The Societal Implications of Ethical Ambiguities in Biohacking

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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

Empowered by the tools of synthetic biology, amateur scientists across the world are editing genomes in their own makeshift home laboratories. The "biohacking" or "DIY-bio" movement was created by these hobbyists to democratize science in society (Keulartz & van den Belt, 2016). Biohacking is a response to the rise of dominant academic institutions and biotechnology corporations that exclusively control much of the research, development, and distribution of new synthetic biology technologies (Delfanti, 2011). However, institutionalized research must adhere to strict codes of ethics, while biohacking is devoid of formal ethical oversight. The ambiguities surrounding the ethics of DIY-bio give biohackers much more freedom in their research. Therefore, biohacking has earned a reputation as the lawless "wild west of synthetic biology" (Blazeski, 2014).

On one hand, the vague ethical framework affords biohackers scientific autonomy to create valuable new technologies. However, unethical and unrestricted biohacking can have major consequences that endanger the health and safety of society. The internet has been especially influential within DIY-bio, generating global networks of biohackers. The DIY-bio community is able to share scientific data and educational resources about synthetic biology online. The large networks can also create an environment in which immoral ideologies can infiltrate and spread rapidly, which causes bio-security concerns (Landrain et al., 2013). Both the risks and rewards of DIY-bio are important to consider before implementing any new restrictions or ethical amendments. As biohacking becomes more prevalent and sophisticated in its capabilities, it is essential to address the research question: what are the societal implications of ethical ambiguity in biohacking? This thesis identifies some of the uncertainties that arise from ethical obscurity within biohacking in order to urge watchfulness over the evolution of the DIY-bio movement and encourage prevention of disastrous outcomes.

Literature Review

Synthetic biology gives humans the power to manipulate biological systems and organisms. Examples of biotechnologies made possible by synthetic biology include new vaccines, biologic drugs, gene therapies, biofuels, and genetically modified crops. One of the most recent and revolutionary innovations in synthetic biology is the discovery of the CRISPR-Cas9 as a gene editing system in 2012 (*CRISPR Enables Gene Editing on an Unprecedented Scale*, n.d.). The ability to directly alter the genomes of organisms opens innumerable possibilities in biological engineering. The potential of synthetic biology to change society is immense, but it must be used responsibly.

Research and development of new technologies in this field is largely institutionalized to academia and industry because synthetic biology is unpredictable and very expensive. Universities and biotechnology corporations, called "Big Bio," have risen to dominance in creating and commercializing synthetic biology technologies because of their large research budgets and access to resources (Keulartz & van den Belt, 2016). In the quest for profit and prestige, Big Bio can lose sight of public need and make their technologies inaccessible and unaffordable for many people. One example of this is in the high prices for essential biologic drugs such as insulin. Just three pharmaceutical companies comprise more than 90% of the insulin market, and play a major role in determining the price of the drug (*How Insulin Pricing Works in the U.S.*, 2019). Big Bio has created many inequities in accessing synthetic biology-based technologies in society because of their economic motivations.

The disconnect between Big Bio and society has led to the rise of biohacking as a social justice movement (Giordano, 2018). Biohackers conduct their own biological research in order to promote science as an open platform for discovery, reducing the power that Big Bio holds in the biotechnology industry and society (Delfanti, 2011). Biohacking has become much more sophisticated as synthetic biology technologies have advanced and become more available to the public. In addition, DIY-bio is unregulated and there is no ethical code that is explicitly enforced. Unethical uses of synthetic biology by any person or organization present immense danger to public health and the environment. The field of synthetic biology is especially risky because, "Experimentation with living organisms is problematic…they are self-replicating and transmissible, so they pose many hazards that one would not encounter in many other types of do-it-yourself science" (Wolinsky, 2009). The only existing ethical framework is the DIY-bio codes of ethics. There are two different codes, one from the North American Biohacking Congress and another from the European Biohacking Congress ("Codes," 2011; Eggleson, 2014). These provide very loose ethical frameworks for biohackers to reference.

In comparison, Big Bio is tightly regulated by Institutional Review Boards, government agencies and detailed codes of ethics. Regulatory agencies such as the United States Food and Drug Administration (FDA) and Environmental Protection Agency (EPA) are extremely stringent in their approval process of new synthetic biology derived technologies. Institutional Review Boards (IRB) can be implemented both within biotechnology institutions and regulatory agencies. An IRB functions to assess proposed studies involving humans or animal subjects and enforce ethical research practices (*Institutional Review Boards Frequently Asked Questions*, 2019). Measures like this ensure that Big Bio institutions abide by ethical guidelines in their research and have been largely successful in preventing major consequences associated with synthetic biology research.

Biohackers are often stereotyped as malicious or as mad scientists experimenting in dark basement laboratories. However, in reality the DIY-Bio movement incorporates a large spectrum of people with different levels of scientific expertise and motivations for biohacking. Many localities have opened community laboratories to engage their citizens in open science, such as the Open Bio Labs in Charlottesville Virginia. Some biohackers also seek to become entrepreneurs through DIY-bio and start companies of their own. Technology incubators and venture capital firms exist to support biohackers in commercializing their technologies. Therefore, the DIY-bio community consists of a variety of different actors with various ethical perspectives and intentions behind undertaking biohacking.

Intellectual property rights incentivize some biohackers to commercialize their technologies by forming startup companies. Startups are disruptive to the Big Bio industry, and many patents have been issued as a result of discoveries made within the DIY-bio community. Therefore, one proposed method of increasing regulation is using the patent office (Gorman, 2011). It is difficult for government agencies such as the FBI, FDA, or EPA to regulate DIY-bio because it does not use government funding and is largely unorganized science (Ikemoto, 2017). In the United States patent office regulations could include, “require lab registration, screen for personnel unfit for work in synthetic biology, and CDC biosafety training” (Gorman, 2011). Though these measures are insufficient to provide regulation over the majority biohackers, it could help establish a culture of safety and compliance within DIY-bio (Gorman, 2011). Using the patent office to establish standards of regulation may help reduce instances of unethical biohacking, but still is not a solution to completely mitigate risks to the public. However, over-regulation threatens to send more biohackers underground to pursue potentially dangerous research due to the counter-cultural roots of the biohacking movement (Landrain et al., 2013). Biohacking is newer and much more difficult to control than Big Bio, and there is no obvious regulatory action that will resolve the ethical issues associated with DIY-bio. Therefore, it is important to further analyze ethics in biohacking in the context of an STS framework to characterize the risks to society and understand the impacts of DIY-bio.

STS Framework and Research Method

Ulrich Beck is a German sociologist who has been very influential in his theories relating to world risk society, which he also refers to as a second reflexive modernity. Max Weber, another German sociologist, famously referred to industrial modernity as an "iron cage" that traps individuals in systems revolving around efficiency and rationality and loss of values (Kim, 2020). Beck directly contradicts Weber's "iron cage" with his theory of world risk society. Beck says that in world risk society, "Modernity becomes *reflexive,* which means, concerned with its unintended consequences, risks and their implications on its foundations." (Beck, 2000, Chapter 12). Therefore, one of the most important elements of the world risk society framework is the concept of "manufactured uncertainties." (Beck, 2009). Manufactured uncertainties are risks that arise from a combination of increased technical knowledge and ignorance of potential outcomes or consequences of a new technology (Beck, 2000, Chapter 12). Greater scientific understanding of the world and new technologies also create greater unawareness of the impacts it will have on society. Manufactured risks are contingent on human actions, and are "hybrids" of factors such as politics, ethics, technology, the media, cultural definitions, and perception (Beck, 2009; Beck, 2000, Chapter 12). The modernization of synthetic biology technologies in society and subsequent rise of biohacking is riddled with manufactured uncertainties. The ethical obscurities within DIY-bio create even greater risks to society.

Beck names three characteristics of manufactured uncertainties: de-localized, incalculable, and non-compensable (Beck, 2009). De-localized means that risks are on a global scale, non-specific to one location or group of individuals (Beck, 2009). This necessitates action and formation of international institutions (Beck, 2000, Chapter 12). Manufactured risks are incalculable because society has never experienced them before. Therefore, it is impossible to control risks directly using existing strategies (Beck, 2009). Finally, manufactured risks are non-compensable because the inability to control risks means that many outcomes and consequences cannot be properly remedied (Beck, 2009). These three criteria apply to the risks associated with biohacking. The benefits or consequences of DIY-bio could impact all of society and biohacking is a worldwide practice, making it de-localized. In addition, synthetic biology and biohacking are both relatively new to society, meaning that the risks are incalculable and cannot be controlled by the same ethical frameworks or regulations used for Big Bio. Many consequences of biohacking are irreparable and irreversible, for example an unauthorized gene drive that entails major environmental problems.

Reflexive modernization focuses on building awareness in societies to identify manufactured risks. Beck says, "the less risks are publicly recognized, the more risks are produced." (Beck, 2000, Chapter 12). Though impossible to control risks directly, it is important that manufactured uncertainties risks are realized in order to facilitate communication and initiate change within society. In order to avoid the "iron cage" of industrial modernization, it is important to apply the concepts of world risk society and manufactured uncertainties to DIY-bio. Specifically, the ethical obscurities within biohacking present an opportunity for many risks to emerge. Document analysis will be used to examine the manufactured uncertainties associated with ethical ambiguity in DIY-bio to facilitate reflexive modernity of biohacking in society. This will include a discussion of the most current DIY-bio ethical codes. Several cases of biohacking will be used to illustrate the impacts of other contributing factors including the internet and mass media in creating manufacturing risks surrounding the ethical ambiguities from the DIY-bio codes of conduct.

Data Analysis: The Origins of Manufactured Uncertainties in Biohacking

Biohackers are afforded freedoms in their research that Big Bio does not have because of the lack of ethical regulation DIY-bio faces. Agencies involved in institutional Big Bio regulation and ethical enforcement cannot easily extend their jurisdiction to DIY-bio (Ikemoto, 2017). Therefore, ethical problems involved in DIY-bio are not solved simply by imposing regulations using existing frameworks and government policies. However, ethical deficiencies in biohacking create manufactured uncertainties with the potential to benefit or harm society.

The only existing ethical documents were written in 2011 at the European and North American Biohacking Congresses ("Codes," 2011; Eggleson, 2014). However, these documents are vague and becoming more outdated as technology advances quickly. The North American DIY-bio Code of Ethics consists of seven values: open access, transparency, education, safety, environment, peaceful purposes, tinkering ("Codes," 2011). The explanation for each of these values is extremely short and nonspecific. For example, the only elaboration on the core value of safety is "adopt safe practices" ("Codes," 2011). In addition, the North American and European Biohacking Congress codes of ethics are different in their principles. A few values are shared by both codes, but the European code also includes modesty, community, respect, accountability, and responsibility in their standards ("Codes," 2011). The existence of discrepancies in these codes leaves many ethical gray areas.

The North American code in particular lacks the promotion of social accountability, and the actual word "responsibility" does not appear anywhere in this code (Eggleson, 2014). The European code explains that regarding the statute of peaceful purposes, "Biotechnology must only be used for peaceful purposes," while the North American code reads, "Biotechnology should only be used for peaceful purposes" ("Codes," 2011). This minute difference in wording gives the notion that the use of biotechnology solely for peaceful purposes is not obligatory in the North American code (Eggleson, 2014). Given the global nature of biohacking and the powerful impacts of synthetic biology, the current ethical frameworks are weak and disunified. It is also unclear if either the North American or European ethical framework extends to biohackers on other continents, such as Asia, Africa, South America, and Australia. There is no formal enforcement of these values, and much is left up to self-regulation and the individual biohacker in interpreting the DIY-bio code of ethics.

The ethical uncertainties of DIY-bio can be used for altruistic purposes in society. One example of the positive effects of biohacking is the creation of a genetically engineered bacteria that is able to fluoresce in the presence of the contaminant melamine in yogurt (Landrain et al., 2013). This alerts consumers and helps avoid any harmful health effects caused by melamine. Another environmentally useful innovation to emerge from biohacking is the creation of a genetically modified bacteria that produces a blue pigment that could be used as ink for pens. This biologically derived blue pigment is non-polluting and much more sustainable to produce than synthetic ink (Landrain et al., 2013). In addition, DIY-bio presents an opportunity to create startup companies. Startups are a threat to Big Bio because they de-centralize control of the biotechnology industry from the most powerful institutions. Amplino is one example of a startup company that has resulted from biohacking. Three European DIY-biologists started from simple materials and invented an inexpensive and portable Polymerase Chain Reaction (PCR) machine (Landrain et al., 2013; Nordling, 2014). They founded the company and began to develop their PCR machine as a diagnostic tool for malaria that could be used all over the world, especially in poor areas. The emphasis of the European DIY-bio Code of Ethics to promote peaceful uses of biotechnology is important in creating positive outcomes from European biohackers, as seen with the founders of Amplino. In this case, the lack of ethical restrictions within DIY-bio resulted in the creation of a company that uplifts society through synthetic biology.

The lack of ethical guidance within biohacking can also manufacture risks that threaten the health and safety of society. For example, Ascendance Biomedical is a company founded by American biohacker Aaron Traywick. Ascendance was established as a gene therapy company, attempting to create and sell therapies for devastating diseases. Ascendance famously tested both an experimental HIV gene therapy and a herpes vaccine on human subjects without any regulatory approval (Bromwich, 2018). After receiving the Ascendance HIV gene therapy treatment, the viral load of HIV patient who acted as the human trial subject increased. This meant that the HIV gene therapy was unsuccessful and made the patient sicker than before (Kaufman & Egender, 2019). In addition, Ascendance distributed an experimental infertility drug called Inovium to around fifty clients (Bromwich, 2018). However, this drug had not undergone any FDA clinical trials at the time and was not authorized for sale in the United States (Bromwich, 2018). Ascendance Biomedical manufactures immense risks to society because of its actions promoting the use of experimental drugs that endanger the health of vulnerable patients. The lack of social responsibility seen in the North American DIY-bio Code of Ethics is reflected in the actions of this American biohacker and his company.

There are biohackers all over the world, and they connect with each other via the internet to share science (Landrain et al., 2013). As of 2013, there were known DIY-bio laboratories across four different continents (Landrain et al., 2013). The connectivity of the worldwide biohacking community has caused the de-skilling of synthetic biology (Tucker, 2011). De-skilling happens as access to information and synthetic biology tools increases. The ability to exchange new ideas and obtain scientific resources online empowers more people to engage in biohacking (Tucker, 2011). The internet speeds up modernization of synthetic biology technologies in society immensely. CRISPR-Cas9 gene editing instructional kits can be easily ordered on websites and delivered to residential addresses, and countless synthetic biology tutorials exist on YouTube. Biohacking conferences have also become increasingly common as people are able to connect and organize meetings online. The internet can be a great educational resource and promote positive discovery and exploration in society. However, de-skilling always results in the creation of new risks. Risks are manufactured through the simultaneous awareness of scientific technologies and unawareness of the potential outcomes or consequences (Beck, 2000, Chapter 12). Therefore, every single biohacker, regardless of ethical motivation or technical skill level, manufactures uncertainties through their participation in DIY-bio and use of synthetic biology technologies.

The use of the internet in de-skilling synthetic biology also manufactures risks associated with bio-security. Unfortunately, it presents opportunities for unethical biohackers to have access to information that allows them to create biological weapons for use in bioterrorism (Tucker, 2011). The entire genome sequence of infectious poliovirus is available to access on the internet, raising concerns of re-creating the virus and releasing it to cause mass illness (*Synthetic Biology*, n.d.). The bio-security risks involved with biohacking are especially exacerbated because of the loose ethical frameworks and regulations surrounding DIY-bio. There are no ethical barriers stopping biohackers from creating a biological weapon if they choose to do so.

In this way, biohacking closely mimics the rise of computer hacking in society. The de-skilling of computer programming occurred as more information about how to code became publicly available and computers became more sophisticated in their abilities (Tucker, 2011; Schmidt, 2008). Cyber-security has become a very important field in response to cyber-attacks and the constant threat of unethical hacking. Similarly, as more people are able to learn about synthetic biology, it is plausible that biohacking will lead to more biological incidents and unethical uses of the technology that cause harm to others. The weak DIY-bio code of ethics as the only governing document in the field means that there are no consequences for unethical uses of synthetic biology by biohackers. Therefore, the ethical ambiguities manufacture even greater risks associated with de-skilling and the role of the internet in biohacking.

Programs like International Genetically Engineered Machine (iGEM) have created opportunities for thousands of high schoolers and undergraduates all over the world to learn synthetic biology techniques. Students compete every year in the iGEM competition and present their synthetic biology projects, including creating a public website to share their findings. The organizational structure of iGEM helps to ensure safety and educates participants about ethical uses of synthetic biology in these projects (*Safety - Igem.Org*, n.d.). De-skilling combined with the more structured ethical environment of the iGEM program seems to teach young people all over the world how to use synthetic biology to make positive impacts in society. However, it is undeniable that there are still manufactured risks in de-skilling these technologies to thousands of students every year. Students will eventually be able to practice biohacking outside the confines of iGEM, where there is little ethical guidance. Teaching so many through the program is still creating risk to society that people may use that knowledge to inflict harm, because de-skilling always manufactures risks. Providing new synthetic biology information through the project webpages also contributes to de-skilling via the internet and the creation of new risks.

The majority of biohackers are righteous in their research, but it only takes the action of one unethical biohacker to inflict major consequences upon society. One dangerous ideology in the biohacking community is the "do-ocracy," in which DIY-biologists are encouraged to unapologetically make decisions and act upon them (Keulartz & van den Belt, 2016). However, this discounts the interests of other stakeholders involved and leads to potentially unethical uses of synthetic biology (Keulartz & van den Belt, 2016). The "do-ocracy" mentality has resulted in real instances of abuse of synthetic biology technologies. For example, infamous biohacker Aaron Traywick utilized social media to live-stream himself to hundreds of people administering his company's experimental HIV gene therapy in a human subject (Bromwich, 2018). Traywick also injected himself with a homemade herpes vaccine in front of an audience at a major biohacking conference, earning mass media coverage (Bromwich, 2018). The biohackers participating in the most reckless stunts tend to be the celebrities of the DIY-bio world and pull the majority of the mainstream media coverage. (Eggleson, 2014). The Netflix documentary series *Unnatural Selection* profiles several well-known biohackers promoting extreme views such as the idea of "playing God" through unregulated gene drives or experimenting on themselves (Kaufman & Egender, 2019). The selective media coverage of unethical behavior by DIY-biologists allows dangerous ideas to spread throughout the international biohacking community. The progressive de-skilling of synthetic biology coupled with "do-ocracy" biohacking philosophies promoted by the media increase the chance that other biohackers will use synthetic biology for unethical purposes, manufacturing risks to society.

Discussion: World Risk Society and Biohacking

The manufactured uncertainties related to ethics in biohacking are hybrids of existing ethical frameworks, cultural perceptions, the media, synthetic biology tools, the internet, and many other factors (Beck, 2000, Chapter 12). Ethical obscurities in biohacking simultaneously fuel biotechnology advancements and create threats of harm to society. In order to achieve reflexive modernization, the various manufactured uncertainties produced by the current DIY-bio ethics must be recognized to anticipate possible implications.

Manufactured uncertainties are not necessarily consequential. In many cases, DIY-bio creates an opportunity for beneficial innovation in society without the hindrance of strict ethical guidelines. The previously discussed examples of positive biohacking projects, such as the creation of engineered bacteria that can detect contaminants in food or produce sustainable ink and the startup Amplino show the value DIY-bio can add to society. The internet is a major de-skilling tool that can be beneficial and encourage the public to become more scientifically literate in synthetic biology, but still manufactures uncertainties. Ulrich Beck says, “Rather, incalculable uncertainty can also be a source of creativity, the reason for permitting the unexpected and experimenting with the new.” (Beck, 2009). Beck agrees that the ethical uncertainties can act as a catalyst for innovation rather than purely as a threat. In the context of reflexive modernization, the positive contributions of biohacking such as the synthesis of new knowledge and technologies that benefit society should be considered when adjusting DIY-bio ethics policies. It is important to preserve the spirit of positive discovery within DIY-bio that stems from the current freedom from regulations or guidelines.

There are still many manufactured uncertainties that arise from the ethical ambiguities and pose danger to society. Cultural differences in biohacking ethics, as seen in the North American and European DIY-bio Codes of Ethics, also contribute to the creation of new risks. The lack of emphasis on social accountability in the North American code has allowed biohackers like Aaron Traywick freedom to unethically produce and test experimental therapies. The ethical shortcomings of the two codes manufactures uncertainties because biohackers are able to independently decide what they believe the limits of biohacking should be. The de-skilling of synthetic biology combined with ethical obscurity manufactures risks relating to bio-security. The existence of freely accessible information such as the genetic sequence for poliovirus on the internet creates a risk that the DIY-bio community may misuse this knowledge and unleash a biological weapon. The internet and the mass media also facilitate the creation of risks through their ability to spread unethical ideologies, such as the "do-ocracy" philosophy, and influence other biohackers negatively. Broadcasting the "do-ocracy" extremist approach to DIY-bio to people all over the world manufactures risks that others may adopt this mindset and engage in unethical biohacking practices. The manufactured uncertainties that threaten society must also be carefully evaluated in order to achieve reflexive modernization. Changes to ethical standards should consider the magnitude of the risks posed by the current ethical codes, especially in combination with actors such as the internet and mass media.

One of the most powerful quotes in the documentary series *Unnatural Selection* is, "We always run the risk of discovering something that we cannot handle" (Kaufman & Egender, 2019). It is imperative to realize that even given the manufactured risks identified, there are uncertainties involved in DIY-bio and its inexplicit ethics that are still incalculable. However, it is also important to create recognition for some of the manufactured uncertainties involved and initiate discussions in pursuit of reflexive modernization. Given that manufactured risks are de-localized, incalculable, and non-compensable, Beck agrees with the principle of, “precaution by prevention” (Beck, 2009). World risk society hinges upon being able to self-reflect and change in response to the recognition of manufactured uncertainties to avoid catastrophic outcomes.

Conclusion

Synthetic biology is quickly being revolutionized by DIY-bio, shifting authority away from Big Bio by democratizing science. It is impossible to control biohacking using the same traditional methods employed to ethically regulate Big Bio institutions because DIY-bio is a grassroots movement powered by the public. Therefore, it is essential that the public is also engaged in evaluating the uncertainties produced. Specifically, manufactured uncertainties arising from ethical deficiencies in DIY-bio must be addressed in order to promote reflexive modernization of biohacking practices. The favorable impacts of ethical obscurities in biohacking have the potential to increase access to affordable biotechnologies for use in advancing medicine, agriculture, biofuel energy sources, and many other areas. Increasing scientific literacy and education surrounding synthetic biology in society is another benefit of DIY-bio. However, the implications of unethical biohacking threaten to destroy the environment and jeopardize the well-being of society. The global scale of DIY-bio means that international collaboration to identify and assess risks and benefits stemming from ethical ambiguities in biohacking is required. It is inevitable that synthetic biology tools will continue to become more sophisticated and manufacture new uncertainties. Therefore, society must remain cognizant of emerging manufactured risks as DIY-bio continues to integrate itself into the field of synthetic biology, and prepare to respond reflexively to prevent harmful consequences stemming from ethical ambiguities in the biohacking.

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