with genetic researchers, such as Clint Miller and Michael Brown from the University of Virginia. This will help to provide insights into the on-ground challenges and ethical dilemmas they face during their work. I will reach out to these individuals via internal email as I attend the University of Virginia. Furthermore, I will reach out to affected communities, such as farmers, drug manufacturers, doctors, and patients who have undergone experimental treatment, as this will offer a personal dimension, shedding light on the hopes, fears, and aspirations of those directly impacted by CRISPR's potential applications.

The analysis will employ the Social Construction of Technology (SCOT) framework, which posits that the development and meaning of technology are co-constructed by various social groups (Pinch and Bijker, 1984). Through this lens, I will explore how different stakeholders, including scientists, ethicists, patients, and the general public, have shaped the ethical discourse around CRISPR. By understanding the diverse viewpoints and the interplay

between them, I aim to provide insights into how CRISPR can be developed and applied in a manner that aligns with societal values and ethics.

### Conclusion

CRISPR technology introduces a significant shift in science, emphasizing the ongoing drive to understand and control nature. With such potential, clear understanding is essential. The planned platform aims to demystify genetic engineering for everyone through visuals, simulations, and expert input, promoting informed engagement.

Additionally, the STS exploration examines the societal, ethical, and cultural impacts of genetic editing. Beyond science are complex ethical and societal challenges. This analysis aims to address these, providing a thorough perspective on the benefits and concerns of CRISPR.

In summary, these two projects, technical and STS-focused, are interconnected. Their goal is to ensure that interaction with CRISPR is both scientifically informed and ethically responsible. As genetic engineering advances, these projects promote informed use of CRISPR technology while considering potential risks.

### References

- Ayanoğlu, F. B., Elçin, A. E., & Elçin, Y. M. (2020). Bioethical issues in genome editing by CRISPR-Cas9 technology. *Turkish journal of biology*, 44(2),110–120. https://doi.org/10.3906/biy-1912-52
- Cyranoski D, Ledford H. Genome-edited baby claim provokes international outcry. Nature. 2018 Nov;563(7733):607-608. *doi: 10.1038/d41586-018-07545-0.* PMID: 30482929.
- Davies B. (2019). The technical risks of human gene editing. *Human reproduction*, 34(11), 2104–2111. <u>https://doi.org/10.1093/humrep/dez162</u>
- Doudna, J. A., & Charpentier, E. (2014). The new frontier of genome engineering with CRISPR-Cas9. *Science*, *346* (6213), 1258096. <u>https://doi.org/10.1126/science.1258096</u>
- Doudna, J. A., & Sternberg, S. H. (2017). *A Crack in Creation: Gene Editing and the Unthinkable Power to Control Evolution*. Houghton Mifflin Harcourt.
- Jasanoff, S., Hurlbut, J. B., & Saha, K. (2015). CRISPR Democracy: Gene Editing and the Need for Inclusive Deliberation. *Issues in Science and Technology*, 32 (1), 37-49. <u>https://issues.org/crispr-democracy-gene-editing-inclusive-deliberation/</u>
- Jinek, M., Chylinski, K., Fonfara, I., Hauer, M., Doudna, J. A., & Charpentier, E. (2012). A Programmable Dual-RNA–Guided DNA Endonuclease in Adaptive Bacterial Immunity. Science, 337 (6096), 816-821. <u>https://doi.org/10.1126/science.1225829</u>

Knoppers, B. M., & Kleiderman, E. (2019). "CRISPR babies": What does this mean for science and Canada?. *Canadian Medical Association journal*, 191(4), E91–E92. <u>https://doi.org/10.1503/cmaj.181657</u>

Kosal M. E. (2020). Emerging Life Sciences and Possible Threats to International Security. *Orbis*, 64(4), 599–614. <u>https://doi.org/10.1016/j.orbis.2020.08.008</u>

Ledford, H. (2015). CRISPR, the disruptor. *Nature*, *522* (7554), 20-24. <u>https://doi.org/10.1038/522020a</u>

Oye, K. A., Esvelt, K., Appleton, E., Catteruccia, F., Church, G., Kuiken, T., & Collins, J. P. (2014). Regulating gene drives. *Science*, *345* (6197), 626-628. <u>https://doi.org/10.1126/science.1254287</u>

Pinch, T. J., & Bijker, W. E. (1984). The social construction of facts and artefacts: Or how the sociology of science and the sociology of technology might benefit each other. Social Studies of Science, 14(3), 399-441. https://doi.org/10.1177/030631284014003004

Rainie, L., Funk, C., Anderson, M., & Tyson, A. (2022). Americans are closely divided over editing a baby's genes to reduce serious health risk. *Pew Research Center*. <u>https://www.pewresearch.org/internet/2022/03/17/americans-are-closely-divided-overediting-a-babys-genes-to-reduce-serious-health-risk/</u>

Raposo V. L. (2019). The First Chinese Edited Babies: A Leap of Faith in Science. JBRA assisted reproduction, 23(3), 197–199. <u>https://doi.org/10.5935/1518-</u> 0557.20190042 Reardon, S. (2016). Welcome to the CRISPR Zoo. Nature, 531 (7593), 160-163.

# https://doi.org/10.1038/531160a

Scheufele, D. A., & Krause, N. M. (2019). Science audiences, misinformation, and fake news. Proceedings of the National Academy of Sciences, 116 (16), 7662-7669. <u>https://doi.org/10.1073/pnas.1805871115</u>